WORK AND DAILY ACTIVITY IMPAIRMENT IN PATIENTS WITH DIGITAL ULCERS (DUS)—RESULTS FROM THE DUO REGISTRY

Methodology:
A work and daily activities assessment questionnaire and dependency.

Background:
Digital ulcers (DU) are difficult to heal, and can lead to severe, life-threatening complications. The DUO Registry is an international, multi-center, observational study to assess outcomes in patients with DU disease associated with dermatomyositis. OBJECTIVES: To assess the impact of DU on patients’ work, daily activities, and dependency.

Methods:
A work and daily activities assessment questionnaire was completed by the patients at enrollment visit into the DUO registry from April 2008 to April 2010. An overall score measuring the impairment in daily activities and work was calculated. In addition, the number of hours of help needed was determined. Overall mean (SD) as well as stratified analyses by number of DU were performed.

Results:
At the cutoff date for this analysis, 1,770 questionnaires were received from patients enrolled in the registry. The questionnaire was completed by 71% (n = 1,250), of which 35% patients were employed. The majority of patients completing the questionnaire were female (92%) with a mean age of 54 years. Problems associated with DU reduced the ability of patients to perform regular daily activities. For those not employed (40%) for patients with DU, of which 35% patients were employed. The majority of patients operated in a less severe stage of DU disease in a 3 y time, postponing DU-related activities in this sub-group, as such was considered. The model was built considering clinical outcomes, something rare on new diseases. The discussion on how to evaluate and on the value of ‘classical modeling’ in rare diseases are still an open issue with a lot to be elucidated.

SYSTEMIC DISORDERS/CONDITIONS — Conceptual Papers & Research on Methods

WEB VERSUS FACE-TO-FACE (FTF) ADMINISTRATION OF A HEALTH UTILITY SURVEY IN THE GENERAL PUBLIC: RESULTS FROM A TIME TRADE-OFF (TTO) SURVEY ON IDIOPATHIC THROMBOCYTOPENIC PURPURA (ITP)

Methodology:
Web-based administration of health utility interviews offers the potential to recruit larger, more representative samples with reduced time and costs compared to FTF administration. This analysis compared health utilities elicited through web vs. FTF administration. METHODS: Six distinct ITP health states were included in a TTO and visual analogue scale (VAS)-based health utility valuation, which was administered FTF (n = 63) and via web (n = 319) to members of the UK general public. The Wilcoxon rank-sum test was used to compare utilities between methods. The interaction between administration method and respondent characteristics were assessed by regression analyses on each pair of health utilities. An additional analysis of exclusion criteria was conducted from least strict to most strict. RESULTS: Demo-graphic characteristics in the FTF and web survey were generally comparable to the UK general population 2001 census data. The mean time to complete the TTO survey was 10.2 minutes in the FTF and 9.9 minutes in the web survey. Valid TTO response rates were higher in the FTF sample (85% to 96%) compared to the web sample (58% to 80%) across health states. Higher proportions of web respondents reported that the TTO exercise was ‘very’ or ‘somewhat useful’ (17% vs. none) that all or most decisions were difficult to make (41% vs. 30%) compared to the FTF sample. Utilities were statistically significantly lower in the web vs. FTF survey (P < 0.05). TTO scores were sensitive to exclusion criteria variations: using TTO vs. FTF respondents. VAS ratings were similar across the two administration methods and less sensitive to exclusion criteria selection. CONCLUSIONS: Our study highlighted trade-offs between the advantages and challenges of web administration. More research is warranted to further improve data quality in web-based utility surveys.

SEQUENCE OF TREATMENT IN IMMUNE THROMBOCYTOPENIC PURPURA (ITP) PATIENTS: RESULTS OF A MEDICAL RECORD REVIEW FROM EIGHT HOSPITALS IN SPAIN

Methodology:
Six distinct ITP health states were included in a TTO and visual analogue scale (VAS)-based health utility valuation, which was administered FTF (n = 63) and via web (n = 319) to members of the UK general public. The Wilcoxon rank-sum test was used to compare utilities between methods. The interaction between administration method and respondent characteristics were assessed by regression analyses on each pair of health utilities. An additional analysis of exclusion criteria was conducted from least strict to most strict. RESULTS: Demo-graphic characteristics in the FTF and web survey were generally comparable to the UK general population 2001 census data. The mean time to complete the TTO survey was 10.2 minutes in the FTF and 9.9 minutes in the web survey. Valid TTO response rates were higher in the FTF sample (85% to 96%) compared to the web sample (58% to 80%) across health states. Higher proportions of web respondents reported that the TTO exercise was ‘very’ or ‘somewhat useful’ (17% vs. none) that all or most decisions were difficult to make (41% vs. 30%) compared to the FTF sample. Utilities were statistically significantly lower in the web vs. FTF survey (P < 0.05). TTO scores were sensitive to exclusion criteria variations: using TTO vs. FTF respondents. VAS ratings were similar across the two administration methods and less sensitive to exclusion criteria selection. CONCLUSIONS: Our study highlighted trade-offs between the advantages and challenges of web administration. More research is warranted to further improve data quality in web-based utility surveys.

PREDICTING EQ-5D UTILITIES FROM NEUROPATHIC PAIN SCARES: COMPARING INDIRECT MAPPING OF PREDICTED ITEM RESPONSES WITH DIRECT MAPPING OF SCORES

Methodology:
Six distinct ITP health states were included in a TTO and visual analogue scale (VAS)-based health utility valuation, which was administered FTF (n = 63) and via web (n = 319) to members of the UK general public. The Wilcoxon rank-sum test was used to compare utilities between methods. The interaction between administration method and respondent characteristics were assessed by regression analyses on each pair of health utilities. An additional analysis of exclusion criteria was conducted from least strict to most strict. RESULTS: Demo-graphic characteristics in the FTF and web survey were generally comparable to the UK general population 2001 census data. The mean time to complete the TTO survey was 10.2 minutes in the FTF and 9.9 minutes in the web survey. Valid TTO response rates were higher in the FTF sample (85% to 96%) compared to the web sample (58% to 80%) across health states. Higher proportions of web respondents reported that the TTO exercise was ‘very’ or ‘somewhat useful’ (17% vs. none) that all or most decisions were difficult to make (41% vs. 30%) compared to the FTF sample. Utilities were statistically significantly lower in the web vs. FTF survey (P < 0.05). TTO scores were sensitive to exclusion criteria variations: using TTO vs. FTF respondents. VAS ratings were similar across the two administration methods and less sensitive to exclusion criteria selection. CONCLUSIONS: Our study highlighted trade-offs between the advantages and challenges of web administration. More research is warranted to further improve data quality in web-based utility surveys.