HEMATOLOGICAL DISEASES—Methods & Concepts

PHM8

ESTIMATING UTILITY VALUES FOR SELF-REPORTED JOINT PAIN AND MOTION LIMITATION OUTCOMES IN ADULT HEMOPHILIA PATIENTS-THE HEMOPHILIA UTILIZATION GROUP STUDY-PART V (HUGS-V)

Wu J[1], Nichol MB[1], Globe D[2], Gwadry-Sridhar F[3], Ullman M[4], Johnson KA[1]
[1]University of Southern California, Los Angeles, CA, USA, [2]Amgen, Thousand Oaks, CA, USA, [3]University of Western Ontario, London, Ontario, Canada, [4]Gulf States Hemophilia and Thrombophilia Center, Houston, TX, USA

OBJECTIVES: To assess 1) the association between estimated-utilities and outcomes of relevance to hemophilia patients joint pain (JP) and motion limitation (ML), and 2) sensitivity of six methods for estimating utilities to these outcomes. **METHODS:** Questionnaires completed by HUGS-V adult patients provided demographic, SF-12, and self-reported JP/ML data. Six estimated-utilities were derived from the SF-12, including HUI3/VAS item models (IM) and categorical models (CM) from the Sengupta-Nichol-Globe, SF-6D (Brazier), and Lundberg VAS algorithms. An analysis of covariance was used to determine differences in mean estimated-utilities between categories of JP/ML (none, mild, severe). Covariate adjusted effect sizes (ES) were calculated for estimated-utilities between categories of JP/ML. Covariates included age, education, employment status, income, and hemophilia severity. **RESULTS:** Of the 143 patients, 37% reported severe JP, and 57% reported severe ML in at least one joint. Mean age was 35.1 years (range 18.1 to 68.4). Mean estimated-utilities ranged from 0.72 (SF-6D) to 0.77 (HUI3 CM). The estimated-utilities were strongly correlated with each other (r range 0.60 to 0.98, p < 0.0001) and were significantly different across the JP/ML categories (P < 0.0001). Patients reporting mild JP/ML compared to no JP/ML, had medium ES (0.6 to 0.7), although the HUI3 IM (ES = 1.0) and SF-6D (ES = 0.9) had large ES. Severe JP/ML showed large effects (ES rang 1.1 to 2.1) compared to no JP/ML. Utilities derived from each estimation method were slightly different with a mean difference less than 0.05 for each paired set of methods. The utility scores were ordered similarly across categories of JP/ML. **CONCLUSION:** The medium to large ES imply the ability to measure moderate to large clinically significant differences in relevant hemophilia outcomes. Although these ES have not incorporated distribution-based outcomes, the estimated-utilities from the SF-12 appear to be clinically meaningful, interpretable, and may be used for cost-effectiveness studies in patients with hemophilia.

HEMATOLOGICAL DISEASES—
Patient-Reported Outcomes

PHM9

THE ASSOCIATION OF BARRIERS TO CARE AND HEALTH RELATED QUALITY OF LIFE IN PATIENTS WITH FACTOR VIII DEFICIENCY-THE HEMOPHILIA UTILIZATION GROUP STUDY-PART V (HUGS-V)

Wu J[1], Globe D[2], Gwadry-Sridhar F[3], Forsberg A[4], Riske B[5], Johnson KA[1]
[1]University of Southern California, Los Angeles, CA, USA, [2]Amgen, Thousand Oaks, CA, USA, [3]University of Western Ontario, London, Ontario, Canada, [4]New England Hemophilia Center, Worcester, MA, USA, [5]University of Colorado Health Sciences Center, Aurora, CO, USA

OBJECTIVES: To assess the association between self-reported barriers to care and self-reported health related quality of life (HRQOL) in Hemophilia patients. **METHODS:** Data were derived from HUGS-V. Parents/patients completed a standardized interview, including demographic, barriers to care, and either the PedsQL or SF-12. Overall barriers to care were assessed from an item "In the past 12 months, has there ever been a time that you needed hemophilia care but it was difficult to get it?" Then, eleven specific barriers were assessed. An analysis of covariance, adjusting for age, education, employment, income, and hemophilia severity, was used to determine differences in HRQOL between patients with and without barriers to care. **RESULTS:** Data for 290 patients (50% adult and 62% with severe hemophilia) were analyzed. Mean age was 9.9 years (children) and 35.2 (adult). Forty-three (14.8%) patients reported one to six barriers to hemophilia care. Mean SF-12 physical and mental composite scores were not significantly different between patients with and without any barrier to care. Covariate adjusted PedsQL subscale and total scores (except for physical summary) were significantly lower in those reporting barriers to care versus no barriers to care. The score differences ranged from 7.5 (physical summary) to 23.5 (emotional function). Children who reported two or more barriers to care had lower HRQOL scores for psychosocial summary (61.6) and total score (67.9) when compared with those who did not report barriers to care (86.5 and 87.6, respectively). The most frequently reported barriers to care were "distance to the clinic" for both adults and children, "insurance coverage" for adults, and "clinic schedule not convenient" for children. **CONCLUSION:** Preliminary data indicate that barriers to care may have a significant association with HRQOL outcome in hemophilia patients, especially in children. Identifying and resolving specified barriers may improve care access and subsequently patient reported outcomes.

INDIVIDUAL'S HEALTH—Clinical Outcomes Studies

PIH1

EVALUATION OF CAUSES AND CONSEQUENCES OF INJURIES IN CHILDREN

Angalakuditi M
Surveillance Data Inc, Plymouth Meeting, PA, USA

OBJECTIVES: To evaluate the common causes and consequences of injury related admission to the hospital in children in Western Australia. **METHODS:** A retrospective study was conducted at a Pediatric Teaching Hospital of patients <18 years of age hospitalized between 11/01/2002 and 12/31/2002. Patient medical records were reviewed if their admission diagnosis was injury related. Data collected from the medical record were date of birth, sex, date of admission, date of discharge, and clinical details such as diagnosis, procedure, causes of injury, and outcomes of the injury. **RESULTS:** One hundred and eighty four patients were admitted as a result of injury during the study period. Of these, one neonate, six infants, thirty-eight toddlers, one hundred and eleven children and twenty-eight teenagers in this study. The common cause of injury-related hospital admission was due to falls (109, 59%). The other causes of injury were crushed in 15 (8%) patients, spilling fluids in 10 (5.4%), and bites in 8 (4.3%) patients. The most common consequence of an injury in children (43/111, 38.7%) and teenagers (12/28, 43%) was bone fracture. However, head injuries are the most common consequence of injury in toddlers (11/38, 29%), infants (5/6, 83.3%) and neonates (1/1, 100%). The radius/ulna (36/63, 57%) was the most common site for bone fractures. Majority (32/37, 86.5%) of the patients who suffered head injuries were diagnosed as minor. **CONCLUSION:** The main cause of injury related admission to the hospital in children was due to a fall