Transition of rheumatologic care, from teenager to adult: which health assessment questionnaire can best be used?

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Abstract

Objective

Transition of care for adolescents includes a transfer from paediatric to adult health care. This requires a transfer of specific measurements, which evaluate disease profiles such as functional ability. One of the most common measurements is the Health Assessment Questionnaire (HAQ).

Methods

Results of the Childhood HAQ (CHAQ) and HAQ were compared among adolescents diagnosed with rheumatic diseases involving the musculoskeletal system. All adolescents had recently dealt with or would in the near future be dealing with transition.

Results

Overall results of both questionnaires were comparable; intra-class correlation for consistency (ICC) was 0.95 (95% confidence interval 0.93–0.97). For a smooth transfer from CHAQ to HAQ, both correlation and agreement are required. Agreement between both questionnaires was not found. Described by limits of agreement, results of HAQ can differ from CHAQ as much as 0.95.

Conclusion

Despite strong correlations for consistency, lack of agreement was found in the results of CHAQ and HAQ. If correlation persists over time, this study suggests evaluating both the childhood and adult version of the HAQ during the transition period. When transfer into adulthood is completed, comparison to earlier tests at younger age is available and reliable.

Key words

Juvenile idiopathic arthritis, transition, health assessment questionnaire, childhood health assessment questionnaire, functional ability, consistency, agreement.

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Introduction

Children with chronic musculoskeletal diseases including Juvenile Idiopathic Arthritis (JIA), especially those with a polyarticular course of disease, may have disease activity and disability due to impaired joint function, persisting into adult life (1-3, 4).

When these patients approach adolescence, health care is to be carried over from a paediatric to an adult health care system. This process, also referred to as the transition of care, implies a prolonged period of care in which disease activity, functional ability, psychological and social aspects are measured with specific instruments. In most cases, these instruments are validated for a specific age group, and as a result, different instruments for children and for adults are used.

Functional ability is an important measurement to predict long-term outcome. In clinical studies, children's functional ability is measured using the Childhood Health Assessment Questionnaire (CHAQ). The CHAQ was adapted for use in children aged between one and 19 from the Stanford Health Assessment Questionnaire Disability Index (HAQ-DI). The CHAQ appears to be the current 'best buy' for measuring daily activities in children with arthritis, and it is also used for long-term outcome of JIA (1, 5, 6). CHAQ is validated for JIA and for other musculoskeletal diseases, including juvenile dermatomyositis and systemic lupus erythematosus (SLE) (7, 8). The CHAQ can be used as a self- or parent-administered instrument for measuring functional ability (9). In the Netherlands, the Dutch parent-administered version is validated by Wulffraat *et al.* (10).

In adult patients with rheumatoid arthritis (RA), the self reported HAQ is known to be the best predictor for functional ability in terms of mortality, work disability, joint replacement, and medical costs (11-14).

The HAQ is validated for a variety of diseases including RA, SLE, psoriatic arthritis and juvenile arthritis, and has been applied to cross-sectional and follow-up studies (15, 16). The short or two-paged HAQ which consists of HAQ-DI, VAS Pain Scale, and the VAS Patient Global, has received the widest attention and is commonly identified in the literature as "the HAQ". The standardised disability index section (HAQ-DI), which measures functional ability, is widely used and has remained unchanged since 1982 (17). In the Netherlands, a Dutch translation is used, derived, and validated from the original HAQ-DI (18).

The functional ability measured by the CHAQ and HAQ is used in several studies to show the effects of medication and medical costs at a group level (19-22).

Long term studies on the follow-up of children with JIA into adult life are scarce. For the study of patients in transition from paediatric into adult health care validated instruments are still required to measure the adolescents' functional ability. Consequently, it is necessary to transfer the results from the CHAQ to HAQ, and hence the results of the CHAQ and HAQ must be comparable and preferably replaceable. In this cross-sectional study we have compared the results of the HAQ and CHAQ in 89 JIA adolescent patients from our out-patient-clinic.

Methods

During a five week-period, all consecutive patients in the out-patient-clinic of both the paediatric and adult departments of rheumatology and immunology of University Medical Centre Utrecht were asked to participate in our questionnaires. Because the use of questionnaires which measure the quality of life are part of standard medical care, no ethical committee's approval was needed. All patients diagnosed with a chronic musculoskeletal disease with potential limitation of movement were asked to fill in both CHAQ and HAQ questionnaires. In addition, disease duration and age at initial diagnosis were noted. All patients were aged between 10 and 25, therefore they had all recently dealt with or were about to deal with a transition of care.

In order to avoid bias, all patients were asked to complete one questionnaire before and one after a visit to the doctor at our outpatient clinic, the order in which the two questionnaires had to be filled in being randomised.

Table I. Patient characteristics.

Variable	Subjects absolute (relative %)
Total respondents	89 (100)
Sex	
Male	30 (34)
Female	59 (66)
Disease	
JIA	68 (76)
Dermatomyositis	4 (5)
SLE	5 (6)
MCTD	3 (3)
Other	7 (8)
Unknown	2 (2)
Age	
10–13 year	27 (30)
14–17 year	40 (45)
18–25 year	22 (25)
Duration of joint complaints	
0–5 year	36 (40)
6–10 year	30 (34)
11–25 year	23 (26)

We divided our patient groups into three different age-categories, 10–13, 14–17 and 18–25 years. Patients over 18 years old are seen at the adult outpatient clinic, those under the age of 18 are seen at the outpatient clinic of the children's department of immunology.

Questionnaires
The HAQ consists of 20 questions, which assess the ability in performing activities of daily living during the previous week (23). The patient's responses to each question can vary from zero ('no disability') to three ('not possible or maximal disability'). The questions are divided in eight domains which represent the following activities: Dressing and Grooming, Getting up, Eating, Walking, Hygiene, Reach, Grip and Other Activities. In the traditional scoring method, the highest score of the questions in a certain domain is taken as the domain score. Fourteen additional questions are related to the use of aids and devices. If any aid or device is needed to accomplish the task in that domain, than the domain score will be minimal two (or three when 'not possible' was answered). The total score of the HAQ is accomplished by the mean of the eight domain scores.

CHAQ consists of 30 questions and as the HAQ, is divided into the same eight domains or functional areas. Through adaptation in each domain, at least one question relevant to the different age groups of the children is realised (9). The patient's response to each question can also vary from zero ('no disability') to three ('not possible'). CHAQ offers the option response 'not applicable' because certain questions are not suitable for all ages. The maximum score in each domain is the score used for analysis; when 'not applicable' is answered, the relating question is to be left out of analysis. In the Netherlands, only the parent-administered CHAQ is validated, therefore this version is used in daily practice. Patients were however instructed to fill in the questionnaires themselves, the CHAQ was used as a self-report questionnaire

Statistics
Median scores and range for the questionnaires were calculated. In order to investigate the possible replacement of the CHAQ by the HAQ, the results are plotted. Secondly, the correlation between both questionnaires is determined, using the intra-class correlation coefficient for consistency (ICC), in accordance with the two-way mixed model (24). The ICC for consistency is also used for comparing the separate domain scores as well as age, disease duration and diagnosis. Thirdly, Bland and Altman plots are made, showing a plot of difference of the results of CHAQ and HAQ against mean (25). To summarise the lack of agreement, the bias of the measurement error, estimated by the mean difference (đ) and the standard deviation of the differences (s), is calculated. Provided differences within đ ± 2s, referred to as "limits of agreement", are to be considered without any clinical importance (25).
The Statistical Package for Social Science (SPSS) version 15.0 for Windows is used.

Results
Ninety-four patients were asked to participate in this study. Three patients failed to complete both questionnaires and were excluded; an additional two patients were excluded because of their mental disabilities, providing a total of 89 patients for our study.
Table I shows the base-line characteristics of the enrolled patients. Sixty-six% of the patients were female, 45% belonged to the age group of 14–17 years. 73% of the patients had JIA, but also patients with other generalised autoimmune diseases were included. Two patients did not fill in their diagnoses and because of the anonymity of the questionnaires, they could not be retrieved. Table II shows the median results of the CHAQ and HAQ (results were not normally distributed). As shown in Fig. 1 the results of CHAQ and HAQ are near the line of equality. An ICC score above 0.80 is considered as a good correlation. The ICC of all patients is 0.95 (95% confidence interval 0.93–0.97).
When the consistency of correlations is calculated per domain, only the domains walking, hygiene and reach show strong correlations (Table III). When the subgroup of JIA patients was taken into account differences were not found, except for another strong correlation, namely in the domain of eating (Tables II and III).
When differences between CHAQ and HAQ were plotted in respect to age and to disease duration, no relation was found (R-square 0.00). Age, diagnosis and disease duration do not change the

Table II. Median results and ICCs of the CHAQ and HAQ for all patients, JIA patients only and other diagnosis only.

	CHAQ	Range (IQR)	HAQ	Range (IQR)	ICC, 95% confidence
All patients (n=89)	0.38	0–2.6 (1.06)	0.25	0–3 (0.88)	0.95 (0.93-0.97)
JIA patients (n=68)*	0.31	0–2.6 (0.63)	0.25	0–3 (1.13)	0.96 (0.93-0.97)
Other diagnosis (n=19)*	0.50	0–2.6 (1.09)	0.50	0–2.5 (0.88)	0.93 (0.83-0.97)

IQR: InterQuartileRange; ICC: Intra-class Correlation Coefficient for consistency.
An ICC score above 0.80 is considered as a good correlation.
*From two patients diagnosis was missing, and are therefore not calculated in these groups.

strong correlation in consistency, over-all ICCs were all above 0.92 (95% confidence interval 0.83–0.99).

In our third step of confirming agreement, the plot of difference against mean show a wide range of the data on the Y-axis, varying from -0.75 till +0.63 (Fig. 2). We calculated the estimated limits of agreement. For our data these figures are:

$$đ - 2s = 0.0646 - (2 \times 0.23545) = -0.4063$$
$$đ + 2s = 0.0646 + (2 \times 0.23545) = 0.5355$$

Thus, the results of the HAQ may be 0.4 below or 0.5 above the CHAQ. The plot of difference against mean (Fig. 2) and the wide range in limits of agreement both imply a lack of agreement between the CHAQ and HAQ.

Discussion

In this cross-sectional study of adolescents with JIA and other rheumatic diseases involving the musculoskeletal system, the median results of CHAQ and HAQ which varies between 0.25 and 0.50, is skewed to a lower level (Table II). This "floor effect" is in line with other authors who described this distribution of the results of both CHAQ and HAQ (15, 26-28).

We found a high correlation between the CHAQ and HAQ (0.95, Table II).

Age, diagnosis and disease duration do not change the strong correlation in consistency, overall ICCs were all exceeding 0.92. No relations were seen in the scatter plots for the difference between CHAQ and HAQ in respect to age and to disease duration, nor could we find a regression (scatter plots not shown). This supports a use of both questionnaires in clinical daily practice for patients of different ages and for different chronically conditions affecting the musculoskeletal system as already in use for diagnosis as JIA, SLE and juvenile dermatomyositis (7, 29, 30).

Replacement of the Childhood HAQ by the Health Assessment Questionnaire in adult health care requires not only strong correlations but also sufficient agreement (25). In Fig. 2, the calculated difference shows a wide range compared to the mean score. The calculated limits of agreement vary between minus 0.41 and plus 0.54, which im-
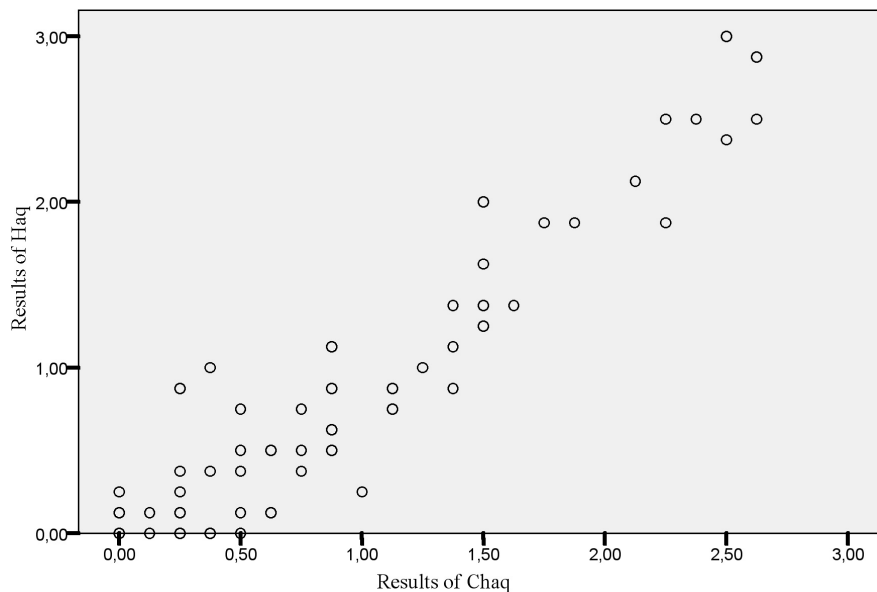

Fig. 1. median outcome of the patient measured by the CHAQ and HAQ.

Table III. Intraclass Correlation Coefficient for consistency (ICC) per domain.

Domain	ICC, all patients (95% confidence interval)	ICC, JIA patients (95% confidence interval)	ICC, other diagnosis (95% confidence interval)
Dressing and grooming	0.75 (0.64-0.83)	0.76 (0.64-0.84)	0.83 (0.60-0.93)
Arising	0.74 (0.63-0.82)	0.73 (0.60-0.83)	0.76 (0.47-0.90)
Eating	0.77 (0.66-0.84)	0.84 (0.76-0.90)	0.38 (0.08-0.70)
Walking	0.82 (0.74-0.88)	0.87 (0.80-0.92)	0.65 (0.29-0.85)
Hygiene	0.84 (0.76-0.89)	0.86 (0.78-0.91)	0.74 (0.44-0.89)
Reach	0.89 (0.84-0.93)	0.89 (0.83-0.93)	0.87 (0.70-0.95)
Grip	0.70 (0.58-0.79)	0.73 (0.59-0.82)	0.62 (0.24-0.83)
Activities	0.63 (0.48-0.74)	0.63 (0.46-0.76)	0.46 (0.02-0.75)

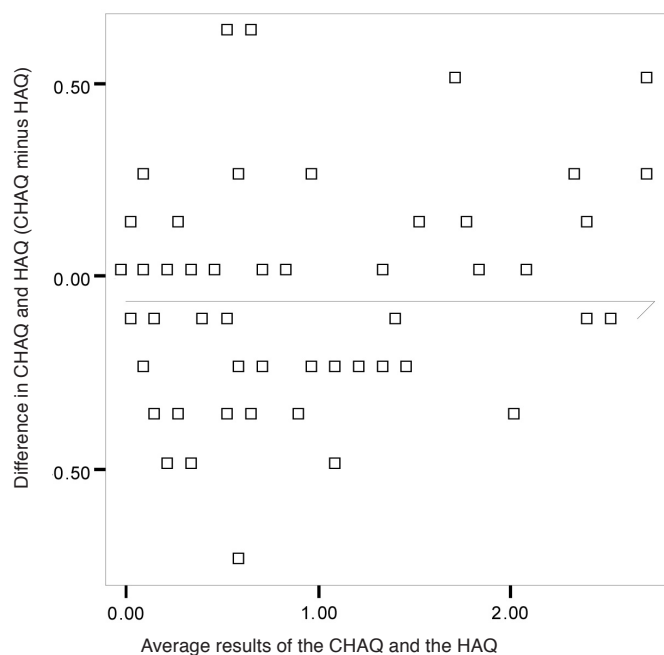An ICC score above 0.80 is considered as a good correlation.

Fig. 2. Plot of difference against mean for the CHAQ and HAQ data.

plies that the results of the HAQ can differ as much as 0.95! This would be unacceptable in clinical practice, as the total results can vary between 0.00 and 3.00. This is also in great contrast to the known minimally clinically important differences (MCID) in improvement for the CHAQ and HAQ (0.13 and 0.17 respectively) (31-33). From our study we may therefore conclude that the outcome of the HAQ may vary from the CHAQ to such an extent, that replacement of CHAQ by HAQ at a certain age is not clinically accepted.

Although CHAQ is derived from the HAQ, several differences are present and can clarify this lack of agreement (10, 34). First of all, the applied linguistics in CHAQ is different from HAQ. In addition, some modifications from the original HAQ have been made to make the CHAQ suitable for children of any age. Thirdly, only the CHAQ uses the possible score "not applicable" for items that are clearly age related. The option 'not applicable' was used frequently; a reason for this may be that the answer 'not possible' was intended. This might have influenced the total calculated score, since the option "not possible" yields the maximum item score whereas the option "not applicable" leaves the question out of scoring. An item analysis was not made to confirm this hypothesis. The Dutch parental version of CHAQ was used in our study as this is the only version which is validated in the Netherlands. Whether this influences agreement is not certain. In this study, no research was carried out to establish if all questions were fully understood by the participants.

Although there was a valid correlation in the total results of CHAQ and HAQ, this was not the case for most of the distinct domains (Table III). One of the reasons may be the low number of questions in each domain; a statistical comparison is therefore hard to make. Secondly, the option 'not applicable' in the CHAQ aimed at distinctive age related questions might influence the score at domain level. An item analysis was not carried out to confirm this hypothesis. A third argument, as discussed above, relates to the modification in and additions of certain questions in the CHAQ.

In the transition phase, it is essential to be able to compare the functional ability of an individual adolescent measured by HAQ to that measured by CHAQ. Although strongly correlated, the lack in agreement does not allow vice versa replacement of both questionnaires. Assuming that a strong correlation between CHAQ and HAQ will persist over time, a longitudinal follow-up including repeated measurements in the transition phase might provide more insight in agreement between both questionnaires, leading to better comparison of CHAQ and HAQ.

Acknowledgements

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