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HEALTH-RELATED QUALITY OF LIFE IN PATIENTS WITH ACTINIC KERATOSIS - RESULTS FROM PATIENTS TREATED IN DERMATOLOGY SPECIALIST CARE IN DENMARK

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OBJECTIVES: Actinic keratosis (AK) is a common skin condition associated with cumulative ultraviolet exposure and an early lesion in skin cancer (melanoma/skin cancer). The disease can potentially influence Health Related Quality of Life (HRQoL), but studies of HRQoL in patients with AK are limited. The objective was to analyze HRQoL in patients with AK using generic and disease-specific HRQoL instruments and to analyze the relationship between instruments. METHODS: AK patients who visited dermatological clinics in Denmark were included in an observational, cross-sectional, study in a multi-center setting. Dermatologists assessed AK severity and provided AK patients with the Dermatology Life Quality Index (DLQI), EQ-5D (5 Li), and EuroQol Visual Analogue Scale (EQ-VAS). RESULTS: A total of 312 patients from 10 clinics were included in the analyses. In general, patients with AK reported impaired HRQoL. The mean DLQI was 8.4 (SD: 6.9), mean EQ-5D 0.77 (SD: 0.24) and mean EQ-VAS 79 (100). HRQoL was least affected in patients with mild actinic disease, whereas patients with severe actinic damage suffered from further impaired HRQoL (mean AKQoL 10.1 and DLQI 6.6). The correlation between DLQI and AKQoL was moderate (0.52), whereas the correlations between DLQI and EQ-5D (-0.36) and between AKQoL and EQ-5D (-0.10) were weak. CONCLUSIONS: All patients with AK had impaired HRQoL. Patients with severe actinic damage were considerably more affected than those with mild disease. Correlations between instruments demonstrate that they are complementary as they measure different aspects of HRQoL and are used for different purposes. EQ-5D is essential for economic evaluations, the DLQI is responsive to changes in treatment and AKQoL captures important aspects related to sun damaged skin.

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CATEGORICAL HEALTH STATES IN CHRONIC SPONTANEOUS URTICARIA (CSU) BASED ON THE WEEKLY URTICARIA ACTIVITY SCORE (UAS7): ARE THEY DISTINCT, DISCRIMINATIVE, AND REPRODUCIBLE?

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OBJECTIVES: Specific ranges of scores reflecting patient severity or changes in severity have not been established for average daily urticaria activity summed over 7 days (UAS7, range 0-42). A common measure for assessing CSU disease activity is whether five health state derived from the continuous UAS7 score can discriminate between patients with different severities of urticaria and are reproducible across multiple studies. METHODS: Data come from three randomized, 1, 2, 3 parallel clinical trials evaluating the effect of onalizumab on symptoms of patients with refractory CSU. Five CSU health states were defined: Urticaria-Free (UAS7=0); Well-Controlled UAS7=1-7); Moderate Urticaria (UAS7=8-17); Severe Urticaria (UAS7=28-42). Comparison variables included the Dermatology Life Quality Index (DLQI), a 10-item dermatologic QoL instrument (range 0-30; higher scores greater QoL impairment), patient diary questions asking about daily interference with activities, and number of diphenhydramine 25mg pills taken in previous 24 hours. Analyses established whether different UAS7 health states showed different values on comparison variables (ANOVA), and patients were classified across trials at baseline and weeks 12, 24, and 40 (ASTERIA I and GLACIAL) and baseline and weeks 12 and 28 (ASTERIA II). RESULTS: Mean values for comparison variables were lowest (zero or very close to zero) for patients who were Urticaria-Free and highest for those with Severe Urticaria. The UAS7 proved to be a reproducible marker of disease severity. Changes in categorical health state severity were highly related to categorical changes in DLQI (p<0.001 for all trials and time points). CONCLUSIONS: Categorical UAS7 health states show meaningful differences in mean values on comparison variables and are highly related to established levels of effect on dermatological QoL. Categorical UAS7 health states could be informative about subgroups for economic models and useful for clinical practice.

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THE BURDEN OF PRIMARY HYPERHIDROSIS ON THE PATIENT: EQ-5D-5L UTILITIES, WILLINGNESS TO PAY AND DAILY TIME SPENT IN MANAGING THE CONDITION

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OBJECTIVES: The objective of this study was to estimate the burden associated with primary hyperhidrosis by assessing patient’s health utilities, willingness to pay and daily time spent in management. METHODS: The data used in this study were collected under a longitudinal, multi-stage research undertaken to develop and validate a new HRQoL instrument from the perspective of patients affected by primary hyperhidrosis. The new instrument targets patients with idiopathic hyperhidrosis (HPH) and primary hyperhidrosis (PHH) to allow comparison with published instruments (HRQoL support group UK and International hyperhidrosis society) from January to August 2013. Only the baseline assessment is used in this analysis. Disease severity was measured using the Hyperhidrosis Disease Severity Scale (HIDSS, 0 = no sweating, 9 = intolerable sweating). Treatment was measured using the EuroQol 5-1 utility index. CONCLUSIONS: The EuroQoL 5-1 was used to assess health utility index. RESULTS: EQ-5D utility health index was lower in patients with more severe hyperhidrosis [mean utility value: 0.8 ± 0.13 for HDSS = 0.0 vs. 0.8 ± 0.15 for HDSS = 3.0, 0.7 ± 0.14 for HDSS = 4.0, chi-square = 25.86, df = 2, p < 0.001]. Further, the health utility index was 0.64 ± 0.22 for WTP £0, 0.81±0.16 to £1 for 4 £1, 0.81±0.15 to £5 for 50 £1, 0.76 ± 0.18 to £100 to 299 £1, 0.57 ± 0.18 for £100 or more. Patients spent a mean of 50±134 minutes (HDSS = 2), 65±19 minutes (HDSS = 3) and 161±293 minutes (HDSS = 4) for daily management of hyperhidrosis. WTP showed the lowest correlation to disease severity. CONCLUSIONS: The current study underscores the multidimensionality of PHH and identifies areas of patient’s subjective expectations regarding their future health-related quality of life (HRQoL) and life-expectancy, and to explore variables associated with under- or overestimating behaviour. METHODS: A cross-sectional questionnaire survey of adult moderate to severe hyperhidrosis patients was conducted. HRQoL expectations were measured by the EQ-5D descriptive system for 6 months ahead and for future ages of 60,70,80 and 90, respectively. Current health state was evaluated with EQ-5D and visual analogue scale (EQ VAS), Dermatology Life Quality Index (DLQI) and Psoriasis Area and Severity Index (PASI). RESULTS: Overall: 167 patients (71% males) were included in the analysis with mean age of 50.38±12.35 years, mean EQ-5D, EQ VAS, DLQI and PASI scores were 0.71±0.30, 50.32±10.81, 5.87±10 and 7.8±2.5, respectively. Currently 56% of the patients were on biological therapy. Patients expected 0.1±0.23 mean improvement in EQ-5D scores within 6 months (p<0.001), inverse or palmpomarital psoriasis, and using only topical treatment or initiation of biologic therapy in the time of the survey with higher expectations. Males overestimated their life-expectancy by 2.96±11.86 years whereas females underestimated by 5.23±9.34 years (p<0.001) compared to the gender-expected statistical estimates of AK. Expectations for future changes in health states from 60 to 90 ages were: 0.56±0.48, 0.38±0.50, 0.15±0.55, and -0.17±0.54 (p<0.001), respectively that are lower than the general population norms in Hungary. Both for 6 months ahead and older ages, expected EQ-5D correlated moderately with current EQ-SD and EQ-VAS and one day with DLQI and PASI (p<0.05). CONCLUSIONS: Patients expected considerable improvement in their HRQoL for the near future and large-scale deterioration for older ages. Exploring unrealistic expectations might help to prevent dissatisfaction with treatment benefits and to improve compliance.

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THE DECISION MAKING PROCESS IN RECEIVING BONE CONDUCTION IMPLANTS (BCIs) FOR SINGLE SIDED DEAFNESS

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OBJECTIVE: The main objective of this study was to evaluate the process in which patients with single sided deafness proceed to receive bone conduction implants. Factors contributing to decisions for or against implantation were also compiled. METHODS: Using a comprehensive search strategy, several online databases were searched to identify and select studies. The studies were included if they included children and children with single sided deafness (SSD), and reporting on patient preference for receiving BCIs were included. Screening of titles, and data extraction and quality assessment were performed by one reviewer. Disagreements were resolved by consultation with a second reviewer. RESULTS: 16 studies were identified covering a total of 914 individuals diagnosed with SSD. All patients who trialled BCI and children who trialled BCI were included. It was estimated that 77% of patients across studies (mean 51%) proceeded to receive a BCI. When reported, the most common reason for rejecting implantation was insufficient benefit with the BCI in social situations, or speech in noise/insufficient/no benefit from BCIs. Radio assessing factors in decision making found that age, gender, aetiology, duration of hearing loss or the presence of contralateral hearing loss did not differ between individuals who decide for or against implantation. One study so far suggests that transcranial attenuation at 2 kHz and tinnitus loudness to play a role in decision making. CONCLUSIONS: When given the option to trial traditional treatments and BCI simulators/Headsbands many patients with SSD reject BCIs. This research highlights the importance of providing trials before implantation. It is still unknown which aspects play a role in decision making and identifying better candidates.
Psoriasis 
A REVIEW OF PATIENT REPORTED OUTCOMES (PROs) IN PSORIASIS ACCORDING TO THE FOOD AND DRUG ADMINISTRATION (FDA) PRO GUIDANCE CRITERIA

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OBJECTIVE: To compare health-related quality of life (HRQoL) of Hungarian and Iranian psoriasis patients and to analyse possible differences in the relationship between EuroQol 5 dimensions (EQ-5D), Dermatology Life Quality Index (DLQI) and Psoriasis Area and Severity Index (PASI) with EQ-5D. METHODS: Same cross-sectional questionnaire surveys were carried out in two countries. Altogether 204 Hungarian and 208 Iranian psoriasis patients enrolled from two Hungarian university clinics and 62 from an Iranian clinic. Besides HRQoL assessment, data on demographics, applied treatment, affected body sites and clinical types were collected. RESULTS: Mean age of the Hungarian and Iranian patients were 51.2 ± 12.9 years with 69% males, and 40.4 ± 17.5 years with 76% males, respectively. Amongst the Hungarian patients 18% had received systemic or only topical therapy in the last 12 months, 31% systemic non-biological treatment and 52% biological therapies whereas in Iran 48% of the patients applied only topicals and 39% treated with non-biological systemic therapy. Mean EQ-SD, DLQI and PASI of the Hungarian and the Iranian sample were 0.69 ± 0.7, 2.69 ± 7.0, 0.10 ± 4.5, respectively. In both countries the disease was diagnosed 11.7 ± 3.7 months prior to the dermatology clinic were reported. CONCLUSIONS: PROs and costs in CU are infrequently addressed in the literature. Findings show patients reduced HRQoL and their willingness for more effective therapies. Frequent medical visits and loss of productivity make CU a burdensome disease in European countries.

Psoriasis: How can the quality of life in hand eczema questionnaires (QOLHEQ) be interpreted? A Banding Study
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OBJECTIVE: The Quality of Life in Hand Eczema Questionnaire (QOLHEQ) is a disease-specific instrument to assess health-related Quality of Life (HRQOL) in hand eczema (HE) patients. The QOLHEQ assesses four domains of HRQOL: (a) symptoms, (b) emotions, (c) activities, and (d) social functioning. We aimed to determine the relationship between disease changes from 0-127 points. The aim of this study was to assign bands of the QOLHEQ-score to devise separate sets of bands. Weighted kappa was calculated in order to identify the set of bands with the best agreement between QOLHEQ and AQ. RESULTS: Overall 272 and 226 HE patients were included in the study. Their mean age was 56.7 years (SD = 12.9) and 54.1% of the sample were female. With a weighted kappa of 0.54 the best agreement was found for the following bands: QOLHEQ 0-9 = minimal impairment; QOLHEQ 10-24 = slight impairment; QOLHEQ 25-58 = moderate impairment; QOLHEQ 59-79 = severe impairment; QOLHEQ 79- very severe impairment. CONCLUSIONS: This is the first study which uses an anchor-based approach in order to devise a banding for the QOLHEQ-score. This banding represents a standardized means of interpreting the QOLHEQ-score. Further studies should be conducted in order to test whether the banding may be adequate for different language version of the QOLHEQ.

Psoriasis: Factors Conditioning Health Related Quality of Life in Patients with Psoriasis in Europe: A Systematic Review of the Literature
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1Novartis Farmaceutica S. A., Barcelona, Spain, 2Outcomes’10, Castellon, Spain, 3Outcomes 10, MEDES, CSIC-IME, IBECS and grey literature [Google Scholar], were searched to identify all clinical trials published in Europe between January 1, 2009 and December 31, 2013. Bibliographic references were hand searched. Editorials, letters, commentaries, opinion papers and studies related to specific treatments were excluded. RESULTS: 27 studies accomplished the inclusion criteria. Most of the publications (66.7%, n = 18) were cross-sectional studies; 25.9% (n = 7) had a prospective design while 7.4% (n = 2) were retrospective. 12 studies analysed the relation between HRQOL and demographic characteristics, determining in 75% and 50% of them, there was a relation between sex (women) and age (younger patients) with poorer HRQOL. 3 publications demonstrated the HRQOL impairment associated with visibility of skin lesions. 4 studies appraised the relationship between disease activity and HRQOL determining a more compromised HRQOL in those patients with active disease. Disease Severity was the most frequent assessed factor, being studied in 13 publications, describing in 92% of them that patients with higher PASI had worse HRQOL. 2 articles indicated that disease symptoms as skin discomfort and pruritus were elements that negatively influenced the HRQOL of these patients. Emotional disturbances were identified as predictors of poorer HRQOL in 5 studies. 3 publications determined that the use of biological therapy contributed to improve HRQOL. CONCLUSIONS: HRQOL has been broadly addressed in patients with psoriasis in Europe. Several disease- and patient-related factors contributed to its deterioration. Therapeutic measures with proved effectiveness in controlling disease symptoms and reducing PASI would be considered in patients with severe disease who have a relation with poorer HRQOL.

Sensory Systems Disorders – Health Care Use & Policy Studies

Psoriasis: Cost effectiveness and value of information analyses of Nutritional support in preventing Pressure Ulcers in high risk hospitalised patients
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