Measuring health related quality of life in adolescent populations. An empirical comparison of the CHU9D and the PedsQL™ 4.0 SF-15

Petersen, Karin Dam

Publication date: 2016

Document Version
Version created as part of publication process; publisher's layout; not normally made publicly available

Link to publication from Aalborg University

Citation for published version (APA):
(102.1) What Were They Thinking? The Evidence for the Health Utilities Index Mark 3
Presenter: David Feeny, PhD Email: feeny@mcmaster.ca

(102.2) Scoring the Child Health Utility 9D Instrument. Estimation of a Chinese Adolescent-specific Tariff
Presenter: Gang Chen, PhD Email: chengang1029@gmail.com

(102.3) Measuring health related quality of life in adolescent populations. An empirical comparison of the CHU9D and the PedsQL™ 4.0 SF-15
Presenter: Karin D. Petersen, PhD MPH Email: kdp@business.aau.dk

(102.4) Health literacy and Logical Inconsistencies in Valuations of Hypothetical Health States: Data from the Canadian EQ-5D-5L Valuation Study
Presenter: Fatima Al Sayah, PhD Email: falsayah@ualberta.ca

Abstracts

(102.1) What Were They Thinking? The Evidence for the Health Utilities Index Mark 3
William Furlong, MSc, McMaster University, Dundas, Ontario, Canada; George Torrance, PhD, McMaster University, Toronto, Ontario, Canada, David Feeny, PhD, Department of Economics, McMaster University, Hamilton, Ontario, Canada
AIMS: Multi-attribute generic preference-based measures of health-related quality of life (HRQL) are used as outcome measures in clinical studies and trials, to monitor population health, and as weights in constructing summary measures of HRQL such as quality-adjusted life years (QALYs). Preferences for health states defined by such a system are elicited from a representative sample of the general population and used to estimate a scoring function. An important element in that elicitation process is the factors that respondents were instructed to consider in providing their valuations. It is crucial to assessments of validity that information on those instructions, and results from debriefing respondents, be reported. The aim of the study is to report on these two components of the Health Utilities Index Mark 3 (HUI3). METHODS: A random sample of community-dwelling respondents in Canada was surveyed, n = 504. In face-to-face interviews respondents provided preference scores for selected HUI3 health states. Respondents also answered questions about the most important health-state characteristics and the importance they associated with various life factors. RESULTS: Fifty per cent of respondents reported that they focussed on two, and 21% on three, of the eight HUI3 attributes. Each of the eight attributes was identified as important; pain (49% of respondents), vision (37%), cognition (34%), emotion (28%), and ambulation (28%) were the most commonly reported. The null hypothesis that all of the attributes were equally important was rejected (p < 0.001). Eighty-nine percent of respondents indicated that the ability to take care of oneself was quite or very important; similarly 76% reported the same for impact on family life, 69% for impact on the happiness of others; 61% for the impact on their ability to work, and 42% for the impact on their leisure activities. The null hypothesis that all of the life factors were equally important was rejected (p < 0.001). CONCLUSIONS: In providing preference scores for HUI3 health states, respondents thoughtfully examined the implications of the health states as described for their ability to live, work,
socialize, and function. These results provide strong evidence of the content and construct validity of the HUI3 scoring function.

(102.2) Scoring the Child Health Utility 9D Instrument. Estimation of a Chinese Adolescent-specific Tariff

Gang Chen, PhD, Monash University, Clayton, Victoria, Australia; Fei Xu, PhD, Nanjing Municipal Center for Disease Control and Prevention, Nanjing, China; Elisabeth Huynh, PhD, University of South Australia, Adelaide, Australia; Zhiyong Wang, Nanjing Municipal Center for Disease Control and Prevention, Nanjing, China; Chao Li, Nanjing Municipal Center for Disease Control and Prevention, Nanjing, China; Katherine Stevens, PhD, University of Sheffield, Sheffield, United Kingdom; Julie Ratcliffe, PhD, Flinders University, Adelaide, SA, South Australia, Australia

AIMS: The Child Health Utility 9D (CHU9D) is a new generic, adolescent-specific preference-based health-related quality of life (HRQoL) instrument. It has been demonstrated to be acceptable, practical and valid for application with children and adolescents aged 7-17 years. This study aims to apply a profile case best-worst scaling (BWS) method to derive an adolescent-specific scoring algorithm for the Chinese version of CHU9D (CHU9D-CHN) that can be used to estimate quality adjusted life years (QALYs) for economic evaluation. METHODS: Two surveys were conducted in Nanjing, China. The first survey recruited participants from primary and high schools (Grades 4 to 12) using a multi-stage sampling method and was designed to identify the best and worst features of a series of 10 health states derived from the CHU9D-CHN descriptive system. The second survey adopted an interviewer-administered conventional time trade-off (TTO) task to value a series of five CHU9D-CHN health impairment states and was administered to a convenience sample of undergraduate students (aged 17 to 20 years) at Nanjing Medical University. The data were analyzed using latent class conditional logit models to estimate values for each level of the nine attributes relating to the CHU9D. A marginal utility matrix was then re-scaled based on the TTO results to generate a scoring algorithm on the QALY scale. RESULTS: A total of 905 students (43% girls) participated the BWS survey, whilst a total of 38 undergraduates (53% girls) participated the TTO survey. Half of participants (n = 19) considered the most severe CHU9D-CHN (PITS) state to be worse than death (i.e. TTO values < 0). Regression results based upon the BWS data indicated that all nine attributes significantly contributed to children and adolescents’ HRQoL. Inconsistent estimates were observed on a few occasions. The optimal adolescent-specific CHU9D-CHN scoring algorithm was reported. CONCLUSIONS: The Chinese adolescent-specific scoring algorithm will enable CHU9D-CHN to be used in economic evaluation. This study provides further insights and support for the use of profile case BWS methods to generate health state values with young people.

(102.3) Measuring health related quality of life in adolescent populations. An empirical comparison of the CHU9D and the PedsQL™ 4.0 SF-15

Karin D. Petersen, PhD MPH, Aalborg University, 9220 Aalborg Ø, Denmark; Gang Chen, PhD, Monash University, Clayton, Victoria, Australia; Christine Mpundu-Kaambwa, MPH, Flinders Centre for Clinical Change and Health Care Research, Adelaide, Australia; Katherine Stevens, PhD, University of Sheffield, Sheffield, United Kingdom; John E. Brazier, PhD, University of Sheffield, Sheffield, South Yorkshire, United Kingdom; Julie Ratcliffe, PhD, Flinders University, Adelaide, SA, South Australia, Australia

AIMS: The main aim of this study was to conduct an empirical assessment of the measurement properties of the Child Health Utility 9 Dimension (CHU9D) compared to the PedsQL™ 4.0 Short Form (SF-15) Generic Core Scales (GCS), hereafter referred to as ‘PedsQL’ in a community based sample of adolescents. METHODS: An online survey, including the preference-based CHU9D and non-preference-based PedsQL for measuring Health related Quality of Life (HRQoL), a self-reported general health question, and a series of socio-demographic questions was developed for administration to Australian adolescents aged 15-17 years old. The PedsQL is a shortened version of the widely used 23-item PedsQL™ 4.0 GCS. Descriptive summary statistics were produced and psychometric analyses were conducted to assess levels of agreement, convergent and discriminant validity between the CHU9D and the PedsQL. The Intraclass Correlation Coefficient (ICC) was also estimated. RESULTS: A total of 775 adolescents completed the survey. The mean ± SD utilities of the CHU9D and PedsQL were 0.724 ± 0.218 and 72.861 ±16.562, respectively. 15.6% self-reported their health to be fair/poor and 10.1% reported living with a long-term disability, illness, or medical condition. For both instruments, there were significant differences on quality of life scores between levels of socio-economic status and self-reported
Among dimensions, the strongest degree of correlation was found between the Emotional function in the PedsQL and the ‘Worried’/‘Sad’ dimension on the CHU9D, and the Physical Health dimension in PedsQL and the ‘Activities’ dimension in the CHU9D (all \( r=0.46 \)). The lowest degree of correlation \( (r=0.16) \) was found between Social function in the PedsQL and the ‘Pain’ dimension in the CHU9D. Overall, the Spearman’s correlation between the two instruments was 0.63, whilst the ICC was 0.77 suggesting a good level of agreement. CONCLUSIONS: This is the first empirical study comparing the CHU9D and PedsQL in assessing the HrQoL. It indicates good levels of agreement. The findings from this study provide further support for the validity of the application of the CHU9D in the economic evaluation of adolescent health care in Australia and internationally. Development of preference weights for the PedsQL would facilitate its future application in economic evaluation.

(102.4) Health literacy and Logical Inconsistencies in Valuations of Hypothetical Health States: Data from the Canadian EQ-5D-5L Valuation Study

Fatima Al Sayah, PhD, University of Alberta, Edmonton, Alberta, Canada; Jeffrey A. Johnson, PhD, University of Alberta, Edmonton, Alberta, Canada; Arto Ohinmaa, PhD, University of Alberta, Edmonton, Alberta, Canada; Feng Xie, PhD, McMaster University, Hamilton, Ontario, Canada; Nick Bansback, PhD, University of British Columbia and Centre for Health Evaluation and Outcomes Sciences, Vancouver, British Columbia, Canada

AIMS: To examine the association of health literacy with logical inconsistencies in time trade-off valuations of hypothetical health states described by the EQ-5D-5L classification system. METHODS: Data from the EQ-5D-5L Canadian Valuation study were used for this analysis. Health literacy was assessed using three screening questions: How often do you have problems learning about your medical condition because of difficulty understanding written information? How confident are you filling out medical forms by yourself? How often do you need someone help you read health-related materials? A logical inconsistency was considered present if a respondent: gave the same or a lower value for the very mild health state compared to value given to 55555; or gave the same or a lower value for the very mild health state compared to value assigned to the majority of the health states that are dominated by the very mild health state. Logistic regression models adjusted for age, sex, education, income, race, study site, language, number of chronic conditions, previous experience of illness, self-rated health, and severity of health states were used. RESULTS: Average age of respondents (N=1209) was 48 (SD=17) years, 45% were male, 7% reported inadequate health literacy, and 11% had logical inconsistencies. Respondents with inadequate health literacy were more likely to report lower education and income, be of non-white ethnicity, reside in rural areas, and report more comorbidities, previous experience with illness, and lower self-reported health. In adjusted analysis, respondents with inadequate health literacy were 2.2 (95%CI:1.2, 4.0) times more likely to have a logical inconsistency compared to those with adequate health literacy. More specifically, those who had problems in “understanding written information” (OR=1.7; 95%CI: 1.1, 2.8) and “reading health information” (OR=2.5; 95%CI: 1.6, 4.1) were more likely to have a logical inconsistency compared to their counterparts. No association was observed for “confidence in completing medical forms” and inconsistent valuations. CONCLUSIONS: Health literacy was associated with logical inconsistencies in valuations of hypothetical health states described by the EQ-5D-5L classification system. Valuations studies should consider assessing health literacy skills of participants, and explore simpler approaches of eliciting preferences of hypothetical health states for individuals with inadequate health literacy.