Pediatric rheumatology

Well-being in children with juvenile chronic arthritis

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Abstract

Objective

The aim of this study was to describe a model for predicting well-being in children with juvenile chronic arthritis (JCA).

Methods

125 children (43 boys) (median age 14.1 yrs; range 10.3 – 17.8) rated disability and discomfort (Childhood Health Assessment Questionnaire). Pain control, pain reduction and fatigue were evaluated (visual analogue scales). In addition, variation of pain intensity was rated by a pain intensity scale. Analysis by the stepwise regression technique was used to explain the variability in well-being. Eight independent variables were included as possible predictors in the model ($p < 0.1$).

Results

The analyses indicated that well-being in children with JCA is related to three clusters of variables; pain "as it normally is", number of pain-free days and attending physical education classes. The analysis explained a substantial portion of the total variance in the children's well-being (55.1%).

Conclusion

Pain is a robust predictor of well-being in children with JCA. This supports the concept of the benefits of reducing chronic joint pain as a major goal in caring of these children.

Key words

Pain, coping, quality of life, juvenile chronic arthritis.

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Introduction

Well-being is one aspect of the quality of life which can be used to describe aspects of the impact of a disease in individuals. Well-being comprises the individuals' affective and cognitive evaluation of their lives. Depending on the child's perception and ability to cope in a particular social context and according to the definition of WHO/ ILAR, QoL is: "*the perception of individuals of their own position in life, context of the culture and value systems of the countries in which they live and in relation to their goals, expectations, standard and concerns*" (1).

Assessments of health status have undergone a paradigm shift over the past two decades (2). Today patient centred values are in focus. Nordenfeldt (3), a supporter of the subjective meaning of the concept, has stated that it is closely connected to that of happiness. Naess (4) has described four areas related to a person's experience of high QoLor well-being. It rises to the extent that the individual is: (a) active; (b) relates well to others; (c) has self-esteem; and (d) has a basic mood of happiness. Kajandi (5) pointed out that the ambition of a person is to integrate indicators from many parts of the conceptual field known as "the good life" in QoL research; a combination of external factors, interpersonal relations and internal (psychological) factors.

Juvenile chronic arthritis (JCA) is a chronic, multi-system, dynamic disease of unknown aetiology (6). Chronic arthritis in childhood can lead to functional, physical and psychosocial disabilities (7) and has a great impact on the child's everyday life (8, 9). Problems relating to chronic pain, joint stiffness, tiredness and limitation of motion can lead to limited participation and to feelings of being different from others and moods of sadness (8, 9). Daily interactions with others, family and peers included, are important variables in perceived health and well-being. Important to a person's well-being is the physical environment (10). For schoolchildren the school is such an environment, where productive well-being is worth considering.

Assessing QoL poses unique problems in relation to children because they may interpret questions differently and not share adults'views about the etiology and treatment of illness (11). In addition, children have a different time perspective regarding the course of a disease (12). Four conceptual criteria of a good QoL instrument for children are described by Pal (13): (a) it has to be child-centred; (b) it has to consider the child as a part of a family unit within a social network; (c) it has to be generalisable; and (d) the assumptions underlying the instrument have to be appropriate.

The Childhood Health Assessment Questionnaire CHAQ (14) is disease-specific instrument developed for a particular condition such as JCA, intended to measure disability and discomfort. Translated versions of the CHAQ into more than 30 languages have been published (15), including Sweden (16). Excellent psychometric properties have been shown (7, 17-21).

The purpose of this work was to describe a model for predicting well-being in children with JCA.

Material and methods

Study sample

The sample consisted of 125 children, 43 boys (34.4%) and 82 (65.6%) girls, with a mean age of 14.3 years and median age of 14.1 years (range 10.3 – 17.8 yrs.). Criteria used for inclusion were all children with the diagnosis juvenile chronic arthritis (JCA) born between 1 March 1984 and 1 November 1991 and treated at any one of five paediatric departments in southwestern Sweden (Göteborg, Borås, Skövde, Karlstad, and Jönköping). Learning difficulties was a criterion for exclusion. The median disease duration was 3.4 years, and ranged from 0.5 to 14.5 years for the total sample.

The EULAR criteria (European League Against Rheumatism) defines three subtypes of JCA: oligoarticular, polyarticular and systemic (22). In this study 66 children (52.8%) were classified at the time of the study as having oligoarthritis, i.e. four or fewer joints involved. Fifty-eight children (46.4%) were classified as having polyarticular JCA since they had 5 or more joints involved during that time period, and one child was in the systemic subgroup. In addition, according to the EULAR criteria (22) disease activity can be classified as: (a) active = increasing number of active joints irrespective of drug therapy; (b) stable = stable number of joints but requiring drug therapy; (c) inactive = no evidence of active synovitis and/or active extra-articular features and without drugs for less than 2 years; and (d) remission = no evidence of active synovitis and/or active extra-articular features and without drugs for two or more years. In this study the disease was classified as active in 34 children (27.4%), while 78 children (62.4%) had stable JCA, 7 children (5.6%) had inactive JCA, and 5 children (4.0%) belonged to the remission group at the time of the study. The joints involved were classified as symmetrical versus asymmetrical and in the upper versus the lower extremities or both extremities. The joints involved were asymmetrical among 14 children (83.2%) and 75 children (60.0%) had affected joints in both the upper and lower extremities at the time of the study.

Questionnaires

Disability and discomfort

Data were collected using the version of the Health Assessment Questionnaire for children (CHAQ) (14), a multi-dimensional measurement instrument. Functional ability is measured in eight domains of daily living: (a) dressing and grooming, (b) getting up, (c) eating, (d) walking, (e) hygiene, (f) reaching, (g) gripping and (h) activity. Each of the items has four possible categories of answers: “without any difficulty” (0), “with some difficulty” (1), “with much difficulty” (2) and “unable to do” (3). The items with the highest score in a domain determine the score for that domain, while the use of any aids or devices or help from another person is assigned a minimum score of 2 for that domain. These eight domains are averaged into a disability index (DI), which can range from 0 to 3 with higher scores indicating greater disability. Questions on absence from school during the last two months and attendance at physical education classes are included in the CHAQ. Discomfort (pain and well-being) was measured by the children using a 100 mm Visual Analogue Scale (VAS).

Pain, coping (pain control and pain reduction), sleeping, fatigue and satisfaction with life

Self-reported VAS was measured by the children to collect data on how the child perceived pain “as it normally is”, sleep, fatigue, satisfaction with life and ability to cope with the pain. The anchors were labelled “no pain” and “most pain imaginable”, “sleep very well” and “sleep very badly”, ”not tired and “very tired”, ”very good life in general” and “very bad life in general”, ”no control of pain” and “complete control of pain”, “no reduction of pain” and “complete reduction of pain”.

Variation in pain intensity

A numerical-verbal pain scale – the Pain Intensity Scale, modified from Richardson *et al.* (23) – was used, in which the children were asked to rate their joint pain on a scale of 0 to 4, four times a day for a period of one week. There is a verbal description of pain for each number: “No pain” (0); “I am only aware of it if I pay attention to it” (1); “I can ignore it at times” (2); “It’s difficult for me to concentrate, I can only do easy activities” (3); “So much that I can’t do anything” (4).

Statistical methods

The mean, median, SD and range were calculated for descriptive purposes. Pitman’s non-parametric permutation test (24) was used for all correlation analyses. In addition, Pearson’s correlation coefficient was calculated for descriptive purposes. Fisher’s non-parametric permutations test (24) was used for tests between groups. Stepwise regression analysis was used to explain the variation in well-being in children with JCA. The dependent variable is the global assessment using CHAQ. To select independent predictors for possible inclusion in the regression model, univariate correlations and tests were performed. Variables with $p < 0.1$ were selected as possible predictors. Stepwise regression was performed after transforming the dependent variable to a normal score using Bloms’ method (25). All tests were two-tailed and conducted at the 5% significance level.

Procedure and ethical considerations

Before this study began, ethical concerns were taken into account in all parts of the study design, in line with the Helsinki Declaration (26). The research ethics committees of the universities of Göteborg, Linköping, and Örebro approved the study design. Informed consent was obtained from the child and the parents. Parents and children were given separate written information about the study, in which the voluntary aspect was central. The questionnaires were sent to the children with a pre-paid reply envelope. One written reminder was sent.

Results

Disability (CHAQ)

Of the eight domains included in the CHAQ, the most difficulties were shown in “gripping”, “activity” and “getting up”. Fifty-two children (42.2%) scored 2 in the gripping category, which means that they could perform the activity “with much difficulty”. The activities “hygiene”, “dressing” and “walking” seemed to be performed with fewer difficulties. The disability index score (DI) was used in the stepwise regression model as a possible predictor.

Discomfort (pain and well-being) (CHAQ)

Based on the results the median pain score (VAS), which measured 32.5 (range 0-100), was not used as a possible predictor variable in the stepwise regression model. The median score for well-being was reported to be 28.0 (range 0-100). On the average, the children were absent from school 3.7 days (range 1-25 days) during the last 2 months. Sixty-five children (55.6%) reported that they never attended or that they only sometimes attended physical education classes. Absence from school and attending physical education classes were used in the stepwise regression model as possible predictor variables.

Pain intensity (Pain Intensity Scale).
The results showed that 85 (73.9%) children had either no pain-free or one pain-free day during the registration week, and 75 (65.2%) had no pain-free days. Thirteen (11.3%) children had 7 pain-free days during the registration week. During this period 46 (40.2%) children scored pain as 3 or more. Pain experienced as 3 means that the children had difficulties concentrating and only did easy activities. Pain-free days, the mean of pain intensity during the registration week and pain variations/ day were all used in the stepwise regression model as possible independent variables.

Pain, pain control, pain reduction, fatigue and sleep
The median value for pain "as it normally is", as measured by VAS, with the end-points "no pain" and "worst pain imaginable", was 38.0. In pain control measured using VAS, with the end-points "no control" and "complete control of pain", the median value was 68.0. In the ability to reduce pain, with the end-points "no reduction of pain at all" and "complete reduction of pain", the median value was 44.0. The median values of the children's VAS ratings for fatigue "as it normally is" and sleep "as it normally is" were 53.5 and 16.0, respectively. Possible predictor variables used in the stepwise regression model therefore were pain "as it normally is" and fatigue "as it normally is".

Multivariate analyses
To find possible independent predictors for stepwise regression analyses, univariate tests and correlations were calculated (Table I). Eight of these independent variables were included as possible predictors in the model ($p < 0.1$) (Table II): the DI score; pain "as it usually is"; attending physical education classes; absence from school; fatigue "as it usually is"; mean pain intensity during a period of one week; number of pain-free days during one week; and pain variations/day. Because of there were some non-responses, the analysis was based on data from 99 children. A stepwise regression analyses was carried out to examine the extent to which demographic and functional status variables predicted well-being. The summary of the stepwise analysis of variance is shown in Table III. As can be seen, this predictive analysis explained a substantial portion of the total variance in well-being (55.1%).

Discussion

The results of a multiple regression analysis depend on the model chosen for prediction. The independent variables in the present model were not intended to completely cover the complex concept of quality of life, but can be seen as a contribution to the understanding of children's perceptions of their well-being. Pain "as it usually is" measured by VAS, the number of pain-free days, and attending physical education classes were found to be significant predictors of well-being in children with JCA, explaining 55.1% of the variance. The predictor variable "pain as it usually is" should not be confused with pain measured by VAS in the CHAQ, a variable not included in the regression model.

According to Naess (4), well-being rises in proportion to the extent that the person is active. Living with chronic

Table I. Descriptive statistics for all continuous variables used in the univariate tests, values from correlations between well-being and independent variables (p and r).

Variables	No.	Mean	Median	Range	r	p-value
Demographic variables						
Age (years)	125	14.30	14.08	10.3 – 17.8	-0.004	0.9678
Disease duration	125	4.71	3.50	0.5 – 14.5	-0.144	0.1189
Disease activity	124	1.86	2.00	1 – 4	-0.144	0.0373
Joints involved (lower/upper extr.)	125	2.30	3.00	1 – 3	-0.259	0.0029
Joints involved (symmetrical/unsym.)	1.25	1.17	1.00	1 – 2	0.294	0.0010
CHAQ variables						
Well-being – Global assessment	117	33.85	28.00	0 – 100	1.00	< 0.001
Dressing	123	0.61	0.00	0 – 3	0.316	< 0.001
Getting up	123	0.89	1.00	0 – 2	0.452	< 0.001
Eating	123	0.85	0.00	0 – 3	0.480	< 0.001
Walking	124	0.62	0.00	0 – 3	0.455	< 0.001
Reaching	123	0.85	1.00	0 – 3	0.499	< 0.001
Gripping	123	0.99	1.00	0 – 3	0.395	< 0.001
Activity	124	0.92	1.00	0 – 3	0.586	< 0.001
Disability (DI) *	124	0.79	0.63	0-2.5	0.551	< 0.001
VAS variables						
Pain "as it normally is" *	121	39.43	38.00	0-100	0.659	< 0.001
Satisfaction with life	119	21.81	14.00	0-100	0.499	< 0.001
Pain control	120	61.08	68.00	0-100	-0.339	< 0.001
Pain reduction	119	46.87	44.00	0-100	-0.247	< 0.001
Fatigue "as it normally is" *	120	49.43	53.50	0-100	0.451	< 0.001
Sleep "as it normally s"	120	27.67	16.00	0-100	0.237	< 0.001
Pain Intensity Scale variables						
Pain intensity during one week (mean) *	115	1.13	1.14	0 – 3.43	0.545	< 0.001
No. of pain-free days during one week *	115	1.42	0.00	0 – 7	-0.471	< 0.001
No. of days with pain ≥ 3 during one week	115	2.23	1.00	0 – 7	0.523	< 0.001
Pain variation during the day *	115	1.32	1.29	0 – 3	0.454	< 0.001
Pain variation during one week	115	0.82	0.75	0 – 3.5	0.388	< 0.001
Other variables						
School absence *	112	3.67	1.50	1 – 25	0.429	< 0.001
Attending PE *	117	1.64	2.00	1 – 3	0.548	< 0.001

*Independent variables used in the regression models.

Table II. Correlations of the variables included in the regression model (Pearson's r). All variables were significant < 0.001.

V1	V2	V3	V4	V5	V6	V7	V8	V9
V1	0.66	0.45	0.55	0.43	0.55	-0.47	0.52	0.55
V2		0.54	0.58	0.38	0.65	-0.54	0.57	0.58
V3			0.30	0.33	0.48	-0.36	0.42	0.47
V4				0.51	0.66	-0.47	0.56	0.58
V5					0.44	-0.33	0.47	0.40
V6						-0.67	0.85	0.66
V7							-0.47	–0.56
V8								0.56

Variables: V1 = Well-being
V2 = Pain "as it usually is"
V3 = Fatigue "as it usually is"
V4 = Attending physical education classes
V5 = Absence from school
V6 = Pain intensity during one week (mean)
V7 = Number of pain-free days during one week
V8 = Pain variations/day
V9 = Disability score (DI)

joint pain and uncertainty about day-to-day variations in pain will probably make a child less active. Vitality and energy, both components of active living and quality of life (4), may decrease due to the uncertainty in daily living caused by the chronic pain. It has been reported that daily living with chronic pain caused by JCA is perceived as an oscillation between hope and despair (9), with feelings of powerlessness and frustration. This is far from a mood of happiness, another well-being factor according to Naess' (4) definitions of QoL. Interpersonal relations is another factor related to a person's well-being according to Naess (4) and Kajandi (5). In our earlier studies (8, 9) it was obvious that children's interpersonal relations were negatively affected by the chronic pain associated with JCA. Experiences of pain and feelings of uncertainty made the children incapable of planning their daily activities. The children with JCA also described experiences of being different from others in our earlier studies (8). Being different from other children decreased their self-esteem and happiness, which are other factors influencing a person's sense of well-being (3, 4).

The results of the present study show that attending physical education classes is a predictor of well-being. In this study most of the children were adolescents (mean-age 14.3 years). During these years a child's image undergoes major changes and physique plays a prominent role. Not being able to attend physical education, probably owing to joint pain, leaves the teenager behind and out of the running, excluded from a normal group activity at school time (8,9). Belonging to a group represents part of interpersonal relations, a factor for a person's well-being (4). Our study shows that almost 50% of the children's well-being is affected by factors not included in our regression model. Some of these factors may be being different from others and oscillating between hope and despair, as was found in our qualitative studies (8, 9).

When defining health and well-being, the person's environment should be included (10). School and its daily activities is one of the main environments for children. School dissatisfaction is more prevalent among boys than girls (27). In this study we did not find gender differences in well-being. In studying QoL in children in Nordic countries, it has been shown that some of the protective factors for well-being were a good school environment, physical activity, feedback from peers and good intimate relationships (28). The results from the present study show that 55.6% of the children with JCAdid not attend or only sometimes attended physical education classes due to their joint pain.

Table III. Final model in stepwise regression. R-square in the final model was 55.1%.

Variable	Parameter estimate	Standard error	P-value
Intercept	-1.226	0.250	< 0.0001
Pain "as it usually is"	0.019	0.004	< 0.0001
Pain-free days	-0.091	0.036	0.013
Attending PE *	0.362	0.134	0.008

*Physical education classes

One way to prepare a child to meet all the challenges of a chronic illness such as JCA is to strengthen the children's sense of who they are, their sense of personal worth and human dignity. To be socially excluded is a humiliation. Self-esteem is important for a person's ability to enjoy well-being according to Naess (4). Increased recourse for information and support to school professionals is desirable.

Assessment of QoL in children is open to serious bias because of the demanding characteristics of the evaluation, which may explain the small amount of research done in this field. Children are often regarded as unreliable informants. Therefore, early attempts to rate the QoLof children were based on data provided by their mothers. Eiser and colleagues (11,12) point out that parents and their children do not always have the same views of the impact of illness on well-being. There have been appeals to involve children more directly in decisions about their own care and treatment. Children may also interpret questions differently (29, 30). However, using children as informants about their own experience has been documented by several investigators as being both valid and reliable (8, 9, 31-33). Children have their own unique understanding of illness, what causes it and how it should be treated. A person's own unique perspective on his/her QoL is of central importance, which is why self-ratings were used in the present study.

We regard QoL as being mainly a psychological indicator. Fluctuations in QoL cannot be regarded merely as a part of the disease, but must also be considered as being affected by interaction with others, of whom family and peers are most important. Reducing the impact of the disease is a fundamental purpose of the professional care of children with JCA. Unlike many physical handicaps, where the disability may be obvious, chronic pain in JCA can be invisible to other people. In line with findings by Ruperto and colleagues (7), our results indicate that chronic arthritis can lead not only to functional and physical disabilities, but also to psychosocial consequences.

Conclusions

Our findings show that pain has a significant impact on well-being in children with chronic arthritis. Pain ”as it usually is”, the number of pain-free days and attending physical education classes were found to be predictors of well-being in children with chronic arthritis. We believe that the results of this study may have consequences for clinical practice in pain management, treatment strategies, and support to professionals. We argue that it is important to assess day-to-day variations in pain in children with chronic arthritis. Our results stress the importance of investing more resources in pain management for these children and support to school professionals.

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