

## 26th Annual Conference of the International Society for Quality of Life Research

© Springer Nature Switzerland AG 2019

### Cutting Edge Research Plenary Session

#### (1) From statistician to clinician: the feedback of PROMIS® CATs within KLIK

Maud van Muilekom, Emma Children's Hospital, Amsterdam UMC, University of Amsterdam, Psychosocial Department, Amsterdam, the Netherlands, Amsterdam, Netherlands; Michiel Luijten, MSc, Emma Children's Hospital, Amsterdam UMC, University of Amsterdam, Psychosocial Department, Amsterdam, the Netherlands, Amsterdam, Netherlands; Hedy van Oers, MSc, Emma Children's Hospital, Amsterdam UMC, University of Amsterdam, Psychosocial Department, Amsterdam, the Netherlands, Amsterdam, Netherlands; Caroline Terwee, PhD, Amsterdam UMC, Vrije Universiteit, Epidemiology and Biostatistics, Amsterdam, the Netherlands, Amsterdam, Netherlands; Raphaële van Litsenburg, PhD, Princess Máxima Center for Pediatric Oncology, Utrecht, the Netherlands, Utrecht, Netherlands; Leo Roorda, PhD, Amsterdam Rehabilitation Research Center | Reade, Amsterdam, the Netherlands, Amsterdam, Netherlands; Martha Grootenhuis, PhD, Princess Máxima Center for Pediatric Oncology, Utrecht, the Netherlands, Utrecht, Netherlands; Lotte Haverman, PhD, Emma Children's Hospital, Amsterdam UMC, University of Amsterdam, Psychosocial Department, Amsterdam, the Netherlands, Amsterdam, Netherlands

**Aims:** KLIK is an evidence-based Patient Reported Outcome Measures (PROM) portal where patients and/or caregivers complete questionnaires about Health-Related Quality of Life (HRQOL), symptoms and psychosocial functioning. Answers are immediately converted into a KLIK eProfile, which clinicians can discuss during consultation. Item responses and domain scores are most commonly fed back in traffic light colors and graphs, respectively. Currently PROMIS® item banks are implemented in KLIK, facilitating Computerized Adaptive Testing (CAT). New feedback options are required for CAT, as not all items are administered (estimates are computable) and PROMIS domain scores require different interpretation. This study aims to develop feedback options for PROMIS CATs within KLIK. **Methods:** Focus groups were held with clinicians (pediatricians, psychologists, nurses, social workers, researchers) using KLIK. Literature-based feedback options were shown for individual items and domain scores. Clinicians were asked about interpretability, comprehensibility, (color)design, and completeness of these options. Moreover, they were requested to describe their optimal feedback option. Data saturation was reached and data was analyzed

using MaxQDA. A self-composed questionnaire will be sent out to quantitatively assess clinicians' preference for feedback options. **Results:** In total, six focus groups were held (N = 27 clinicians). According to clinicians, individual item feedback is necessary for using PROMs in clinical practice. Presenting the full item banks, with only responses (in traffic light colors) of administered items, was described as their optimal feedback option. Inclusion of response estimates of items that were not administered was considered difficult to interpret. Regarding domain score feedback, clinicians preferred graphs over textual options. In addition, they preferred separate graphs per domain, ranked in order of scores that were most alarming. These graphs should include normative lines (including standard deviation lines), traffic light colors and a well-defined y-axis (i.e., same directionality). There was disagreement about including numerical scores within graphs. Questionnaire results will be presented at the conference (collection not finished). **Conclusion:** Overall, simplicity was considered most important when developing a new feedback method for PROMIS CATs. Once the questionnaires have been analyzed, we will, in collaboration with the Dutch-Flemish PROMIS National Center, design and subsequently evaluate the optimal feedback option to successfully implement PROMIS CATs in KLIK.

#### (2) Demographic and symptom differences in PRO-TECT trial (AFT-39) cancer patients electing to complete weekly home patient-reported outcome measures (PROMs) via an automated phone call vs. email: implications for implementing PROs into routine care

Angela Stover, PhD, University of North Carolina at Chapel Hill, Chapel Hill, NC, United States; Sydney Henson, Lineberger Comprehensive Cancer Center at UNC-Chapel Hill, Chapel Hill, NC, United States; Jennifer Jansen, Lineberger Comprehensive Cancer Center at UNC-Chapel Hill, Chapel Hill, NC, United States; Antonia Bennett, PhD, University of North Carolina at Chapel Hill, Chapel Hill, NC, United States; Mattias Jonsson, Lineberger Comprehensive Cancer Center at UNC-Chapel Hill, Chapel Hill, NC, United States; Andrew Shirk, Lineberger Comprehensive Cancer Center at UNC-Chapel Hill, Chapel Hill, NC, United States; Ethan Basch, MD, University of North Carolina at Chapel Hill, Chapel Hill, NC, United States

**Aims:** Adults receiving chemotherapy can experience high symptom burden, and thus patient-reported outcome measures (PROMs)

**Aims:** Total shoulder arthroplasty (TSA) is considered as the standard reconstructive surgery for patients suffering from severe shoulder pain and dysfunction caused by osteoarthritis, rheumatoid arthritis, rotator cuff tear, etc. Multiple Patient-reported outcomes (PROMs) have been developed and validated that can be used to evaluate TSA outcomes. A formal analysis of outcome measure used in TSA is lacking. Therefore, the current study aims to summarize what PROMs are commonly used to assess TSA outcomes, to classify the type of measure (International society for quality of life (ISOQOL) definitions of functioning, disability, and health (FDH), quality of life (QoL) and health-related quality of life (HRQoL)) and to compare the content of these measures by linking them to the International Classification of Functioning, Disability and Health (ICF) framework. **Methods:** A structured literature review was performed in three databases including MEDLINE, EMBASE, and CINAHL to identify which PROM was used in TSA studies. Meaningful concepts of the identified measures were extracted and linked to the relevant second-level ICF codes using standard linking rules. Outcome measures were classified as being FDH, HRQoL or QoL measures based on the content analysis. **Results:** Thirty-five measures were identified across 400 retrieved studies. Twelve PROMs were kept into conceptual analysis. The most frequently used PROM was the American Shoulder and Elbow Society score accounting for 21% (246) of the total citations, followed by the single item pain-related scale (17%) and Simple Shoulder Test (12%). One hundred and ninety individual items were linked to 36 s-level ICF codes. Most codes (65%) fell under activity and participation categories. The top 3 most predominant codes were: sensation of pain (13%), hand and arm use (13%), recreational activity (8%). Ten PROMs included in this study were categorized as FDH measures, one as HRQoL measure, and one as unknown. **Conclusion:** Our systematic review demonstrated that there is an inconsistency and lack of clarity in conceptual frameworks of identified outcome measures. Despite this, common core constructs are evaluated. Decision-making about individual studies or core sets for outcome measurement for TSA would be advanced by considering our results, patient priorities, and measurement properties.

#### **(2110) Content validity and feasibility of frequently used health-related quality of life measures in older people with hip fracture: a qualitative study**

Magdalena Brandl, Medical Sociology, University of Regensburg, Regensburg, Germany; Susanne Brandstetter, Dr.biol.hum., University Children's Hospital Regensburg (KUNO-Clinics), University of Regensburg, Regensburg, Germany; Rainer Kretschmer, MD, Department of Trauma Surgery, University Regensburg, Regensburg, Germany; Christian Apfelbacher, Prof. Dr. PhD, Medical Sociology, University of Regensburg, Regensburg, Germany

**Aims:** Content validity and feasibility of the questionnaires most commonly used in elderly patients with hip fracture are unclear. The aim of this study was to evaluate patients' views on the content validity and feasibility of the four most commonly used questionnaires for measuring health-related quality of life (HRQOL) in patients with hip fracture over 60 years. **Methods:** We recruited 32 patients with no relevant cognitive impairment above 60 years of age during their inpatient stay ( $n = 25$ , mean age = 81 years) after hip fracture. Patients were asked to complete up to four HRQOL questionnaires: EuroQOL-5D (EQ-5D), Nottingham Health Profile (NHP), 12-Item Short-Form-Survey (SF-12), WHO Quality of Life-BREF (WHOQOL-BREF). We used think-aloud and verbal probing techniques while the patients filled out the questionnaires to identify response issues. After administration of the questionnaires, we used a semi-structured interview guide to query aspects of content validity

(comprehensibility, relevance, comprehensiveness) and feasibility. The interviews were recorded, transcribed verbatim and subjected to content analysis. **Results:** Regarding feasibility, only nine patients were able to self-complete the questionnaires and only six patients filled out all four questionnaires. Patients favored short questionnaires with a clear layout. Regarding content validity, the biggest problems occurred in the comprehensibility of the items. The patients had problems with items that were phrased too vaguely (often in NHP) or lacked an example (in WHOQOL-BREF). Patients sometimes considered an item as not relevant, if the example (EQ-5D and SF-12) was inappropriate or the dichotomous answer categories (NHP) were unsatisfactory. Patients sometimes considered the EQ-5D as too superficial and therefore not comprehensive. Overall patients named medication intake, problems with vision and nutrition intake as important for their HRQOL, but none of the instruments included these themes. **Conclusion:** The assessment of HRQOL by a self-completion questionnaire represents a challenge for high-aged persons after hip fracture although their cognitive impairment was absent or mild. Based on these data we would cautiously recommend the use of the SF-12 or EQ-5D questionnaire in this patient group, as patients had the fewest problems completing these. Patients perceived the WHOQOL-BREF as too long and the NHP as not relevant, mainly due to inappropriate response categories.

#### **(2114) Reliability of a specific questionnaire to evaluate the quality of life in people with knee and hip osteoarthritis in Colombia**

Saray-Celena Salas-Vargas, Universidad del Rosario, Bogota, Colombia; Eliana-Isabel Rodríguez-Grande, MSc. Physical therapist, Escuela de Medicina y Ciencias de la Salud, Universidad del Rosario, Bogota, Colombia

**Aims:** To determine the reliability of the Osteoarthritis Knee and Hip Quality of Life questionnaire in the Colombian elderly population with osteoarthritis of the knee and hip. **Methods:** The methodological approach of this study is quantitative, with a cross-sectional design. The participants completed the questionnaire with a lapse between measurements between 5 and 8 days. The psychometric properties of reproducibility, internal consistency and level of agreement of the questionnaire were determined through intraclass correlation coefficient, Cronbach's Alpha and Bland and Altman's graphical analysis, respectively. **Results:** Sixty-two older adults with osteoarthritis of the knee and hip aged between 57 and 82 answered the questionnaire. Near perfect reproducibility (CCI = 0.89) was found for the physical activity domain; and substantial (CCI = 0.62–0.77) for the domains of pain, mental health and activities. A very satisfactory internal consistency was also obtained in the domains of mental health and physical activity (Alfa = 0.90–0.94), while that of pain was adequate (Alpha = 0.89). As for what was found with the level of agreement, the average of the differences in the domains of physical activity, pain and mental health was  $-7.0$ ,  $-8.0$  and  $-6.9$  points, respectively. **Conclusion:** The Osteoarthritis Knee and Hip Quality of Life questionnaire showed good psychometric properties in the domains of physical activity, pain and mental health, mainly. This instrument can be used in the clinical setting but requires adjustments to be used in research.