PCN70
THE IMPACT OF HODGKIN’S LYMPHOMA ON HEALTH-RELATED QUALITY OF LIFE
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OBJECTIVE: Hodgkin’s lymphoma (HL) significantly impacts the health related Quality of Life (HRQoL) of patients. Treated patients often report increased stress, fatigue, nausea, sexual dysfunction, decreased social and emotional function, and vocational limitations; however few studies have assessed these domains. This review summarizes the impact of HL on HRQoL and recommends which HRQoL constructs should be assessed in the clinic and in clinical trials. METHODS: A systematic review of the literature was conducted in order to better understand the impact of HL and its treatments on HRQoL. The identified articles were reviewed for references to HRQoL and specific tools to assess these constructs. The major impacts of the disease and treatment effects are compared across tools assessing these domains. RESULTS: Some 20 instruments were used to assess HRQoL in patients with HL who were identified. In these 30 articles over 20 instruments were used to assess HRQoL. The most common cancer-specific instruments employed were the EORTC QLQ30 and FACT-Lym and various fatigue scales. No HL specific instrument was identified as being widely used. TABLES summarizing the domains covered by each instrument are provided. The EORTC and FACT-Lym appear to provide the best coverage of relevant HRQoL domains, however, using more than one instrument is necessary to capture all relevant domains. CONCLUSION: Although HL significantly impacts HRQoL very few studies have collected this data in a comprehensive manner. This work reviews the literature on the HRQoL in patients with HL and provides insights regarding the key set of HRQoL constructs that should be assessed in the clinic and in clinical trials to best characterize the impact of HL and treatment. Although the FACT-Lym provides good coverage of HRQoL domains in HL, additional validation work is needed to ensure the reliability and validity of the tool in this population.

PCN71
SOCIETAL PREFERENCES (UTILITIES) FOR ADVANCED MELANOMA HEALTH STATES IN THE UNITED KINGDOM (UK) AND AUSTRALIA
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OBJECTIVE: To estimate general public preference-based utilities for standardized health states that include common responses and toxicities observed during treatment of advanced melanoma. METHODS: A cross-sectional study was used to elicit standard gamble utilities for melanoma in the UK and Australia. Health states included partial response (PR), stable disease (SD) and progressive disease (PD). Common grade III/IV toxicities (occurring in >10% of patients) were abstracted from the literature for dacarbazine, temozolomide, interferon-α2b. These may also apply for ipilimumab, a developmental immunotherapy. Health state descriptions were based on WHO response definitions, Common Toxicity Criteria for Adverse events v3, and feedback from five clinical experts and three quality-of-life researchers. RESULTS: Utilities were elicited from 120 participants in the UK (n=64) and Australia (n=56). Mean utilities estimated (for UK vs. Australian respondents) were as follows: PR (0.85 vs. 0.89); SD (0.77 vs. 0.80); PD (0.59 vs. 0.44); and best supportive care (0.59 vs. 0.44). Utility decrements associated with the toxicities were: hair loss (−0.03); skin reaction (−0.03 vs. −0.08); diarrhea (−0.06 vs. 0.12); toxicity, but indication that treatment may be working (−0.06 vs. −0.08); nausea/vomiting (−0.07 vs. −0.13); flu-like syndrome (−0.09 vs. −0.13); stomatitis (−0.10 vs. −0.15); 1-day out/inpatient care for grade 3/4 toxicity (−0.11 vs. −0.15); symptomatic melanoma (−0.11 vs. −0.22); and hospitalization for grade 3/4 toxicity (−0.13 vs. −0.22). CONCLUSION: The development process for these standardized health states for advanced melanoma can serve as a model for developing disease-specific health states that incorporate both intended treatment responses and adverse events. PR and SD are preferred, and symptomatic melanoma and hospitalization for toxicity yield the highest disutilities. The method of decrementing utility values by subtracting toxicity utility weights holds promise for assigning utilities to serious diseases treated with toxic therapies.

PCN72
DISABILITY AND HEALTH-RELATED QUALITY OF LIFE IN LONG-TERM SURVIVORS OF CANCER IN CHILDHOOD IN BRAZIL: AN ASSESSMENT OF THE CONSTRUCT VALIDITY OF THE HEALTH UTILITIES INDEX (HUI3)
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OBJECTIVE: There is limited experience with patient-reported health status and health-related quality of life (HRQoL) in survivors of cancer in childhood in low-income countries. The purpose of this study was to collect these measurements in Brazil, test hypotheses about differences among diagnostic groups, and compare the results with those from other countries in an overall assessment of the construct validity of the HUI3. METHODS: Survivors were eligible if: diagnosed with cancer in childhood; attending the long-term follow-up clinic for one treatment center; at least 8 years off therapy; cancer free, literate; and at least 13 years of age. Health status measurements were collected in
the clinic using a Brazilian Portuguese Health Utilities Index self-report questionnaire. Responses were converted to attribute levels, and utility scores for morbidity in individual health attributes and for overall HRQL, using standard HUI Decision Tables and Utility Functions. Standard t-tests and 1-way ANOVA were used to analyze HUI3 utility scores within and across diagnoses and between countries. HUI3 overall HRQL scores were categorized to mild/moderate/severe disability (1.00 = No disability, 0.89–0.99 = Mild, 0.70–0.88 = Moderate, <0.70 = Severe disability). RESULTS: A total of 138 consecutive survivors participated in the survey. More than 71% reported some disability (mild-moderate-severe). More than one-third reported some cognitive disability and/or pain while approximately one-quarter reported problems with vision, speech or emotion. As hypothesized, retinoblastoma survivors had significant visual morbidity (p = 0.048). Survivors of germ cell tumors had significant pain morbidity (p = 0.003) and lowest mean HRQL utility score (0.49) among the diagnostic groups. HRQL means of survivors were similar (p > 0.05) among countries (Brazil, Canada, Central America, Uruguay) within diagnostic groups of acute lymphoblastic leukemia and hodgkin’s disease. CONCLUSION: The results show that the Brazilian survivors experience a wide range of disabilities and impaired HRQL similar to those reported in other countries and affirm the construct validity of the HUI3.

**PCN73**

**COMPARISON OF SURVIVAL QUALITY FROM TWO TREATMENT STRATEGIES FOR ACUTE LYMPHOBlastic LEUKEMIA (ALL) IN CHILDHOOD: DANA-FARBER CANCER INSTITUTE (DFCI) AND BERLIN-FRANKFURT-MONSTER (BFM)**

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OBJECTIVE: To determine the difference in survival quality of patients treated according to two major treatment strategies for ALL in childhood, for use in a cost-utilty study. METHODS: Children diagnosed with ALL between 1985 and 2003, and treated in one of five centers according to a DFCI or BFM-based protocol, were eligible if they were alive at least two years post-therapy. Parents of eligible survivors, in a cross-sectional survey, were asked to complete a Health Utilities Index (HUI) 15-item self-complete questionnaire with a ‘past 1-week’ recall period. HUI3 health-related quality of life (HRQL) and single-attribute scores were determined for each patient according to standard algorithms. Chi-square was used to test for differences in confounding factors between study groups: gender, and age at diagnosis (in quintiles). Differences in mean HRQL and single-attribute scores between DFCI and BFM groups were tested using one-way ANOVA. Statistical significance was set at p < 0.05. RESULTS: 612 parent assessments were available for analysis: 463 for DFCI survivors and 188 for BFM survivors. No significant differences between DFCI and BFM survivors were detected for proportion of males and females (p > 0.079), and age at diagnosis (p > 0.243). There were no significant differences detected between DFCI and BFM survivors in mean single-attribute or HRQL scores (p > 0.176). The mean HRQL score was 0.90 (SD = 0.166) for DFCI survivors, 0.92 (SD = 0.140) for BFM survivors, and 0.91 (SD = 0.159) for the pooled set of survivors. CONCLUSION: Clinical research has reported previously that there is no significant difference in mortality rates between DFCI and BFM treatment strategies. These HRQL results indicate that survivors of these treatment strategies also do not experience a difference in quality of survival. Future work for the cost-utilty study will focus on the incremental HRQL of patients during phases of active therapy and the costing of hospital-based health care services.

**PCN74**

**WILL KNOWLEDGE OF GENETIC RISK FOR CANCER INFLUENCE QUALITY OF LIFE AND SCREENING BEHAVIOR? FINDINGS FROM A POPULATION-BASED STUDY**

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OBJECTIVE: Determine the impact of testing for high prevalence, low penetrance gene variants associated with colorectal cancer (polymorphisms, haplotypes) on a person’s quality of life (QOL), health habits, and cancer screening intentions. METHODS: First-degree relatives of colorectal cancer patients and a matched group of persons without a family history of colorectal cancer from the Colorectal Cancer Familial Registry—a population-based registry in Washington State—were invited in 2006–7 to participate in a web-based survey of testing for gene variants associated with colorectal cancer risk. Participants were asked how such tests might influence their QOL, health habits, and intent to obtain colorectal cancer screening. RESULTS: A total of 310 relatives and 170 persons without a family colorectal cancer history completed the questionnaire. For the positive genetic test scenario, 69% of respondents stated they would be “somewhat worried”; 18% said they would be “very worried.” QOL measured by the standard gamble for the carrier state was modestly lower than current health; the difference was significant only for relatives (no relatives with colorectal cancer 0.89 vs. 0.88, p = 0.11; relatives with colorectal cancer 0.90 vs. 0.88, p = 0.02). The difference in QOL was not significant after adjustment for sociodemographic and health factors. In the positive gene test scenario, 30% of respondents stated they would change their diet substantially, 25% would increase exercise, and 43% would start colorectal cancer screening. Relatives of colorectal cancer patients did not differ significantly from those without a family history in their reported intent to change these behaviors. CONCLUSION: Testing for high prevalence gene variants associated with colorectal cancer risk may increase cancer worry while only modestly influencing overall QOL. Testing could improve cancer preventive health habits and colorectal cancer screening adherence. The findings suggest that testing might reduce colorectal cancer incidence, particularly among those at higher risk for colorectal cancer.

**PCN75**

**BURDEN OF IMMUNE THROMBOCYTOPENIC PURPURA ON HEALTH-RELATED QUALITY OF LIFE**

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OBJECTIVE: Adult chronic immune thrombocytopenic purpura (ITP) is characterized by autoimmune-mediated platelet destruction and suboptimal platelet production. Signs and symptoms can range from bruising to gastrointestinal and intracranial bleeding. The disease may therefore impact one’s health-related quality of life (HRQoL). We quantified the burden of ITP on