



AUTOIMMUNE BULLOUS DISEASES

## **AUTO-IMMUNE BULLOUS DISEASES BURDEN SCALE: DEVELOPMENT AND VALIDATION OF A NEW ASSESSMENT TOOL**

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**Introduction:** The notion of burden tends to replace quality of life (QoL) scales to assess disability as it includes other dimensions such as psychological impact, social integration, economic constraints, etc.

**Objective:** We report the construction of a French burden scale (BS-AIBD) for autoimmune bullous diseases (AIBD).

**Material and Methods:** All incident or prevalent patients with AIBD seen on 2 sites of the reference center were eligible. An anonymous questionnaire was given after signed informed consent. Exclusion criteria were age < 18 yo, patients unable to answer a questionnaire and/or to speak French. The BS-AIBD construction consisted of 3 phases. In the exploratory phase, a preliminary BS-AIBD was elaborated from a verbatim report based on the complaints of patients of the Association Pemphigus Pemphigoid France. In the development phase, we conducted a descriptive study of the preliminary BS-AIBD, a correlation matrix, a principal component analysis and a study of the dimensional structure using a scree plot. A pilot BS-AIBD was obtained by excluding non-discriminative, redundant and/or contradictory questions (Q). Finally, the validation phase included an evaluation of the internal consistency reliability of the pilot BS-AIBD (Cronbach's  $\alpha$  coefficient) and of the concurrent validity (Pearson's coefficient between the pilot BS-AIBD and validated QoL questionnaires).

**Results:** The exploratory phase generated a preliminary BS-AIBD of 39 Q that was completed by 115 patients (41 pemphigus, 74 mucous membrane pemphigoid). The analysis showed a one-dimensional questionnaire. Nineteen Q could be eliminated after the development phase. The Cronbach's  $\alpha$  coefficient was respectively 0.93 and 0.90 for the preliminary and the pilot BS-AIBD. The concurrent validation showed a strong correlation





between the pilot BS-AIBD and validated QoL questionnaires (DLQI, ABQOL).

Conclusions: A BS-AIBD was built and validated. It allows to calculate a burden score whose variations could be analyzed in the French AIBD patients cohort.

