Eur J Pediatr (2000) 159: 283–288

ORIGINAL PAPER

R. Felder-Puig · E. Frey · G. Sonnleithner · D. Feeny
H. Gadner · R. D. Barr · W. Furlong · R. Topf

German cross-cultural adaptation of the Health Utilities Index and its application to a sample of childhood cancer survivors

Received: 30 March 1999 and in revised form: 8 July 1999 / Accepted: 20 October 1999

Abstract Steady progress in developing effective treatments for childhood cancer and other severe pediatric diseases has established the need to consider the nature and frequency of late physical and psychological effects. The Health Utilities Index Mark 2 and Mark 3 (HUI2/3) systems were developed by Feeny, Furlong, Torrance et al. in Canada. These systems are generic multi-attribute measures of a person's health status and health-related quality of life. The first German version of the Canadian HUI2/3 questionnaire was created in our clinic, following recommended guidelines for cross-cultural adaptation of health-related quality of life measures. The usefulness of the resultant version was investigated using a sample of 142 patients who presented to our oncological outpatients' department for a routine health care visit after completion of treatment. The 15 items of the HUI2/3-questionnaire were answered independently by three groups of assessors – nurses, physicians, and parents or patients. Two additional questions covered ratings of the severity of treatment effects and the specification of these effects. The questionnaire was both easy to use and acceptable to the assessors. Percentage agreement between observers about levels for individual attributes ranged from 56% to 100%, with the lowest agreement on the subjective attributes of emotion, pain and cognition. These results are in accordance with previous studies using the original instrument. HUI2 global utility scores were significantly related to ratings of treatment sequelae, giving support to the discriminant validity of the measure.

Conclusion The German version of HUI2/3 is a useful instrument with generally high inter-observer agreement and good suitability for outcome measurement in childhood cancer patients. Further research is needed to assess the usefulness of the instrument in other clinical populations and its sensitivity in longitudinal studies.

Key words Health-related quality of life · Health status · Cross-cultural adaptation · Children · Health Utilities Index

Abbreviations *HRQL* health-related quality of life · *HUI2/3.15Q* 15-item Health Utilities Index Mark 2 and Mark 3 questionnaire · *HS* health status · *HUI2* Health Utilities Index Mark 2 · *HUI3* Health Utilities Index Mark 3

R. Topf (✉) · R. Felder-Puig · E. Frey · G. Sonnleithner
H. Gadner
St. Anna Children's Hospital,
Kinderspitalgasse 6, 1090 Vienna, Austria
Tel.: +43-1-40170; Fax: +43-1-40170 70

D. Feeny · R. D. Barr · W. Furlong
McMaster University, Hamilton, Ontario, Canada

D. Feeny
University of Alberta and Institute of Pharmaco-Economics,
Edmonton, Alberta, Canada

Introduction

With the increasing number of children suffering from chronic disorders, health-related quality of life (HRQL) research attracts more and more professional attention in pediatrics. Regarding the measurement of HRQL, agreement has emerged that a good pediatric instrument should be multidimensional, appropriate for use across a wide range of ages, quick and easy to complete, and suitable for collecting information from subjects and other types of assessors. Furthermore, it should possess the usually required psychometric properties with regard to sensitivity, reliability and validity [9, 11, 24, 25].

One such instrument is the 15-item Health Utilities Index Mark 2 and Mark 3 questionnaire (HUI2/3.15Q). This questionnaire is based on two complementary multi-attribute, comprehensive health status (HS) classification systems: the Health Utilities Index Mark 2 (HUI2) and Health Utilities Index Mark 3 (HUI3) [16, 17, 18, 29]. Based on a generic framework, HUI2 and HUI3 can theoretically be used across nearly all age groups and in a wide variety of clinical and general populations. The two systems address various domains of HS which have been identified by previous research as being the most important dimensions of HRQL to parents and children [10].

The HUI2 classification system consists of the seven attributes sensation, mobility, emotion, cognition, self-care, pain and fertility. It has been used in numerous pediatric populations including childhood cancer patients, children admitted to intensive care, and children of extremely low birth weight [1, 2, 6, 14, 15, 19, 26]. The HUI3 system evolved from the HUI2 and has eight attributes: vision, hearing, speech, ambulation, dexterity, emotion, cognition and pain. It has been used in four major population health surveys in Canada – e.g. Statistics Canada 1992 [27] – and numerous clinical studies [4, 5, 12, 21, 31, 32].

Conceptually, HUI2 and HUI3 are based on functional capacity rather than on performance and on a "within the skin" approach. The HUI2/3.15Q was designed such that each attribute is represented by one or two questions and each question offers four to six response options. These options correspond to descriptive phrases that range from normal to very poor functioning. Both systems can be used to describe an individual's HS in terms of a 7- or 8 element vector, respectively (e.g. 1111111 for an individual with no functional deficits in any of the HUI2 attributes). The systems further offer the possibility of providing single-summary utility scores indicating HRQL on a scale from 0 (representing the utility of death) to 1 (representing the utility of perfect health) [29, 30]. These utility scores are based on a theory of rational decision-making under uncertainty and were derived from results of prior research [3, 13, 30]. While the HS vector describes type and severity of disabilities, the utility score reflects a subjective appraisal of HRQL by giving preference weights to each attribute and level. The psychometric properties of the instrument with regard to acceptability, sensitivity, reliability and validity are well documented [1, 2, 7, 14, 15, 20, 22].

The objectives of this study were to create a German-language HUI2/3.15Q equivalent to the original instrument of Canadian origin and to report results from testing the German questionnaire in a sample of childhood cancer survivors.

Materials and methods

Cross-cultural adaptation

The German version of the original instrument was developed following recommended guidelines for cross-cultural adaptation of HRQL-measures [23]. First, the original Canadian instrument was translated into German by a professional translator. The resultant version was reviewed and extensively discussed by a multidisciplinary team from our clinic, including a pediatric oncologist, an oncology nurse, a psychotherapist and a psychologist specializing in methodology. Some of the questions and responses were slightly modified in order to produce items fully comprehensible in the German language. For example, the term "being able to walk around the neighborhood" could have been misinterpreted in the German translation as "being able to walk only short distances", so we changed the phrase to "being able to walk". The revised German questionnaire was then back-translated independently by two English native speakers into English. These two versions were reviewed by the authors of the original instrument and modifications were made until consensus between the Austrian and Canadian research groups was reached and a final German version was established.

As perceptions of health and illness may be culturally determined, an extensive cross-cultural adaptation would also include the assessment of preferences for different health states in a representative sample of the Austrian population. Considering that HUI2 and HUI3 are based on a strictly functional approach and that both Austria and Canada are Western industrialized nations with high quality health care and also do not represent markedly dissimilar cultures, we decided to use the preference measures for the original instrument. However, we must keep in mind that the hypothesis that ratings of different health states in order of preference would be consistent amongst inhabitants of these two countries still has to be verified.

Pilot study

As the original instrument has been used in a number of studies about childhood cancer survivors, we decided to recruit the pilot study population from our oncology outpatients' department in order to allow for comparison of results. The questions of the HUI2/3.15Q were to be answered independently by three groups of observers: nurses and physicians who were involved in the continuing after-care of the patients, and patients or parents. We determined the age of 13 as the cut-off point at and above which it was more than reasonable to expect that subjects would possess the cognitive abilities to understand and reliably complete the questionnaire. For patients below the age of 13, parents would give the answers about their children. Additional inclusion criteria were the ability to read and write German and a minimum age of 6 years for patients. The developers of the HUI2/3.15Q recommend this minimum age because some of the constructs do not apply readily to pre-school children.

There is some evidence that adolescents and parents show only poor agreement on subjective dimensions of well-being [9, 11, 20, 24, 25, 28]. To evaluate the level of agreement between patients and parents, we also asked mothers or fathers of adolescents (≥13 years) to complete a questionnaire and we compared the two assessments prior to further analysis. Both patients and parents were asked to sit separately and complete the scales independently from each other.

After approval from the local ethical committee had been received for this study, data were collected during a 4-month period ending in December 1997. Nurses and physicians completed the HUI2/3.15Q during routine health-care visits and offered a questionnaire to each patient or parent. To keep the number of missing values small, we asked all assessors to re-check their questionnaire after completing it.

To test for the relationship between HUI2 utility scores and the degree of severity of late effects caused by the disease and/or the treatment, we added the following items to the questionnaire: one item covering ratings of medical and/or psychological sequelae of disease and/or treatment (no/minor/moderate/severe/very severe problems) as well as one question inquiring about the type of these sequelae (open-ended item). Responses to the first item were used to set up groups with different degrees of sequelae in order to assess the discriminative ability of the HUI2 system.

Data on patients' age, sex, diagnosis and date of diagnosis were obtained from medical records. Descriptive statistical analyses were performed to identify the range of affected attributes from the responses of the different groups of assessors. To examine inter-observer reliability, we calculated percentage agreements and kappa-values for the individual attributes. While percentage agreement gives the frequency of concurrent responses, the kappa statistic is a measure of concordance for categorical data which takes into account the proportion of agreement expected by chance [8]. One-way analyses of variance were used to test for statistically significant differences in mean HUI2 scores among patients grouped according to degrees of disease- and/or treatment-related sequelae. These differences were also assessed at the attribute level using Kruskall-Wallis tests. A *P* value of ≤ 0.05 was considered to provide statistical significance.

Results

Subject group and assessors

In total, 145 patients or parents fulfilled the selection criteria and were approached. All of them agreed to participate in the study. The questionnaires were not returned by two patients and one parent, so the final sample consisted of 142 subjects.

The 60 female and 82 male patients had a median age of 13 years (range 6–30) and were between 3 months and 26 years post diagnosis (median 4.5 years). A variety of diagnoses were represented: acute lymphoblastic leukemia ($n = 54$), non-Hodgkin's lymphoma ($n = 21$), Hodgkin's disease ($n = 16$), acute myeloid leukemia ($n = 6$), anemic diseases ($n = 4$), chronic myeloid leukemia ($n = 1$), severe combined immunodeficiency syndrome ($n = 1$), osteosarcoma ($n = 9$), Wilms' tumour ($n = 8$), Ewing's sarcoma ($n = 5$), rhabdomyosarcoma ($n = 5$), neuroblastoma ($n = 3$) and other malignant tumors ($n = 9$). Our sample did not include brain tumor survivors, as these patients are not treated in our clinic.

Of the 142 subjects, 75 were 13 years and older and self-completed the questionnaire. Forty-nine of the 75 were accompanied by a parent who was also asked for an HS assessment about the child. For the remaining 67 patients who were younger than 13 years, HS assessments were done by 52 mothers and 15 fathers. Assessments by health care professionals for all 142 subjects were obtained from seven physicians and five nurses.

Feasibility and acceptability of the instrument

None of the respondents had problems understanding and completing the questionnaire. The medical and nursing staff took 5 min or less to complete a questionnaire for each patient. When processing the data, we found no missing responses, except for the open-ended question inquiring about the type of disease- and/or treatment-related sequelae, so HUI2/3 data from all returned questionnaires could be analyzed. The health-care professionals mainly criticized the apparent redundancy between some questions, and some were of the opinion that too much attention was given to the domains of vision, hearing and speech as these attributes were covered by two questions each.

Agreement between adolescent patients' (≥13 years) and parents' responses

Because of the discrepancies in perception of HS or HRQL reported in the literature, we questioned both patients and parents and received double reporting for 49/142 patients. No discrepancies were seen in 30/49 patients. In the remaining 19 patients, patients' and parents' responses differed by not more than one level in the following attributes: emotion of HUI2 ($n = 8$), cognition of HUI2 or HUI3 ($n = 5$), emotion of HUI3 ($n = 3$) and pain of HUI2 or HUI3 ($n = 3$). These differences were considered small enough to justify aggregating data obtained from parents of children aged below 13 years and from patients who were 13 and older into "patients' or parents' assessments".

Affected attributes of HRQL

Considering the results from both systems and the three groups of observers, 69 to 98 out of 142 survivors (48.6%–69.0%) showed deficits in at least one of the HUI2/3 domains. The distribution of the affected attributes is shown in Table 1. Fertility was not assessed in this study and was assumed to be normal in computing HUI2 utility scores.

The most frequently affected attributes were emotion (17.6%–47.2%), vision (approximately 20.0%), pain (12.0%–20.4%) and cognition (6.3%–23.9%). The majority of these problems were only mild (i.e. level 2). The highest degree of moderate to severe impairment (i.e. levels 3 or greater) was identified in speech (5.6%, $n = 8$) and in cognition (7.7%, $n = 11$) in assessments by patients or parents. In all other domains and assessments, the rate of moderate to severe deficits was at most 4.2% (range 0.0%–4.2%).

Table 1 Frequencies of affected attributes (attribute levels >1) assessed by physicians, nurses and patients or parents. Figures in parentheses are percentages

	Physicians	Nurses	Patients/parents
HUI2			
Sensation	27 (19.0)	29 (20.4)	41 (28.9)
Mobility	7 (4.9)	8 (5.6)	8 (5.6)
Emotion	42 (29.6)	56 (39.4)	67 (47.2)
Cognition	9 (6.3)	15 (10.6)	34 (23.9)
Self-care	5 (3.5)	6 (4.2)	5 (3.5)
Pain	21 (14.8)	17 (12.0)	29 (20.4)
HUI3			
Vision	24 (16.9)	25 (17.6)	30 (21.1)
Hearing	1 (0.7)	1 (0.7)	2 (1.4)
Speech	5 (3.5)	4 (2.8)	11 (7.7)
Ambulation	7 (4.9)	8 (5.6)	8 (5.6)
Dexterity	3 (2.1)	2 (1.4)	1 (0.7)
Emotion	46 (32.4)	39 (27.5)	25 (17.6)
Cognition	9 (6.3)	15 (10.6)	34 (23.9)
Pain	24 (16.9)	14 (9.9)	26 (18.3)

The global HRQL scores, calculated using the HUI2 utility function, from the physicians' responses showed a mean of 0.94 (median 0.98, SD 0.12, range 0.14–1.00), the scores from the nurses' responses had a mean of 0.93 (median 0.95, SD 0.11, range 0.23–1.00) and the scores from patients' or parents' responses had a mean of 0.91 (median 0.93, SD 0.12, range 0.19–1.00).

Inter-observer agreement

Statistical measures of inter-observer attribute level agreement are summarized in Table 2. Percentage agreement ranged from 56% to 100% and was greater than 80% for all attributes except emotion, pain and cognition. It was less than 75% for only one attribute: emotion. Kappa estimates ranged from 0.14 to 1.00, exhibiting a much broader range than the percentage agreement statistics. In some attributes percentage agreement was high and kappa values were low. This is due to the limited variability in responses, as a large proportion of patients showed full functional capacity in these attributes.

Table 2 Inter-observer agreement. *Ph-N* physicians–nurses, *Ph-P/P* physicians–patients or parents, *N-P/P* nurses–patients or parents, κ kappa, *%* percentage agreement

	Ph-N		Ph-P/P		N-P/P	
	κ	%	κ	%	κ	%
HUI2						
Sensation	0.87	96	0.64	86	0.72	89
Mobility	0.31	93	0.31	93	0.54	95
Emotion	0.31	67	0.14	56	0.39	68
Cognition	0.51	92	0.26	79	0.38	82
Self-care	0.72	98	0.79	99	0.91	97
Pain	0.38	85	0.24	78	0.22	78
HUI3						
Vision	0.83	95	0.66	89	0.78	93
Hearing	1.00	100	0.66	99	0.66	99
Speech	0.89	99	0.61	96	0.51	95
Ambulation	0.31	93	0.31	93	0.54	95
Dexterity	0.39	98	0.49	99	0.66	99
Emotion	0.46	77	0.19	68	0.31	75
Cognition	0.51	92	0.26	79	0.38	82
Pain	0.30	83	0.37	81	0.17	79

Discriminant validity

Analysis of the two study-specific measures added to the survey revealed that most survivors showed no or only mild sequelae of the disease and/or treatment and that the most frequently observed late effects were fears of medical interventions, somatic problems related to organ toxicity, and obesity. To test for the ability of the HUI2 system to discriminate between different degrees of sequelae, we performed analyses of variance with the HUI2 utility scores as dependent variables. There was a significant relationship between the degree of severity of late effects and the HUI2 scores for all groups ($P \leq 0.05$), with one exception. In the physicians' assessments, the HUI2 scores did not differentiate between survivors reported to have no sequelae and survivors with mild sequelae ($P = 0.22$). At the attribute level, differences between the three groups were significant for the attributes of emotion and pain in all assessments ($P \leq 0.04$). Group means and standard deviations of HUI2 utility scores for the three groups are presented in Table 3. It should be noted that there was high variability in HUI2 scores in patients with moderate to severe sequelae, while the scores in patients with no or mild sequelae were much less variable.

Discussion

The objectives of this paper were to describe the development of a German version of the HUI2/3.15Q and to provide initial data regarding its acceptability, inter-rater reliability and discriminant validity using a sample of childhood cancer survivors.

The questionnaire was well accepted by health-care providers, patients and parents, and was quick and easy to use. This is particularly important with regard to the

Table 3 Relationship between ratings of disease- and/or treatment-related sequelae and HUI2 utility scores

Observers	Severity of sequelae	*n*	HUI2-mean	SD
Physicians	No	76	0.97	0.05
	Mild	47	0.95	0.10
	Moderate–severe	19	0.78	0.23
Nurses	No	88	0.96	0.05
	Mild	46	0.93	0.05
	Moderate–severe	8	0.64	0.28
Patients/parents	No	74	0.94	0.08
	Mild	60	0.88	0.14
	Moderate–severe	8	0.80	0.18

usual time and resource constraints in the clinical setting. Collecting HS information from both patients or parents and health-care professionals is of direct practical use, as it reveals important perception differences or communication problems, on the basis of which appropriate interventions can be developed to improve the quality of health care.

The HUI 2/3.15Q, eliciting information to classify subjects' HS according to two complementary systems, includes questions that were considered redundant by some respondents. This was found to be irritating by some of the assessors. However, it is often important to collect data using both systems. One reason is that the HUI2 has been used in a number of clinical studies and provides a large pool of comparison data, especially for childhood cancer patients. Another reason is that the HUI3 includes some additional attributes (e.g. dexterity) and different constructs for assessment of pain and emotion to those captured by HUI2. The instrument has also been criticized by some of our colleagues for the fact that 6 of a total of 15 questions refer to the domains of vision, hearing and speech, specifically as these attributes are not of major concern to most childhood cancer survivors. However, it should be noted that there were reported deficits in each of these attributes from our survey.

In our subject group about 50 to 70% of survivors, depending on the assessor and the system, were reported to have some HS reduction. Most problems were identified in the attributes of emotion, vision, pain and cognition. These results are in accordance with Canadian and British surveys of childhood cancer survivors [1, 6, 15].

The validity of responses given by parents about the HRQL of their children is a matter of controversy in the literature [9, 11, 20, 24, 25, 28]. Our data indicate a high level of agreement between adolescents and their parents. These findings must, however, be considered in the light of the specific situation of this clinical population. During treatment, patients and their families spend a lot of time together, often 24 hours a day. Maintaining an open level of communication throughout the course of the illness is particularly promoted in our clinic. We assume that in healthy children or in pediatric patients with less severe conditions there would be more discrepancies between adolescents' and parents' assessments.

With percentage agreement greater than 75% for all individual attributes except emotion (56%–75%), agreement between patients or parents and health-care professionals appeared to be fairly good. In the majority of non-concurrent assessments, the ratings differed by only one level. Physicians tended to report fewer deficits than parents or patients, particularly in the attributes of emotion, pain and cognition. This pattern was also observed in the assessments made by nurses, although nurses deviated less from patients or parents than did physicians. In general, nurses spend more time with patients and families and may therefore have more insight into their problems and feelings. During consultation, patients may feel awkward about admitting problems to physicians because, for example, they are afraid of appearing ungrateful. Therefore physicians probably underestimate the existence or severity of symptoms which are less directly observable.

The ability of the original HUI2 system to discriminate between brain tumor and other childhood cancer patients as well as between childhood cancer patients on and off treatment has been demonstrated [14]. As our sample included only patients off treatment, and was very heterogeneous with regard to diagnosis and follow-up time, we decided to use the severity of late effects caused by the disease and/or the treatment as the discriminant criterion. The HUI, being a generic measure, does not directly capture organ toxicity or obesity or fears of medical interventions, which were among the most common sequelae reported in our sample. However, these late effects seemed to manifest indirectly in disability associated with one or more of the HUI attributes if, for example, the late effects caused pain or an emotional problem. These findings suggest good discriminant validity of the system in childhood cancer survivors.

In summary, the HUI 2/3 is a practicable instrument that accounts for the multidimensionality of comprehensive HS, including physical domains and psychologic factors. Due to its generic framework, its application is not limited to childhood cancer patients. It can be used across a wide range of age groups, which facilitates longitudinal as well as cross-sectional comparisons. Another advantage of the system is that it provides measures of both HRQL and HS. While the global utility score enables comparison across time and different subject groups, the HS vector offers detailed information about the type and severity of disabilities.

A weakness of the system is that it omits some characteristics that may be important for the well-being of pediatric patients, for example the quality of social relations or family functioning. It is possible that these variables are indirectly identified with the emotion attribute of HUI3, which refers to the degree of happiness. This issue certainly requires further investigation. The HUI approach has also been criticized for its conceptual focus on "within the skin" functional capacity, rather than performance, as some researchers claim that disability cannot be investigated outside social and environmental contexts [25].

Our findings suggest that the German version of the HUI2/3.15Q is a useful instrument with generally high inter-observer agreement and is suitable for outcome measurement in childhood cancer patients. Further research is needed to assess the usefulness of the instrument in other clinical populations and its sensitivity in longitudinal studies.

Acknowledgements The contributions of Ms Angelika Azzedine, Dr Waltraud Emminger, Ms Dana Galle, Dr Wolfgang Mor, Dr Birgit Neophytou, Prof. Dr Renate Pantzer, Ms Doris Rauchenwald, Dr Ulrike Schulz, Dr Gudrun Waldner, and Ms Christa Zuwak to this study are gratefully acknowledged.

References

1. Barr RD, Furlong W, Dawson S, Whitton AC, Strautmanis I, Pai M, Feeny D, Torrance GW (1993) An assessment of global health status in survivors of acute lymphoblastic leukemia in childhood. Am J Pediatr Hematol 15:284–290
2. Barr RD, Pai MKR, Weitzman S, Feeny D, Furlong W, Rosenbaum P, Torrance GW (1994) A multi-attribute approach to health status measurement and clinical management – illustrated by an application to brain tumors in childhood. Int J Oncol 4:639–648
3. Barr RD, Feeny D, Furlong W, Weitzman S, Torrance GW (1995) A preference-based approach to health-related quality of life for children with cancer. J Pediatr Hematol Oncol 2:305–315
4. Barr RD, Petrie C, Furlong W, Rothney M, Feeny D (1997) Health-related quality of life during post-induction chemotherapy in children with acute lymphoblastic leukemia in remission: an influence of corticosteroid therapy. Int J Oncol 11:333–339
5. Barr RD, Simpson T, Whitton A, Rush B, Furlong W, Feeny D (1999) Health-related quality of life in survivors of tumours of the central nervous system in childhood – a preference-based approach to measurement in a cross-sectional study. Eur J Cancer 35:248–255
6. Billson AL, Walker DA (1994) Assessment of health status in survivors of cancer. Arch Dis Child 70:200–204
7. Boyle MH, Furlong W, Feeny D, Torrance GW, Hatcher J (1995) Reliability of the Health Utilities Index-Mark III used in the 1991 cycle 6 Canadian General Social Survey Health Questionnaire. Qual Life Res 3:249–257
8. Bortz J, Lienert GA, Boehnke K (1990) Verteilungsfreie Methoden in der Biostatistik. Springer, Berlin Heidelberg New York, pp 458–465
9. Bradlyn AS, Ritchey AK, Harris CV, Moore IM, O'Brien RT, Parsons SK, Patterson K, Pollock BH (1996) Quality of life research in pediatric oncology. Cancer 78:1333–1339
10. Cadman D, Goldsmith C, Torrance GW, Boyle M, Furlong W (1996) Development of a Health Status Index for Ontario children. Final report to the Ontario Ministry of Health on research grant DM 648 (00633). McMaster University, Hamilton, Ontario
11. Cella DF, Tulsky DS (1993) Quality of life in cancer: Definition, purpose, and method of measurement. Cancer Invest 11:327–336
12. Costet N, Le Galès C, Buron C, Kinkor F, Mesbah M, Chwalow J, Clinical and Economic Working Groups, Slama G (1998) French cross-cultural adaptation of the Health Utilities Indexes Mark 2 (HUI2) and 3 (HUI3) classification systems. Qual Life Res 7:245–256
13. Feeny D, Barr RD, Furlong W, Torrance GW, Weitzman S (1991) Quality of life of the treatment process in pediatric oncology: an approach to measurement. In: Osoba D (ed) Effect of cancer on quality of life. CRC Press, Boca Raton, pp 89–104
14. Feeny D, Furlong W, Barr RD, Torrance GW, Rosenbaum P, Weitzman S (1992) A comprehensive multiattribute system for classifying the health status of survivors of childhood cancer. J Clin Oncol 10:923–928
15. Feeny D, Leiper A, Barr RD, Furlong W, Torrance GW, Rosenbaum P, Weitzman S (1993) The comprehensive assessment of health status in survivors of childhood cancer: application to high-risk acute lymphoblastic leukaemia. Br J Cancer 67:1047–1052
16. Feeny D, Furlong W, Boyle M, Torrance GW (1995) Multi-attribute health status classification systems. PharmacoEconomics 7:409–502
17. Feeny DH, Torrance GW, Furlong WJ (1996) Health Utilities Index. In: Spilker B (ed) Quality of life and pharmacoeconomics in clinical trials, 2nd edn. Lippincott-Raven, Philadelphia, pp 239–252
18. Furlong W, Torrance GW, Feeny D (1996) Properties of the Health Utilities Index: preliminary evidence. Qual Life Newsl 13–14, June 95–Jan 96, p 3, 4, 10
19. Gemke RJBJ, Bonsel GJ, van Vught AJ (1995) Long-term survival and state of health after paediatric intensive care. Arch Dis Child 73:196–201
20. Glaser AW, Davies K, Walker D, Brazier D (1997) Influence of proxy respondents and mode of administration on health status assessment following central nervous system tumours in childhood. Qual Life Res 6:43–53
21. Glaser AW, Furlong W, Walker DA, Fielding K, Davies K, Feeny D, Barr RD (1999) Applicability of the Health Utilities Index to a population of childhood survivors of central nervous system tumours in the United Kingdom. Eur J Cancer 35:256–261
22. Grootendorst PV, Feeny DH, Furlong W (1997) Does it matter whom and how you ask? Inter- and intra-rater agreement in the Ontario health survey. J Clin Epidemiol 50:127–135
23. Guillemin F, Bombardier C, Beaton D (1993) Cross-cultural adaptation of health-related quality of life measures: literature review and proposed guidelines. J Clin Epidemiol 46:1417–1432
24. Jenney MEM, Kane RL, Lurie N (1995) Developing a measure of health outcome in survivors of childhood cancer: a review of the issues. Med Pediatr Oncol 24:145–153
25. Pal DK (1996) Quality of life assessment in children: a review of conceptual and methodological issues in multidimensional health status measures. J Epidemiol Community Health 50:391–396
26. Saigal S, Rosenbaum P, Stoskopf B, Hoult L, Furlong W, Feeny D, Burrows E, Torrance G (1994) Comprehensive assessment of the health status of extremely low birth weight children at eight years of age: Comparison with a reference group. J Pediatr 125:411–417
27. Statistics Canada (1992) The 1991 General Social Survey – Cycle 6. Health public use microdata file documentation and users' guide. Statistics Canada, Ottawa
28. Theunissen NCM, Vogels TGC, Koopman HM, Verrips GHW, Zwinderman KAH, Verloove-Vanhorick SP, Wit JM (1998) The proxy problem: child report versus parent report in health-related quality of life research. Qual Life Res 7:387–397
29. Torrance GW, Furlong W, Feeny D, Boyle M (1995) Multi-attribute preference functions. Health Utilities Index. PharmacoEconomics 7:503–520
30. Torrance GW, Feeny DH, Furlong WJ, Barr RD, Zhang Y, Wang Q (1996) Multiattribute utility function for a comprehensive health status classification system. Health Utilities Mark 2. Med Care 7:702–722
31. Whitton AC, Rhydderch H, Furlong W, Feeny D, Barr RD (1997) Self-reported comprehensive health status of adult brain tumor patients using the Health Utilities Index. Cancer 80:258–265
32. Wyatt JR, Niparko JK, Rothman M, deLissovoy G (1996) Cost utility of the multichannel cochlear implant in 258 profoundly deaf individuals. Laryngoscope 106:816–821