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

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 HU12/3 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
**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. 11111111 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 different 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)