QUALITY OF LIFE IN ADOLESCENTS WITH MIGRAINE AND OTHER HEADACHES

Quality of life in adolescents
with migraine and other headaches

De kwaliteit van leven van jongeren
met migraine en andere vormen van hoofdpijn

ACADEMISCH PROEFSCHRIFT

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Voor mijn vader.

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GENERAL INTRODUCTION

Background

In 1975 the research line "Stress and Migraine" was started at the "Free University", Amsterdam. Later this research program was continued at the Institute for Medical Psychology and Psychotherapy, Erasmus University Rotterdam.

A first aim of this research line was to investigate the relations between personality traits, perception of stress, and the incidence of migraine and tension-type headache. Physiological mechanisms were studied that can explain how stress may trigger a headache attack. Headache subjects were typified by higher trait and state anxiety levels [1]. They showed a higher degree of achievement motivation and rigidity [2]. However, in a later study [3], no difference in achievement motivation between migraine patients and controls was found. As a possible physiological intermediate between stress and headache, a minor vasodilatation of the superficial temporal arteria could be identified.

In a large epidemiological study in adults, Passchier, Schouten, van der Donk, and Romunde [4] showed that the personality trait of inadequacy is associated with a higher risk of frequent headaches. Additionally, in relatively young subjects (20 through 49 years of age) with frequent headaches, social inadequacy, injuredness, and rigidity were also more often reported than in controls.

Another epidemiological study investigated personality variables and stress in relation to headache frequency, duration, and intensity in adolescents with frequent headaches. In this study, stress, school problems, and fear of failure showed a positive relation with headache frequency and intensity [5].

Based on these epidemiological findings, a new study was performed. Here, the effect of relaxation training in groups on headache-intensity and frequency was studied in a school setting. Subjects were between twelve and eighteen years of age. No positive effects of this training on headache were found [6]. However, a broader behavioural treatment program on migraine in adolescents, including biofeedback treatment in a clinical setting, did show a positive effect on headache intensity and frequency [7]. In this study temperature biofeedback in combination with behavioural therapy was the most effective psychological treatment of migraine.

Subsequently, another question of research emerged: Do these behavioural treatment programs, besides a positive effect on headache intensity and frequency, also show positive effects on the adolescents' quality of life? Two pilot studies were performed. The first pilot study contained a review of the literature on psychological and physiological well-being, and the role functioning of adolescents with migraine or chronic headache [8]. Clear effects of chronic headache and migraine on specific quality of life domains were found. However, none of the reviewed studies focused explicitly on quality

of life and none of the studies was performed on samples from the general population. In stead, these studies examined maladaptive functioning in samples of adolescent headache and migraine patients from neurological clinics. The second pilot study included 94 students at a school for technical education. Data on an *ad-hoc* constructed quality of life questionnaire were related to the data collected on headache intensity and frequency. It was shown that headache activity was significantly and negatively correlated with satisfaction with own health and satisfaction with the subjects' situation at home [9]. The absence of a valid and reliable instrument to measure quality of life in young subjects with migraine or chronic headache was strongly felt. To fill this gap, and to investigate the effects of recurrent headache or migraine on the quality of life of adolescents systematically, the study "Quality of life in adolescents with migraine and other headaches" was initiated.

Structure of the thesis

Chapter 1 will present an introduction to the field of overall quality of life measurement in juvenile subjects. First, some remarks will be made on the historical background of quality of life research, followed by a demarcation of the quality of life concept. Reasons for quality of life research in juvenile subjects will be given and requirements to a quality of life measurement scale aimed at young subjects will be presented.

In chapter 2 characteristics of tension-type headache and migraine in young subjects will be given, followed by epidemiological data. Finally, the existing literature on the effects of headache on quality of life will be reviewed.

Chapter 3 will presents the aims of the study. Further, an outline of the design of the study is presented.

Chapter 4 will describe a study regarding item selection and reduction of the new quality of life questionnaire, the Quality of Life Headache-Youth (QLH-Y). Results of factor analyses and homogeneity analyses of the constructed subscales will be presented.

In chapter 5 another study will be presented that further clarifies the psychometric properties of the QLH-Y, including the sensitivity of the QLH-Y to headache diagnoses and to typical differences in quality of life between migraine subjects, no-migraine headache subjects, and no-headache controls will be described.

Chapter 6 will describe the relation between changes in actual headache and quality of life and the ability of the QLH-Y to detect this relation.

Chapter 7 will describe how negative affectivity and experienced stress may affect

the relation between headache and quality of life in adolescents.

In chapter 8 the general conclusions of the study, its implications, and remarks on future studies will be presented.

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Chapter 1.

QUALITY OF LIFE MEASUREMENT IN JUVENILE SUBJECTS

Some historical remarks

Historically, the term quality of life (QL) was introduced as a political idea [1]. President Lyndon B. Johnson introduced the idea in 1964 by declaring that: ".... goals cannot be measured by the size of our bank balances. They can only be measured in the quality of the lives that our people lead" [2]. However, as de Neeling reports [3], as early as in 1948 other concepts with a content similar to QL are mentioned in the medical literature (e.g. "subjective improvement" and "performance status" [4]). In the 1960's and 1970's the use of the quality of life concept became increasingly popular in political campaigns.

In the medical literature "health-related QL" comprises those aspects of the QL that are supposed to be related to a subject's health. In 1958 the World Health Organisation defined health as a state of "physical, mental, and social well-being". In 1966, in an editorial of the *Annals of Internal Medicine*, Elkinton [5] calls upon the introduction of the QL concept into medical research. In the years to follow the inclusion of a measure for QL in clinical studies became increasingly accepted. Throughout the years 1967 to 1969 three medical articles were published with "quality of life" as part of the title. From 1970 to 1974 this number increased to 33 [6]. This trend continued in the next two decennia: In 1980, 207 papers were published with "quality of life" as a keyword, 10 years later this number had augmented to 846 [7]. In the 1990's QL research has become a principal outcome criterion in medical research.

A common definition of health-related QL [8] is "a multidimensional concept that includes the broad areas of functional status, psychological and social well-being, health perceptions, and disease and treatment-related symptoms".

Towards a demarcation of the concept QL

In the literature there is an ongoing debate about the content of the concept QL. Definitions vary from "the global evaluation of the good or satisfactory character of life" [9] to a more specific definition in which QL is described at multiple levels: an overall QL assessment at the highest level, distinct QL domains on a intermediate level, and, at the lowest level, each QL domain divided in specific components [10]. In a more pragmatic approach health related QL is seen as "a day-to-day functional

representation of a patient's functional, psychological, and social response to a disease" [11].

Some authors heavily criticize the scientific status of QL research. Hunt for example [12], criticizes QL research mainly because of a lacking "gold standard", no external criterion of QL against which measures might be tested, can be identified. Another point of criticism from Hunt on QL research is the equivocal definition of the concept QL. For, in contrast with the conceptual confusion about the concept QL, there *is* some agreement about the components of such constructs as health status, disability, and functional capacity and there *are* reasonably good measures of these, which are reliable and valid. Therefore, as Hunt states, there is no good reason why outcome research should continue to include QL assessment.

In medical evaluation research, QL and health status are often treated as synonyms (see for example [13]). An example of health status assessment is provided by Essink-Bot [14]. She describes health status as a hypothetical concept, including the "comprehensive domains physical, sociological, and social functioning" (page 11). Following Essink-Bot, health status can be approached from different perspectives that can be ranged on a hypothetical scale of decision levels. At the one end of the scale the "societal perspective" may be found. From this perspective health status research may focus on the relative benefits of investments in health care. At the other end of the scale the "individual patient perspective" may be found. From this perspective, decisions are taken as regards treatment selection for the individual patient. Between these two ends of this hypothetical scale, two other positions may be found, the "health care policy perspective" and the "patient group perspective".

As is shown here, there is far from consensus on the concept health related QL. However, it is a concept that has gained an important position in contemporary medical outcome studies. In studies that evaluate the impact of a specific disorder and its treatment, a pragmatic approach may be most functional. Schipper's definition of QL fits into such a pragmatic approach. Here, QL is defined as (page 172-173) [15]: ".....patient centred and functional. It represents an aggregate of day-to-day functional capacity across four areas: physical and occupational, psychological, social interactional, and somatic sensation".

Why should we measure QL?

In spite of the increasing criticisms on QL research, a British joint governmental/pharmaceutical industry working party on the conduct of economic evaluations of medicines has recently recommended the use of proven generic measures of QL [16].

Spilker [10] describes several reasons for measuring QL: At the *individual patient level,* QL research can help to improve the quality and the outcome of that patient's treatment. Since QL measurements result in a more refined effect evaluation, a better monitoring of treatment outcomes can be accomplished and treatment can be further improved. At the *patient group level,* QL trials may be used to differentiate between medical treatments with marginal differences in mortality and morbidity and to evaluate the effects of treatment aimed at a better quality of the lives of patients with incurable diseases. At *a population level,* QL investigations can help improve the allocation of health services. By use of a broad scope of QL parameters health services can be more efficiently targeted at that part of the population that present the poorest QL. Additionally, companies may use QL data for commercial purposes as these data may illustrate the superiority of a new treatment compared with a conventional treatment.

Aaronson [17] motivates the use of QL scales in studies that evaluate the effects of medical treatment and of health services in order to fulfil the need to broaden the scope of evaluation parameters. Emerging new medical technologies require a systematic evaluation of the functional, psychological, and social health of the individual.

Also for Spitzer and Dobson [18] the motivation for developing their health status assessment scale, the RAND 36 Item Health Survey (SF-36), was to complement the "hard variables" generally used in the assessment of different treatments for cancer and other diseases with a "hardened" quantitative index to measure QL. At the patient group level, QL assessment may also be used to estimate the burden of specific diseases and to compare the impact of different diseases on these patients' physical, occupational and psychological functioning, and on their somatic sensations.

How should we measure QL in young subjects?

QL measurement should be essentially patient centred [17]. Therefore, in assessing QL, the patient has to be the primary source of information. To assure a systematic evaluation of QL, one has to standardise the method of enquiry. The prevailing standardised method of QL evaluation is by written self-report measurement scales. Many *ad-hoc* QL measurement scales have been developed that do not properly identify the concept to be measured or describe the psychometric properties of the measurement scale. In a sound QL measurement scale QL is conceptually identified and the domains are explicitly stated [19]. Additionally, one has to ensure that each concept is measured comprehensively.

Conceptual identification and appropriateness of QL in youngsters

In children and adolescents the concept QL may include the same domains as in adult, (i.e. "a day to day functional representation of a patient's functional, psychological, and social response to a disease" [11]). However, in young subjects the content of these broad domains differs from that in adults. Young subjects have age-related interests, preferences, and problems and engage in age related activities. For example, social functioning in children and adolescents includes typical age-related family relationships and relationships with peers. Further, in most children and adolescents, functioning at school is an important part of their functional status. Therefore, adult tools are generally not applicable in a pediatric target population. An instrument to measure QL in young subjects should be based on an age related conceptualisation of QL.

Generic or disease-specific approach?

To measure QL, a generic approach, a disease-specific approach, or a combination of both can be chosen. Generic instruments are comprehensive instruments that at least cover the physical, psychological and social domains [20]. These instruments can be applied on different groups of patients and on healthy subjects. Spitzer [6] advocates the use of a generic instrument to measure QL. As a generic instrument may serve as a common yardstick, it may lead to a "gold standard" of QL. The major advantage of a gold standard of QL is the opportunity it offers to compare QL between groups and between a patient group and a general population.

On the other hand, McKenna [21] advocates the use of disease-specific QL scales. Disease specific instruments are the counterparts of generic instruments. McKenna rejects the use of generic instruments mainly because of the lack of a proper gold standard of QL. The core of McKenna's criticism on Spitzer's gold standard of QL, the Rand corporation Health Survey-36 items (SF-36), is that its items only cover function and well-being and that these items were not derived from patients. Thus, following McKenna, the SF-36 fails to meet the basic requirement of a QL measurement scale, that it is patient based. In line with McKenna, Bergner argues that QL is an essentially individual experience: "Each investigator must think about his or her own study, the study population, and the intervention and decide what should be assessed (...) in general, the assessment should examine factors that are likely to be affected by the intervention or have been troubling patients in the past, factors that may be affected, and factors that are very unlikely to occur but are possible" [22]. A

major advantage of disease specific QL measurement scales is that these may capture disease specific phenomena not covered by a generic QL questionnaire.

Aaronson's [8] modular approach to the study of health-related QL, in which a core of general items is supplemented with disease and treatment specific items, seems a proper method for addressing the dilemma of generic versus disease specific QL research [23]. This approach combines the advantages of the disease-specific and the generic strategy. As such, a combination of optimal sensitivity of the instrument and optimal comparability of the data is reached.

Who is the rater?

In QL assessment the target individual should be the primary source of information [8]. In juvenile subjects, depending on the developmental level of the subject, fulfilling this requirement may be more intricate than in adults. Obviously, children have to be able to read and write to fill out a written self-report questionnaire. Written self-report data on QL have been collected in target populations as young as 11 years of age (e.g. see Starfield, *et al.* [24]). As an alternative to a written questionnaire, a visualised QL scale can be employed in the youngest subjects (e.g. the Dartmouth COOP Charts for Children and Adolescents [25]). However, the reliability of this single item measurement can be questioned.

In the youngest children the subject-centred approach to QL assessment cannot be applied and QL registration has to be accomplished by-proxy. Physicians may not be the most suitable informants for a by-proxy registration of QL [15]. Alternatively, a by-proxy registration can be accomplished by nurses, social workers, family members or teachers, presuming that these proxies have sufficient observational information about the subject.

Feasibility

The measurement of QL in young subjects must comply with specific demands related to the developmental stage of the young subjects, the subjects' stage of cognitive development, their reading skills and their ability to focus attention to a task without being distracted.

Instruction, wording and layout of the questionnaire

Validity and reliability of a test will be enhanced when items and test instruction are unambiguous and understood properly. Regarding the phrasing of the items, most QL questionnaires ask for changes in QL *caused by the subject's disorder*. The subjects are asked to make causal inferences on their QL. This requires an organised pattern of knowledge derived from experience on which to build these inferences. In children and adolescents the availability of these cognitive inferential schemata will be limited, depending on their level of cognitive development. Therefore, in QL measurements in children and adolescents, a questionnaire format that does not ask for attributions of QL status to a certain disorder may be preferable.

The procedure of measurement

To obtain a reliable result that allows inter-subject comparisons and comparisons between groups, the procedure of measurement should be standardised. To reduce biases like social desirability, a neutral administration is required, and the choice of a self-administered questionnaire may be safest. To be able to compare scores between groups, within groups, or within subjects over time, the procedure of measurement has to be standardised. For example, an in-class assessment can only be compared with other in-class assessments, not with assessments at the doctor's office.

Length of the questionnaire

Due to their level of cognitive development, the time span in which young subjects can focus attention at one cognitive task will be shorter than in adults. Therefore, the length of the questionnaire should be a matter of greater concern with young subjects than with adults.

Time reference

QL instruments differ in terms of their time reference. As Barofsky indicates [26], inspection of three commonly used QL scales for adults reveals as many different time references. The EUROQOL assessment asks for an evaluation of today's QL, the RAND SF-36 asks to make statements over the last month and the Nottingham Health Profile has no particular time interval. Regarding young subjects, a time frame longer than one week seems inappropriate.

Psychometrics

Reliability of the instrument

Reliability indicates how free a test is from measurement error [27].The reliability of a test can be demonstrated by computing test-retest, alternate-form, split-half, or interrater reliability. Alternatively, a measure for internal reliability can be computed.

Test-retest reliability is obtained by comparing scores from the same subjects on an identical test at different points in time. For example, if a stable subject variable is evaluated (e.g. "intelligence"), test-retest reliability testing may offer a proper indication of the reliability of a test. However, when it is likely that the scores of a test vary over time, as in QL research, test-retest reliability testing is problematic. Therefore, in QL research test-retest reliability using a large time-interval may not be appropriate. Alternate-form reliability refers to the correlation between scores obtained on two different forms of the same test. A split-half reliability coefficient reflects the size of the correlation between two parts of one test that measure the same construct. Interrater reliability informs the tester about the size of the correlation between test scores obtained simultaneously by two or more raters employing the same test on the same subjects. Internal reliability or internal consistency reflects the unidimensionality of a test. The matching statistic is called coefficient alpha. Testing internal reliability is appropriate when the scale measures a single construct only.

Validity

Validity is the extent to which a measure assesses what it is supposed to assess. Different categories of validity can be distinguished: content validity, criterion-related validity and construct validity are the most important. Content validity is "the degree to which the items included on a scale are appropriate and thorough enough so that proper measurement can take place" ([27], page 45). As such, content validity deals with the selection, wording and comprehensiveness of the items. It determines if the test includes enough items to represent all of the behaviours within the domain to be measured adequately and it estimates the degree to which the items are appropriate to the domain to be tested. Content validity reflects only on the content of the test and does not provide evidence that supports inferences made from tests. On the other hand, indices for criterion validity and construct validity may provide such evidence. Two forms of criterion-related validity can be distinguished, predictive validity and concurrent validity. Predictive validity is an indication of how well a test predicts a behaviour in the future. Concurrent validity refers to the validity of a test to be employed to describe behaviour that occurs simultaneously. Construct validity

goes a step further than criterion-related validity. It determines the meaningfulness of a test. Criterion-related validity differs from construct validity in that in the latter a-priori hypotheses are formulated and tested about the direction and the size of the correlations between the scale and other measures. Construct validation can be performed in a convergent and in a divergent approach. In the convergent approach the two scales measure the same construct and high correlations are expected. Likewise, in the divergent approach, low or zero correlations are anticipated when two scales that are not similar are compared. Finally, face validity is the degree to which the items of a test superficially or intuitionally appears to measure the concept in question. Regarding the evaluation of the psychometric properties of a test, face validity does not provide meaningful information.

Sensitivity for change

To detect any difference in QL as a result of treatment, a good QL questionnaire has to be capable to detect change. Therefore, such a questionnaire should be sufficiently sensitive to change in QL.

Feasibility and psychometrics of some existing QL measurement scales for young subjects

To illustrate the feasibility and psychometrics of QL self assessment scales for children, some generic and disease-specific scales will be presented briefly here.

Generic QL scales for children

A literature search revealed that no generic QL scales for children could be found. However, several generic health status assessment scales exist. Landgraf and Abetz [28] present a review on generic health assessment scales for children. In four of these measurement scales the young subjects themselves are inquired about their QL: the Child Health & Illness Profile (CHIP, 153 items) [24], the Dartmouth COOP Functional Health Assessment Charts (9 items) [29, 30, 31], the questionnaires employed in the Health Institute Child Health Assessment Project (THI/CHAP, 107 items) [32, 33] and the Ontario Child Health Study (OCHS, 169 items) [34].

The CHIP-AE

The Child Health and Illness Profile-Adolescent Edition (CHIP-AE) [24] is an instrument with both generic and disease-specific or injury-specific modules, designed to assess adolescent health status in six domains (i.e. Satisfaction with Health, Comfort, Achievement, Resilience, Activity and Disorders). Each domain includes two or more subdomains. The questionnaire includes 107 generic items and 46 disease-specific or injury-specific questions. For the answering categories a Likert-format was chosen. Several sets of answering categories were chosen for the different domains.

To examine reliability and validity, the scale was administrated to 3451 youngsters between eleven and seventeen years of age. As measures for reliability, internal consistency reliability was tested by generating Cronbach's alpha for each of the subdomain scores. Two of the subdomains did not show a satisfying internal consistency reliability. For these subdomains, test-retest stability served as the critical assessment of reliability. As another indication for reliability, parent-child agreements were computed for scores on 10 of the 20 subdomains. Criterion validity was assessed by (1) comparing the responses of the adolescent with those of a parent, thus treating the parent-assessment as a gold standard for the child's health status; (2) computing percentages for sensitivity and specificity, and (3) computing correlations between the scores on the domain Achievement and their actual grades in academic subjects. After hypotheses were formulated about expected degrees of covariance, convergent and discriminant validity were tested by comparing scale scores with scores on standard instruments measuring similar and different constructs. As another indication for discriminant validity, subgroup differences in age, gender and socioeconomic status were compared within the study sample. The results are reported to support the reliability and validity of the questionnaire. However, not all hypothesized differences in health status were well-articulated. Neither were all predicted relationships with scales measuring similar constructs confirmed.

COOP/WONCA charts

The COOP/WONCA charts [29, 30, 31] are designed to measure Functional Status. The instrument consists of 6 charts measuring six domains of Functional Status: "Physical Fitness", "Feelings", "Daily activities" (*related to physical and emotional health*), "Social Activities" (*related to physical and emotional health*), "Change in Health", "Overall Health" and "Pain". The time span is two weeks. All charts have six answering categories that are illustrated with simple drawings. Test-retest correlations were found to be between .31 and .72 for children (age range 8-12 years) and between .57 and .94 for youths (age range 13-18 years). As measures for concurrent validity, product moment correlations between COOP/WONCA charts and

previously validated measures of function were computed (i.e. the RAND measures). The average of these correlations for the six charts was found to be .62.

THI/CHAP

The instrument employed in The Health Institute Child Health Assessment Project (THI/CHAP) [32, 33] is a health assessment scale for children and youngsters from 0 to 15 years of age that assesses physical and psychosocial functioning. For youngsters between 10 and 15 years of age, a 106-items self assessment scale is available. Internal reliabilities for this scale were computed as .62-.91 for the different subscales. At present only preliminary data on validity are available.

OCAS

The Ontario Child Health study (OCAS) [34] surveyed the health status of children between four and 16 years from all households (*N*=2052) in Ontario, Canada. Information on three domains was gathered: "Risk Factors", "Health Status" and "Consequences". In total, the scales consist of 169 items. To construct scales to measure "Health Status", 40 items were chosen on face-validity from the Child Behaviour Checklist. An indication of construct validity for the symptom checklist was obtained by computing the degree of agreement between scores on the checklist and a diagnosis set by a psychiatrist. A satisfactory agreement between the psychiatric diagnosis and scores on the checklist was reached for somatisation, not for emotional disorders. For the domains "Risk Factors" and "Consequences", no psychometric characteristics are presented.

Disease-specific QL scales for children

A review of the literature reveals the existence of numerous disease specific QL scales for juvenile patients: QL scales for young patients with spina bifida [35], asthma [36, 37, 38], cancer [39, 40], diabetes [41] congenital agranulocytosis [42], spine deformities [43] rheumatoid arthritis [44], epilepsy [45], allergic rhinoconjunctivitis [46], Crohn's disease [47], neuromuscular disorders [48], children of short stature [49], and children following liver transplantation [50] were identified. Reports on the development and psychometric properties of these questionnaires show varying degrees of age-specific comprehensiveness, age-specific feasibility, and psychometric soundness.

To illustrate the varying conceptual identification, feasibility and psychometric properties of disease-specific QL scales, three of these disease-specific scales will be shortly presented here: The Juvenile Arthritis Quality of Life Questionnaire (JAQQ) [44], the Diabetes Quality of Life measure (DQOL) [41] and the Paediatric Asthma Quality of Life Questionnaire [37].

JAQQ

The Juvenile Arthritis Quality of Life Questionnaire (*JAQQ*) [44] is a disease-specific self- or parent-report questionnaire containing 74 items. The format of the questionnaire combines six-point Likert scales and VAS scales. It was developed to be used in children with juvenile arthritis of 2 years of age or older. QL is evaluated in the dimensions Fine gross motor, Psychosocial, Pain and systemic symptoms. Parent-child agreement is presented as an indication for reliability. Self-report is demonstrated to be reliable from 9 years of age. Content validity and face validity are demonstrated by expert judgments and are reported to be satisfactory.

DQOL

The Diabetes Quality of Life measure (DQOL) [41] is a self-report measurement scale that was developed to assess the psychosocial impact of intensified regimens in diabetes patients. The DQOL was modified for specific use in young diabetes populations (age range 10-21 year). The modified DQOL includes 56 five-point Likert-scale items within three subscales: Diabetes Life Satisfaction, Disease Impact and Disease-Related Worries. Additionally, a general self-rating of overall health was included as a four-point Likert scale. The scale variances of the modified DQOL demonstrate a significant relation to adolescents' perception of their general health status. Satisfactory internal reliability and predictive validity of the subscales of the DQOL are reported.

Paediatric Asthma Quality of Life Questionnaire

The Paediatric Asthma Quality of Life Questionnaire [37] is a unidimensional self-report measurement scale containing 23 items that children with asthma have identified as troublesome in their daily lives. The questionnaire is aimed at children between 7 and 17 years of age with a wide range of asthma severity. Discriminant validity was indicated by the instrument's responsiveness to an altered health status either as a result of treatment or natural fluctuations in their asthma ($p < 0.001$) and by its capability to differentiate these patients from those who remained stable

($p<0.0001$). High test-retest correlations were obtained (ICC=.95) and the instrument showed a high degree of discriminant validity ($p<.001$).

Conclusion

In studies on the effects of a disease and its treatment on a specific patient group, a pragmatic approach to the study of QL may be the most viable. Schipper's definition of QL [15] fits into such a pragmatic approach.

QL research should be essentially patient centred. Scales to assess QL should be constructed based on the target population's specific perception of their QL. A major advantage of generic scales is the comparability of the data, between different groups of patients, or between a patient group and healthy controls. However, a serious disadvantage of generic scales is their lack of sensitivity for changes in QL due to non- disabling diseases. Optimally, a measurement scale to assess QL in a juvenile patient group with a non disabling disease should combine a generic evaluation of QL with disease-specific modules. In such a target population Aaronson's modular approach to the measurement of QL, in which elements of the generic and the disease-specific approaches are combined, seems appropriate.

An instrument designed to measure QL in young subjects needs to comply with basic psychometric requirements of validity, reliability, and responsiveness and with age-related requirements to feasibility.

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Chapter 2[1].

QUALITY OF LIFE IN ADOLESCENTS WITH MIGRAINE AND OTHER HEADACHES: A REVIEW OF THE LITERATURE

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Quality of life (QL) research in juvenile headache patients represents an integrative approach to the study of headache impact on the lives of children and adolescents. Better than separate investigations, QL assessment offers a comprehensive approach to the study of sickness impact, in which the quality of the major aspects of the subjects' life is assessed together.

The authors of this chapter adhere to the position that QL should be perceived as a multidimensional concept which encompasses psychological and social well-being, physical, role, and social functioning, health perception, and pain [1, 2]. Spilker's multi-level model of QL [3] is an approach that further clarifies the authors' position. Three levels of QL are described: (1) The individual's overall satisfaction with life and one's general sense of personal well-being; (2) broad domains of QL (e.g. physical, psychological, and social domains); (3) specific components of each domain (i.e. two specific components of the psychological domain are anxiety and depression).

As can be derived from data from the 1988 US National Health Survey [4], the impact of frequent or severe headache on the QL of children and adolescents is salient. There are several reasons for measuring QL in young headache patients. (1) From a public health point of view (population level), there is a need to study the impact of the headaches on general health and one's ability to function actively in society in order to stimulate health care in a rational way. (2) Headache is a subjective experience with few, if any, objective symptoms. In routine laboratory investigations no abnormalities are found. Therefore, studies on the effects of headache and its treatment on the lives of young subjects should include subjective measures. This evaluation should be systematic and reproducible. Accordingly, in treatment effect studies (group level), the inclusion of valid and reliable QL measurements will result in a more comprehensive evaluation of the effects of headache and its treatment. (3) To select a proper treatment, the clinician facing children and adolescents with frequent

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[1] In: *Koot, HM, & Wallander, JL, eds. Quality of life in children and adolescents: Concepts, methods, and findings. London: Harwood Scientific Publishers (In press).*

headache or migraine may want to survey the impact of the disorder on the subjects' QL (individual level) systematically. Subsequently, an optimal treatment can be chosen and QL measurement can be part of the effect evaluation. For example, the choice of a migraine medication may in part be determined by the severity of the impact of the disorder on the QL of the patient. Consequently, as it broadens the scope of effect parameters, a later QL measurement will facilitate the monitoring of effects and side effects of the prescribed medication.

In this chapter first the characteristics and prevalence of primary headache in children and adolescents are presented. Second, some causal and maintaining factors in juvenile headache are given. Then, studies on the effects of headache on separate QL domains in young headache and migraine subjects are presented and discussed. After that, since no studies could be identified in which the effect of headache on overall QL in children was studied, some studies are presented that explored the effect of primary headaches on overall QL in adults. Finally, suggestions to implement QL research in young subjects with migraine or no-migraine headache are given.

Characteristics of migraine and tension-type headache in children and adolescents

All headaches discussed in this chapter refer to the criteria of the International Headache Association [5] (see table 1). Despite their limitations [6], the IHS criteria are considered a major advance in the field of headache classification [7]. To obtain high interobserver reliability in headache diagnosis, well-defined criteria are required. The IHS criteria satisfy this requirement [8].

In children few headaches are associated with structural lesions [9]. Following the IHS criteria, headaches not associated with structural lesions are migraine, tension-type headache, and cluster headache. Cluster headache is a condition that rarely occurs in children and adolescents [10]. Therefore, in this chapter the description of headache conditions is restricted to migraine and tension-type headache.

Migraine

Pediatric migraine is an idiopathic recurring headache disorder manifesting itself in attacks lasting 2-72 hours. Typical characteristics of migraine-type headache are unilateral location, pulsating quality, moderate or severe intensity, aggravation by routine physical activity and associated nausea, photophobia, and phonophobia. A typical migraine attack can be divided into different stages like a pre-headache, headache and post-headache phase. Although strictly spoken a migraine diagnosis should not be applied until a subject has experienced five attacks, a migraine attack can also occur as infrequently as once in a lifetime. On the other hand, some migraine subjects even experience several attacks a week. The duration of the attacks varies from attack to attack and from subject to subject. In any migrainous subject a migraine attack can vary from a fragment of the clinical spectrum to one in which all phases occur [11]. Besides headache, migraine can be accompanied by a wide spectrum of symptoms. Vague symptoms like mood changes, increased thirst or a sensation of lethargy can occur before the attack. An aura may precede a migraine attack, which is a sensation that forewarns the actual attack. Visual or sensory auras are most common. The most frequently reported visual aura is a "scintillating hemianopic phenomenon that spreads across the visual field" [11]. As sensory auras, positive (tingling), and negative phenomenons (numbness) are described. A variety of autonomic disturbances may accompany a migraine attack (i.e. nausea, vomiting, skin pallor, changes in the cardiovascular system, fluid and electrolyte disturbances, and respiratory manifestations). More seldom disturbances accompanying a migraine attack are motor disturbances, disturbances of language, and cognitive disturbances. Headache in migraine usually has a gradual onset. See table 1 for IHS criteria for migraine.

The diagnosis of migraine in children is often problematic, because (1) non-specific headache symptoms are presented in an early stage of the disorder; (2) specific migraine symptoms are often absent in children; (3) the children's stage of intellectual development hampers a subtle report of headache symptoms; (4) in children with migraine, vegetative symptoms are often more prominent than in adults [12]; (5) headache in children is often inextricably linked with wide-ranging psycho-social problems [13]. Though in adult migraine patients head pain is most often reported to occur unilaterally, head pain in migrainous children is not [14]. Since in pediatric patients the actual duration of migraine attacks is commonly much shorter than in adults, Winner, Martinez, Mate, and Bello [15] propose a revision of the IHS criteria so that a migraine attack only requires a minimum of thirty minutes duration. Furthermore, Winner proposes modifications relating to duration, location, quality of intensity, and symptoms related to photophobia and phonophobia (see table 2).

Table 1. IHS criteria for migraine.

Migraine without Aura	Migraine with Aura
A. At least five past attacks fulfilling B-D	A. At least two attacks fulfilling B
B. Headache attacks lasting 4-72 hours *	B. Headache has at least two of the following four characteristics:
C. Headache has at least two of the following characteristics: 1. Unilateral location 2. Pulsating quality 3. Moderate or severe intensity 4. Aggravation by routine activities	1. One or more fully reversible aura symptoms indicating focal cerebral cortical and/or brainstem dysfunction 2. At least one aura symptom develops gradually over more than 4 min. or two or more symptoms occur in succession 3. No aura symptoms last more than 60 min. If more than one aura symptom is present, accepted duration is proportionally increased
D. During headache at least one of the following: 1. Nausea and/or vomiting 2. Photophobia and phonophobia	4. Headache follows aura with a free interval of less than 60 min. (It may also begin before or simultaneously with the aura)

* In children below age 15 attacks may last from 2-48 hours

Table 2. Proposed modification for IHS criteria for Pediatric Migraine (Winner *et al.*, 1995).

Pediatric Migraine without Aura	Pediatric Migraine with Aura
A. At least two past attacks fulfilling B-D	A. At least two past attacks fulfilling B
B. Headache attacks lasting 30 minutes to 72 hours	B. At least three of the following four characteristics:
C. Headache has at least two of the following characteristics: 1.Bilateral (frontal/temporal) location 2. Pulsating quality 3. Moderate or severe intensity 4. Aggravation by routine activities	1. One or more fully reversible aura symptoms indicating focal cerebral cortical and/or brainstem dysfunction 2. At least one aura symptom develops gradually over more than 4 min. or two or more symptoms occur in succession 3. No aura symptoms last more than 60 min. If more than one aura symptom is present, accepted duration is proportionally increased
D. During headache at least one of the following: 1. Nausea and/or vomiting 2. Photophobia and phonophobia	4. Headache follows aura with a free interval of less than 60 min. (It may also begin before or simultaneously with the aura)

The differences in severity, duration, and symptoms between attacks and the variations in the duration of the attack-free periods complicate the measurement of QL at one moment only. Therefore, to obtain representative QL data, measurements at more points in time are required.

Tension-type headache

Tension-type headache can be classified into two subtypes. An *episodic* tension type headache diagnosis requires at least 10 previous headache episodes that last from thirty minutes to seven days. These headaches should at least have two of the following characteristics: (1) of a pressing/tightening character, (2) of mild or moderate intensity, (3) occurring bilaterally, and (4) not aggravated by routine physical activity. The headaches should not be accompanied
by vomiting, nausea, photophobia, or phonophobia. For a *chronic* tension-type headache diagnosis the subject should suffer from headache more than 15 days a month (180 days a year), during more than 6 months.

Tension-type headache is generally described and defined by the following clinical picture [16]:

> The headache is almost continuous or daily, varying in severity, and has primarily a nonthrobbing quality, which may be described as an ache, pressure, or tightness, and usually a frontal location, although vertex and occiput are other possible sites. Gastrointestinal and neurological symptoms are lacking (page 163).

In children with tension-type headache the typical pallor and behavioural change of the child with migraine are not seen, and the parent is usually only aware of headache if informed by the child [13].

Most headache subjects are symptom-free between attacks. Frequency and intensity of headache attacks may have a cyclic feature. In post menarche adolescent females for example, headache symptoms may be linked in time to the menstrual cyclus.

Prevalence of headache in children and adolescents

Headache in children is extremely common. In a stratified 4% sample of the entire Amsterdam population between 10 and 17 years (n=2300) only 12% of the

subjects mentioned absence of headache the past year [17]. In a study on 8993 children in the age from 7 to 15 years Bille (1962) found that 58% of the boys and 59% of the girls were familiar with headache. Frequent non-migraine headache was found in 5.9% of the boys and 7.7% of the girls. The prevalence of migraine was 3.3% for boys and 4.4% for girls. Other studies showed a migraine prevalence in schoolchildren from 2% [18] to 10.6 % [19]. Differences in prevalence rates may be due to differences in employed migraine criteria and procedure of data aggregation. It is estimated that 10% to 15% of adult migraineurs experience an aura with some attacks. In children and adolescents the prevalence of auras accompanying a migraine attack is also common [19, 20]. The prevalence of frequent no-migraine headache and migraine increases with age [19, 21, 22]. Sillanpaa *et al.* [22], in a study of school children in Finland, found that 37% of the children had experienced headache by the age of seven. By the age of 14 this number had risen to 69%. The prevalence of migraine was found to increase from 2.7% by the age of seven to 10.6% at the age of 14. Passchier and Orlebeke [17] reported that the number of adolescents from 12 to 17 years of age who suffer each week from one or more headaches is about 15%.

Causal, triggering, and maintaining factors in primary headache

Most children familiar with primary headache and their parents will make an effort to reduce the frequency, duration and intensity of the children's headache attacks. To do so, the children may refrain from known causal, triggering and maintaining factors. As such, the headache may hamper the children's functional status. The best-known triggering factor in migraine is experience of stress. Several studies following a prospective study design, including the use of a diary, show that more stress occurs the day before a migraine attack [23]. In youngsters too, epidemiological and clinical findings suggest that experienced stress elicit migraine [23, 24, 25, 26]. Also, Passchier and Orlebeke [17] demonstrated that most young headache subjects, when asked for the cause of their headache, attribute a major causal effect to stress. In a prospective study on no-migraine headache and psychosocial factors in college students Labbe, Murphy, and O'Brien [27] found that perception of stress was one of the best predictors of a headache attack. Migraine and no-migraine headache subjects seem to tolerate lower levels of stress. In children and adolescents a lower tolerance of stress will affect role functioning at school, psychological functioning, and overall satisfaction with life.

Effects of juvenile headache on separate QL domains

Since no study can be identified that systematically compares the QL of young headache and migraine subjects as a whole with the QL of no-headache controls, first, investigations are presented that study the effects of headache or migraine on one or more specific QL domains in children and adolescents. Effects of headache on the QL domains of psychological functioning and well-being, somatic functioning, role functioning, and social functioning will be presented.

Somatic functioning, psychological functioning, and well-being in young headache subjects

Compared with no-headache controls, subjects who are familiar with headache or migraine report a maladaptive behavioural/psychological functioning [28]. While migraine attacks may lead to a short but strong interruptions of the activities of daily life, tension headache has its negative effects in particular on emotional functioning of the subject (i.e. increased fatigue and depression), as Andrasik and Passchier state. In children, as Passchier and Knippenberg [29] showed in a review of the literature, migraine or chronic headache seems associated with impairment in physical well-being (somatic complaints), psychological well-being (anxiety, depression, and emotional inhibition), with daily functioning (school absence and social dysfunction), and with the global evaluation of health and of happiness. Also several other studies suggest that headache or migraine in children result in distinct psychological consequences: Engström [30] found that juvenile subjects (9-18 years) with recurrent headache score higher on anxiety, compared with subjects with irritable bowel syndrome or healthy control subjects. Further, juvenile headache subjects present higher scores on depression than healthy controls. Andrasik, Kabela, Quinn, Attanasio, Blanchard, *et al.* [31] performed a study in which children experiencing recurrent headache or migraine were compared with no-headache peer controls matched for age, sex, and social class. Children with migraine revealed higher scores on all scales measuring depression and somatic complaints; adolescent headache sufferers also revealed increased levels of trait anxiety. Larsson [32], in a cross-sectional study comparing a non-clinical sample of adolescents with recurrent headache with a group of matched headache-free controls, found more psychological distress and somatic symptoms in subjects with recurrent headache than in their headache free counterparts. Also Wisniewski, Naglieri, & Mulick [33] showed that, compared with no-headache controls, juvenile subjects who are familiar with

headache report more somatic complaints. As Bree, Passchier, and Emmen [34] demonstrated, they generally evaluate their health as less satisfactory.

Cunningham, McGrath, Ferguson, Humphreys, D'Astous, *et al.* [35] performed a study in which they compared children with migraine with a "pain" control group (i.e. children with musculo-skeletal pain) and with a "no-pain" control group. The amount of pain experienced by the children in the migraine group and the "pain" group was statistically controlled. Children with headache were found to present a similar pattern of behavioural and personality characteristics as children with musculo-sceletal pain. Both pain groups showed a greater incidence of internalising behaviour problems and somatic complaints compared with the "no-pain" group. Further, both pain groups were observed to be less happy. Cunningham *et al.* suggest that the personality and behavioural features of children with migraine may not be characteristic of pediatric migraine patients, but instead result from the common chronic pain experience.

Frequent headache and migraine do not seem to affect cognitive functioning [36] or intellectual development. In children, Bille [21], in his classical study on Swedish primary school pupils, showed that children with migraine did not have marks above or below their peers without headache or migraine. Neither did they show any differences in other cognitive and intellectual tasks.

Role and social functioning in young headache subjects

Role and social functioning at school

Migraine causes significantly reduced school attendance. Collin, Hockaday, and Waters [37] reported that over a time span of twelve weeks, the prevalence of school absence due to headache for children 5 to 19 years of age was 3.7%. Based on data from the 1989 National Health Survey, Stang and Osterhaus [18] estimated for children aged 6 to 17 years in the USA that 10% of school-aged migraineurs missed at least one day at school over a two-week period because of migraine; nearly 1% missed four days. Data from the 1988 National Health Survey demonstrate that regarding number of annual school absence days in children and adolescents with chronic disorders, only asthma had a significantly greater impact than frequent or severe headache [4]. For comparison, the average annual school absence days due to frequent or severe headaches was 3.3, for asthma 4.6. However, headache subjects reported more bother by their disorder than asthma subjects. Of the subjects with frequent or severe headache, 57% experienced a great deal of bother by their disorder, whereas 34% of the children with asthma reported a great deal of bother. Apparently, though asthma leads to more school absence days, frequent or severe headache is more disturbing.

Role and social functioning in the family

Caring for a child with a physical disease puts a strain on the child's family. School absence and frequent somatic complaints due to frequent headache or migraine may lead to what Breslau, Strauch, and Mortimer [38] describe as "perceived role restriction" in the parents. They define perceived role restriction as "the extend to which a person feels unable to pursue one's own personal interests due to the responsibilities involved with raising a child with a chronic physical condition" [39]. Perceived role restriction is not found to be related to the objective aspects of the child's disability. Rather, it is related to the extent to which the child's family perceives social support from their social network. Therefore, though severe tension headache and migraine are not regarded as disabling physical diseases, these disorders may lead to a perceived role restriction in the family to the same degree as a disabling disease. As such, it can be expected that the QL related to the young headache patients' role functioning in his or her family will be decreased. However, this has sofar not been studied in families with children with migraine or other headache complaints.

Overall QL in adult headache and migraine patients

The number of studies comparing the QL of headache patients with other patient groups and no headache controls is limited. Using the generic Medical Outcomes Study Short Form Health Survey (SF-20), Solomon, Skobieranda, and Gragg [40] showed that the QL of adult chronic headache patients is significantly poorer than the QL of patients with physically disabling chronic diseases. They demonstrated that patients with chronic headache had a poorer physical, social, and role functioning, and poorer mental health than did patients with chronic diseases such as arthritis and diabetes. These authors also showed that in adults, QL differs among headache diagnoses [41]. Social functioning was poorer for cluster and tension-type headache than for migraine. Further, Solomon *et al.* [41] demonstrated that a significantly higher percentage of tension-type headache patients have a poor health associated with mental health than patients with migraine. They defined a poor health associated with mental health as the lowest 19% of scores in the general population on five items of the SF-20 which survey "general mood or affect in the past eight weeks". In line with this study, Passchier, Boo, Quaak, and Brienen [42] showed that tension headache patients are at least equally impaired in QL as migraine patients. However, they conclude that the impairment is mainly present in tension-type headache and migraine patients who visit the doctor for their complaints.

Concerning migraine headache patients, Osterhaus and Townsend [43] showed that these patients' physical functioning and health perception scores were similar to those of patients suffering of arthritis, gastrointestinal disorders and diabetes. Yet, in migraineurs, role functioning, social functioning, pain and mental health scores were lower than in other chronic diseases. In a study on the health status of migraine patients, Essink-Bot, Royen, Krabbe, Bonsel, and Rutten [44] demonstrated that the health status of migraineurs is significantly impaired in comparison with a control group. The largest differences between migraine sufferers and controls were observed in the domains pain, role limitations, household work, social functioning, home-life, vitality, energy, overall health, and valuation of own health. However, the sizes of the effects were only small to medium. In these studies group differences were explored between migraine patients and controls. Another question of research is if the QL of migraine patients varies parallel with variations in their migraine activity. While Dahlöf and Dimenäs [45] showed that migraine patients experience a poorer QL, even between attacks, Santanello, Hartmaier, Epstein, and Stephen [46] demonstrated that the QL of migraine patients is significantly decreased during a migraine attack compared with a migraine-free period. Thus, even between attacks the QL of migraine patient seems poorer than in healthy controls. Yet, during a migraine attack the migraine patients' QL seems even poorer than in a migraine free period.

No studies could be identified that studied the effect of tension headache on overall QL.

Conclusion

This chapter shows that QL research is relevant for juvenile headache patients. Several studies on the effects of headache and migraine on separate QL domains in juvenile subjects were presented. All these studies point at the serious influence of migrainous and no-migraine chronic headache on the life of the young patient. However, the effects of migraine or no-migraine headache on the overall QL of juvenile subjects have not yet been studied. A main reason for this may be the lack of an instrument to assess the QL of juvenile subjects with headache or migraine systematically. Therefore, a new instrument to assess QL in children and adolescents with migraine or non migraine headache has to be developed and evaluated. Subsequently, this instrument can be employed to explore the effects of migraine and no-migraine headache and its treatment on QL in this population.

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Chapter 3.

AIMS AND DESIGN OF THE STUDY

The aims of the study described in this thesis were:

(1) To develop a new instrument to measure quality of life (QL) in young subjects with frequent headache or migraine. To provide the opportunity to compare the data gathered with this instrument with other patient groups and with controls, ideally, the new instrument has to be of a generic character. However, the typical effects of frequent headache and migraine on the functional status of juvenile subjects required disease-specific items related to this QL domain. Therefore, to fulfill both these requirements, the new instrument had to combine generic and disease-specific features.

(2) To evaluate the psychometric properties (i.e. reliability, validity and responsiveness) of this new instrument.

(3) To compare the QL of adolescents with migraine, adolescent subjects with no-migraine headache, and control subjects without headache complaints.

(4) To explore the association between within-subject-variation of headache activity across time and parallel within-subject-variation of QL as measured with the QLH-Y.

(5) Previous studies in the research line "Stress and migraine" indicated a close relation between certain personality variables, experienced stress and migraine. These same variables might be related to QL as well. As such, personality variables or the experience of stress might spuriously inflate or influence the relationship between headache and QL. Therefore, another aim of this study was to explore the potential moderating or confounding effect of these variables on the relation between headache and QL in adolescents with recurrent headache or migraine.

General design of the study

(1) After the QL domains were demarcated. the initial item pool was generated. Previously identified subjects with migraine were interviewed to generate items for the domain Functional Status. To cover the other QL domains, items from existing domain-specific measurement scales were selected. Answering categories were assigned to all items. Then, all items were reviewed and adapted. After a pilot study was performed, a preliminary version of the QLH-Y was constructed. This preliminary version of the QLH-Y was then completed by

all students of a secondary school. Factor analyses and homogeneity analysis on these data together with the response from the students on the format and content of the items resulted in the final version of the QLH-Y (described in chapter 4).

(2) A new study sample was selected: Sixty-four subjects with recurrent headache (of which 38 were diagnosed as having migraine) and 96 matched controls were recruited from the total population of two secondary schools (*N*=1566). These subjects completed the QLH-Y four times with 1-week intervals. Simultaneously, parents/caretakers completed a parent version of the QLH-Y. Based on data from this study, the psychometric properties of the QLH-Y were evaluated (chapter 5).

(3) As part of the study as described in chapter 5, subjects with recurrent headache kept a diary. In this diary, headache activity, experienced stress and medication were recorded. The relation between changes in headache activity and changes in QL was examined employing these data (chapter 6).

(4). Six months after study 2 was initiated, a follow-up was performed. All subjects from the study as described in chapter 5 completed the QLH-Y a fifth time. In addition, they completed a neuroticism inventory as a measure for trait negative affectivity. Data from the diary (see chapter 6) regarding headache activity and experienced stress, were used to explore the moderating effect of negative affectivity and experienced stress on the relation between headache and QL in adolescents (chapter 7).

Chapter 4[1].

ITEM SELECTION AND SCALE CONSTRUCTION OF THE QLH-Y

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Abstract

We developed a new Quality of Life (QL) measurement scale for adolescents between 12 and 18 years of age with chronic headache or migraine. The Quality of Life Headache-Youth (QLH-Y) is a 71-item (69 Likert-format items and two visual analogue scales) QL measurement scale. It assesses an individual's QL in six QL domains. This study (n=223) was aimed at item selection and scale construction. Thirteen subscales were developed to cover the four QL domains Psychological Functioning, Functional Status, Physical Functioning and Social Functioning. The QL domains Satisfaction with Life in General and Satisfaction with Health are covered by two visual analogue scales. Internal consistency of nearly all subscales was satisfactory.

Introduction

Health-related quality of life (QL) is now regarded as an important outcome variable of medical treatment, besides disease-specific measures [1, 2, 3]. The QL is now commonly perceived as a multidimensional concept which encompasses psychological and social well-being, physical, role and social functioning, health perception and pain [1, 4]. It is often reported that adult migraine patients show more anxiety, neuroticism and depression [5]. The risk to develop Major Depression Disorder is reported to be increased four-fold and Panic Disorder twelve-fold for young adults with migraine [6]. Furthermore, children with headache show less social participation and more somatic complaints. In addition, they are less happy at school and are more anxious then children with no pain. The data of Andrasik and co-workers [7] revealed higher scores on depression, somatic complaints and trait anxiety for adolescent headache sufferers.

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In current QL studies, it has been demonstrated that adult migraine patients have a lower QL than the normal population and no-headache patients, such as those with arthritis and diabetes mellitus. The lower QL was not only associated with pain, but also with poor role functioning, mental health, and social functioning [8, 9]. Recent empirical findings have indicated that a low QL score may also be found in juvenile migraine patients [10, 11]. Research in this area has been impeded, however, by the lack of an adequate QL measure suitable for application in this group. Although numerous QL-measurement scales are available for adults, these scales are not readily applicable to adolescents, as they aim explicitly at an adult population (more than 18 years of age) and enjoy a vocabulary which is inappropriate for adolescents. For adolescents a self-report measure is preferable. Therefore, the purpose of this study was to develop a self-administered instrument for the measurement of QL in young patients with recurrent headache, in particular migraine. Such a measure must be sensitive to the actual presence of headache or migraine and suitable in a repeated measurement design (e.g. when employed in clinical trials).

This paper reports on the development of a QL instrument designed to be used in adolescents with recurrent headache or migraine. The conceptualization of QL as described above was operationalized in the following QL domains: (a) Psychological Functioning; (b) Functional Status; (c) Physical Functioning; (d) Social Functioning; (e) Satisfaction with Life in General and (f) Satisfaction with Health. The study describes generation, selection and adaptation of items, item reduction and scale construction. Findings related to internal consistency reliability are presented. Further, in this study the effect of the position of a global visual analogue scale relative to other items in the test results was explored.

Method

Construction of the initial item pool

To construct a first version of the questionnaire, first, the format of the questionnaire was determined. A visual analogue scale format was chosen to cover the QL domains Satisfaction with Life in General and Satisfaction with Health. These visual analogue scales were constructed as 100 mm. horizontal lines with "completely satisfied" and "completely dissatisfied" as anchor points on the left and right ends of the line, respectively. Since visual analogue scales are not previously employed in QL research in adolescents, these anchor points were chosen by the authors. The questions to be answered on these visual analogue scale were stated as follows:

"How satisfied or dissatisfied were you with life in general last week?" for the QL domain Satisfaction with Life in General and "How satisfied or dissatisfied were you with your health last week?" for the QL domain Satisfaction with Health. For the items to cover the other QL domains, a Likert-format was adopted.

Second, to construct an initial item pool of suitable items, two different strategies were adopted, (1) items were derived and adapted from existing questionnaires and (2) based on findings from earlier research on the target population and on interviews with identified adolescent migraine headache patients new items were generated. Following the first strategy, to construct questionnaire modules covering the QL domains Psychological Functioning, Physical Functioning and Social Functioning, we selected commonly employed existing measurement scales that can be considered to tap these QL domains. From these scales that had previously been shown to be valid and reliable, items were derived and adapted to be applicable in the target population of this study. To cover the QL domain Psychological Functioning, items were based on the State-Trait Anxiety Inventory-Youth (STAI-Y, Dutch translation [12]), from the Dutch translation of the Profile of Mood States (POMS [13]), and from the "Depressie Vragenlijst voor Kinderen" (DVK: Dutch Depression Questionnaire for Children [14]. To counterbalance for the excess weight of negatively stated depression items in this domain of the initial item pool, we added 10 positively stated items which had an antonym content similar to a number of DVK items. To cover the QL domain Social Functioning, items were derived and adapted from the Groningen Questionnaire for Social Behaviour [15]. To cover the QL domain Physical Functioning, items were derived and adapted from Wisniewski's Children's Psychosomatic Checklist [16]. Following the second strategy, to generate items to cover the QL domain Functional Status, disease specific items had to be developed to investigate the level of impediment caused by headache and migraine symptoms. To actualize and extend our knowledge on the effects of chronic headache or migraine on an adolescents' functional status based on earlier research [17, 18, 19] and clinical work, we interviewed five young migraine patients (three girls, aged 13, 15 and 17 years and two boys 14 and 16 years old). Based on these interviews, and on our prior experience with adolescent headache and migraine patients, items were generated on the perceived interference of the headache with daily activities.

Then, four response categories were assigned to all Likert-format items (0, "rarely or never", 1, "sometimes", 2, "often", 3, "very often or always" *or* 0, "not at all", 1, "a little", 2, "quite a bit", 3, "very much"). Additionally, for reasons of future item evaluation, in this preliminary version of the questionnaire a fifth category ("?") was added to all Likert-format items. This answering category offered the subjects an opportunity to indicate that the item was unclear or difficult to understand. For all the

items, a "How did you feel last week?" format was chosen, because a week is a common time frame in QL questionnaires.

Finally, the visual analogue scales and their anchor points and all Likert-format items were reviewed by a panel of eight 12 to 17-year-old youngsters, by an experienced child psychologist, and by a senior secondary school teacher. Based on the oral and written comments of the panellists, the teacher and the child psychologist, changes were made in the verbal level of the items to make them more appropriate for adolescents of this age. A total of 127 constructed and selected Likert-format items and the visual analogue scale Satisfaction with Life in General were included in the first, preliminary, version of the QLH-Y which was used in this study.

Subjects

All the students (*N*=229) at one secondary school ("MAVO") in a small Dutch town (20,000 inhabitants) participated in this study. The "MAVO" secondary school can be regarded as requiring an average level of intelligence and aptitude, compared with other school types in the Netherlands. All the students who attended the school and their parents/guardians were informed about the study and asked to participate. None of the students or parents refused to participate. Because of a 3% absence rate at the time of testing, a response rate of 97% was achieved. Mean age of the subjects (*n*=223, 43% boys and 57% girls) was 13.9 years (SD=1.3 years, range=12-18 years).

Procedure

Students completed the first version of the QLH-Y simultaneously in class. The goal of the study was explained (i.e. to develop a QL measurement scale for adolescents), followed by standard oral instructions, given by one of the researchers (not by the students' teachers), on how to fill out the questionnaire. At this stage they were given the opportunity to withdraw from the study. To prevent any answering bias [20], the more specific purpose of the questionnaire (i.e. to develop a questionnaire to measure QL in adolescents with chronic headache or migraine) was not explained. Students were asked to reply with a question mark if an item was unclear or difficult to understand.

Only the visual analogue scale Satisfaction with Life in General was included in this study. To study the extent to which scores on a global visual analogue scale may be biased by their position in relation to other, more detailed scales, all the subjects

were randomly assigned to two variants of the first version of the QLH-Y. One version started with the global visual analogue scale and the other ended with it.

Analyses

To obtain data on item response rates and on the percentage of items which were not clearly understood (indicated by a question mark reply), frequency tables were computed for all the separate items. Because of the exploratory nature of the analyses, Principal Component Analyses (PCA) were chosen to reveal the underlying factor structure of the QLH-Y. It was assumed that significant intercorrelations of the subscales were unavoidable, so factors were rotated obliquely to obtain a set of subscales which would validly reflect the item content and would be readily interpretable. Items designed or selected to cover the same QL domain were factor analysed together, except for the QL domain Psychological Functioning. As the number of items which covered this domain was relatively large compared to the number of subjects in this study, the 85 items selected to cover this QL domain were factor analysed in two subsets. One subset contained the 43 POMS and STAI items (factor analysis 1) and another subset contained the 42 DVK and added items (factor analysis 2). To construct subscales, subsets of items were selected with a loading of 0.40 or more, without any significant crossloadings on other factors. Homogeneity analyses were then performed on these subsets of items to achieve an optimal item reduction with maximum internal consistency. Subscale scores were then computed by summarizing the item scores within one subscale. Any missing values were substituted by the mean of the subjects' non-missing items under the same subscale, provided that the missing items did not exceed 25% value rate (otherwise the subscale was ascribed a missing value). To explore the size of the interrelations, Pearson Product Moment correlations were computed between all the sum scores of the subscales. A one-way analysis of variance was performed to investigate whether the position of the visual analogue scale (at the beginning or at the end) had any significant effect on the visual analogue scale scores.

Results

Three subjects who had not completed more than 10% of the items, were removed from the data set. Furthermore, eight out of the 127 original items were removed because more than 5% of the subjects had replied with a question mark (item not understood). This left 119 items. The two factor analyses within the QL domain

Psychological Functioning resulted in 10 interpretable factors. Factor analysis 1 (originally the POMS and STAI items) yielded five factors which were labelled *Stress*, *Harmony*, *Anger/Hostility*, *Fatigue* and *Strength/Vitality*. Factor analysis 2 (originally the DVK and added items) also yielded five factors, which were labelled *Depression*, *Cheerful Mood/Good Humour*, *Negative Attribution*, *Fear of Failure* and *Optimism about the Future*. Factor analysis 3 (the QL domain Functional Status, 18 items) resulted in two factors: *Headache Impact on Daily Activities* and *Headache Impact on Leisure Activities*. Factor analysis 4 (the QL domain Social Functioning, 14 items) resulted in three factors: *Functioning at Home and at School*, *Social Interaction with Peers* and *Social Interaction with Brothers and Sisters*). Factor analysis 5 (the QL domain Physical Functioning, 10 items) resulted in one factor labelled *Somatic Symptoms other than Headaches*. These five factor analyses therefore resulted in 16 different factors. Three factors were then excluded from any further analyses because they did not comply with the QL definition described above (the factors *Anger/Hostility* from factor analysis 1 and the factors *Negative Attribution* and *Fear of Failure* from factor analysis 2). Homogeneity analyses were performed on the subsets of items with a loading of 0.40 or more on one of the 13 remaining factors and without any significant crossloadings on other factors. This item reduction, which combined maximum internal consistency with a minimum number of items, resulted in 13 subsets of items to cover the four QL domains Psychological Functioning, Functional Status, Physical Functioning and Social Functioning.

A total of 58 out of the 127 items were removed (eight because of poor response and 50 during scale construction), which left 69 items for the second version of the QLH-Y. After the addition of the two visual analogue scales *Satisfaction with Life in General* and *Satisfaction with Health* to cover the QL domains with the same names, this resulted in the second version of the QLH-Y. Table 1 presents the names which were assigned to the different subscales, the number of items in the subscales, the means of the scale totals divided by the number of items of the subscale, the standard deviations of the subscales divided by the number of items, Cronbach's alpha measures for internal consistency, and examples of the items.

Table 1. Constructed subscales after factor analyses and analyses of homogeneity: names of subscales, number of items (nx), means divided by the number of items (M/nx), standard deviations divided by the number of items (SD/nx), Cronbach's alphas (alpha) and examples of items.

QL domain (*n*=223)	Name of subscale	Number of items (nx):	M/nx	SD/nx	alpha	Examples of items:
Psychological Functioning	(1) Stress	8	.62	0.47	0.85	I was feeling nervous. I was feeling worried.
	(2) Harmony	5	1.88	0.55	0.82	I was feeling at ease. I was feeling satisfied.
	(3) Fatigue	4	0.82	0.65	0.80	I was feeling exhausted. I was feeling tired.
	(4) Strength/Vitality	3	1.69	0.67	0.76	I was feeling full of energy. I was feeling strong.
	(5) Depression	6	0.55	0.47	0.74	I was feeling hopeless. I did not sleep well.
	(6) Cheerful Mood/Good Humour	5	1.41	0.48	0.73	I was feeling cheerful. When I woke up, I thought about the nice things to come.
	(7) Optimism about Future	3	1.47	0.78	0.82	I thought that later everything will be fine. I thought that I will be happy in the future
Functional Status	(8) Headache Impact on Daily Activities	8	0.73	0.66	0.87*	My headache interfered with -my homework.
	(9) Headache Impact on Leisure Activities	6	0.57	0.63	0.82*	-going out. -my hobbies.
Physical Functioning	(10) Somatic Symptoms other than Headache	9	0.59	0.52	0.84	I was troubled by belly pain. I was troubled by dizziness.
Social Functioning	(11) Functioning at Home and at School	6	1.79	0.53	0.68	I got on well with (one of) my parents. I managed to finish my (home)work in time.
	(12) Social Interaction with Brothers and Sisters	3	0.26	0.77	0.66	I got on well with my brothers and sisters. I had an argument with (one of) my brothers or sisters.
	(13) Social Interaction with Peers	3	1.86	0.74	0.72	I got on well with youngsters of my own age. I could talk to a friend about personal things or problems.
Satisfaction with Life in General	(14) Visual analogue scale: "Satisfaction with Life in General"	1	68.68	23.75		How satisfied or dissatisfied were you with your life in general, last week?

*Subjects without headache in the week previous to completion of QLH-Y were excluded from analyses on the QL subdomain "Functional Status".

Table 2. Pearson intercorrelations of the subscales

n=223	(1) Stress	(2) Harmony	(3) Fatigue	(4) Strength/ Vitality	(5) Depres-sion	(6) Cheerful Mood/ Good Humour	(7) Optimism about Future	(8) Headache Impact on Daily Activities	(9) Headache Impact on Leisure Activities	(10) Somatic Symptoms other than Headache	(11) Functionin g at Home and at School	(12) Social Interaction with Brothers and Sisters	(13) Social Interac-tion with Peers	(14) Visual Analogue Scale "Satisfaction with Life in General"
(1) Stress	1.00													
(2) Harmony	-0.26	1.00												
(3) Fatigue	0.42	-0.20	1.00											
(4) Strength/ Vitality	-0.07	0.45	-0.21	1.00										
(5) Depression	0.60	-0.31	0.39	-0.15	1.00									
(6) Cheerful Mood/Good Humour	-0.21	0.65	-0.24	0.53	-0.36	1.00								
(7) Optimism about Future	-0.03	0.36	-0.09	0.41	-0.10	0.40	1.00							
(8) Headache Impact on Activities of Daily Life	0.43	-0.07	0.32	0.05	0.44	-0.01	0.01	1.00						
(9) Headache Impact on Leisure Activities	0.39	-0.02	0.20	0.16	0.34	0.13	0.10	0.70	1.00					
(10) Somatic Symptoms other than Headache	0.48	-0.17	0.40	-0.09	0.71	-0.21	-0.06	0.62	0.47	1.00				
(11) Functioning at Home and at School	-0.15	0.45	-0.19	0.23	-0.24	0.42	0.31	-0.09	-0.02	-0.18	1.00			
(12) Social Interaction with Brothers and Sisters	-0.04	0.16	-0.12	0.08	-0.10	0.11	0.10	-0.09	-0.05	-0.07	0.17	1.00		
(13) Social Interaction with Peers	0.05	0.29	-0.03	0.42	0.12	0.36	0.20	0.13	0.18	0.01	0.04	0.04	1.00	
(14) Visual Analogue Scale "Satisfaction with Life in General"	-0.24	0.40	-0.21	0.18	-0.29	0.42	0.21	0.02	0.00	-0.19	0.29	0.05	0.12	1.00

Correlations less than 0.18 are not significant on p=0.001, two-tailed.

Apart from the two visual analogue scales, the minimum number of items per subscale was three, with a maximum of nine. Means of subscales of the QL domain Psychological Functioning varied systematically. As can be expected from a normal population as tested in study 1, the mean scores on positively labelled subscales were consistently higher than those on negatively labelled subscales. All subscales, except *Functioning at Home and at School* and *Social Interaction with Brothers and Sisters*, showed a coefficient of internal consistency (Cronbach's alpha) of above 0.70, which was considered satisfactory [21].

As an index of the relation between the subscales, Pearson's product moment intercorrelations were computed between the subscales. As can be seen from Table 2 and following Cohen's criteria [22], *Depression* displayed a high correlation with *Stress* (.60) and *Cheerful Mood/Good Humour* with *Harmony* (.65). *Somatic Symptoms other than Headache* was highly correlated with *Depression* (.71) and *Headache Impact on Daily Activities* (.62), and displayed a moderate correlation with *Headache Impact on Leisure Activities* (.47) and *Fatigue* (.40).

The analysis of variance performed on the visual analogue scale *Satisfaction with Life in General* did not show any significant effect of the position of the visual analogue scale, i.e. at the beginning or at the end of the questionnaire. All standard deviations were found to be between 0.5 and 0.8 on a scale score range from 0 to 3.

Discussion

This study was performed to develop a new QL measurement scale for adolescents, designed primarily for use by youngsters with severe headaches or migraine. The new questionnaire, the QLH-Y, consisted of 69 Likert-format items divided over 13 subscales to cover the QL domains Psychological Functioning, Functional Status, Physical Functioning and Social Functioning together with two visual analogue scales to cover the QL domains Satisfaction with Life in General and Satisfaction with Health. All of the multiple-item subscales, except for two of the three Social Functioning subscales, showed satisfactory internal consistency (Cronbach's alpha over 0.70). The subscales *Somatic Symptoms other than Headache*, *Headache Impact on Daily Life*, *Stress* and *Depression* demonstrated high intercorrelations, which is in accordance with the findings of Wisniewsky and colleagues [16], who used similar measures. Furthermore, in our study, the subjects who experienced feelings of harmony also showed a tendency to report feelings of strength and vitality and to be in good humour.

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Chapter 5[1].

PSYCHOMETRIC PROPERTIES OF THE QLH-Y

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Abstract

This study (*n*=159) was conducted to evaluate stability, parent-youth agreements, intercorrelations and responsiveness of the subscales of the Quality of Life Headache-Youth questionnaire (QLH-Y). Stability coefficients were between 0.47 and 0.72 for the 1-week interval and between 0.31 and 0.60 for the 6-months interval. Parent-youth agreements were found to be comparable with what is reported in the literature in this age group. Nearly all of the QLH-Y subscales appeared to be sensitive to differences between subjects with recurrent headache and no-headache subjects. The quality of life (QL) domain Functional Status was most sensitive for the occurrence of a recent headache attack. Implications of these findings for reliability and validity of the questionnaire are discussed.

Introduction

This study evaluated the stability, parent-child agreement, intercorrelations, and responsiveness of the QLH-Y subscales. Based on these parameters, inferences on test-retest and interrater reliability are presented and discussed. For this purpose three subgroups of adolescents (i.e. migraine, no-migraine headache, and no-headache), completed the QLH-Y at five different times. At four of these five measurement points, simultaneously the parents of the subjects completed a parent version of the QLH-Y.

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[1] Published as section of the paper: *A quality of life instrument for adolescents with chronic headache: Cephalalgia 1996; 16: 183-196.*

Method

To assess the stability of the scales, the subjects' scores on the QLH-Y were obtained at five different time points. Observer reports from parents/guardians on their children's QL were obtained to gain an insight into parent-youth agreement on the adolescents' QL. To obtain measures for construct validity of the questionnaire, the QLH-Y's responsiveness for migraine or other headache diagnoses and for actual headache occurrence was evaluated. To do so, QLH-Y scores were obtained from three samples of adolescents: one sample of subjects diagnosed by a neurologist as having migraine headaches based on the criteria of the International Headache Society; one sample of subjects with frequent headaches but diagnosed by the neurologist as non-organic, no-migraine headache; and one sample without any headache symptoms.

Subjects

In cooperation with the Rotterdam Municipal Health Service, all the students at two comprehensive schools were screened for headaches or migraine using a short *ad-hoc* questionnaire, to recruit a sample of adolescents with migraine, a sample of adolescents with no-migraine headaches, and a "no headache" sample in the same age group and with the same sex distribution. One of these schools was for "Technical Education and Lower Economic and Administrative Education" (N=917), the other was for Lower and Higher General Secondary Education and Pre-University Education ("VWO") (N=649). Both schools were situated in the same medium-sized Dutch town (nearly 60,000 inhabitants). The questionnaire asked the students whether they had been bothered by headaches at any time and, if they had, since when and how often. They were then asked whether their headaches had been diagnosed as migraine by a doctor, or whether their headache symptoms resembled migraine. For this purpose, a short description of occurrence and its symptoms was given. Students were included in the headache or migraine subgroup if: (a) headache symptoms were present which had ever been diagnosed by a physician as "migraine" or which were considered by the subjects to resemble the symptoms in the migraine description; (b) if the headache frequency was at least twice a month; (c) if the headaches had been present for at least one year; and (d) if they were aged between 12 and 18 years.

Of the 1566 students, 1515 (96.7%) completed our *ad-hoc* headache and migraine screening questionnaire. From the group of students who had ever been bothered by headaches (N=981), 129 respondents fulfilled the criteria for inclusion in the headache or migraine subgroup. These 129 subjects were asked to participate

further in the study, together with their parents. Sixty-four students, 42 girls (66%) and 22 boys (34%) (mean age 14.4 years, SD=1.5) and their parents/guardians agreed to participate. All the selected subjects with headache, probably migraine, were seen by a neurologist for an expert diagnosis, which resulted in 38 migraine patients versus 20 no-migraine headache patients. Six subjects did not attend their appointment at the doctor's office. Consequently, they were excluded from the statistical analyses in which "Diagnosis Group" was a variable of interest.

From the subjects who were never bothered by headaches (N=534), a no-headache sample was selected (n=104) with a similar distribution of age, sex, and school type to the no-migraine headache sample and the migraine sample. These students and their parents were asked to participate further in the study. Ninety-five headache-free subjects, 63 girls (66%) and 32 boys (34%) (mean age: 14.4, SD=1.5) and their parents/guardians agreed. Written informed consent was obtained from all the parents of the selected subjects.

The control subjects were not seen by a doctor, neither did they keep a headache diary. To assure that control subjects factually had been free from headache, one item added to the QLH-Y asks the subjects to comment on the incidence of headache the previous week. From the 96 control subjects, 16% reported more than two headaches in the 4-week research period. From the 64 selected headache subjects, four reported a headache frequency of two or less during the four weeks. In other words, 13% of the subjects were apparently appointed to the wrong study group (i.e. headache subjects versus no-headache controls).

Instruments

QLH-Y

After the first study described in chapter 4, 69 multiple choice items remained in the second version of the QLH-Y. Both the visual analogue scale *Satisfaction with Life in General* and the visual analogue scale *Satisfaction with Health in General* were included in the second version of the QLH-Y. As the results of our first study did not suggest that the multiple choice items had biased the visual analogue scale scores, the visual analogue scales could be positioned as seemed most convenient. The visual analogue scale *Satisfaction with Life in General* was placed at the beginning of the questionnaire, while the visual analogue scale *Satisfaction with Health* was placed halfway through the questionnaire, preceded by the items on Psychological Functioning and followed by the items on Physical Functioning. One item was added that asked about the occurrence of a headache in the week prior to completion of the QLH-Y, so that we could compare the subjects who had a headache in the week

before completion of the QLH-Y to the subjects without a recent headache. This item, which resulted in the variable "Presence of a Headache Prior to Completion of the QLH-Y", did not form part of any of the QLH-Y subscales.

QLH-P

For this study, a parent version of the QLH-Y was developed (the QLH-P). The format of all the items in the parent version was as follows: "To what degree do you think that your son/daughter felt, thought about, or was bothered by ..... last week?". All the items in the QLH-P had the same content as the items in the youth version of the questionnaire (QLH-Y), except the three residing under the subscale *Optimism about the Future.* The original items "I thought that I would be happy in the future"; "I thought later everything will be fine"; "I thought that later I would have a nice house and a good job and be able to earn enough money" were substituted by two global items on how the parents thought their children perceived the future: "My child was optimistic about the future" and "My child was pessimistic about the future". Response categories in the QLH-P were identical to the QLH-Y answer categories.

Procedure

The 159 subjects were asked to complete the QLH-Y five times. The interval between two subsequent measurements during the first four measurements (called Week 0, Week 1, Week 2, and Week 3) was one week, while the interval between the first and the fifth measurement (called Week 26) was six months. At Week 0, 1, 2, and 3, one of each subject's parents was asked to complete the parent-version (QLH-P) of the QLH-Y, simultaneously with, but independently of their son or daughter. All the questionnaires were posted with a prestamped envelope enclosed, in which questionnaires could be returned. To obtain a maximum degree of independent completion of the questionnaires, QLH-P and QLH-Y were sent separately with return envelopes enclosed. All the subjects were given a 30 Dutch guilders (about $ 15) incentive for their participation in this investigation.

Analyses

To obtain data on the stability of the subscale scores, intraclass correlations [1] were computed between the subscale scores at Week 0 and the subsequent scores at Week 1, Week 2, Week 3, and Week 26.

As a measure of parent-youth agreement, intraclass correlations were computed on the data obtained at Week 0, Week 1, Week 2, and Week 3: The sum scores on the subscales obtained on the QLH-Y were evaluated against the sum scores on the QLH-P subscales.

To obtain indications for the validity of the QLH-Y, regression analyses were performed with the broad QLH-Y subscales Satisfaction with Life in General and Satisfaction with Health as dependent variables. The scores on the other QLH-Y subscales were entered as independent variables. The degree to which scores on these latter, specific, QLH-Y subscales predict scores on the broad QL domains Satisfaction with Life in General and Satisfaction with Health was then used to test the construct-validity of the visual analogue scales.

To study the responsiveness of the QLH-Y subscales for medical diagnosis of migraine or other headache and for actual headache occurrence, for all the data available (Week 0 to Week 26) and for each QLH-Y subscale, repeated measures analyses of variance were performed with "Diagnosis Group" and "Presence of a Headache Prior to Completion of the QLH-Y" as independent variables. The variables age and gender were treated as covariates and linear time effects over the five measurements were evaluated. The variable "Diagnosis Group" distinguished between three samples of adolescents: the subjects with headache diagnosed as migraine (n=38), the subjects with headache diagnosed as no-migraine headache (n=20) and the subjects without headaches ever (n=95). The variable "Presence of a Headache Prior to Completion of the QLH-Y" represented the scores on the item added to the questionnaire that asked the subjects whether they had experienced a headache during the previous week.

The SPSS-pc software was used for all the data analyses.

Results

Of the 159 subjects who participated in this study, 154 (97%) filled out and returned the questionnaire at Week 0, 153 (96%) at Week 1 and at Week 2, 155 (97%) at Week 3, and 135 (85%) at Week 26.

Except for the two headache impact subscales, Table 1 displays intraclass correlations between the QLH-Y scores at Week 0 and the QLH-Y scores at Week 1, Week 2, Week 3, and Week 26 for all subjects. For the two headache impact subscales, only subjects in the migraine and no-migraine samples were used (n=64). criteria [3], all one- and two-week stability coefficients represented large degrees of association (r>0.50), except the two-week stability coefficients for the two visual analogue scales, where moderate degrees of association were found. With respect to

the 3-week stability coefficients, besides the two visual analogue scales, those of the subscales *Fatigue* and *Somatic Symptoms other than Headache* were of moderate size. Three of the 26-week stability coefficients represented large degrees of association between the two measurements (*Optimism about Future, Functioning at Home and at School, Social Interaction with Peers*, and *Social Interaction with Brothers and Sisters*), whereas the other 26-week stability coefficients were found to be of moderate size.

Table 1. Stability coefficients: intra class correlations between scores on subscales at Week 0 with scores on subscales at Week 1 (one week after Week 0 completion), Week 2 (two weeks after Week 0), Week 3 (three weeks after Week 0), and Week 26 (26 weeks after Week 0)

Subscale *n*=154 (except subscales 8 and 9: n=64)	Intraclass correlations: Week 0 with Week 1 (*n*=153)	Intraclass correlations: Week 0 with Week 2 (*n*=153)	Intraclass correlations: Week 0 with Week 3 (*n*=154)	Intraclass correlations: Week 0 with Week 26 (*n*=135)
(1) Stress	0.61	0.60	0.54	0.41
(2) Harmony	0.55	0.55	0.52	0.49
(3) Fatigue	0.57	0.55	0.30	0.31
(4) Strength/Vitality	0.60	0.56	0.55	0.47
(5) Depression	0.55	0.56	0.50	0.47
(6) Cheerful Mood/Good Humour	0.59	0.54	0.55	0.48
(7) Optimism about Future	0.71	0.62	0.57	0.56
(8) Headache Impact on Activities of Daily Life	0.53	0.64	0.55	0.42
(9) Headache Impact on Leisure Activities	0.54	0.66	0.56	0.36*
(10) Somatic Symptoms other than Headache	0.60	0.61	0.46	0.60
(11) Functioning at Home and at School	0.72	0.63	0.63	0.53
(12) Social Interaction with Peers	0.65	0.59	0.58	0.55
(13) Social Interaction with Brothers and Sisters	0.72	0.65	0.66	0.56
(14) VAS "Satisfaction with Life in General"	0.47	0.44	0.41	0.41
(15) VAS "Satisfaction with Health"	0.50	0.49	0.44	0.42
Mean of correlation subscales (via Fisher-z transformations)	0.60	0.58	0.52	0.47

All correlations printed: significant on p=0.001, except *: p=0.004. For subscales 8 and 9, only the subjects familiar with headache were included (n=64).

Table 2. Interrater agreement: intraclass correlations (*r*) between subject scores at QLH-Y and parent scores on a parent version of the QLH-Y (QLH-P) at Week 0, Week 1, Week 2, and Week 3.

Subscale: (*n*=159)	Week 0 subject-parent icc correlations	*p*- -value	Week 1 subject-parent icc correlations	*p*- value	Week 2 subject-parent icc correlations	*p*- value	Week 3, subject-parent icc correlation	*p*- value
(1) Stress	0.48	0.000	0.45	0.000	0.46	0.000	0.26	0.001
(2) Harmony	0.31	0.000	0.23	0.002	0.46	0.000	0.48	0.000
(3) Fatigue	0.30	0.000	0.26	0.001	0.42	0.000	0.31	0.000
(4) Strength/Vitality	0.28	0.000	0.17	0.016	0.32	0.000	0.28	0.000
(5) Depression	0.43	0.000	0.33	0.000	0.35	0.000	0.30	0.000
(6) Cheerful Mood/Good Humour	0.27	0.000	0.25	0.001	0.37	0.000	0.33	0.000
(7) Optimism about Future	-0.13	0.948	-0.20	0.994	-0.18	0.989	-0.20	0.994
(8) Headache Impact on Activities of Daily Life	0.47	0.000	0.43	0.000	0.18	0.085	0.44	0.000
(9) Headache Impact on Leisure Activities	0.31	0.007	0.43	0.000	0.03	0.411	0.12	0.188
(10) Somatic Symptoms other than Headache	0.39	0.000	0.48	0.000	0.40	0.000	0.26	0.000
(11) Functioning at Home and at School	0.36	0.000	0.40	0.000	0.48	0.000	0.41	0.000
(12) Social Interaction with Peers	0.44	0.000	0.41	0.000	0.51	0.000	0.51	0.000
(13) Social Interaction with Brothers and Sisters	0.47	0.000	0.65	0.000	0.69	0.000	0.58	0.000
(14) VAS "Satisfaction with Life in General"	0.33	0.000	0.34	0.000	0.31	0.000	0.31	0.000
(15) VAS "Satisfaction with Health"	0.40	0.000	0.48	0.000	0.62	0.000	0.58	0.000
Mean of correlation subscales QLH-P with subscales QLH-Y (via Fisher-z transformation)	0.38	0.000	0.40	0.000	0.38	0.000	0.35	0.000

Again we determined the number of findings by chance (p<.01 and protection level=0.05) [2]: In our case three out of the 60 stability coefficients could reach the 0.05 level of significance. Following Cohen's criteria, significant (p<.01) subject-parent agreements of small size were found for one of the four measurements of the subscales *Stress, Harmony,* and *Fatigue* and for two of the four measurements of the subscales *Strength/Vitality* and *Cheerful Mood/Good Humour.* Large degrees of association between parent-report and self-report were found for two of the four measurements of the subscale *Social Interaction with Peers* and the *Visual Analogue Scale Satisfaction with Health.* No significant parent-youth agreements were found for any of the four measurements of the subscale *Optimism about future*, for two of the four measurements of the subscale *Headache Impact on Leisure Activities* and for one of the four measurements of the subscale *Strength/Vitality.* Other subject-parent agreements represented moderate degrees of association. Means of the correlations between the means of the subscale scores on the QLH-Y and QLH-P (via Fisher-z transformations) was 0.38 at Week 0; 0.40 at Week 1; 0.38 at Week 2; and 0.35 at Week 3 (see Table 2).

The two linear regression analyses with the dependent variables *Satisfaction with Life in General* and *Satisfaction with Health* (visual analogue scales) and the 13 QLH-Y subscales as independent variables, showed that 44% of the variance of the visual analogue scale *Satisfaction with Life in General* could be accounted for by the two QLH-Y subscales *Stress* and *Harmony* (regression analysis, method stepwise, *p*-in 0.05; *p*-out: 0.100; adjusted *R*-square=0.44; *F*=22,15; significance: *p*=0.000). No other subset of the QLH-Y subscale scores explained a significant part of the variance of the scores on the visual analogue scale *Satisfaction with life in general.* For the visual analogue scale *Satisfaction with Health*, only one subscale entered the regression analysis. The subscale *Somatic Symptoms other than Headache* accounted for 27% of the variance in this visual analogue scale (regression analysis, method stepwise, *p*-in 0.05; *p*-out: 0,100; adjusted *R*-square=0.27; *F*=21,25; significance: *p*=0.000).

Table 3. Means (standard deviations) of QLH-Y subscales, three subgroups: (1) subjects with no migraine headache (n=20); subjects with migraine (n=38); no-headache controls (n=95), means over all five measurement.

n=159 Subscale:	No-migraine headache subjects, means (SD)	Migraine subjects, means (SD)	No-Headache control subjects, means (SD)
(1) Stress	0.65 (0.64)	0.70 (0.49)	0.35 (0.36)
(2) Harmony	1.39 (0.66)	1.79 (0.67)	2.13 (0.63)
(3) Fatigue	0.84 (0.62)	0.70 (0.57)	0.51 (0.56)
(4) Strength/Vitality	1.45 (0.72)	1.55 (0.75)	1.85 (0.79)
(5) Depression	0.70 (0.59)	0.60 (0.40)	0.37 (0.40)
(6) Cheerful Mood/Good Humour	1.55 (0.61)	1.64 (0.70)	1.90 (0.67)
(6) Optimism about Future	1.27 (0.96)	1.36 (0.96)	1.35 (0.80)
(7) Headache Impact on Daily Activities	0.67 (0.56)	0.48 (0.52)	- (-)
(9) Headache Impact on Leisure Activities	0.49 (0.45)	0.45 (0.56)	- (-)
(10) Somatic Symptoms other than Headache	0.71 (0.53)	0.64 (0.38)	0.39 (0.34)
(11) Functioning at Home and at School	1.57 (0.57)	1.80 (0.60)	1.80 (0.60)
(12) Social Interaction with Peers	1.82 (0.66)	1.99 (0.74)	1.97 (0.74)
(13) Social Interaction with Brothers and Sisters	1.37 (0.72)	1.47 (0.93)	1.56 (0.74)
(14) VAS "Satisfaction with Life in General"	71.84 (26.45)	75.21 (25.57)	85.11 (16.74)
(15) VAS "Satisfaction with Health"	67.93 (25.15)	75.54 (25.51)	84.29 (21.30)

Table 4. Analyses of variance, repeated measurements: percentages explained variance (squared eta). QLH-Y subscales as dependent variables.

Subscale: (n=159)	Significance of effects of covariate "gender" (p-values)	significance of effects of covariate "age" (p-values)	Effects of "Diagnosis Group" * squared eta	Effects of "Diagnosis Group" * significance (p-value)	Linear Time effects Week 0 to Week 3 squared eta	Linear Time effects Week 0 to Week 3 significance (p-value)	Interaction linear time effect and "diagnosis group" Week 0 to Week 3 squared eta	Interaction linear time effect and "diagnosis group" Week 0 to Week 3 significance (p-value)
(1) Stress	0.002	0.803	0.13 (H)	0.000	0.12	0.000	0.02	0.170
(2) Harmony	0.651	0.369	0.10 (NH)	0.000	0.01	0.156	0.04	0.937
(3) Fatigue	0.681	0.391	0.06 (H)	0.003	0.15	0.000	0.05	0.017
(4) Strength/Vitality	0.011	0.308	0.06 (NH)	0.003	0.01	0.178	0.00	0.655
(5) Depression	0.018	0.667	0.13 (H)	0.000	0.08	0.001	0.01	0.500
(6) Cheerful Mood/Good Humour	0.777	0.075	0.06 (NH)	0.002	0.02	0.111	0.00	0.988
(7) Optimism about Future	0.101	0.098	0.03 (NH)	0.032	0.00	0.962	0.00	0.816
(8) Headache impact on Daily Activities (n=64)	0.214	0.771	**	*	0.28	0.000	0.01	0.441
(9) Headache Impact on Leisure Activities (n=64)	0.840	0.980	**	*	0.19	0.001	0.00	0.413
(10) Somatic Symptoms other than Headache	0.107	0.142	0.15 (H)	0.000	0.14	0.000	0.01	0.385
(11) Functioning at Home and at School	0.760	0.238	0.06 (NH)	0.006	0.00	0.386	0.01	0.468
(12) Social interaction with peers	0.038	0.007	0.00	0.807	0.00	0.726	0.00	0.621
(13) Social Interaction with Brothers and Sisters	0.462	0.005	0.01	0.240	0.00	0.777	0.03	0.139
(14) VAS "Satisfaction with Life in General"	0.152	0.821	0.10 (NH)	0.000	0.12	0.000	0.02	0.317
(15) VAS "Satisfaction with Health"	0.127	0.328	0.09 (NH)	0.000	0.13	0.000	0.03	0.099

* Headache subjects contrasted with no headache subjects
** Not computed since headache impediment was not assessed for no headache patients.
(H), Headache subjects score higher; (NH), higher scores for no-headache subjects.

Table 3 displays mean scores and standard deviations of the three subgroups on all QLH subscales, pooled over the five measurements.

Table 4 illustrates the results of repeated measures multiple analyses of variance (MANOVA), where percentages of explained variance (squared eta) of QLH-Y subscales are displayed with "Diagnosis Group" and "Time" as independent variables.

Linear time effects represent the degree in which subscale scores over the subsequent measurements change as a linear function of time. These linear time effects were largest on the subscale *Headache Impact on Daily Activities*, *Headache Impact on Leisure Activities,* and *Fatigue.* Other significant linear time effects were found on the subscales *Stress*, *Depression*, *Somatic Symptoms other than Headache,* and the two visual analogue scales *Satisfaction with Life in General* and *Satisfaction with Health.* All linear time effects indicated a decrease of scores from Week 0 to Week 3, except scores on the subscales *Satisfaction with Life in General* and *Satisfaction with Health*, which increased over time. Most time related changes in subscale scores occurred between Week 0 and Week 1. None of the subscale means in the follow-up (Week 26) were significantly different from Week 0 to Week 3 scores (not printed in Table 4). For the variable "Diagnosis Group", following Cohen's criteria [3], a large effect (explaining > 13.8% of variance) was found on the subscale *Somatic Symptoms other than Headache.* Medium effects (5.9%-13.8% explained variance) were found on the subscales *Stress, Harmony, Fatigue, Strength/Vitality, Depression, Cheerful Mood/Good Humour, Optimism about Future,* and the two visual analogue scales. *Post-hoc* contrasts demonstrated group differences between headache patients and no-headache controls but not between migraine patients and no-migraine headache patients (*post-hoc* contrasts between migraine subjects and no-migraine headache subjects are not given in Table 4). Compared with no-headache controls, headache subjects reported more *Stress*, *Fatigue*, *Depression*, and *Somatic Symptoms other than Headache*, less *Harmony*, *Strength/Vitality*, *Optimism about Future*, a less *Cheerful Mood/Good Humour*, a worse *Functioning at Home and at School* and a lower *Satisfaction with Life in General* and *Satisfaction with Health.*

Only for the subscale *Fatigue*, a significant interaction was found between "Time" and "Diagnosis group"; with the subjects unfamiliar with headache presenting a more clearly linear time effect compared to those with headache or migraine.

Table 5. Study 2; analyses of variance: percentages explained variance (squared eta). QLH-Y subscales as dependent variables.

Subscale: (n=64)	Effects of "Presence of a Headache Prior to Completion of QLH-Y", (headache subjects only)									
	Week 0		Week 1		Week 2		Week 3		Week 26	
	squared eta	p-value	squared eta	p-value	squared eta	p-value	squared eta	p-value	squared eta	p-value
(1) Stress	0.01	0.510	0.05	0.089	0.03	0.179	0.00	0.714	0.02	0.274
(2) Harmony	0.00	0.734	0.03	0.237	0.00	0.720	0.03	0.217	0.00	0.669
(3) Fatigue	0.00	0.611	0.03	0.192	0.02	0.328	0.03	0.237	0.03	0.227
(4) Strength/Vitality	0.00	0.778	0.00	0.772	0.03	0.239	0.04	0.145	0.00	0.993
(5) Depression	0.03	0.164	0.03	0.192	0.07 (↑)	0.044	0.00	0.732	0.00	0.732
(6) Cheerful Mood/Good Humour	0.01	0.481	0.01	0.552	0.00	0.970	0.00	0.678	0.04	0.176
(7) Optimism about Future	0.00	0.862	0.01	0.439	0.05	0.104	0.00	0.831	0.03	0.291
(8) Headache Impact on Daily Activities	0.10 (↑)	0.018	0.24 (↑)	0.000	0.22 (↑)	0.000	0.08 (↑)	0.033	0.22 (↑)	0.001
(9) Headache Impact on Leisure Activities	0.12 (↑)	0.011	0.16 (↑)	0.003	0.23 (↑)	0.000	0.16 (↑)	0.003	0.19 (↑)	0.003
(10) Somatic Symptoms other than Headache	0.02 (↑)	0.276	0.04	0.123	0.10	0.019	0.12 (↑)	0.007	0.05	0.091
(11) Functioning at Home and at School	0.02	0.313	0.06 (↓)	0.064	0.00	0.768	0.00	0.763	0.06	0.086
(12) Social Interaction with Peers	0.02	0.356	0.01	0.436	0.01	0.416	0.04	0.124	0.01	0.416
(13) Social Interaction with Brothers and Sisters	0.02	0.313	0.07 (↓)	0.044	0.00	0.839	0.00	0.713	0.12	0.014
(14) VAS "Satisfaction with Life in General"	0.00	0.966	0.00	0.810	0.00	0.830	0.00	0.655	0.03	0.279
(15) VAS "Satisfaction with Health"	0.00	0.681	0.01	0.592	0.04	0.161	0.01	0.403	0.02	0.414

* Not contrasted since headache impediment was not assessed for no headache patients.
(H), Headache subjects score higher; (NH) no-headache subjects score higher. (↑) Higher and (↓) lower scores for subjects with headache prior to completion of the QLH-Y.

As illustrated in Table 5, at Week 0 the variable "Presence of a Headache prior to Completion of the QLH-Y" accounted for a significant part ($p<0.05$) of the variance of the two Functional Status subscales: medium to high effects were found (percentages of explained variance ranging from 8% up to 24%).

Significant effects ($p<.05$) of "Gender" were found on the subscales *Stress* (squared *eta*=0.05), *Strength/Vitality* (squared eta=0.06), *Depression* (squared eta=0.05), *Social Interaction with Peers* (squared eta 0.03) with girls scoring higher on *Stress*, *Depression* and *Social Interaction with Peers* but lower on the *Strength/Vitality* subscale than boys. Age effects were found on *Social interaction with Peers* (squared eta=0.05) and *Social Interaction with Brothers and Sisters* (squared eta=0.06), with higher scores for older subjects.

Discussion

The results of this study elucidate the psychometric properties of the QLH-Y, a new QL measurement scale for adolescents, designed primarily for use by youngsters with recurrent headache or migraine. The subscales in five of the six modules of the QLH-Y, that each represent one of the QL domains, are of a generic character and are suitable not only for adolescents with severe headaches or migraine, but also for other groups of adolescents. The sixth module, tapping the QL domain Functional Status, was designed as a disease-specific module. It measures Functional Status related to the effects of headache or migraine.

The mean 1-week stability coefficient was found to be 0.60 (range: 0.47 to 0.71), while the mean 6-month stability coefficient was 0.47 (range: 0.31 to 0.60). Test-retest correlations are widely used as indications for reliability of a test (i.e. test-retest reliability). However, when test scores are likely to change over time the interpretation of a test-retest correlation as a coefficient for test-retest reliability is problematic. QL assessment should be responsive to change. Hence, to interpret test-retest correlations properly, error variance should be distinguished from "true" variance [4]. In this study, test-retest correlations seem to represent acceptable degrees of association between the subscale scores at different measurement times, given the situation-dependent character of the concept measured. For, since an unidentified part of the test-retest variance not explained by the test-retest correlation can be expected to be due to "true" variance (i.e. the variance due to true changes in QL), the true test-retest reliability of the questionnaire probably will be better than indicated by these test-retest correlations.

Another source of potential contamination of test-retest correlations as an indication for reliability is represented by different time effects on the QL

measurements (e.g. a learning effect). To explore this potential contamination, this study presented an analysis of the time-related intra-subject variance of the scores on the QLH-Y subscales associated with headache activity. Significant time-effects were found on eight of the QLH-Y subscales, accounting for 12% through 28% of the intra-subject variance during the first four measurements. Thus, this part of the intra-subject variance across the measurements can be ascribed to time-effects. This finding demonstrates that a significant part of the intra-subject error variance is due to "true variance" (i.e. the time-effects). Test-retest correlations as an indication for reliability should be corrected for these time-effects. Hence, "true" test-retest reliability coefficients will be higher than the test-retest correlations as found in this study.

The relatively high parent-youth agreement, compared to percentages found in the literature [5], suggests that, to a relatively high degree, parents and youngsters used the same behavioural, cognitive, and emotional constructs when responding to the items in the QLH-Y and the QLH-P. A prerequisite to find this agreement is low error variance in the data and the use of reliable instruments. Thus, the relatively high parent-youth agreement on the QL of the subjects as measured by the youth version (QLH-Y) and the parent version (QLH-P) indicates the reliability of the QLH-Y

The scores on the visual analogue scale *Satisfaction with Life in General* were closely related to the scores on the subscales *Stress* and *Harmony*, while the scores on the visual analogue scale *Satisfaction with Health* displayed a strong relation with the subscale *Somatic Symptoms other than Headache*. These findings are in accordance with expectations and indicate the construct validity of the two global visual analogue scales.

All QLH-Y subscales, except two of the three Social Functioning subscales discriminated between subjects familiar with headache and the no-headache control subjects. The subjects with migraine or recurrent no-migraine headache experienced more stress, fatigue, depression and somatic symptoms, felt less strong, had a less cheerful mood and reported a lower satisfaction with health and with life in general than the subjects who were never bothered by headaches. These findings are in accordance with the well-documented observation that, compared to no-headache controls, juvenile subjects who are familiar with headache or migraine, report a maladaptive behavioural/psychological functioning [6], report more somatic complaints [7], generally evaluate their health as less satisfactory [8] and are observed to be less happy [9]. Since expected differences in QL were found between headache subjects and controls, this finding supports the construct validity of these QLH-Y subscales.

Within subjects who were familiar with headaches, the QLH-Y scores of the migrainous headache sufferers did not differ significantly from the subscale scores of the no-migraine headache sufferers. This finding indicates that in the subjects with headache, their type of headache did not influence their QL. In previous studies [9,

10] it is argued that the higher scores of young migraineurs on scales measuring depression, anxiety, and somatic symptoms are a consequence of the migraineurs having to live with chronic pain. In concordance with these hypotheses, our present study suggests that the lower Psychological Functioning, higher report of Physical Functioning, and lower Satisfaction with Health in General and Satisfaction with Health we found in young migraine patients, are not typical for migraine patients, but can be demonstrated in no-migraine chronic headache patients as well. This suggests that this aberrant pattern of scores on the QL domains might be related to the experience of chronic pain in general and not be distinctively related to the experience of migraine.

In their review of studies on psychological factors in migraine, Passchier and Andrasik [11] mentioned four studies on adult migraine patients in which elevated stress levels were reported on the day before a migraine attack and two studies in which "fatigue" was reported prior to a migraine period, while other studies showed contradictory results. In our study the QL domain Functional Status (represented by the two *Headache impact* subscales) was the only QL domain sensitive to the actual presence of a headache in the week prior to completion of the QLH-Y. Apparently, the two QLH-Y subscales representing the domain Functional status are most sensitive for actual headache. An explanation for the lack of association between the actual headache and other QL domains may be the use of the questionnaire method to assess headache activity prior to registration of QL by the QLH-Y. Use of a headache diary may be more sensitive in accurately discerning the relation between actual headache and QL.

As a research instrument, the QLH-Y has now proven its value as a measure for evaluating and comparing the QL of adolescents with and without headaches or migraine. The generic character of many subscales makes it possible to record the impact of diseases other than migraine on the QL of adolescents as well. The specific sample of subjects in this study however, limits our ability to extrapolate from these results to the whole adolescent population suffering from headache. Future studies with more subjects, representative of general (sub)populations are necessary before using QLH-Y scores to compare adolescents with chronic headache, or migraine and the normal population. Further research should also focus on obtaining norm scores for different subgroups of adolescents. Additionally, the sensitivity of the QLH-Y for the actual presence of headache should be explored more accurately by employing, for example, a headache diary. Factors other than somatic diseases might also influence an adolescent's quality of life. In a future study we will explore the interaction between personality variables and the report of headache and migraine symptoms on the one hand, and the self report of different aspects of quality of life on the other. Although completion of the QLH-Y takes less than 15 minutes, further development of

this scale will give priority to shortening the questionnaire to facilitate its use in routine clinical practice.

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Chapter 6[1].

HOW ARE CHANGES IN HEADACHE INTENSITY IN ADOLESCENTS RELATED TO CHANGES IN EXPERIENCED QUALITY OF LIFE?

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Abstract

Objective: To investigate the relationship between changes in actual presence of headache and the experience of different domains of Quality of Life (QL) in adolescents.
Design: Diary-entered measurements of headache activity were related to simultaneously recorded data on a QL questionnaire for adolescents.
Setting: Subjects completed both the QL questionnaires and the headache diaries at home.
Subjects: Subjects were selected by screening the total population of two secondary schools (*N*=1566) for headache and migraine symptoms. Sixty-four students subject to chronic headache or migraine participated in the study. All subjects were diagnosed by a neurologist, following the IHS criteria for headache or migraine.
Conclusion: Changes in headache intensity and frequency were related to changes in self-reported QL within all QL domains. More headache coincided with a lower self-reported QL.

Introduction

During the last ten to fifteen years, Quality of Life (QL) measurement has received increasing interest in the evaluation of medical treatment, in addition to the more traditional indicators of therapeutic success, such as prolonged survival, retardation of the disease process, and control over major symptoms. During the last decade, a wide variety of QL measurement scales for many fields of medical research have been developed. Recently, we developed the Quality of Life Headache-Youth (QLH-Y) questionnaire to assess QL in adolescents with chronic headache including

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migraine [1]. The questionnaire measures retrospectively, with a time frame of one week, the following QL subdomains: (1) Psychological Functioning; (2) Functional Status; (3) Physical Functioning; (4) Social Functioning; (5) Satisfaction with Life in General; and (6) Satisfaction with Health. The internal consistency and stability of this questionnaire have been demonstrated in the chapters 4 and 5 of this thesis. As is shown in these chapters, the QLH-Y scores of adolescent with recurrent headache differ significantly from QLH-Y scores of headache free controls. As a group, subjects familiar with headache experienced more stress and fatigue, felt less strong, and reported a less cheerful mood compared with subjects never bothered by headache. Additionally, in those subjects familiar with headache, the headache experienced during the week prior to completion of the questionnaire, appeared to have a significant impact on their activities of daily life and leisure time. Though Solomon *et al.* [2] describing a group of 208 adult headache patients found that "chi-square tests for the difference between proportions of patients in poor health with different headache diagnoses (migraine, tension-type, cluster-type and mixed-type) were statistically significant ($p<0.05$) for physical functioning, social functioning, mental health, and pain", in adolescents we did not find evidence of characteristic dissimilarities in QL in non migraine versus migraine headache patients.

To our knowledge, no previous study has been published in which the relation between changes in actual headache activity and experienced QL in adolescents was explored. However, several studies have been performed in which QL in migraine and other headache patients is compared with QL in healthy controls. In one of these studies, Osterhaus [3] showed that adult migraineurs report substantially diminished functioning and well-being, compared to the general US population. In another study [4] it is concluded that (adult) migraine patients experience a poorer QL, even between attacks. In this latter study, migraine subjects were compared with headache- and migraine-free control subjects. The relation between changes in actual headache activity and experienced QL was not the research question. The impact of migraine on health status has been studied by Essink-Bot *et al.* [5]. They showed that migraine causes significant problems for the household, work, social life, home life, and sex life. However, subjects in that study were adults and a headache diary was not employed.

The purpose of the present study was to test the hypothesis that changes in QL in adolescents are related to changes in headache frequency and intensity analogous to our previous findings on the relationship between QL and familiarity with headache (headache subjects versus headache free subjects). In our earlier study on the psychometric properties of the QLH-Y, some preliminary data were presented on the sensitivity of the QLH-Y subscales for headache activity the week previous to completion of the questionnaire. We found that actual headache the week before completion of the QLH-Y only accounted for a significant part of the variance in the

"Functional Status" QL domain. After correction for the effect of familiarity with headache (headache subjects versus headache free subjects) the actual presence of headache did not account for a significant part of the variance of other QL domains. Since these data were based only on a one-item retrospective question on headache activity experienced during the previous week, presumably, the sensitivity of this self-report on headache activity was rather low. A more sensitive headache enquiry might have resulted in the demonstration of a broader impact of actual headache on QL in adolescents. We expected that changes in headache activity and changes in different aspects of QL would be related in a similar manner as was found for the relations between familiarity with headache and QL: A higher headache activity is expected to coincide with a lowered QL.

In order to study the relation between changes in headache activity and experienced QL in adolescents, a reliable, accurate, and sensitive day-to-day headache history was required. Day-to-day recording of headache and migraine-symptoms by way of a diary has become common practice in determining the effects of different headache treatments. The technique was introduced by Budzynski [6] and modified by Epstein and Abel [7]. The work of Blanchard has become a widely recognized landmark in this field [8]. Usually, frequency, duration, and intensity of headache are recorded several times daily. Recently, a variety of clinical trials on pharmacological [9-12], psychological [13-16] and other [17, 18] headache treatments have been described, where a headache diary was one of the major effect measures. In this study we employed a headache and migraine diary for adolescents, which was based on this commonly used standard. Intra-subject variation in headache intensity and frequency in adolescent headache sufferers, as recorded in this diary, was studied in relation to QL subscale scores on the QLH-Y questionnaire.

Subjects and methods

Subjects

To recruit a sample of adolescents with migraine or chronic headache, in cooperation with the Rotterdam Municipal Health Service, all students at two comprehensive schools were screened for headache or migraine by way of a short ad-hoc headache screenings questionnaire. One of these schools was a Technical Education and Lower Economic and Administrative Education school (N=917), the other was a school for Lower and Higher General Secondary Education and Pre-University Education (N=649). The headache screening questionnaire asked the students whether they had been bothered by headaches at any time and, if they had, since when and how often.

They were then asked whether their headaches had been diagnosed as migraine by a doctor, or whether their headache symptoms resembled migraine. For this purpose, a short description of migraine and its symptoms, as used by the Dutch Association for Migraine Patients in one of their information pamphlets on migraine, was given. Students were included in the study: (1) if they were aged between 12 and 18 years old; (2) if headache symptoms were present which had ever been diagnosed by a physician as "migraine" or which were considered by the subjects to resemble the symptoms described in the migraine pamphlet (3) if the headache frequency was at least twice a month; and (4) if the headaches had been present for at least one year. Of the 1566 students who were the total population of the two schools, 1515 (96.7%) completed the headache and migraine screening questionnaire. From the group of students who had ever been bothered by headaches (*N*=981), 129 respondents fulfilled the criteria for "headache, likely migraine". These subjects were asked to participate further in the study. For different reasons, 65 of these subjects refused to participate, whereas 64 students (42 girls (66%) and 22 boys (34%); mean age 14.4 years, SD=1.5, range: 12-18 years) agreed to participate. The 65 dropouts did not differ significantly in sex, age, and school type from the subjects who were willing to participate. The 64 participants in the study were seen by a neurologist, The subjects' headache could not be ascribed to organic causes.

Instruments

Headache and Migraine Diary

The QLH-Y diary, modelled after Blanchard [8], records headache intensity and duration four times daily, at breakfast, lunch, dinner, and bedtime. Headache intensity is rated on a 5-point Likert scale, and headache duration is noted by entering the beginning and ending of a headache episode (e.g. from 1.00 PM to 5.00 PM). The Likert scale for recording headache intensity employed the levels described by Richardson [19]: 0 was labelled as "No headache", 1 as "Headache-I am only aware of it if I pay attention to it"; 2 as "Headache-but I can ignore it at times"; 3 as "Headache-I can't ignore it but I can do my usual activities"; 4 as "Headache- It's difficult for me to concentrate. I can only do easy activities"; and 5 as "Headache-such that I can't do anything". Additionally, at each of the four daily measurement points, the subjects were asked to record their medication.

QLH-Y Questionnaire

The QLH-Y questionnaire consists of 69 multiple-choice items that cover the four QL domains "Psychological Functioning", "Functional Status", "Physical Functioning", and "Social Functioning" and two visual analogue scales covering the QL domains "Satisfaction with Life in General" and "Satisfaction with Health". For a more detailed description of format and content of the QLH-Y questionnaire, see Langeveld *et al.* (1996) [1], where data are presented on its validity and reliability to detect differences in perceived QL in adolescents with migraine, adolescents with other headaches or headache-free control subjects.

Procedure

Subjects were given written instructions on how to complete the QLH-Y diary and QLH-Y questionnaire, illustrated by an extensive example. Subjects completed the QLH-Y diary over a 4-week period (Day 1 to 28). On day 7 (week 0), 14 (week 1), 21 (week 2), and 28 (week 3), the QLH-Y questionnaire was completed. All questionnaires and diaries were mailed with a prepaid envelope enclosed, in which questionnaires and diaries had to be returned on days 8, 15, 22, and 29. After all diaries and questionnaires were completed and returned, subjects were rewarded for their participation in the investigation by a gift voucher for 30 Dutch guilders (about $15).

Analyses

After four weeks, for each of the 64 subjects included in this study, four QLH-Y questionnaires, completed on days 7, 14, 21, and 28 of the study, were available. To analyse the relation between change in headache intensity and frequency on the one hand and QLH-Y subscale scores on the other, headache indexes were computed for each subject and for each week the QLH-Y was completed. These headache indexes were computed by adding up the diary intensities of all diary reported headache attacks during one week [8]. To explore the time-dependent variation of QLH-Y scores and headache index, for all four measurements, means and standard deviations were computed. Repeated measurements analyses of variance were computed on these data to test the statistical significance of any time dependent variation found.

As we showed in a previous study [1], part of the variance in the QL reports of the adolescents in the study sample can be ascribed to relatively stable inter-subject variation. To a certain degree, the reported QL can be predicted by the foregoing QL

measurements. A similar intercorrelation of subsequent measurements can be expected for the report of headache frequency and intensity over a certain time span. Therefore, to obtain a proper measure of the association between headache and QL at any of the points of measurement, we had to control for the effects of the same variables at each of the earlier points in time. This was done by computing partial correlations between QLH-Y subscale scores and actual headache indexes at one point of measurement, controlling these correlations for the effects of similar subscale scores and headache indexes as measured one week earlier.

Results

Of the 64 participants in this study, 60 subjects (93%) filled in the questionnaire and the diary at Week 0, 58 (90%) at Week 1, 57 (89%) at Week 2, and 55 (85%) at Week 3. Overall, ten subjects did not return one or more of the questionnaires and diaries. Three of these did not return both questionnaire and diary at any of the four measurements. The other seven subjects with incomplete responses did not return both questionnaire and diary on one or more occasions. These seven did not differ significantly from the 57 subjects with complete data, as for headache frequency and intensity and number of migraine attacks (chi- square tests). The analyses were conducted only for those measurements for which both questionnaire data and diary data were available.

Compared with the migraine subjects, the no-migraine headache subjects reported significantly more headache activity.

During the 4-week research period all headache and migraine subjects' use of medication was recorded by use of a diary. Subjects with no migraine headache used more analgesics than subjects with migraine. Also the total consumption of medicines was higher in the no migraine headache group.

Table 1 displays mean scores and standard deviations of the 64 subjects of this study on all QLH-Y subscales and on the headache indexes. Subscale scores are presented as mean item scores: For each subscale, item scores were summated and divided by the number of items. Minimum item score of the QLH-Y items is zero and maximum item score is three, except for the two visual analogue scales, which range from zero to one hundred.

Table 1. Means and standard deviations (in brackets) on QLH-Y subscale scores on four measurement times

n=65									Linear time effect
Subscale:	Week 0		Week 1		Week 2		Week 3		(*p*-value)
QL domain Psychological Functioning									
1) Stress	.78	(.54)	.61	(.53)	.70	(.64)	.50	(.53)	.008
2) Harmony	1.76	(.62)	1.80	(.64)	1.63	(.69)	1.88	(.70)	.112
3) Fatigue	.89	(.61)	.70	(.63)	.74	(.65)	.56	(.53)	.000
4) Strength/Vitality	1.49	(.65)	1.50	(.72)	1.45	(.77)	1.56	(.71)	.405
5) Depression	.77	(.49)	.58	(.52)	.62	(.50)	.55	(.37)	.029
6) Cheerful Mood/Good Humour	1.60	(.59)	1.57	(.70)	1.53	(.69)	1.71	(.70)	.237
6) Optimism about Future	1.40	(1.00)	1.37	(.90)	1.33	(.90)	1.41	(.93)	.388
QL domain Functional Status:									
7) Headache Impact on Daily Activities	.73	(.59)	.48	(.45)	.55	(.56)	.42	(.49)	.000
9) Headache Impact on Leisure Activities	.63	(.63)	.39	(.48)	.45	(.49)	.36	(.44)	.001
QL domain Physical Functioning									
10) Somatic Symptoms other than Headache	.77	(.43)	.62	(.44)	.67	(.43)	.52	(.36)	.000
QL domain Social Functioning:									
11) Functioning at Home and at School	1.75	(.56)	1.77	(.53)	1.67	(.57)	1.69	(.67)	.353
12)) Social Interaction with Peers	1.98	(.65)	1.85	(.66)	1.89	(.71)	1.91	(.81)	.929
13) Social Interaction with Brothers and Sisters	1.45	(.75)	1.45	(.79)	1.35	(.72)	1.38	(.79)	.164
QL domain Satisfaction with Life in General:									
14) VAS "Satisfaction with Life in General"	66.53	(30.03)	76.67	(24.87)	76.09	(25.42)	79.57	(24.63)	.016
QL domain Satisfaction with Health:									
15) VAS "Satisfaction with Health"	67.64	(26.80)	75.15	(24.38)	75.76	(21.91	79.85	(20.76)	.000
Headache index (derived from the diary)	2.40	(2.06)	2.00	(1.98)	2.02	(2.18)	1.54	(1.65)	.000

Note: Subscale score range: 0-3.

Note: All significant linear time effects indicate a decline in mean scores across time, except for the VAS-scale where an increase was found

Table 2. Partial correlations of QLH-Y subscales with headache index, controlling QLH-Y subscale scores for similar QLH-Y scores and headache index the previous week

QLH-Y subscale:	Week 1		Week 2		Week 3	
	partial correlation with headache index	significance (*p*-value, 1-sided)	partial correlation * headache index	significance (*p*-value, 1-sided)	partial correlation * headache index	significance (*p*-value, 1-sided)
QL domain Psychological Functioning:						
1) Stress	.12	.21	-.08	.29	-.14	.16
2) Harmony	-.34	.01	-.14	.16	.00	.50
3) Fatigue	.43	.00	.13	.18	-.23	.06
4) Strength/Vitality	-.18	.10	-.15	.15	.17	.12
5) Depression	.19	.09	-.06	.33	-.04	.39
6) Cheerful Mood/Good Humour	-.35	.01	.01	.47	.20	.08
6) Optimism about Future	-.09	.26	-.11	.28	.20	.09
QL domain Functional Status:						
7) Headache Impact on Daily Activities	.32	.01	.46	.00	.39	.00
9) Headache Impact on Leisure Activities	.24	.05	.21	.07	.20	.16
QL domain Physical Functioning:						
10) Somatic Symptoms other than Headache	.17	.11	.045	.37	.12	.21
QL domain Social Functioning:						
11) Functioning at Home and at School	-.14	.12	-.020	.45	.26	.04
12) Social Interaction with Peers	-.04	.39	.23	.05	-.06	.33
13) Social Interaction with Brothers and Sisters	-.28	.03	-.02	.45	.17	.13
QL domain Satisfaction with Life in General:						
14) VAS "Satisfaction with Life in General"	-.40	.00	-.14	.18	.24	.05
QL domain Satisfaction with Health:						
15) VAS "Satisfaction with Health"	-.42	.00	-.17	.13	-.16	.15

Mean subscale scores of positively phrased subscales (e.g. "Harmony", "Strength/Vitality") were found in the second and third quartile of the subscale range. For negatively phrased subscales (e.g. "Stress", "Depression") the mean subscale scores were found predominantly in the lowest quartile of the subscale range. Repeated measures analyses of variance showed a significant linear time effect on the subscales "Stress", "Fatigue", and "Depression" in the QL domain Psychological Functioning, on the subscale "Somatic symptoms other than headache" in the domain Physical Functioning, on the two visual analogue scales representing the QL domains Satisfaction with Health and Satisfaction with Life in General, on the headache impact subscales, and on the headache index derived from the headache diary entries. The two headache impact subscales presented the most prominent changes over time, particularly between Week 0 and Week 1. All linear time effects indicated increasing scores for positively phrased QLH-Y subscales and decreasing scores for negatively formulated QLH-Y subscales across the subsequent measurements. In parallel, a lowering headache activity across time was found. On later measurements subjects reported a better QL, less headache activity, and less impact of headaches on their lives.

Table 2 presents the partial correlations between headache index and QL subscale scores, controlling for similar QLH-Y subscale scores and headache index one week earlier.

The partial correlations between headache index and QLH-Y subscale scores at Week 1, controlling for effects of similar QLH-Y subscale scores and headache index as measured at Week 0, were significant and in the expected direction ($p<.05$, 1-tailed) for the QLH-Y subscales "Harmony", "Fatigue", "Cheerful Mood/Good Humour", "Social Activities with Brothers and Sisters", "Headache impact on Activities of Daily Life", "Headache Impact on Leisure Activities", "Satisfaction with Life in General", and "Satisfaction with Health". However, only the partial correlation of the QLH-Y subscale "Headache impact on Activities of Daily Life" with actual headache index remained significant at both subsequent measurements.

Discussion

In this study we investigated the relation between changes in frequency and intensity of headache, and simultaneously occurring changes in QL in adolescents. Data in a headache diary were employed to analyse the association between actual presence of headache and experienced QL, as measured by the QLH-Y. The data from the headache diary in our present study demonstrated a significant association

between changes in actual recorded headache and the four QL domains: "Functional Status", "Psychological Functioning", "Satisfaction with Life in General", and "Satisfaction with Health". Following Cohen's criteria [20], associations of medium size (indicated by correlations between 0.31 and 0.50) were found between headache activity and the Functional Status subscale "Headache Impact on Activities of Daily Life". Since the partial correlations that were found were corrected for similar scores obtained during the previous week, this medium association indeed represents the association between recorded headache impact with actual headache and not with a more stable factor like familiarity with headache. Further, headache activity had a significant impact on the QL domains Psychological Functioning (i.e. represented by the QLH-Y subscales "Harmony", "Fatigue", and "Cheerful Mood/Good Humour") and the QL domains Satisfaction with Life in General and Satisfaction with Health. High headache activity was found to coincide with a poor Psychological Functioning, Satisfaction with Life in General and Satisfaction with Health. Changes in actual headache coincide with changes within these QL domains in the expected direction.

Changes in QLH-Y scores were most closely related to changes in headache activity between Week 0 and Week 1. Except for the QLH-Y subscale "Headache Impact on Daily Activities", partial correlations between QLH-Y subscales and actual headache at Week 2 were lower than at Week 1. Most of the partial correlations at Week 2 were not significant. This finding may be due to a declining compliance in diary completion during the four measurements. The headache diary employed had a paper and pencil format, requiring daily written recording of headache and accompanying symptoms. Possibly, daily headache diary completion was too demanding for the subjects to guarantee high compliance continuously for four weeks. This may have resulted in less reliable headache documentation at later measurement times and fewer subjects who completed the diary in the final weeks. This lowered degree of compliance at later measurements may explain the many non-significant partial correlation coefficients for Week 2 and Week 3 measurements. For optimal reliability of headache documentation, in future studies, it may be preferable to employ a more advanced method of pain recording. Recording of chronic pain using an electronic diary might be a preferable method as it has been demonstrated to be highly reliable even for periods of more than two months [21].

Significant linear time effects were found on half of the QLH-Y subscales and on headache impact and headache activity as reported in the diaries. Noncompliance will result in a more impulsive and inconsistent completion. However, our results showed a systematic unidirectional change over time. Therefore, this finding cannot be due to simple noncompliance. Rather we ascribe this finding to a testing effect: the subjects, when asked for the first self-report on pain and QL may have been over-alert to pain and their own QL. With later measurements, when subjects had

accommodated to the testing procedure, these cues may have had to compete with other external and internal cues. On later measurements, pain, function, affect, headache impact and general satisfaction will be rated as less deviating from normal (see for example Pennebaker [22]). In our study, less headache and better QL were reported on later measurements. Based on these data and in line with the testing effect as described by Pennebaker, it can be argued that self-observation during these four measurements led to a change in the perception of severity of headache symptoms and the perception of experienced QL.

No-migraine headache subjects reported a higher headache activity and a higher consumption of analgesic medication than migraine subjects.

The relevance of this present study is that the data from the headache diary showed a not previously found relationship between actual presence of headache and the experience of different domains of QL in adolescents. Our findings allow no conclusions on the direction of causality. For example, based on these findings it cannot be concluded that a change in headache activity *causes* a change in experienced QL or vice versa. Since this study was not designed to draw any conclusions on the effects of different headache or migraine medication on QL, we choose not to include the individual consumption of headache medication in the analyses. Therefore, changes in headache frequency and intensity found in the present study cannot be ascribed to a specific intervention. Further study, following an experimental study design, might result in an answer to the question of direction of causality regarding the sequence of headache and experienced QL changes.

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Chapter 7[1].

DO EXPERIENCED STRESS AND TRAIT NEGATIVE AFFECTIVITY MODERATE THE RELATIONSHIP BETWEEN HEADACHE AND QUALITY OF LIFE IN ADOLESCENTS?

Johannes H. Langeveld, Hans M. Koot, Jan Passchier

Abstract

Objective: To test the moderating effects of trait negative affectivity (NA) and experienced stress (ES) on the interrelation between headache and health-related Quality of Life (QL) in adolescents.
Methods: Subjects with migraine or with no-migraine primary headache (n=64) were selected from the total population of two secondary schools (N=1566). Across a 4-week interval, subjects completed a neuroticism scale as a measure for NA, a headache and stress diary, and a QL questionnaire.
Results: Headache was found to affect independently the QL domains Functional Status, Satisfaction with Life in General, and Satisfaction with Health. ES was found to moderate the effect of headache on Psychological Functioning and Satisfaction with Life in General.
Conclusion: Actual headache in adolescents familiar with headache leads to a lower functional status and life satisfaction. The effect of headache on life satisfaction QL is greater in subjects high on experienced stress.

Introduction

Health-related Quality of Life (QL) has become an important aspect of health outcome in the effect evaluation of medical treatment [1]. Another valuable application of QL registration is to survey the impact of different diseases on QL [2]. Functional status (role activities, mobility, physical activities, and self-care), psychological functioning, social functioning, and the report of physical symptoms are defined as core QL domains [3]. Further, an evaluation of satisfaction with life in general and with health is commonly included in QL evaluations. Initially, QL evaluation was primarily

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performed in patients with life-threatening diseases, requiring treatments that heavily interfere with the patient's physiological, psychological, social, and role functioning [4]. Currently, QL evaluation is also targeted on patient groups with less severe disorders such as headache sufferers [5]. Since in children chronic physical conditions may have a greater effect on their QL than on traditional medical outcome variables such as mortality, issues of quality of life have also become salient in juvenile subjects [6].

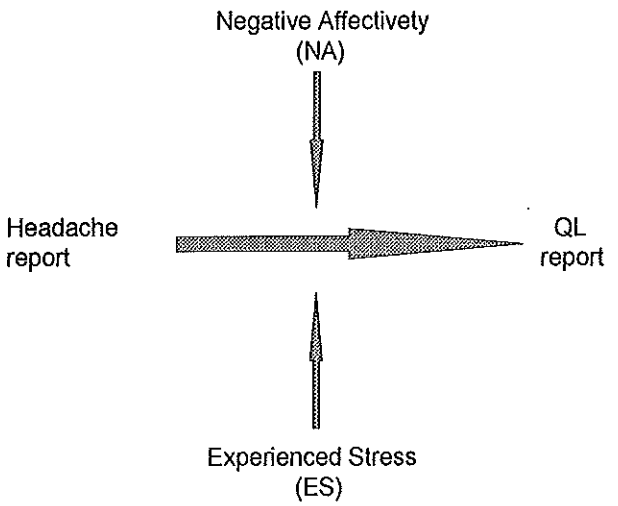
The burden of migraine, although not a life-threatening disorder, is often underestimated [7]. Therefore, systematic evaluation of QL is a worthwhile procedure to document quantitatively the influence of migraine on the life of young migraine patients. Linet *et al.* [8] found in a large epidemiological study, that the experience of migraine or no-migraine headache and subsequent impairment of role functioning is relatively common in adolescents and young adults. Counting school or work absence, as was done in that study, is one feasible approach to quantify the impact of the subjects' headache on one QL domain, here Functional Status. Another approach is to employ specific self-report scales designed for measuring one or more QL domains. For example, Kaiser [9] used standardized self-report measures in an attempt to survey the impact of a headache on Psychological Functioning in adolescents. It was found that 86% of a sample of 13- to 18-year-old subjects with chronic daily headache present scores indicating high levels of depression. Using a similar approach, Engström [10] showed that, compared to healthy individuals, 9-18-year-old headache patients report more somatic complaints, are less communicative, less vital, score lower on relations with others and higher on physiological anxiety. Langeveld *et al.* [11] developed the Quality of Life Headache-Youth questionnaire (QLH-Y) as an integrative measurement scale for QL (see chapters 5 and 6 of this thesis). In a study employing this instrument, they found that adolescent headache subjects, compared with healthy control subjects, reported a poorer QL. More specifically, the headache subjects revealed poorer psychological functioning, more physical symptoms, a poorer functioning status, and less satisfaction with life in general and satisfaction with health. Furthermore, in adolescents changes in actual headache across adjacent weeks were found to be related to parallel changes in the QL domains of Functional Status, Psychological Functioning, Satisfaction with Life in General, and Satisfaction with Health [12].

Following common sense, for some QL domains the direction of causality regarding the interrelation of headache and quality of life is evident. For example, it is most likely that the frequent experience of headache will result in increased school absence. Here, a causal effect in the opposite direction is unlikely. For other QL domains the direction of causality is less apparent. For example, regarding the QL domain of psychological functioning, poor psychological functioning may result in

headache complaints, but could also be a consequence of headache. Concerning the interrelation between migraine and the QL domain of psychological functioning, on the basis of epidemiological and clinical findings, some authors suggest that migraine may be elicited by experienced stress in youngsters [13, 14, 15, 16]. Other authors [17] state that low psychological functioning most probably is a consequence of the experience of chronic pain. The problem of causality in the interrelation between headache and psychological functioning may be even more complex than just a question of causal direction. It could be hypothesized that a third- or moderator-variable influences the relation between headache and QL. A moderator is a variable that affects the direction and/or strength of the relation between an independent-, or predictor-, variable and a dependent-, or criterion-, variable [18]. Several studies point at stress and trait negative affectivity as potential moderators on the relation between headache and QL. Crandall *et al.* [19] operationalized experienced stress (ES) as "daily hassles" and showed that daily hassles as measured with the "Undergraduate stress questionnaire" predicted physical symptoms and future headache frequency. Concerning headache in college students, Labbe *et al.* [20] suggest that, besides level of emotional functioning (i.e. anxiety and depression) and gender, perception of stress at home, school, and work may be a powerful predictor of future headache frequency. Siegel and Brown [21] performed a study on stressful circumstances, illness symptoms, and depressed mood in female adolescents, that indicated that ES rated as negative was associated with both poor physical health and mental health. Thus, in adolescents, experienced stress can be expected to have a main negative effect on the QL domains Physical functioning and Psychological functioning. Further, a main effect of ES on headache activity and an interactional effect of ES and headache activity on these QL domains can be expected, indicating that ES might moderate the association between headache and quality of life.

In a similar way, trait negative affectivity (NA) might moderate the relation between headache and QL, as high NA may both increase the number of self-reported headache symptoms and lower the level of self-reported QL. As such, an interactional effect of NA and headache activity on QL can be expected. In line with Watson and Pennebaker [22], it can be hypothesized that the relation between self-reported physical symptoms (such as headache) and self-reported health might be spuriously inflated by the moderating effect of NA.

Figure 1.
Moderator model, in which the effect of self-reported headache activity on self-reported QL is moderated by effects of Negative Affectivity (NA) and Experienced Stress (ES).



In the present study, we tested main effects of NA and ES on QL in adolescents, concurrently with the effect of headache activity. Further, we tested whether the observed positive relation between *actual* headache and different aspects of QL in adolescent headache subjects [12] is moderated by NA or ES. Data were employed from one of our previous groups of subjects [11]. The following hypotheses are tested: In a multi-factorial design (1) headache NA and ES have main and independent effects on quality of life; (2) the relation between headache and QL is moderated by the levels of NA and ES, i.e. the strength of the effect of headache on QL will be affected by the effects of NA and ES on QL.

To illustrate the hypotheses tested in this study, in Figure 1, a moderator model for the relations between headache, trait negative affectivity, experienced stress and quality of life is depicted.

Method

Subjects

To recruit a sample of adolescents with migraine or chronic headache, in cooperation with the Rotterdam Municipal Health Service, all students of two comprehensive schools were screened on headache or migraine by way of a short questionnaire. One of these schools was a Technical Education and Lower Economic and Administrative Education school (N=917). The other was a school for Lower and Higher General Secondary Education and Pre-University Education (N=649). The headache screening questionnaire asked the students whether they had been bothered by headaches at any time. If they had, they were asked to indicate since when and how often. They were then asked whether their headaches had been diagnosed as migraine by a doctor, or whether their headache symptoms resembled migraine. For this purpose, a short description of migraine and its symptoms, as used by the Dutch Association for Migraine Patients was given. Migraine was described as a type of headache that occurs attack-wise, most often at one side of the head and that is frequently accompanied by nausea and vomiting. Students were included in the study: (1) if they were aged between 12 and 18 years; (2) if headache symptoms were present which had ever been diagnosed by a physician as "migraine" or which were considered by the subjects to resemble the symptoms in the migraine description; (3) if the headache frequency was at least twice a month; and (4) if the headaches had been present for at least one year. For more details on subject selection, see Langeveld *et al.* [12]. From the 1566 students, 129 fulfilled the criteria for inclusion in the headache or migraine subgroup. Of these, sixty-four students and their parents agreed to participate. These subjects were seen by a neurologist for an expert diagnosis. The neurologists' expert diagnoses resulted in 38 migraine headache subjects (24 girls [60%] and 14 boys [40%]) versus 20 no-migraine headache subjects (14 girls [70%] and 6 boys [30%]). No organic pathology was found in the participants screened by the neurologist. Six participants did not meet at the doctors office (4 girls and 2 boys) and therefore, no diagnosis was set for these participants. All 64 students included in the study returned one or more complete diaries and questionnaires. Of these, 54 returned all completed diaries and questionnaires. The missing values from the ten participants with incomplete responses were exchanged with the mean of each participants' scores at other measurement times. The two diagnostic groups did not differ in age (t=0.41, p=.685) or gender distribution (X^2=.16, p=.693).

Variables and instruments

Health-related Quality of Life

To assess health-related quality of life we employed the Quality of Life Headache-Youths (QLH-Y) questionnaire [11]. The QLH-Y consists of 69 multiple-choice items (four response categories, with values 0 through 3), which cover the four QL domains Physical Functioning, Functional Status, Psychological Functioning, and Social Functioning. Two visual analogue scales cover the QL domains Satisfaction with Life in General and Satisfaction with Health. The items within the domain Physical Functioning (10 items) survey the subjects' physical symptoms, except headache. The domain Functional Status (13 items) includes items that measure the impact of headache on the subjects' daily living. The domain Psychological Functioning (34 items) includes the subscales "Stress", "Harmony", "Fatigue", "Strength/Vitality", "Depression", "Cheerful Mood/Good Humour", and "Optimism about Future". The domain Social Functioning (12 items) includes the subscales "Functioning at Home and at School", "Social Interaction with Peers", and "Social Interaction with Brothers and Sisters". Nearly all subscales of the QLH-Y have shown satisfactory internal consistency (Cronbach's alpha of above .70 [23]), with lowest coefficients of internal consistency (.66 - .72) for the two subscales within the QL domain Social Functioning. Transformations (i.e. new value=[1-old value]) were performed on all items within the QL domains Physical Functioning and Functional Status and on 18 items within the QL domain Psychological Functioning. After these transformations, higher scores on all domains indicated a higher QL. Scores for the different QL domains are then computed by summating subscale scores within each domain. For a more detailed description of format and content of the QLH-Y questionnaire, see Langeveld *et al.* [11], where a detailed description of the procedure of construction of the questionnaire is given and where the psychometric properties of the QLH-Y are presented.

Headache activity

An index for headache activity was derived from the QLH-Y headache diary, modelled after Blanchard [24]. Headache intensity was rated on a 5-point Likert scale (see for a detailed description of the diary Langeveld *et al.* [12]). For each subject a headache index was computed by adding up the diary intensities of all diary-reported headache during the four-week study period [25]. This headache index was then treated as a measure for headache activity.

Experienced stress

To record events of experienced stress (ES), a life-event schedule could be employed. Yet, as Crandall states [19] "even the most carefully created life-events schedule may not properly characterize the stressors in the lives of particular samples" (page 630). Therefore, a qualitative method of gathering data on experienced stress in our sample was chosen. We defined ES as "any thoughts or events that the subjects perceive as stress provoking". To assure accuracy, a day-to-day recording of the subjects' experienced stress was preferable. Therefore, a diary format was chosen and experienced stress was recorded once a day as part of the QLH-Y diary. In the QLH-Y diary, instances of experienced stress were captured by asking the subjects: "Please write down any thoughts that frequently came onto your mind this day or bothered you". After completion of the diary, two senior psychologists independently coded all instances reported in the diaries (n=951) as (1) "school-related ES"; (2) "health-related ES"; (3) "interpersonal ES"; (4) "other incidences of ES"; and (5) "not stress provoking instances". For each subject, all coded ES instances, collected over the four weeks the diary was kept, were summated into total category scores and into a total score for ES (sum of ES categories 1-4). Cohen's Kappa for interrater agreement regarding the coding in five categories (1-5) as described above was .76. Cohen's Kappa for the stress provoking (categories 1-4) and no stress provoking (category 5) distinction was .93.

Trait negative affectivity

Trait negative affectivity (NA) can be assessed by common personality inventories including the Eysenck Personality Neuroticism scale [22]. For this study, to measure NA the "Korte Amsterdamse Biografische Vragenlijst voor Kinderen" (KABVK) Neuroticism scale was chosen. The KABVK is a shortened version of the Eysenck Personality Inventory [26], translated into Dutch and modified to be applicable with youths between nine and fifteen years of age. The validity of the three original Eysenck scales Neuroticism, Extraversion, and Psychoticism is supported by a study by Zuckerman [27]. Test-retest reliability of the KABVK neuroticism scale is reported as .68 for boys and .72 for girls [28]. Some examples of items on the KABVK Neuroticism scale are: "Often falling asleep is hard for me"; "I am often scared that something terrible will happen to me"; "Often, I feel guilty"; "Many things scare me".

Procedure

All subjects (n=64) were instructed on how to complete the QLH-Y questionnaire in writing. It was illustrated by an extensive example how to complete the QLH-Y diary, which they filled out over a four-week period (Day 1 to 28). On day 7 (measurement 1, called "Week 0"), 14 (measurement 2, "Week 1"), 21 (Measurement 3, "Week 2"), and 28 (Measurement 4, "Week 3") of the period of diary recording all subjects completed the QLH-Y questionnaire. To prevent contamination between state and trait measures of stress, respectively NA, all subjects filled out the KABVK personality questionnaire six months after day 1 of the diary recording period. All questionnaires and diaries were posted with a prestamped envelope enclosed, in which questionnaires and diaries had to be returned on day 8, 15, 22, and 29. When all diaries and questionnaires had been completed and returned, subjects were given an appreciation for their participation in the investigation by a gift voucher worth 30 Dutch guilders (about $ 15).

Data analyses

To test any differences between the groups on the study variables, t-tests were performed.

In order to explore the interrelations between the variables in this study, Pearson correlations were computed.

To test the two main hypotheses of this study, six separate hierarchical multiple regression analyses were performed, one for each QL domain. Multicollinearity effects between first-order terms (i.e. the independent variable and the potential moderators) and the higher order terms (i.e. the interaction terms) can be problematic [29, 30]. Therefore, the independent variables were "centred" before they were entered in the regression analysis. To centre a variable, the mean of a variable is subtracted from all individual scores, producing a revised sample mean of zero. For each regression analysis one of the six QL domains was treated as a dependent variable. Since NA was assessed as a trait (i.e. trait NA), not as a state, in all six regression analyses at step one, NA was entered as an independent variable. Further, at step two and three, ES and headache activity were entered. Finally, since interaction effects must be entered after main effects, at step four and five interactions between NA and headache activity, and between ES and headache activity were entered.

Results

In Table 1 number of days bothered by headache, headache indexes (as measures for headache activity), NA scores, and number of ES incidences are presented for migraine subjects and no-migraine subjects. Migraine headache subjects reported a significantly lower number of days with headache over the 4-week measurement period than the no-migraine headache subjects. Additionally, their summated headache index was significantly lower. No significant differences in NA between migraine and no-migraine subjects were found. In migraine subjects the total score of ES and the number of ES incidences not related to specific situations were significantly higher than in no-migraine headache subjects. By far the most instances of experienced stress were related to school. Only about 5% of reported experienced stress of the headache subjects was related to the subjects' health.

Table 1.

Headache Activity, Number of Experienced Stress (ES) Incidents, Negative Affectivity (NA), and Quality of Life in the 4-Week Research Period for Migraine and No-migraine Headache Subjects

	Migraine (n=38)		No-migraine Headache (n=20)		
	Mean	(SD)	Mean	(SD)	t-value
Number of Days with Headache	9.05	(5.73)	14.70	(7.48)	3.20**
Summated Headache Index	5.92	(5.21)	10.79	(9.00)	2.37*
Negative Affectivity	6.36	(2.70)	5.95	(2.96)	-.53
Number of ES Incidences					
Related to School	7.55	(5.87)	5.20	(5.90)	-1.45
Related to Health	1.03	(1.24)	0.50	(1.40)	-1.47
Related to Interpersonal	2.95	(3.45)	1.75	(2.49)	-1.37
Other Incidences	1.71	(3.36)	0.40	(0.60)	-2.33*
Total Incidences	13.24	(9.83)	7.85	(7.55)	-2.32*
QL Domains					
Physical Functioning	33.42	(1.10)	33.62	(1.64)	.53
Functional Status	52.23	(3.55)	51.65	(2.96)	-.62
Psychological Functioning	89.93	(11.08)	88.96	(9.71)	-.30
Social Functioning	20.44	(5.79)	19.25	(5.18)	-.63
Satisfaction with Life in General	299.73	(84.49)	297.06	(78.48)	-.11
Satisfaction with Health	307.71	(77.52)	288.81	(77.51)	-.81

Note. n=58; * p<.05; ** p<.01, two-sided.
High scores on QL domains indicate a better quality of life.

Table 2.

Pearson Correlations between Trait Negative Affectivity (NA), Experienced Stress (ES), Headache Index (summated), and QLH-Y Scores

	NA	ES	Headache Activity	Physical Functioning	Functional Status	Psychological Functioning	Social Functioning	Satisfaction with Life in General
NA	1.00							
ES	.14	1.00						
Headache Index	.24	.05	1.00					
QL Domains								
Physical Functioning	-.57***	-.04	-.27	1.00				
Functional Status	-.27	.15	-.44**	.54***	1.00			
Psychological Functioning	-.32	-.38**	-.21	.33*	.04	1.00		
Social Functioning	-.19	-.24	-.08	.01	-.07	.53***	1.00	
Satisfaction with Life in General	-.31*	-.28	-.44**	.43**	.21	.74***	.26	1.00
Satisfaction with Health	-.14	-.20	-.51***	.49***	.18	.47***	.12	.72***

Note. n=64; High scores in QLH-Y scales indicate a higher quality of life.

* p<.05; ** p<.01; *** p<.001

Table 3.
Results of Multiple Hierarchical Regression Analyses of QL Domains on Trait Negative Affectivity (NA), Experienced Stress (ES), Headache Index, and Interactions between Headache and NA and Headache and ES

Step	Predictor	ß	R^2 change (adjusted)	*F*-change	cum. R^2 (adjusted)	final *F*
		Physical Functioning				
1	NA	-.54***	.31	20.51	.31	
2	ES	.10	-.02	-10.50	.29	
3	headache index	-.21	.01	-2.86	.30	
4	NA * headache index	.06	-.01	-1.65	.29	
5	ES * headache index	-.22	.03	-.44	.32	5.06**
		Functional Status				
1	NA	-.15	.05	3.36	.05	
2	ES	.26	.01	.83	.06	
3	headache index	-.53***	.14	2.24	.20	
4	NA * headache index	.21	.04	-0.22	.24	
5	ES * headache index	-.17	.01	-.57	.25	3.93**
		Psychological Functioning				
1	NA	-.30*	.08	4.68	.08	
2	ES	-.28*	.10	.83	.18	
3	headache index	-.13	.00	-1.56	.18	
4	NA * headache index	-.12	-.02	-1.05	.16	
5	ES * headache index	-.30*	.06	.36	.22	3.26**
		Social Functioning				
1	NA	-.19	.00	1.15	.00	
2	ES	-.28	.02	.21	.02	
3	headache index	.08	-.03	-.47	-.01	
4	NA * headache index	-.20	.02	.16	.01	
5	ES * headache index	.16	-.01	-.08	.00	.97
		Satisfaction with Life in General				
1	NA	-.23	.07	4.20	.07	
2	ES	-.17	.08	-.61	.15	
3	headache index	-.39*	.09	1.85	.24	
4	NA * headache index	-.10	-.02	-1.46	.22	
5	ES * headache index	-.31*	.07	.51	.29	4.49**
		Satisfaction with Health				
1	NA	.03	.00	.85	.00	
2	ES	-.11	.01	.28	.01	
3	headache index	-.60***	.23	4.34	.24	
4	NA * headache index	.13	.01	-.94	.25	
5	ES * headache index	-.21	.02	-.38	.27	4.15**

Note. n=64; *$p \leq .05$; ** $p \leq .01$; *** $p \leq .001$. Headache index (summated) is treated as a measure for headache activity.

Table 2 displays the Pearson zero-order correlations between all variables entered in the regression analyses. NA correlated strongly with Physical Functioning. Moderate but significant correlations were found between NA and Satisfaction with Life in General and between ES and Psychological Functioning. Headache activity showed moderate to strong correlations with Functional Status, Satisfaction with Life in General, and Satisfaction with Health. All correlations indicated a poorer quality of life co-occurring with higher levels of NA, ES, and headache. Correlations between NA, ES and headache were weak and not significant. Intercorrelations between QL domains varied from low and non-significant to high.

In Table 3, results are displayed of the hierarchical regression analyses with NA, ES, and headache activity (i.e. summated headache index) as independent variables and the QL domains as dependent variables. Further, interaction effects between NA and headache activity and between ES and headache activity on QL are presented.

As is shown in Table 3, and following Cohen's criteria, NA had a strong effect on the QL domain Physical Functioning and a moderate effect on the QL domain Psychological Functioning. Furthermore, ES showed a small, but significant effect on Psychological Functioning. Headache activity showed strong predictive relationships with the QL domains Functional Status and Satisfaction with Health, and predicted moderately the QL domain Satisfaction with Life in General, controlling for levels of NA and ES.

Interactional effects of moderate size were found of ES and headache on the QL domains Psychological functioning and Satisfaction with Life in General. To explore the direction in which these interactions affect the interrelation between headache and QL, simple regression lines were plotted for high (above the 66th percentile) and low (below the 33rd percentile) values of the moderator variables (Figures 2 and 3). From these regression lines it can be read that in the presence of high ES, headache showed a more negative effect on Psychological Functioning, and on Satisfaction with Life in General.

After a Bonferroni correction was performed on the six multiple regression analyses (a familywise protection level of .05 results in a per comparison protection level of .008), all final *F*-tests remained significant.

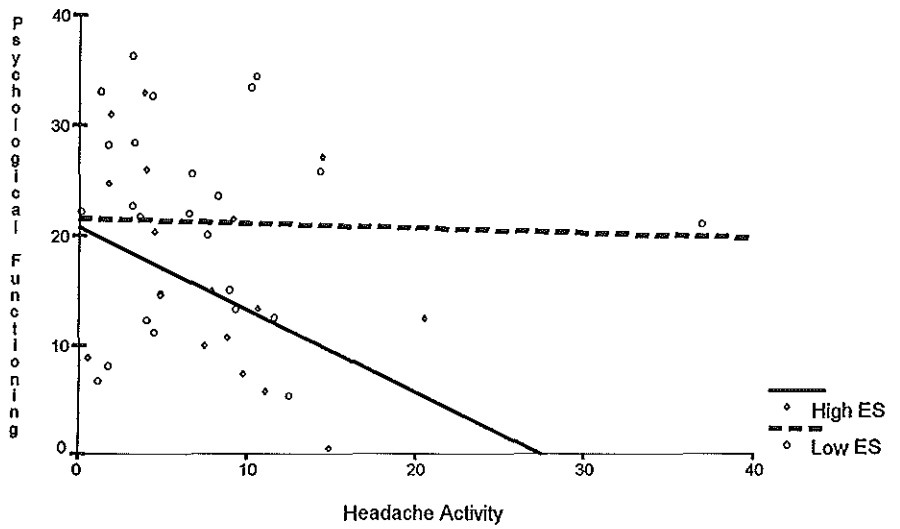


Figure 2.
Significant effects of interactions between experienced stress (High ES, Low ES) and headache activity on the QL domain Psychological Functioning.

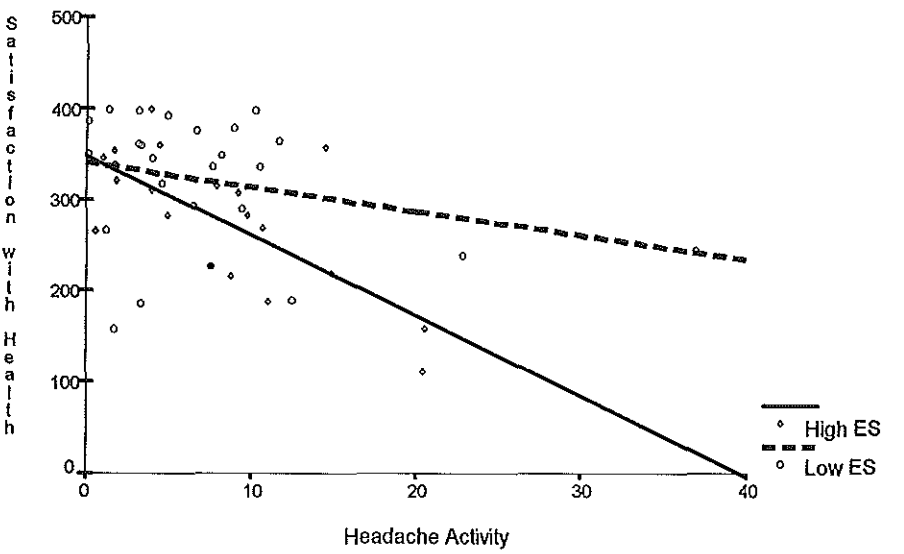


Figure 3.
Significant effects of interactions between experienced stress (High ES, Low ES) and headache activity on the QL domain Satisfaction with Health.

Discussion

Main Effects

In our sample of headache subjects, studied in a multifactorial design including measures for trait negative affectivity and experienced stress, diary-recorded actual headache firmly predicted the QL domains Functional Status, Satisfaction with Life in General, and Satisfaction with Health. The more headache was reported by the adolescents, the lower the QL they reported, which supports the first hypothesis that headache has a main effect on QL, independently from effects of negative affectivity and experienced stress. Thus, we found that in adolescent headache subjects, headache leads to a lowered QL, unbiased by effects of trait negative affectivity and experienced stress on QL.

Further, we found that negative affectivity significantly predicted the QL domains Physical Functioning and Psychological Functioning. Subjects high on negative affectivity are more tuned towards the observation and report of physical symptoms and psychological distress. This finding is in line with Watson and Pennebaker's [22] conclusion that questionnaire data on subjective health and distress are affected by trait negative affectivity or, in other words, by a tuning towards the report of somatopsychic distress. A final main effect on QL (i.e. on the domain Psychological Functioning) was found of diary-recorded experienced stress. Subjects who experience more stress during a week, subsequently report a poorer Psychological Functioning.

Moderating model

The second hypothesis of this study was partly supported as interactional effects between headache and experienced stress were found on the QL domains Psychological Functioning and Satisfaction with Life in General. Adolescents subjects with recurrent headaches who had reported high levels of experienced stress during the 4-week study period showed more problems with regard to psychological functioning than those who reported low levels of experienced stress. Further, these subjects revealed a lower satisfaction with life. This finding implicates that in adolescents the relation between headache and different aspects of quality of life is clearly moderated by experienced stress, but not by trait negative affectivity.

Other findings

The adolescent migraine subjects in our study reported less headache than the no-migraine headache subjects, but more experienced stress. These findings are in line with studies in adult tension headache and migraine patients [31, 32]. Further, in our study migraine patients and no-migraine headache patients revealed rather similar patterns of quality of life including psychological functioning. This is in accord with the results of a study by Passchier, de Boo, Quaak, and Brienen [33] which also demonstrated similar patterns of quality of life in adult subjects with different headache diagnoses. In our study no differences in trait negative affectivity were found between adolescents with migraine and those with other types of headache. As such, no support for the assumption of the existence of an anxious and depressive migraine personality in young subjects was found. In adults, Blanchard, Andrasik, and Arena [32] came to the same conclusion.

In contrast with our previous study on the interrelation of diary-recorded changes in headache activity and quality of life [12], in our present study no significant effect of headache activity on psychological functioning was found. Apparently, the aggregate and summated index for psychological functioning which was used in the present study disguises more subtle time-related or short term effects of headache on the different psychological functioning subscales as was shown in our previous study.

Implications

For the pediatric clinician, these findings suggest that headache complaints and reports of a lowered QL in adolescents do not simply reflect the effect of an emotional characteristic like a tuning towards the over-report of negative affect and bodily symptoms. Neither does a lowered QL in subjects with recurrent headache barely reflect high levels of experienced stress. Rather, our findings confirm that, as in adults [7] in adolescents the burden of migraine and other frequent headache syndromes on QL is serious.

Further, as we found that the effect of headache on QL is greater in subjects high on experienced stress, we suggest that intervention programs directed at reduction of headache impact on QL in young chronic headache or migraine subjects should include cognitive-behavioral techniques aimed at the increase of stress coping skills.

These data suggest that the responses of adolescents to questionnaire gathered data on physical symptoms and psychological distress are more likely to be affected by their emotional characteristics (i.e. trait negative affectivity) than data

recorded by use of a diary. Hence, when adolescents are asked to report on their health and physical symptoms, the timespan should be as short as possible. Therefore, we encourage the increased use of diary formats in health- psychological research in young subjects.

Limitations

Despite these distinct findings, several aspects concerning the design of our present study diminish the strength of our conclusions.

First, the number of participants in our study is limited. Therefore, the power of our findings is less than optimal. This means that only strong effects reach the level of significance. Although the power for each regression analysis was sufficient (power .67-.93) for all scales except the Social Functioning scale, the power for subsequent steps in each analysis was limited. In other words, because of multiple testing on a limited number of participants, some of our findings may reflect findings by chance.

Secondly, only the migraine diagnosis was set following internationally accepted criteria. Beyond the study's inclusion criteria, no other specific headache diagnoses were set. As a consequence, regarding headache diagnosis, the no-migraine headache sample may be rather mixed. However, in our participants no organic pathology was found. In children and adolescents, most common non-organic headaches are migraine and muscle contraction headache [34]. Thus, the majority of the no-migraine headaches participants most probably are muscle contraction headaches.

Finally, although measurement of QL was performed *after* the diary registration of experienced stress and headache activity, the participants were asked to rate their QL retrospectively for the previous week. Therefore, one might question the prospective design of our study. Hence, the design of our study does not definitely rule out that QL may affect on experienced stress and headache instead of an opposite direction of causality, as assumed in our study.

General conclusion

The general conclusion of this study is that in adolescents with recurrent headache, actual headache as measured by a diary leads to a lower health-related quality of life in different QL domains. This effect cannot be attributed to the subjects' emotional characteristics or to instances of stress they have experienced. However, adolescents high on experienced stress show a greater impact of headache on their

psychological functioning and satisfaction with life. As such, experienced stress moderates the relation between headache and QL in adolescents.

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Chapter 8.

GENERAL DISCUSSION

The objectives of this study were: (1) To develop a new instrument to measure quality of life (QL) in juvenile subjects with recurrent headache or migraine; (2) To evaluate the psychometric properties of this new instrument, including the questionnaire's sensitivity to change; (3) To compare the QL of adolescents with migraine, adolescent subjects with no-migraine headache, and control subjects without headache complaints. (4) To explore the association between within-subject variation of headache activity across time and QL within-subject variation. (5) To investigate the influence of negative affectivity and experienced stress on the relation between headache and QL. In this chapter the main findings and implications of the study are discussed and suggestions for future research are presented.

The need for a QL questionnaire for adolescents with headache or migraine

When the development of the QLH-Y was initiated, in 1992, in the Netherlands both the pharmacological industry and several behavioural research programs had expressed a wish to broaden the scope of effect measures to be used in treatment effect studies on adolescent headache patients. To reach this aim, QL data were considered to be included in these studies. Additionally, from a political point of view, the study of health care outcomes in children and adolescents was gaining increasing interest. Since no instrument was available to gather these data, this research project was fostered.

The development of the QLH-Y

Conceptual identification and operationalization of "quality of life"

In line with Spilker's conceptual identification of quality of life [1], the QLH-Y was designed to evaluate QL at three levels. Items related to the first level ask for a global evaluation of life and of health. At the second level, QL is evaluated in broad domains. At the third level, specific subscales evaluate the specific components of each domain.

Based on the definition of QL this study was built upon [2], four broad predefined QL domains were specified: Physical Functioning, Functional Status, Psychological Functioning, and Social Functioning.

The subjects in the studies

Five previously identified adolescent subjects with migraine were interviewed to generate items within the Functional Status domain.

Gender and age of the eight child panellists matched gender and age grouping of the target population (adolescents with chronic headache or migraine): Girls were slightly over-represented; age range of the panellists was between 12 and 17 years. Child panellists were asked to comment on the questionnaire orally and to write down their comments on each item.

To construct the generic subscales of the QLH-Y, in the first study (described in chapter 4) a study sample was recruited from the general population, not from a migraine or headache population. A general population was chosen because the instrument to be constructed had to be sensitive also for minor changes in QL. Further, the generic modules of the questionnaire had to be applicable on all adolescents, not only on headache and migraine subjects. All subjects in this study (n=223) were instructed orally and in writing to respond with a question mark for each item which was not clearly understood.

To construct the disease-specific Functional status module from the initial item pool, all subjects in the first study were inquired on the prevalence and the frequency of their headache complaints. Only those subjects were included in the analyses regarding this module who had indicated to be bothered by headache.

Subjects in the second study, referred to in the chapters 5 through 7, were recruited from the entire population of two secondary schools. Subjects with migraine had their diagnosis set by a neurologist following the IHS criteria. The selection of no-migraine headache subjects was less stringent. They were seen by a neurologist and diagnosed as no-migraine headache, not related to organic pathology. Previously, at the questionnaire-based population screening, these subjects had indicated to be bothered by headache at least twice a month and at least during one year. Results from a study by Labbe *et al.* generally support the validity and reliability of children's reports on headache symptoms via a questionnaire format [3]. Most probably, a tension-type headache diagnosis would be appropriate for most of these subjects [4, 5]. Findings on the quality of life of migraine patients compared with no-migraine headache patients would have been more conclusive if more precise diagnostic information about the no-migraine headache patients had been obtained. However,

since the main aim of this study was to develop a QL questionnaire, not to test hypotheses about the QL of tension-type headache subject, the strategy of subject selection in this study was considered as appropriate.

Generation and selection of items

Generic or disease-specific modules

The interviews with young migraine patients showed that the effect of headache and migraine is in particular disease-specific for the QL domain Functional Status. Therefore, for this domain a disease-specific approach was adopted. Regarding other QL domains, the interviewed subjects reported also a poorer QL, but within variations as found in the general population. Therefore, for these QL domains a generic approach was adapted.

Likert-format items

When the QLH-Y was constructed, no well-proven generic QL assessment scale for juvenile subjects was available. Therefore, items for the initial item pool for these QL domains were selected and adapted from existing valid and reliable questionnaires. These questionnaires had already proven to be valid and reliable indicators for psychological functioning, social functioning and physical functional. A traditional Likert-format with four response categories was chosen for the items within these QL domains. In the procedures and analyses related to subscale construction within these domains, a variable-centred approach was employed. Opinions on the wording of the items of the QLH-Y were obtained from an experienced child psychologist, a senior teacher, and from a panel of eight subjects at the age of the subject population. Subsequently, items were adapted to fit the target population optimally. All subjects in the first study were asked to respond on the content and form of the items.

Visual analogue scales

The two global evaluations of life, the subscales "Satisfaction with Life in General" and "Satisfaction with Health", were designed as visual analogue scales (VAS scales). The VAS scales are graphically represented as 100 mm. lines with anchorpoints at the right-hand side and the left-hand side of the line. Subjects are asked to indicate on these lines how satisfied they are with their life and with their health. The VAS-scales were thought to facilitate a QL evaluation at first gaze. In pain

research it has been claimed that a VAS-scale has a high degree of sensitivity [6, 7, 8]. Later, the basis for this claim was seriously doubted [9]. In the studies described in this thesis absolute VAS scales are employed. In contrast with comparative VAS scales, the ends of absolute VAS scales are defined in absolute statements (for example, "I feel very good" or "I feel very bad"). The ends of a comparative VAS scale are defined in terms of relief or improvement (for example, "I feel much worse" or "I feel much better"). As Carlson [10] showed in patients with chronic pain, the validity and sensitivity of absolute VAS scales as used in the QLH-Y are more reliable and valid than comparative VAS scales.

Subscale constructions and item reduction

The components of the domains were empirically identified employing a factor analytic approach. Eight components were identified within the domain Psychological Functioning (i.e. "stress", "harmony", "fatigue", "strength/vitality", "depression", "cheerful mood/good humour", and "optimism about future"). Two components were found within the domain Functional Status, and three components were identified within the domain Social Functioning. The Physical Functioning domain displayed an unidimensional structure. Final item selection and adaption were performed based on (1) the responses from the panel in the pilot study and from the subjects in the first study, (2) the factor analyses, and (3) the homogeneity analyses of the item clusters as identified by factor analysis. After item reduction the QLH-Y included 69 Likert-format items and two VAS scales.

The number of constructed subscales per QL domain varies notably. One explanation for this varying number of subscales may be found in the differences in length and the structure of the questionnaires from which the QLH-Y items were derived. For example, within the domain Psychological Functioning seven subscales represent as many specific components. Psychological Functioning items were derived and adapted from a depression questionnaire and a questionnaire that assesses different aspects of Psychological Functioning. In contrast, the domain Physical Functioning only contains one subscale. Items within this domain were derived and adapted from a questionnaire of which a one-factor solution explains 70% of the scale variance.

Another reason for the varying number of subscales per domain is the difference in numbers of items per domain: The Psychological Functioning domain includes the highest number of items (34 items). In contrast, the Physical Functioning domain is covered by only nine items. Due to the lower power of a factor analysis on few items, a factor analysis on such a domain will result in a solution with fewer factors than a factor analysis on a domain that includes many items.

Evaluation of the features of the QLH-Y

Feasibility

Format and number of items

The QLH-Y questionnaire includes 69 Likert-format items and two VAS scales. In the Netherlands, students at secondary schools are used to Likert-format items. Already at primary school students are to complete aptitude tests with multiple answering categories. VAS scales are less common in the Dutch educational system. Therefore, most adolescents are unexperienced in completion of a VAS scale. However, results from the pilot study and from the first study showed that completion of the VAS scales was uncomplicated.

In the pilot study and in the first study described in chapter 4, subjects were asked to respond on form and content of the questionnaire. Completion of the scale takes less 20 minutes. No negative responses were given on the form or format of the questionnaire. Only a few subjects did not return the questionnaire or did only partially complete it. Thus, the length of the questionnaire and the format of the items do not seem to influence response-rate negatively.

Developmental appropriateness

QL research should be essentially patient-centred. However, because the cognitive development of young children does not allow self-reporting, questionnaires to assess QL or functional status in a pediatric population often employ a by-proxy format. In adolescents a by-proxy format is not appropriate, since, as Achenbach reported [11], the agreement between parent-reports and self-reports on the behavioural problems of adolescents is poor. Adolescents already employ cognitive strategies as employed by adults to process, store, and retrieve information [12], though conceivably in a less advanced mode. Therefore, as in adults, to measure QL in adolescents a self-report mode of administration, as was chosen for the QLH-Y, is appropriate.

As part of the item reduction phase in the development of the QLH-Y, items not clearly understood by the subjects and items that revealed a poor response rate were eliminated. Further, ambiguous items will have resulted in cross-loadings on factor analyses and will not have contributed to the homogeneity of the subscales. These items were excluded during item reduction. Thus, it was found that the wording of the QLH-Y items was developmentally appropriate for adolescents.

Psychometrics

Reliability

To obtain indications for reliability of the QLH-Y, coefficients for internal reliability, test-retest stability coefficients, and inter-observer agreement were computed. Satisfactory coefficients of internal reliability (above .70 [13]) were obtained for all subscales except for two of the three Social Functioning subscales. Overall, high test-retest stability coefficients were found. Apparently, the way adolescents perceive their QL is rather stable. Those subjects who perceive their QL as poor in one week will evaluate their QL negatively again at a later measurement time, supporting the test-retest reliability of the QLH-Y. Only the scale "satisfaction with life in general" revealed test-retest stability coefficients just below .50. Since this scale also showed the highest sensitivity for change, this relatively low test-retest reliability coefficient probably does not reflect measurement error, but rather the more instable character of the perception of own life satisfaction, compared with other QL domains.

As a measure for parent-subject agreement, intraclass correlations were computed between parent/caretaker scores on a parent version of the QLH-Y (QLH-P) and subject scores on the self-report version of the QLH-Y. Parent scores were obtained for all measurements from one and the same parent or caretaker. Most of these correlations exceed the commonly reported relatively low parent-youth agreement regarding this age group on behavioural, cognitive, and emotional constructs, as described by Achenbach [11]. One might derive from this finding that parents are more competent to adequately rate their teenage children's QL than they are competent to rate their children's behavioural problems, as the Achenbach study refers to. Also the findings regarding parent-subject agreement support the reliability of the QLH-Y.

Validity and sensitivity

Content validity determines if the content of the items in a test and the number of items are appropriate to the domain to be tested. In QL studies in children and adolescents, few studies report on content validity, as can be derived from Landgraf and Abetz' [14] review. To investigate content validity of a questionnaire in this domain, a sample of subjects in the target population can be asked to evaluate the appropriateness of the questionnaire. In this study, a panel adolescents were asked to review the content and format of the questionnaire. The comments of this panel were integrated in the development of the test. However, the panellists were not asked to

evaluate content against their perception of the concept QL. Therefore, the content validity of the QLH-Y is only partly confirmed

As no other measurement scale for QL in this population was available at that time, the concurrent validity of the QLH-Y could not be determined[1].

Information about the construct validity of the QLH-Y was obtained from the repeated measurement analyses of variance in the study described in chapter 5 and from the study on the effects of changes in headache activity on QL as described in chapter 6. In the study described in chapter 5, headache subjects were compared with no headache subjects on their QL as measured by the QLH-Y. It was expected that headache subjects would show a poorer QL than no-headache controls and that all QLH-Y scales would display a sensitivity for actual headache. These expectations were confirmed. The QL domains Physical Functioning and Psychological Functioning were found to be most sensitive for headache diagnosis and actual headache.

This study showed that VAS scales are reliable, valid and sensitive to be used in QL studies in young subjects. The relatively high interrater agreement regarding the VAS scales indicate the reliability of these scales. The validity of these scales is indicated by the substantive association between scores on the global VAS scales and on relevant specific scales. The sensitivity of the VAS scales is indicated since the VAS scales were among the QLH-Y scales that showed the highest sensitivity for actual headache (chapter 6).

Differences in QL between subjects with recurrent headache and no-headache controls

Clearly, adolescents with recurrent headache or migraine showed a poorer QL regarding all QL domains. However, measurements with the QLH-Y did not capture differences in QL between migraine subjects and no-migraine headache subjects. This finding is in concordance with a study in adults by Passchier, Boo, Quaak, and Brienen [15], who showed that tension headache patients are at least equally impaired in QL as compared with migraine patients.

In our study, subjects with no-migraine headache reported more headache during the 4-week research period than did migraine patients. They also used more

[1]It was considered to use the adolescent version of the COOP/WONCA charts (see chapter 1) to determine concurrent validity of the QLH-Y, but the content of the COOP/WONCA is too divergent from the content of the QLH-Y QL domains to be used as a validation measure.

analgesics than subjects with migraine. These factors were not controlled for in the analyses performed to explore the discriminant validity of the QLH-Y. Both the differences in headache activity and in consumption of analgesics can be expected to affect the quality of life of the subjects. Although the direction and size of these presumably interfering effects are unknown, these effects may partly explain the absence of differences in QL found between the two groups.

Changes in headache activity related to changes in QL

Variation in headache activity across measurements was most consistently related to the within-subject variation in the QL domain Functional Status. Across measurement times, the study revealed no relation between the within-subject variation in headache activity and the within-subject variation of the scores on the Psychological Functioning subscales "stress", "depression", and "optimism about the future", on the Social Functioning subscale "social functioning with peers" and on the single Physical Functioning subscale. Several other studies have indicated a significant relation between psychological distress and familiarity with headache or migraine [16, 17, 18, 19]. Nevertheless, in none of these studies, the relation between *changes* in experienced stress and depression and *changes* in headache activity was investigated. The findings of the present study indicate that, although as a group headache subjects report more stress and depression than controls, variations in headache activity over time within these subjects do not seem to affect variations in self-reported stress and depression.

The moderating effect of experienced stress and trait negative affectivity on the relationship between headache and QL

In chapter 7, a study was described that explored the moderating effects of experienced stress and negative affectivity on the relation between headache activity and QL. No earlier published study was identified in which the relation between stress and headache was investigated by employing a diary format for the recording of both these variables, as was done in this study. In other studies on this topic, a questionnaire format was used for one or both these variables. Some studies on this topic related to young subjects [16, 20, 21] found a positive relation between stress and headache. More stress was reported by headache subjects compared with no headache controls. Also in our study a similar positive relation was found between headache diagnosis and stress (see chapter 5 of this thesis). Interestingly, although

this study showed that headache subjects as a group report higher levels of stress than no headache controls, no association was found between variations in levels of experienced stress across time and variations in headache activity across time.

Within the subjects with recurrent headache, this study showed that those adolescents who had experienced a high headache activity during the 4-week study period reported a poorer QL than subjects who had experienced a low headache activity during this period: Subjects with a high headache activity reported a lower Satisfaction with Health and Satisfaction with Life in General and a poorer Functional Status. This association was not stronger in subjects high on negative affectivity or in subjects who had experienced more stress than others. Thus, the effect of headache activity on these QL domains occurs independently from negative affectivity or experienced stress.

Despite sample size limitations, Interaction effects were found between headache activity and experienced stress on the QL domains Psychological Functioning and Satisfaction with Life in General. Adolescents who had experienced high levels of stress *and* high headache activity, reported a lower QL on these domains than subjects with high headache activity and low levels of experienced stress. Thus, subjects who are bothered by stress can be expected to experience a greater effect of their headache on their QL.

Since subjects with migraine did not differ in trait negative affectivity compared with no-migraine headache subjects, no support was found for the existence of a typical anxious and depressive migraine personality. However, as a whole, migraine subjects and no migraine headache subjects did show a higher trait negative affectivity compared with no headache controls. This finding is in support of Cunningham *et al.*'s suggestion [22], that personality characteristics of children with migraine may be a common feature of all young chronic pain patients and may result from their common pain experience.

Generalisation of findings

The first objective of this study was to develop a questionnaire to assess QL in adolescents with recurrent headache. Additionally, this study also reveals some typical aspects of the QL of these adolescents. The primary goal of the study in which subjects with recurrent headache were compared with subjects unfamiliar with headache, was to study the validity and sensitivity of the questionnaire. Since no gold standard or common yardstick for QL exists, QL research is essentially comparative. The QL of a single subject or of a group of subjects (i.e. a patient group) can only be estimated in comparison with other subjects or in comparison with a previous

measurement. Therefore, the data from the validation study may also be used to draw some conclusions concerning the QL in migraine and no-migraine subjects in general. A prerequisite for such a generalisation is that the samples in the study are representative for the general population. Subjects were recruited from all common secondary school types in the Netherlands and all ages between 12 and 18 years were equally represented, supporting the generalisability of the findings in this study. However, all subjects in the validation study were recruited from one middle-sized city in a particular area in the Netherlands, which weakens the generalisability of the findings of this study to other populations than secondary school students in middle-sized Dutch towns.

Implications

The QLH-Y as an instrument in clinical practice, clinical research, and public health

This study showed that the QLH-Y is a reliable, valid, and sensitive instrument for assessing QL in adolescent with recurrent headache or migraine.

In clinical practice dealing with subjects with recurrent headache or migraine, a QL questionnaire like the QLH-Y may serve two purposes. First, it may identify those subjects who are most bothered by their headache or migraine. Following, these subjects could be given higher priority in treatment. Second, in this population a QL questionnaire may be used in treatment evaluation, in which patients serve as their own controls. However, in its present form the use of the QLH-Y in clinical praxis is not yet indicated, because (1) no norm scores are available yet for the QLH-Y and (2) the QLH-Y may be too long to enable fast and smooth administration as is required in clinical praxis.

As a research instrument, the QLH-Y has proven its value. As such, in clinical research, the QLH-Y may offer a broader scope to the evaluation of treatment effects in young headache subjects than traditional pain measurement only. Therefore, the benefit of the implementation of a QL instrument like the QLH-Y as part of a headache treatment evaluation is evident.

In public health research, the generic modules of the QLH-Y may be employed to survey the impact of different diseases on the lives of juvenile subjects. To adapt the QLH-Y to be applicable on other patient groups than recurrent headache or migraine patients, other disease-specific subscales have to be constructed to represent the QL domain Functional Status.

Future research

The validation of a questionnaire is an ongoing process. The results of the intervention studies in which the QLH-Y is now being used, will increase our knowledge on the validity and other psychometric properties of the QLH-Y. Better indications for construct validity can be obtained by implementing the QLH-Y simultaneously with other newly developed QL questionnaires for young subjects. Further, with the Functional Status module exchanged by other disease-specific modules, the QLH-Y can be made applicable on other juvenile patient groups. Then, the QL of subjects with recurrent headache can be compared with the QL of other patient groups, including their Functional Status.

This study showed that VAS scales are valid, reliable, and sensitive instruments for studying QL in adolescents. VAS scales are easy to administrate. Therefore, in the further development of the QL measurement in adolescents, it may be considered to rely increasingly on the use of VAS scales.

It was shown that the QLH-Y is well applicable in a research setting. However, in clinical praxis, the QLH-Y may be too long. Therefore, the development of a shortened version of the questionnaire should be a topic of future research. One strategy to shorten the QLH-Y may be to reduce the number of items within the Psychological Functioning domain, since items within this domain (34 items) are over-represented compared with the other domains (e.g. none of the other domains include more than 14 items). Subscales within the domains Psychological Functioning were constructed by factor analytical methods.

To reduce the number of Psychological Functioning items, alternatively, a factor solution with fewer factors could be chosen[1]. A similar approach of item reduction can be adopted within the Social Functioning QL domain[2].

To further develop the QLH-Y into a QL measurement scale to be used in clinical praxis, norm scores should be made available for the QLH-Y. To obtain authoritative norm scores representative samples of the general population have to be enquired.

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[1]A post-hoc two-factor solution for example, resulted in one subscale including eight positively formulated items (coefficient alpha of .87) and one subscale including eight items with negative formulation (coefficient alpha of .92). This item reduction would lower the number of items in the Psychological Functioning domain from thirty-four to sixteen.

[2]A post-hoc one-factor solution for the Social Functioning domain resulted in one scale including nine items with an internal reliability of .73. Following, the number of items to cover this domain would be reduced from twelve to nine.

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SUMMARY

This thesis deals with the assessment of quality of life (QL) in adolescents with recurrent primary headache. First, the development of a questionnaire to assess QL in adolescents with headache is described. The psychometric properties of the new questionnaire are presented, including the questionnaire's sensitivity for change in headache activity. Employing this new questionnaire, the QL of adolescents with migraine is compared with the QL of adolescents with other types of headache and with adolescents with no headache complaints. Further, the study explores how changes in headache activity are related to changes in QL. Finally, the moderating effects of "experienced stress" and "negative affectivity" on the relation between headache activity and QL are tested.

Chapter 1 presents some backgrounds of the concept QL. Historically, the origin of the concept QL can be traced back to both political programs and to medical research. In the 1960's, the improvement of QL was introduced in American political campaigns as a new aim of governmental policy. Parallel to this political development and based on a broader definition of health as defined by the World Health Organisation in 1958, the QL concept was introduced also in the medical literature . In the 1990's QL measures have become generally accepted to broaden the scope of studies into the effects of diseases and their treatments on the lives of patients.

In medical research, QL is defined in different ways. However, a consensus on the conceptualization of the QL concept can be distinguished. In studies that explore the effects of a disorder and its treatment on the lives of patients, a pragmatic approach to the demarcation of the QL concept should be preferred. As such, QL can be seen as an aggregate of measures of daily functioning: somatic status, psychological functioning, occupational and role-functioning, and social interactions.

In medical research QL can be assessed for different reasons: (1) At the *individual patient level*: Since QL evaluation results in a more refined effect evaluation, the inclusion of QL measures results in an improved evaluation of treatment effects, and a better monitoring of treatment outcomes can be accomplished. (2) At the *patient group level*: By employing QL evaluation, a better differentiation between treatments with marginal differences in effects on mortality and morbidity can be reached (i.e. palliative treatment of incurable cancer or medication of migraine patients). As a result, better treatment programs can be developed for a specific patient group. (3) At the *population level*, QL evaluation can help improve the allocation of health services.

In children and adolescents an age-appropriate conceptualisation of QL is required, since young subjects have age-related interests, preferences and problems. An instrument to measure QL in adolescents should be based on this age related

conceptualisation of QL. Further, such an instrument should comply with age-related demands related to the developmental stage of the young subjects, and the subjects' stage of cognitive development. Additionally, an instrument to measure QL in adolescents should comply with common psychometric requirements as reliability, validity and sensitivity.

In **chapter 2**, a literature study is presented, first describing the characteristic features of the two most common forms of primary headache, tension-type headache and migraine. Further, prevalence, morbidity and causal factors of primary headache in children and adolescents are discussed. The prevalence of headache and migraine increases with age. Around 35% of 7-years old children report to have experienced headache. At the age of fifteen this number has risen to nearly 70%. The prevalence of migraine is reported to increase from 2.7% by the age of seven to 10.6% at the age of 14. The prevalence of migraine in adolescents (12 to 17 years of age) is reported to be about 15%. Both in children with migraine and in children with other types of primary headache high numbers of annual school absence days are found. Children and adolescents with frequent or severe headache report a great deal of bother by their disorder, even more than children with asthma. A congenital component in the occurrence of migraine is generally accepted. The experience of stress seems to trigger and intensify a migraine attack. No studies examining the overall QL of adolescent headache subjects could be identified. However, different studies have shown that the experience of recurrent headache leads to a poorer QL in several specific QL domains (i.e. Psychological Functioning, Role and Social Functioning and Physical Functioning).

Chapter 3 presents the study purposes and general design of the study. The main purpose of the study was to develop and evaluate an instrument to assess QL in adolescents with recurrent headache. Further purposes were to explore the effects of migraine and no-migraine primary headache on QL and to test moderator effects on the relation between headache and QL in adolescents.

Chapter 4 describes the development of a new generic quality of life measurement scale for adolescents between twelve and eighteen years with chronic headache or migraine. A preliminary version of the new questionnaire, the Quality of Life Headache-Youth (QLH-Y) was constructed. New items were generated based on interviews with young migraine patients. Other items were selected and adapted from existing questionnaires that had already proven to assess one QL domain reliably and validly. New common answering categories were assigned and the items were reviewed by a panel of youngsters, by an experienced teacher and by a child

psychologist. Then, after inappropriate items were adapted or removed, the questionnaire was completed by all students of a secondary school (*n=223)*. Based on these data, new scales were constructed employing a factor-analytic approach. A further item reduction was accomplished by analyses of internal reliability of the constructed scales. As a result, the final version of the QLH-Y consists of two overall assessments of the QL domains Satisfaction with Life and Satisfaction with Health and 69 multiple choice items to assess the four broad QL domains Physical Functioning, Functional Status, Psychological Functioning, and Social Functioning. All of the multiple-items subscales, except two of the three Social Functioning subscales, showed satisfactory internal consistency.

In **chapter 5**, psychometric properties of the final version of the new quality of life measurement scale are presented. To reach this purpose, a second study was performed. Subjects with recurrent headache were selected from the total population of two schools for secondary education in a medium sized Dutch town. All selected subjects with recurrent headache (*n*=64) were diagnosed by a neurologist on their type of headache, resulting in 38 subjects with migraine and 20 subjects with other non-organic primary headache. Six subjects did not meet at the doctor's office. From the population of the two schools, 96 headache-free controls were selected, who were matched to the subjects with headache on age, gender, and school type. All subjects with headache and control subjects completed the questionnaire five times: Four measurements were performed with 1-week intervals. The final measurement was conducted six months after the subjects' first completion of the QLH-Y. Simultaneously with the first four measurements, one and the same parent of the subjects completed a parent version of the QLH-Y. To assess the psychometric properties of the questionnaire, indications for stability, parent-youth agreement, validity, and sensitivity were computed. The general conclusion of this study on the psychometric properties of the QLH-Y was that it measures the QL of adolescents with primary headache in a valid and reliable way. On all QL domains, subjects with recurrent headache showed a poorer QL compared with headache free controls. However, no differences were found between the QL of migraine subjects and of subjects with other types of headache. The subscales within the QL domain Functional status showed the highest sensitivity to actual headache prior to completion of the QLH-Y.

In **chapter 6**, the results of a study into the relationship between changes in the actual presence of headache and the experience of different domains of quality of life in adolescents are presented. During the first four weeks of the study described in chapter 5, all students with recurrent headache completed a headache diary. In this headache diary, the intensity of the experienced headache was recorded four times

daily. For each of the four weeks "headache indexes" were computed by summating all recorded headache intensities during that week. To explore the effect of actual headache on the QL of the subjects, partial correlations were computed between the headache and QL of the subjects, corrected for the subjects' QL and headache the previous week. Functional status was most affected by actual headache. Further, headache activity showed a significant impact on the QL domains Psychological Functioning, Satisfaction with Life in General and Satisfaction with Health.

Chapter 7 describes a study into the effects of experienced stress and negative affectivity on the interrelation between headache and health related QL. As is described in chapter 5 and 6, familiarity with headache and headache activity was found to be clearly related to a lowered QL. However, for most QL domains the direction of causality of this interrelation is less evident. Headache may lead to a lowered QL, but it could also be hypothesized that low QL may result in headache. This problem of causality may even be more complex, as a third variable may influence, or moderate, the relation between headache and QL. A moderator is a variable that affects the direction and/or strength of a relation between an independent or predictor variable and a dependent variable. Several studies point at experienced stress and trait negative affectivity as potential moderators on the relation between headache and QL in adolescents.

To explore the moderating effect of negative affectivity on the relation between headache and QL, all subjects with primary headache as described in chapter 6 (n=64) completed a common neuroticism scale that is known to reliably and validly measure trait negative affectivity. To explore the moderating effect of experienced stress, as part of the headache diary described in chapter 6, all subjects familiar with headache were asked to daily record all events and thoughts that frequently came to their mind that day. Subsequently, two experienced child psychologists independently categorised all these self-reports as "stressful events or thoughts" or "no stressful events or thoughts". For each week and for each subjects, an experienced stress sum score was computed by summating all reported events or thoughts categorised as "stressful". By way of multiple regression analyses, the relative effects of negative affectivity, experienced stress and headache and interactions on the QL of the subjects were assessed. This study showed that the effect of actual headache on QL in adolescents cannot be attributed to the subjects' emotional characteristics or to instances of experienced stress they had experienced. However, adolescents high on experienced stress showed a greater impact of headache on their psychological functioning and satisfaction with health. As such, experienced stress was found to moderate the relation between headache and QL in adolescents.

In **chapter 8**, the general implications and limitations of this study are discussed and suggestions for further research are presented. The QLH-Y is a new instrument to assess QL in juvenile subjects with recurrent non-organic headache. This study showed that the QLH-Y is a reliable, valid and sensitive instrument to assess QL in adolescents with recurrent non-organic headache. As a research instrument to be used in clinical research and in public health research, the QLH-Y has proven its value: Employing the QLH-Y, this study revealed how recurrent headache affects the QL of adolescents. Further, it showed how changes in headache intensity co-variate with changes in QL and it explored the moderating role of negative affectivity and experienced stress on the interrelation between headache and QL in adolescents. However, to be used as a QL assessment scale in clinical praxis, QLH-Y norm scores should be made available, based on a more numerous and more diverse sample of subjects. Further, to facilitate the completion of the QLH-Y in clinical praxis, the development of a shortened version of the QLH-Y is recommended.

SAMENVATTING

Dit proefschrift beschrijft de ontwikkeling van een vragenlijst voor het registreren van kwaliteit van leven (KL) bij jongeren met hoofdpijn en migraine. De psychometrische eigenschappen van deze vragenlijst, waaronder de gevoeligheid voor verandering van hoofdpijn, worden beschreven. Met behulp van deze lijst werd de KL van jongeren met migraine vergeleken met die van jongeren met andere hoofdpijn dan migraine en van jongeren zonder hoofdpijn-klachten. Ook werd onderzocht op welke wijze veranderingen in hoofdpijn-activiteit samenhangen met veranderingen in KL. Verder werd de invloed van "ervaren stress" en neuroticisme, of "negatieve affectiviteit", op de relatie tussen hoofdpijn en migraine enerzijds en KL anderzijds onderzocht en beschreven.

in **hoofdstuk 1** wordt allereerst ingegaan op de historie van het begrip "KL". In Amerikaanse politieke campagnes in de jaren '60 werd het begrip geïntroduceerd als nieuwe beleidsdoelstelling. Doel van politiek beleid zou meer moeten zijn dan economische vooruitgang. Verbetering van de KL van de burgers werd geopperd als alternatief beleidsdoel. Parallel aan deze politieke ontwikkeling en voortbouwend op een bredere interpretatie van het begrip gezondheid, zoals in 1958 geïntroduceerd door de Wereld Gezondheids Organisatie, werd ook in de medische literatuur het begrip KL geïntroduceerd. Drie decennia later, in de negentiger jaren, wordt algemeen erkend dat KL-evaluatie een centrale positie dient te hebben in onderzoek naar de effecten van medische behandelingen.

Hoewel medische onderzoekers verschillende definities van KL hanteren, is er toch een zekere consensus met betrekking tot de afbakening van de inhoud van het begrip KL. In studies die het effect van een aandoening en haar behandeling op het leven van patiënten onderzoeken, verdient een pragmatische patiënt-gecentreerde afbakening van het begrip KL de voorkeur. In die zin vertegenwoordigt KL een verzamelnaam voor het dagelijks functioneren in vier domeinen: somatische status, psychologische status, beroeps- en rol-functioneren en sociale interacties.

Er zijn verschillende redenen voor het registreren van KL in medisch onderzoek: (1) Op het niveau van de individuele patiënt: Omdat KL-registratie leidt tot een meer verfijnde effect-evaluatie kunnen de effecten van een individuele behandeling beter worden gemonitoreerd. (2) Op het niveau van de patiëntengroep: Middels KL-evaluatie kan een betere differentiatie van de effecten van verschillende behandelingen op een patiëntengroep bereikt worden. (3) Op populatie-niveau: Door middel van een inventarisatie van de KL van een populatie kan gezondheidsbeleid beter gericht worden op die groepen van de bevolking die de meest gebrekkige KL laten zien. (4) Tenslotte kan KL-evaluatie gebruikt worden voor commerciële

doeleinden, om de superioriteit van een nieuwe behandeling boven een conventionele behandeling aan te tonen.

KL-meting bij kinderen en jongeren stelt bijzondere eisen aan de invulling van het begrip KL en aan de methode van KL-registratie. Een meetinstrument dat ontwikkeld is voor het registreren van KL bij volwassenen voldoet in de regel niet voor kinderen. Er zijn daarom leeftijd-specifieke KL-instrumenten ontwikkeld. Iedere ziekte of aandoening heeft een specifieke invloed op de kwaliteit van het leven van een patiënt. Daarom dient een KL-instrument voor jongeren niet alleen leeftijd-specifiek te zijn, maar ook dient minimaal een gedeelte van een KL-instrument voor kinderen ziekte- of aandoening-specifiek te zijn. Er zijn verschillende methoden om de KL bij kinderen te registreren. De meest gangbare is het gebruik van een vragenlijst.

Hoofdstuk 2 beschrijft allereerst de kenmerken, de prevalentie en het ontstaan van de meest voorkomende vormen van hoofdpijn en migraine bij jongeren. Het vóórkomen van hoofdpijn en migraine neemt toe met de leeftijd. Van de 7-jarigen blijkt rond de 35% wel eens last van hoofdpijn gehad te hebben. Voor 14-jarigen is dit gestegen tot bijna 70%. Migraine komt minder vaak voor. Algemeen wordt aangenomen dat tussen de 5% en 10% van de schoolgaande kinderen last van migraine heeft. Ook bij migraine is een stijging van de prevalentie waar te nemen parallel met de toename van de leeftijd van de kinderen. Hoewel men het er over eens is dat het ontstaan van migraine gedeeltelijk erfelijk bepaald is, lijkt de beleving van stress een belangrijke factor te zijn bij het ontstaan van een migraine-aanval.

Verder wordt in dit hoofdstuk ingegaan op bekende effecten van hoofdpijn op verschillende deelgebieden van de KL van jongeren. Zowel kinderen met migraine als kinderen met andere vormen van chronische hoofdpijn blijken lichamelijk, psychisch en sociaal slechter te functioneren dan hun hoofdpijn-vrije leeftijdsgenoten. Ook leidt hoofdpijn en migraine tot schoolabsentie.

Omdat er geen eerdere studies gevonden werden die expliciet de KL van jongeren met hoofdpijn beschrijven, worden in dit hoofdstuk ook de effecten van hoofdpijn en migraine op de KL van volwassenen beschreven. Men heeft aangetoond dat de KL van chronische hoofdpijn patiënten slechter is dan de KL van patiënten met invalidiserende ziektes als reuma en diabetes. Sommige studies laten verschillen zien in de KL van migraine patiënten vergeleken met de KL van patiënten met spanningshoofdpijn, andere doen dat niet. Om de KL van jongeren met frequent voorkomende hoofdpijn systematisch te kunnen beschrijven, dient er een goed meetinstrument beschikbaar te zijn. Dit instrument kan dan ook gebruikt worden om de effecten van hoofdpijn- en migraine-behandeling beter te kunnen evalueren.

Hoofdstuk 3 geeft de doelstellingen en het ontwerp van deze studie. Doel van de studie was het ontwikkelen en evalueren van een meetinstrument voor het registreren van KL van jongeren met migraine en andere vormen van niet organische hoofdpijn. Verdere doelstellingen waren de inventarisatie van de effecten van primaire hoofdpijn op de KL van jongeren met hoofdpijn en migraine en de exploratie van moderator-effecten op de relatie tussen hoofdpijn en de KL.

In **hoofdstuk 4** wordt beschreven hoe het nieuwe meetinstrument voor KL bij jongeren met hoofdpijn tot stand is gekomen.

Op basis van literatuurgegevens werden de volgende vier specifieke KL-domeinen gedefinieerd voor deze doelgroep: Lichamelijk Functioneren, Psychologisch Functioneren, Functionele Status en Sociaal Functioneren. Daarnaast werden twee algemene domeinen gedefinieerd: Tevredenheid met het Leven in het Algemeen en Tevredenheid met de Gezondheid. Vervolgens werd de vorm van het instrument bepaald. Gebaseerd op beschikbare kennis aangaande het meten van psychologische-, sociale- en gezondheids-variabelen bij kinderen, werd gekozen voor een door de deelnemers zelf in te vullen vragenlijst. Voor de twee algemene KL-domeinen werd gekozen voor een "visueel analoge schaal" (VAS-schaal). Deze bestaat uit een tien centimeter lange lijn waarop de proefpersonen gevraagd wordt hun niveau van tevredenheid aan te geven, ergens tussen "helemaal tevreden" en "helemaal ontevreden". Als vorm voor de vier specifieke domeinen werd gekozen voor meerkeuze vragen.

De inhoud het merendeel van de vragen horend bij drie van de vier specifieke domeinen werd afgeleid uit bestaande vragenlijsten. Van deze vragenlijsten is eerder gebleken dat deze het onderhavige KL-domein of een gedeelte daarvan op een valide en betrouwbare wijze meten. De vragen met betrekking tot het Functionele Status domein werden samengesteld aan de hand van interviews met jonge migraine-patiënten. Aan alle vragen werden vier antwoord categorieën gekoppeld. Alle vragen werden daarna aangepast en verbeterd. Zo ontstond een eerste versie van de vragenlijst, bestaande uit 127 meerkeuze vragen en twee VAS-schalen.

Deze eerste versie van de vragenlijst werd hierna afgenomen bij de volledige populatie (n=223) van een school voor Middelbaar Algemeen Vormend Onderwijs (MAVO) in een kleine gemeente in Nederland. De verzamelde data werden geanalyseerd middels factoranalyse en homogeneïteits-analyse. Deze analyse technieken resulteerden in de uiteindelijke versie van de "Quality of Life Headache in Youth" (QLH-Y). Deze bestaat uit 69 meerkeuze-vragen, verdeeld over dertien specifieke deelschalen en twee algemene VAS-schalen.

Hoofdstuk 5 beschrijft een studie naar de psychometrische kwaliteiten van de QLH-Y. Daartoe werd, middels een korte vragenlijst, de volledige populatie van twee scholengemeenschappen (*N*=1566) in een middelgrote gemeente in Nederland onderzocht op het vóórkomen van hoofdpijn en migraine. Alle leerlingen die minstens een jaar lang en minstens twee maal per maand last van hoofdpijn hadden, werden gevraagd mee te doen aan het onderzoek. Van deze 129 leerlingen gaven 64 jongeren en hun ouders te kennen mee te willen doen aan het onderzoek. Deze werden allen door een neuroloog onderzocht, resulterend in 38 migraine-diagnoses. Bij de overige deelnemers met hoofdpijn werd geen migraine gediagnostiseerd. Er werd bij geen van de deelnemers een organische oorzaak voor de hoofdpijn gevonden. Uit de populatie van de twee scholengemeenschappen werden verder 96 leerlingen zonder hoofdpijn geselecteerd, op zodanige wijze dat de verdeling van leeftijd, geslacht en schooltype overeenkwamen met de verdeling van deze variabelen in de groep geselecteerde proefpersonen met hoofdpijn. Alle proefpersonen vulden de QLH-Y vijf keer in. De eerste vier keer gebeurde dit steeds met een tussenperiode van één week. De laatste afname vond een half jaar na de eerste plaats. Gelijktijdig met iedere afname van de QLH-Y vulde steeds dezelfde ouder van de deelnemende jongeren een ouder-versie van de vragenlijst in.

Op basis van de verzamelde gegevens werden de psychometrische eigenschappen van de vragenlijst onderzocht. De algemene conclusie was dat de QLH-Y een meetinstrument is dat de KL van jongeren met hoofdpijn en migraine op een betrouwbare en valide wijze registreert. Op alle gebieden van KL lieten de deelnemers met hoofdpijn en migraine een slechtere KL zien dan jongeren zonder hoofdpijn. Er kon geen onderscheid gemaakt worden in de KL van migraine en van andere hoofdpijn-patiënten.

In **hoofdstuk 6** wordt een studie beschreven waarin onderzocht werd hoe veranderingen in hoofdpijn intensiteit de KL van jongeren kan beïnvloeden. Tijdens de eerste vier weken van het in hoofdstuk 5 beschreven onderzoek hielden alle jongeren uit de hoofdpijngroep een hoofdpijn dagboek bij. Hierin werd vier maal daags de intensiteit van de ervaren hoofdpijn genoteerd. Per week werden nu zogenaamde "hoofdpijn-indexen" berekend en het effect van veranderingen in hoofdpijn activiteit op KL werd onderzocht. Het domein Functionele status, zoals gemeten met de QLH-Y, bleek het meest beïnvloed te worden door actuele hoofdpijn. Verder bleken de domeinen Psychologisch Functioneren, Tevredenheid met het Leven in het Algemeen en Tevredenheid met de Gezondheid ook gevoelig te zijn voor veranderingen in hoofdpijn-activiteit.

Hoofdstuk 7 beschrijft een onderzoek naar de modererende effecten van ervaren stress en "negatieve affectiviteit" op de relatie tussen hoofdpijn en KL. Het begrip negatieve affectiviteit wordt in nieuwere literatuur gebruikt als alternatief voor de persoonlijkheids variabele neuroticisme, waarvan gemeend wordt dat het in een te grote mate verbonden is aan één theoretisch perspectief. Negatieve affectiviteit kan gedefinieerd worden als de mate waarin een persoon geneigd is tot het waarnemen van negatieve gevoelens en lichamelijke onbehagen. Negatieve affectiviteit kan gemeten worden middels bestaande vragenlijsten voor het meten van neuroticisme.

Zoals in hoofdstuk 5 en 6 beschreven is, blijkt hoofdpijn bij jongeren duidelijk gerelateerd te zijn aan een verminderde KL. De richting van causaliteit van deze interrelatie is voor sommige KL-domeinen duidelijker dan voor andere. Een alternatieve verklaring voor de gevonden relatie tussen hoofdpijn en KL zou de invloed van een derde variabele kunnen zijn op zowel hoofdpijn activiteit als op de KL. Deze derde variabele zou als moderator op kunnen treden. Een moderator is een variabele die de richting en de sterkte van de relatie tussen twee andere variabele beïnvloedt. Ervaren stress en negatieve affectiviteit zijn potentiële kandidaten voor de rol van moderator.

Om het potentiële modererende effect van negatieve affectiviteit en ervaren stress te onderzoeken, werd bij de 64 jongeren met hoofdpijn of migraine uit het onderzoek beschreven in hoofdstuk 6 de hoeveelheid ervaren stress geïnventariseerd. Dit werd gedaan door de deelnemers dagelijks in het hoofdpijn dagboek te laten aangeven welke gedachten of gebeurtenissen de jongeren die dag veel bezig hadden gehouden. Alle beschreven gedachten of gebeurtenissen werden daarna gecodeerd in de volgende rubrieken: (1) ervaren stress verbonden met school; (2) ervaren stress verbonden met gezondheid; (3) interpersoonlijke ervaren stress; (4) andere stressvolle gebeurtenissen en (5) gedachten of gebeurtenissen die niet met stress verbonden zijn. Om een maat voor negatieve affectiviteit te verkrijgen, werd bij de deelnemende jongeren met hoofdpijn een vaak gebruikte vragenlijst voor het meten van neuroticisme bij kinderen afgenomen.

Middels "multiple regressie analyse" werden nu de relatieve effecten van negatieve effectiviteit, ervaren stress en hoofdpijn op de KL van de deelnemers met hoofdpijn nagegaan. Moderator-effecten zijn interactie-effecten. Er werd daarom ook gezocht naar interactie-effecten tussen de onafhankelijke variabelen op de KL van de deelnemers. Na correctie voor effecten van ervaren stress en negatieve effectiviteit bleek hoofdpijn activiteit nog steeds significante en negatieve effecten te hebben op de KL-domeinen Functionele Status, Tevredenheid met het Leven in het Algemeen en Tevredenheid met de Gezondheid. Negatieve effectiviteit bleek een significant effect te hebben op de KL-domeinen Lichamelijk Functioneren en Psychologisch Functioneren. Ervaren stress bleek een significant effect te hebben op Psychologisch

Functioneren. Significante interactie-effecten werden gevonden tussen hoofdpijn en ervaren stress, niet tussen hoofdpijn en negatieve affectiviteit. Deelnemers met veel hoofdpijn en met veel gerapporteerde ervaren stress gedurende de studieperiode bleken een slechtere KL aan te geven dan deelnemers met evenveel hoofdpijn maar met minder ervaren stress. Deze slechtere KL kwam tot uitdrukking in lagere scores op de KL-domeinen Psychologisch Functioneren en Tevredenheid met het Leven in het Algemeen. Dus, gevonden werd dat bij deze groep jongeren de relatie tussen hoofdpijn activiteit en KL gemodereerd werd door de hoeveelheid ervaren stress, niet door de persoonlijkheidstrek negatieve affectiviteit.

In hoofdstuk 8 worden de algemene conclusies van deze studie samengevat en besproken. Verder worden suggesties voor verder onderzoek gedaan. Deze studie heeft aangetoond dat de QLH-Y een betrouwbaar en valide instrument is om de KL bij jongeren die last hebben van regelmatig terugkerende hoofdpijn te registreren. Als groep hebben jongeren met regelmatig terugkerende hoofdpijn een verlaagde KL. Dit geldt voor alle KL-domeinen. Er werden geen significante verschillen in KL gevonden tussen jongeren met migraine en jongeren met andere typen regelmatig terugkerende hoofdpijn. Grootste effect van hoofdpijn intensiteit op KL werd gevonden in het KL-domein Functionele Status. Als een onderzoeksinstrument heeft de QLH-Y haar waarde nu bewezen. Om de toepasbaarheid van de QLH-Y in de klinische praktijk te verbeteren, verdient het aanbeveling om middels een nieuwe studie met een groter aantal deelnemers normscores voor de QLH-Y te berekenen. Ook de beschikbaarheid van een verkorte versie van de QLH-Y zou de toepasbaarheid van dit nieuwe instrument in de klinische praktijk vergemakkelijken.

SAMMENDRAG

Avhandlingen beskriver livskvalitet hos ungdom med migrene eller annen type tilbakevendende ikke-organisk hodepine. Hovedmål var å utvikle et nytt spørreskjema for systematisk kartlegging av livskvalitet, videre å utforske sammenhengen mellom hodesmerter og livskvalitet hos ungdom. Modererende effekt av "opplevd stress" og "negative affectivitity", på forholdet mellom hodepine og livskvalitet ble også undersøkt.

Første kapittel beskriver bakgrunnen for begrepet livskvalitet. I amerikansk politikk ble begrepet "bedret livskvalitet" lansert på 60-tallet. Samtidig ble begrepet innført i medisinsk litteratur, basert på den definisjonen av "helse" som Verden's Helse Organisasjon introduserte i 1958. Siste ti-år er livskvalitet blitt et anerkjent mål på hvordan sykdom og behandling påvirker pasienters liv.

I medisinsk forskning defineres livskvalitet på forskjellig vis. Det er likevel en viss enighet om begrepets innhold. Livskvalitet kan betraktes som et sammensatt funksjonsmål omfattende somatisk- og psykologisk funksjon, arbeids- og rollefunksjon, samt sosial interaksjon. Livskvalitet inkluderes som evalueringsmål i medisinsk forskning av følgende grunner: (1) På pasient nivå: Evaluering av livskvalitet gir mer presis informasjon om hvordan sykdom- og behandling virker inn på den totale helsetilstand hos den individuelle pasient. Ved bruk av livskvalitet som effektmål blir evalueringen mer pålitelig. Gevinst av dette kan være bedre observasjon av behandlings-effekt. 2) På pasientgruppe nivå: Evaluering av livskvalitet gjør det lettere å vurdere effekt av ulike behandlingsformer. 3) På populasjonsnivå: Gjennom kartlegging av befolkningens livskvalitet kan helsefremmende tiltak rettes mot de grupper som viser dårligst livskvalitet. 4) Livskvalitetsmålinger kan benyttes i markedsføring, som begrunnelse for at en behandlingsform er mer effektiv enn en annen.

Det finnes ulike måter å kartlegge livskvalitet. Den mest vanlige metode er ved bruk av spørreskjema. For systematisk kartlegging av livskvalitet hos ungdom med tilbakevendene hodepine trengs et alderstilpasset måleinstrument. Instrumentet bør inkludere en eller flere sykdoms-spesifikke moduler.

Kapittel 2 beskriver forekomst, etiologi og konsekvenser av ikke-organisk hodepine hos ungdom. Ved 7-års alder har cirka 35% av barn vært plaget med hodepine, ved 14-års alder nesten 70%. Mellom 5% og 10% av skolebarna plages med migrene. Også her er det en aldersrelatert stigning i forekomst. Ved migrene foreligger en arvelig disposisjon. Migreneanfall kan utløses av en rekke faktorer, deriblant opplevelse av stress. Studier har vist at barn med migrene og andre former

for kronisk hodepine har dårligere kroppslig, psykisk og sosialt funksjonsnivå og større skolefravær enn jevnaldrende uten hodepineplager. Livskvaliteten hos pasienter med kroniske hodesmerter kan være dårligere enn hos pasienter med sykdommer som reumatisme og diabetes mellitus. Det er tidligere ikke gjort livskvalitetsstudier av ungdom med tilbakevendene hodepineplager.

Kapittel 3 omhandler studiets målsetning. Hovedmål var å utvikle et valid instrument for kartlegging av livskvalitet hos ungdom med migrene eller andre typer hodepine. En annen målsetning var å kartlegge hvordan hodesmerter påvirker livskvaliteten og på hvilken måte opplevd stress og nevrotisisme ("negative affectivity") påvirker forholdet mellom hodesmerter og livskvalitet.

Kapittel 4 beskriver utviklingen av forskningsinstrument til registrering av livskvalitet. Fire spesifikke livskvalitet domener ble definert: Kroppslig funksjon, Psykologisk funksjon, Funksjonell status og Sosial funksjon. To generelle livskvalitet domener ble definert: Tilfredshet med livet generelt og Tilfredshet med helse. For de fire spesifikke livskvalitetsdomener valgte en flervalgsspørsmål, hvor svar velges mellom fire alternativer. For de to generelle livskvalitets domener ble det brukt "visuell-analoge skalaer" (VAS-skalaer), hvor grad av tilfredshet angis på en skala. Innholdet i tre av de spesifikke livskvalitets domener ble avledet fra eksisterende spørreskjema. Innholdet i domenen Funksjonell status ble konstruert på grunnlag av intervju med migrene pasienter i alderen 12-18 år. Instrumentets første versjon bestod av 127 flervalgsspørsmål og to VAS-skalaer. Dette ble utprøvd på samtlige elever ved en videregående skole i en mindre by i Nederland. På bakgrunn av resultatene ble den endelige utgaven av spørreskjemaet "Quality of Life Headache in Youth" (QLH-Y) utarbeidet. Det består av 69 flervalgs-spørsmål og to VAS-skalaer.

I **kapittel 5** beskrives psykometriske kvaliteter ved spørreskjemaet QLH-Y. Alle elever i to ungdoms- og videregående skoler ble undersøkt på forekomst av tilbakevendende hodepine og migrene (n=1566). Skolene omfatter all type utdanning tilgjengelig i Nederland for ungdom i alderen 12-18 år. Alle elevene fylte ut et *ad hoc* konstruert spørreskjema. De 129 elevene som anga plager med hodepine minst to ganger i måneden i minst ett år, oppfylte inklusjonskriteriene. Halvparten av disse (64) og deres foreldrene var villige til å delta i undersøkelsen. Deltagerne ble vurdert av nevrolog. Dette resulterte i 38 migrene diagnoser, og resten hovedsakelig spennings-hodepine. Det ble ikke funnet organisk etiologi hos noen av dem. Fra skolens populasjon ble det også selektert ut 96 elever uten hodepine plager. Fordelingen av alder, kjønn og skoletype var den samme som i elevgruppen med hodepineplager. Alle deltagerne fylte ut QLH-Y fem ganger. De fire første gangene

med en ukes mellomrom, den femte gangen et halvt år etter den første utfyllelsen. Parallellt fylte en av foreldrene ut en foreldreversjon av spørreskjemaet.

Spørreskjemaets psykometriske egenskaper ble vurdert blant annet ved å undersøke i hvilken grad besvarelsene viste overensstemmelse og stabilitet over tid. Det ble videre gjort analyser for å kartlegge følsomhet for forskjeller i alder, kjønn, hodepine-diagnose og tidseffekter. QLH-Y spørreskjemaet viste seg å være et valid og pålitelig instrument for registrering av livskvalitet hos ungdom med tilbakevendene hodepine eller migrene.

Kapittel 6 beskriver hvordan variasjon i smertenivå påvirker livskvaliteten. I løpet av de fire første ukene av forskningsprosjektet skrev de 64 elevene hver sin "hodepine-dagbok". Hver uke ble det beregnet en "hodepine-indeks" ved å summere intensiteten av alle smerteepisodene.

Funksjonell status var den livskvalitets domenen som var mest påvirkelig av variasjon i smertenivå. Psykologisk funksjon, Generell tilfredshet med livet og Tilfredshet med helse viste seg også å være følsom for endring i smerteaktivitet.

Kapittel 7 beskriver hvordan opplevd stress og nevrotisisme, eller "negative affectivity", kan påvirke forholdet mellom hodepine og livskvalitet. En del nyere litteratur benytter betegnelsen "negative affectivity" i stedet for nevrotisisme, det vil si et individs tendens til negativ fokusering på følelsesmessige eller kroppslige opplevelser.

Mens hodepine klart kan føre til nedsatt livskvalitet hos ungdom, vil nedsatt livskvalitet muligens også kunne lede til hodepine. For noen livskvalitets domener er årsaksforholdet hodepine-livskvalitet klarere enn for andre. En alternativ forklaring på denne ko-variasjon er at en tredje variabel både fører til økt hodepine og nedsatt livskvalitet. En slik "modererende" variabel påvirker retning og styrke i et forhold mellom to andre variabler. Opplevd stress og "negative affectivity" er to variabler som muligens kan moderere forholdet mellom hodepine og livskvalitet.

For å studere dette nærmere, ble intensiteten av opplevd negativ stress kartlagt hos de 64 elevene fra undersøkelsen beskrevet i kapittel 6. Etter fire ukers registrering av tanker og hendelser, ble materialet gruppert i følgende kategorier: (1) opplevd stress knyttet til skole; (2) opplevd stress knyttet til helse og sykdom; (3) interpersonlig opplevd stress; (4) andre stressfremkallende hendelser; og (5) tanker og hendelser som ikke kan betegnes som stressfremkallende. Et anerkjent spørreskjema ble benyttet for å måle "negative affectivity" hos elevene. Gjennom "multiple-regresjons-analyser" undersøkte en hvordan "negative affectivity" og hodepine påvirker livskvaliteten. Interaksjons-fenomen mellom de uavhengige variabler ble også kartlagt. Etter korreksjon for effekt av opplevd stress og "negative

affectivity" viste det seg at hodepine forsatt hadde en signifikant negativ virkning på livskvalitets domenene Funksjonell status, Tilfredshet med livet generelt og Tilfredshet med helse. "Negative affectivity" virket inn på livskvalitets domenene Somatisk og Psykologisk funksjon, mens opplevd stress hadde en klar virkning på Psykologisk funksjon. Signifikante interaksjonsfenomener ble funnet mellom hodepine og opplevd stress, men ikke mellom hodepine og "negative affectivity": Elever med mye smerteplager og stor grad av opplevd stress rapporterte dårligere livskvalitet enn elever med like mye smerter, men med mindre grad av opplevd stress. Dårligere livskvalitet kom til uttrykk ved lavere skårer i livskvalitets domenene Psykologisk funksjon og Tilfredshet med livet generelt.

Kapittel 8 gir en oppsummering og drøfting av konklusjonene. Dessuten gis forslag til videre forskning innen feltet. Studiet har vist at spørreskjemaet QLH-Y er et valid og pålitelig måleinstrument for kartlegging av livskvalitet hos ungdom med migrene eller annen type hodepine. Som gruppe viser disse ungdommene nedsatt livskvalitet målt i alle livskvalitets domener. Det ble ikke funnet signifikante forskjeller i livskvalitet mellom gruppen med migrene og gruppen med annen type hodepine. Det ble funnet størst korrelasjon mellom smertenivå og livskvalitet i domenen Funksjonell status. Opplevelse av stress påvirker forholdet mellom hodepine og livskvalitet. QLH-Y har vist sin verdi som forskningsinstrument. En normering av skårene vil gjøre spørreskjemaet mer anvendelig i klinisk praksis. Videre vil en forkortet versjon av QLH-Y øke instrumentets tilgjengelighet.

APPENDIX 1:

The QLH-Y questionnaire

QLH-Y

A questionnaire for youngsters
aged between 12 and 18 years

Name:.....
Date of filling in this questionnaire:.....

Answer each of the questions with your own opinion. Do not take too long to think about each question. An answer will always be correct as long as it is your own opinion. You may not give more than one answer per question. It is very important that you answer ALL the questions. At the end of each page, check carefully to make sure that you have not missed any out.

How satisfied or unsatisfied were you last week about your life in general?

Give your answer to this question by drawing a cross on a line. On the left and right-hand sides of the line, two answer options are given. The more satisfied you were about your life, the more to the right that you should draw your cross. The more unsatisfied you were about your life, the more to the left that you should draw your cross.

First, an example of a question that you *do not* need to answer.

How satisfied were you last week about the television programmes?

If you were completely satisfied about the television programmes, draw your cross on the extreme right-hand side of the line.

Thus:

How satisfied were you last week about the television programmes?

completely unsatisfied — completely satisfied

If your were completely unsatisfied about the television programmes, draw your cross on the extreme left-hand side of the line.

Thus:

How satisfied were you last week about the television programmes?

completely unsatisfied — completely satisfied

Therefore, the more satisfied you were, the more to the right that you should draw your cross.

The more unsatisfied you were, the more to the left that you should draw your cross.

You choose where to draw the cross.

This is the end of the example.

Please answer the question below by drawing a cross on the line.

How satisfied or unsatisfied were you last week about your life in general?

completely unsatisfied — completely satisfied

On the following pages, a list of words or statements is given. Read the words or statements carefully. We would like to know the extent to which these words or statements applied to you **last week**. You can indicate this by drawing a circle around the answer that fits your situation most closely. There is no such thing as an incorrect answer! The figures have the following meanings:

0 = "seldom or never" 1 = "sometimes"
2 = "often" 3 = "very often or always".

First, some examples:
If you found last week that the television programmes were "very often or always" interesting, draw a circle around the figure 3:

Last week, I found the television programmes:

	seldom or never	some-times	often	very often or always
interesting	0	1	2	(3)

If you found last week that the television programmes were "seldom or never" interesting, draw a circle around the figure 0:

Last week, I found the television programmes:

	seldom or never	some-times	often	very often or always
interesting	(0)	1	2	3

If you found last week that the television programmes were interesting "sometimes", draw a circle around the figure 1 and if you found the television programmes "often" interesting, draw a circle around the figure 2.

All the questions are about **last week**!

It is not permitted to give two answers by drawing a circle around two figures. Please make sure that you answer ALL the questions.
If you want to change your answer afterwards, do that in the following way:

Last week, I found the television programmes:

	seldom or never	some-times	often	very often or always
interesting	0	(1)	2	~~3~~

Now turn to the next page.

Last week, I was feeling:

		seldom or never	some-times	often	very often or always
1.	Exhausted	0	1	2	3
2.	Nervous	0	1	2	3
3.	Panicky	0	1	2	3
4.	Tired	0	1	2	3
5.	Tense	0	1	2	3
6.	At the end of my strength	0	1	2	3
7.	At ease	0	1	2	3
8.	Worried	0	1	2	3
9.	Worthless	0	1	2	3
10.	Fine	0	1	2	3
11.	Worn out	0	1	2	3
12.	Anxious	0	1	2	3
13.	Satisfied	0	1	2	3
14.	Happy	0	1	2	3
15.	Uncertain	0	1	2	3
16.	Hopeless	0	1	2	3
17.	Full of energy	0	1	2	3
18.	Lively	0	1	2	3
19.	Strong	0	1	2	3
20.	Relaxed	0	1	2	3

Give the answer that fits your situation **(last week)** most closely:

		seldom or never	some-times	often	very often or always
21.	If there were activities at home that we could all do together, I also took part	0	1	2	3
22.	I got on well with (one of) my parents	0	1	2	3
23.	I could talk to (one of) my parents about personal things or problems	0	1	2	3
24.	I got on well with (one of) my brothers or sisters	0	1	2	3
25.	I could talk to (one of) my brothers or sisters about personal things and problems	0	1	2	3
26.	I had an argument with (one of) my brothers or sisters	0	1	2	3
27.	I got on well with youngsters of my own age	0	1	2	3
28.	I could talk to a friend about personal things or problems	0	1	2	3
29	I did some things with youngsters of my own age, such as sport, going to the cinema, going out, etc.	0	1	2	3
30.	My school results or the results at work were good	0	1	2	3
31.	I managed to finish my (home)work on time	0	1	2	3

		seldom or never	some-times	often	very often or always
32.	I enjoyed myself at school or at work	0	1	2	3
33.	I did not sleep well	0	1	2	3
34.	I did not feel like doing anything	0	1	2	3
35.	I felt gloomy	0	1	2	3
36.	When I woke up, I thought about the nice things to come	0	1	2	3
37.	I did not feel well	0	1	2	3
38.	I think that I have a nice life	0	1	2	3
39.	I thought that later I would have a nice home and a good job and be able to earn enough money	0	1	2	3
40.	I thought that later everything will be fine	0	1	2	3
41.	I felt cheerful	0	1	2	3
42.	I thought that I will never be anything later because I am not good at anything	0	1	2	3
43.	I thought that I would be happy in the future	0	1	2	3
44.	I kept having the feeling that I did not fit in when youngsters of my own age are busy with something nice	0	1	2	3
45.	Generally, I was in a good mood	0	1	2	3

How satisfied or unsatisfied were you last week about your health?
Answer this question in the same way as the one at the beginning of this questionnaire: by drawing a cross somewhere on the line. The more satisfied you were last week with your health, the more to the right that you should draw your cross. The more unsatisfied you were, the more to the left that you should draw your cross.

Please answer the following question by drawing a cross on the line:

How satisfied or unsatisfied were you last week about your health?

completely unsatisfied

completely satisfied

Draw a circle around one of the four figures:
Last week I was troubled by:

		seldom or never	some-times	very often	often or always
46.	Belly Pain.	0	1	2	3
47.	Difficulty falling asleep	0	1	2	3
48.	Feeling tired	0	1	2	3
49.	Feeling that I was going to be sick (nauseous)	0	1	2	3
50.	Muscle stiffness	0	1	2	3
51.	The feeling that my heart was beating very fast	0	1	2	3
52.	Eye pain when reading	0	1	2	3
53.	Dizziness	0	1	2	3
54.	Headaches	0	1	2	3
55.	Feeling weak	0	1	2	3

The following questions are related to the way in which the headaches interfered with you last week. Answer ALL of the questions, even if you did not suffer from headaches last week (in that case, draw circles around the figure 0). To answer the questions, draw a circle around one of the four figures at the end of each question.

The figures now mean:

0 = "not at all", 1 = "slightly", 2 = "rather a lot", 3 = "very much"

Last week, my headaches or migraine interfered with:

		not at all	slightly	rather a lot	very much
56.	My hobbies	0	1	2	3
57.	My homework.	0	1	2	3
58.	Going out	0	1	2	3
59.	My relationship with my parents, or brothers and sisters	0	1	2	3
60.	My relationships with friends	0	1	2	3
61.	My sleep or sleeping habits	0	1	2	3
62.	My appetite	0	1	2	3
63.	My reading ability	0	1	2	3
64.	Memorizing something that I had read	0	1	2	3
65.	Thinking things over	0	1	2	3
66.	Listening to music	0	1	2	3
67.	Cycling	0	1	2	3
68.	Taking part in sporting activities	0	1	2	3
69.	Watching television	0	1	2	3

This is the end of the questionnaire.
Please check carefully that you have not missed out any of the questions or given more than one answer to a question. Thank you for your cooperation!

APPENDIX 2: The headache diary, instruction

DAGBOEK © J.H. Langeveld, J. Passchier NAAM: .....

VOORBEELD	HIERONDER (B) ALTIJD IN-VULLEN:	HIERONDER (C-G) ALLEEN INVULLEN ALS JE ERVOOR HOOFDPIJN HEBT GEHAD!				
	HIERONDER (B-E) 4 KEER PER DAG INVULLEN				HIERONDER (F-G) 1 KEER PER DAG INVULLEN (BEDTIJD)	
(A) TIJDSTIP VAN INVULLEN	(B) INTENSITEIT ERGSTE HOOFDPIJN (Hoe erg) *Eén cijfer (0-5) invullen*	(C) HOOFDPIJN VAN .. TOT ..	(D) KLACHTEN VÓÓR- EN SAMEN MET DE HOOFDPIJN *Eén of meer Cijfers invullen:*	(E) MEDICIJN TEGEN HOOFDPIJN? *welk/hoeveel?*	(F) TOEN JE HOOFDPIJN HAD, VOELDE JE JE TOEN *Zet een rondje rond een cijfer:*	(G) WAT HEB JE VANDAAG NIET KUNNEN DOEN OF MOETEN UITSTELLEN DOOR DE HOOFDPIJN *Invullen:*
Bij ontbijt: (Over bedtijd-ontbijt)	0	van: uur tot: uur			helemaal niet / een beetje / nogal / erg	hardlopen
Bij Lunch: (Over ontbijt-lunch)	0	van: uur tot: uur	1		gespannen 0 (1) 2 3	
Bij Avondeten: (Over lunch-avondeten)	4	van: 3 uur tot: 6 uur	2 3 4 8	aspirine	moe 0 1 2 (3)	
Bij Bedtijd: (Over avondeten-bedtijd)	2	van: 6 uur tot: 10 uur	8		somber 0 (1) 2 3	
HIERONDER (H) VUL JE 1 KEER PER DAG IN (Bedtijd)						
(H)	Waar heb je vandaag veel aan gedacht of je druk over gemaakt:	Gisteren wedstrijd gewonnen. Proefwerk teruggekregen				

Uitleg:

Bij ontbijt: Dit meisje heeft tussen bedtijd en ontbijt ('s-nachts dus) geen hoofdpijn gehad. Zij heeft daarom *bij* het *ontbijt* onder **B** een 0 ingevuld.

Lunch: Om twaalf uur toen zij haar boterham at (*lunch*) had zij die ochtend geen hoofdpijn gehad, maar wel een vreemd voorgevoel in haar lichaam. Hieraan kon zij voelen dat zij hoofdpijn kon krijgen. Zij vulde daarom bij *lunch* onder **B** weer een 0 in. Bij **D** schreef zij een 1 (dat voorgevoel).

Avondeten: 's-Middags kreeg zij een aanval van hoofdpijn. De hoofdpijn maakte het voor haar moeilijk zich te concentreren en ze kon alleen nog makkelijke dingen doen. Onder **B** vulde zij daarom bij het avondeten een 4 in. De hoofdpijn voelde bonzend en kloppend en zat alleen aan de rechterkant van haar hoofd. Ze was daarbij misselijk en de hoofdpijn werd erger bij inspanning. Daarom vulde zij toen onder **D** in: 2, 3, 4, 8. Zij had ook een medicijn genomen, een aspirine. Dat vulde ze onder **E** in. ***Bij bedtijd*** vulde zij in dat zij die avond wel hoofdpijn had, maar deze was minder erg dan 's-middags. Onder **B** vulde ze daarom een 2 in. De hoofdpijn zat nu in het hele hoofd, voelde niet meer kloppend aan en zij kon weer alles doen zonder dat de hoofdpijn erger werd (**D**). Bij bedtijd vulde ze onder **F** toen nog in dat zij zich die dag *een beetje gespannen, erg moe en een beetje somber* voelde. Dat ze die dag door de hoofdpijn niet had kunnen hardlopen vulde zij onder **G** in. Als laatste schreef zij bij **H** dat zij die dag veel gedacht had aan de wedstrijd die zij de dag ervoor gewonnen had en aan het proefwerk dat zij die morgen terug had gekregen.

WEEK: 21 tot en met 27 juni 1993 DAGBOEK © J.H. Langeveld, J. Passchier **NAAM:** . . . . . .

Maandag . .	**HIERONDER (B) ALTIJD IN-VULLEN:**	**HIERONDER (C-G) ALLEEN INVULLEN ALS JE ERVOOR HOOFDPIJN HEBT GEHAD! (B (EN OOK H) VUL JE ALTIJD IN, OOK ALS JE VANDAAG GEEN HOOFDPIJN HEBT)**					
	HIERONDER (B-E) 4 KEER PER DAG INVULLEN				**HIERONDER (F-G) 1 KEER PER DAG INVULLEN (BEDTIJD)**	
(A) **TIJDSTIP** VAN INVULLEN	**(B)** INTENSITEIT ERGSTE HOOFDPIJN (Hoe erg) *Eén cijfer (0-5) invullen (Geen hoofdpijn=0)*	**(C)** HOOFDPIJN VAN .. TOT ..	**(D)** KLACHTEN VÓÓR- EN SAMEN MET DE HOOFDPIJN *Eén of meer Cijfers invullen:*	**(E)** MEDICIJN TEGEN HOOFD-PIJN? *welk/hoeveel?*	**(F)** TOEN JE HOOFDPIJN HAD, VOELDE JE JE TOEN *Zet een rondje rond een cijfer:*	**(G)** WAT HEB JE VANDAAG NIET KUNNEN DOEN OF MOETEN UITSTELLEN DOOR DE HOOFDPIJN *Invullen:*
Bij ontbijt: (Over bedtijd~ontbijt)		van: uur tot: uur			helemaal niet / een beetje / nogal / erg	
Bij Lunch: (Over ontbijt~lunch)		van: uur tot: uur			gespannen 0 1 2 3	
Bij Avondeten: (Over lunch~avondeten)		van: uur tot: uur			moe 0 1 2 3	
Bij Bedtijd: (Over avondeten~bedtijd)		van: uur tot: uur			somber 0 1 2 3	

HIERONDER (H) VUL JE 1 KEER PER DAG IN (Bedtijd)	
(H) Waar heb je vandaag veel aan gedacht of je druk over gemaakt:	

UITLEG (zie ook het uitgewerkte voorbeeld)

In kolom **A** staan de vier tijdstippen dat je het dagboek invult. De tijdstippen zijn **vet** gedrukt. De tijden waarover je het dagboek invult staan (tussen haakjes).

Vul bij **B** één van de volgende cijfertjes in over de ergste hoofdpijn:
0= Geen hoofdpijn.
1= Hoofdpijn die ik alleen voel als ik er op let.
2= Hoofdpijn die ik af en toe kan onderdrukken of net kan doen alsof deze er niet is.
3= Hoofdpijn die ik steeds voel, maar ik kan mijn gewone activiteiten blijven doen.
4= Hoofdpijn die het mij moeilijk maakt mij te concentreren. Ik kan alleen makkelijke dingen doen.
5= Hoofdpijn waardoor ik helemaal niets meer kan doen.

Bij **C** vul je in van hoe laat tot hoe laat je hoofdpijn had

Vul bij **D** één of meer van de volgende cijfertjes in:
1= Vreemd gevoel vooraf (bijvoorbeeld; lichtflitsen zien of een raar gevoel in je lichaam hebben)
2= Hoofdpijn aan één kant van het hoofd (óf rechts, óf links)
3= Bonzende of kloppende hoofdpijn
4= Misselijk
5= Overgeven
6= Last van geluid
7= Last van licht
8= Hoofdpijn is erger bij inspanning
0= Niets hiervan
(**N.B.** Je mag hier meer dan 1 cijfertje invullen)

Bij **E** vul je alle medicijnen in die je tegen de hoofdpijn ingenomen hebt.

F vul je één keer per dag in. Achter ieder van de drie woordjes zet je een cirkeltje om één van de vier cijfertjes.

Ook **G** vul je één keer per dag in. Je schrijft daar alle dingen op die je vandaag niet door de hoofdpijn hebt kunnen doen.

Ook **H** vul je één keer per dag in, op dagen met hoofdpijn én op dagen zonder hoofdpijn.

NAWOORD

Dit proefschrift is ontstaan vanuit een project dat oorspronkelijk zeer beperkt in omvang was. Mijn emigratie naar Noorwegen, anderhalf jaar na mijn entree bij de afdeling Medische Psychologie van de Erasmus Universiteit Rotterdam, leek in eerste instantie ook het einde te betekenen van het project "Quality of life in adolescents with migraine and other headaches". Echter, mede dankzij de grote steun en inzet van velen is dit onderzoek toch uitgemond in een academisch proefschrift. Een aantal van hen wil ik hier graag bij naam noemen en in het bijzonder mijn dank betuigen:

Mijn promotor Jan Passchier en mijn co-promotor Hans Koot. Zonder jullie commentaren, suggesties en mentale steun zou het vergaarde onderzoeksmateriaal nooit geworden zijn tot publiceerbare manuscripten.

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De leerlingen, hun ouders, hun leraren en de directie van de "Bernardus Mavo", Hillegom, de "Scholengemeenschap 's-Gravenpoort" en de "Scholengemeenschap de Glopper" in Capelle aan de IJssel, voor hun deelname aan dit project.

Mevr. dr. A.A.J.M. Hazebroek-Kampschreur, die bemiddeld heeft in het contact met de beide scholengemeenschappen in Capelle aan de IJssel.

De neurologen die de deelnemende jongeren onderzocht hebben op hun hoofdpijn klachten, mevr. dr. M.C.B. Loonen, mevr. dr. C.A.M. Chalet en dr. W.J.F. Hoppenbrouwer.

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Wouter Langeveld, die de nederlandse samenvatting heeft helpen corrigeren.

Riet, die jaren geleden voor mijn "basic trust" zorg gedragen heeft, noodzakelijk om tijdens een project als dit niet op te geven.

Maren, naast de kinderen die ons gezamenlijke "project" vormden de afgelopen jaren, waren de te publiceren artikelen mijn persoonlijke project. Jouw motiverende steun heeft sterk bijgedragen aan het slagen van mijn project.

CURRICULUM VITAE

Johannes Hendrik (Hans) Langeveld was born in 1959 in Hilversum, the Netherlands. After completing grammar school he studied physical therapy in Amsterdam, and graduated in 1982. From 1982 to 1988 he was employed as a physical therapist at different institutions in Norway within the medical fields of rheumatology, psychiatry, and neurology. From 1987 to 1992 he studied psychology, first in Bergen, Norway, later in Leiden, the Netherlands. He graduated in clinical-, health-, and personality psychology. Between 1992 and 1993 he was employed as a research assistant at the Department of Medical Psychology and Psychotherapy, Erasmus University Rotterdam. In 1994 he started working as a clinical psychologist at the Out-Patient Clinic for the Elderly at Rogaland Psychiatric Hospital, Stavanger, Norway. Since 1997, the author has been working at a clinical ward for general psychiatry at the same hospital.