

At Risk Groups in Primary Sjögren's Syndrome: Longitudinal Data on Quality of Life

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Introduction

Primary Sjögren's syndrome (pSS) is a chronic inflammatory condition, which presents with symptoms of dryness, pain, fatigue and often symptoms of anxiety and depression. Cross-sectional studies have demonstrated that health related quality of life is significantly reduced in the pSS population however longitudinal studies are few. EQ-5D-3L is a standardised instrument for measuring quality of life. This study aims to determine how symptom burden, disease activity and demographics associate with quality of life longitudinally in pSS.

Methods

Longitudinal EQ-5D-3L data from the Newcastle pSS cohort (n=146, median follow up 6.35 years) were evaluated using a survival analysis strategy. EQ-5D Time trade off (TTO) scores 0-1 represent death and full-health respectively whereas negative scores indicate health states worse than death. The follow up time at which EQ-5D ≤ 0 was recorded as an 'EQ-5D event'. Patients were stratified by symptom burden in 5 domains; dryness, fatigue, pain, anxiety and depression. Kaplan-Meier and Cox proportional hazards analysis were performed in R using symptom burden group, EULAR SS Disease Activity Index (ESSDAI), gender, disease duration and age at baseline as covariates.

Results

Of the 146 pSS participants analysed in this study 27 (18%) experienced a decline in quality of life to a health state comparable to or worse than death. Symptom burden group had a significant relationship with time to 'EQ-5D event'. Baseline ESSDAI, age at baseline visit, disease duration and gender were not significant risk factors for an 'EQ-5D event'. (Figure 1, A and B)

Conclusion

In pSS, symptom burden has a significant relationship with quality of life longitudinally however disease activity does not. The direct and indirect health costs of pSS are substantial, and improvements in symptom burden have the potential to produce significant impacts on long-term quality of life in pSS. Larger longitudinal studies using international cohorts are necessary for validation.

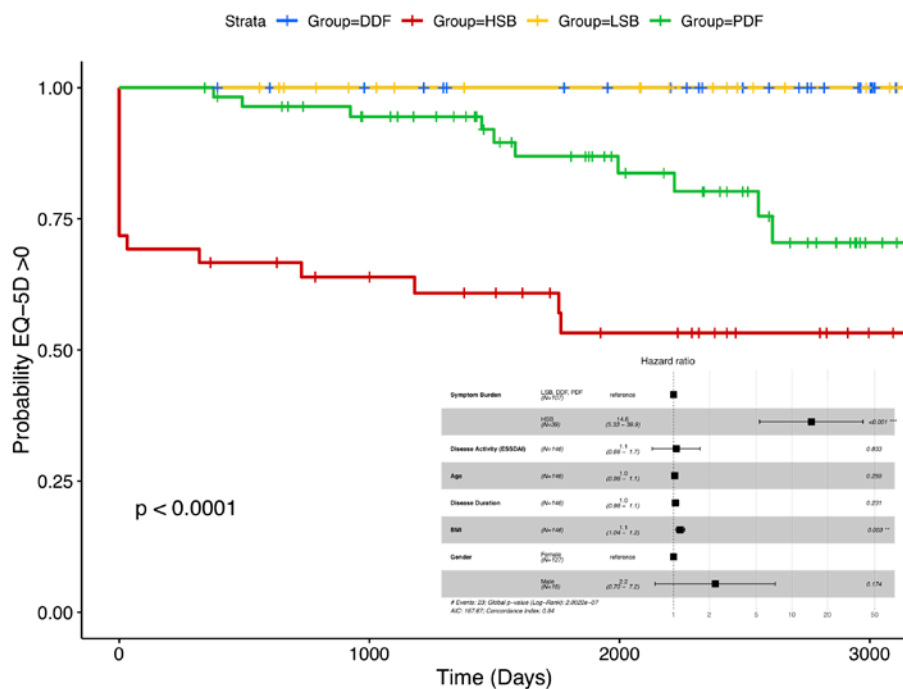


Figure 1. Kaplan-Meier estimator curves showing time to 'EQ-5D event' data between 4 symptom burden groups. 'EQ-5D event' = EQ-5D ≤ 0 . Inset: Cox Proportional Hazards analysis showing impact of symptom burden, disease activity and demographic covariates on risk of event occurrence. HSB = High Symptom Burden (all 5 domains), PDF = Pain Dominant with Fatigue, LSB = Low symptom Burden (all 5 domains), DDF = Dryness Dominant with Fatigue, BMI = Body Mass Index.