Appendix S1

Statistical methods for psychometric validation

Construct validity. With regard to construct validity (domain structure), an exploratory factor analysis (principal factor analysis) was performed with the number of factors left free in order to highlight the underlying constructs of module 1. This analysis also aimed to categorize each item into its respective domain. An oblique promax rotation after an orthogonal varimax rotation was performed because the hypothetical constructs that constitute the burden were believed to be interrelated with each other. Exploratory factor analysis explores the possible underlying factor structure of a set of observed variables without imposing a pre-conceived structure on the outcome. Numerous questionnaires have been developed using such method (such as the well-known Treatment Satisfaction Questionnaire for Medication; TSQM). The technique for extracting factors attempts to remove as much common variance as possible from the first factor, while retaining the variance for the other factors.

Adjustment to the frames of reference by rotation methods improves the interpretation of factor loadings by reducing some of the ambiguities that go with the preliminary analysis. The process of manipulating the references axes is known as rotation. Rotation applied to the reference axes means the axes are turned about the origin until an alternative position has been reached. If we consider that no correlation exists between the underlying constructs, then the axes are held at 90°. Otherwise, an oblique rotation may subsequently be performed: the factors are permitted to be correlated with one another.

Items were considered for deletion if they loaded on 2 or more factors (standardized regression coefficients, SRC ≥ 0.4) or did not load on any of the factors (SRC < 0.4). After this analysis, HFB version 2.0 was designed.

Dimension scores were subsequently calculated by adding up each individual item of the first module of the questionnaire. A score, the sum of all dimensions scores, was calculated. Then, the sum of all the questions of module 2 was calculated and transformed into a percentage (ranking from –50% to 50%). Module 1 score was then weighted by the results of module 2 and this constituted the HFB score. This was done in order to take into account a potential positive impact of the IH on the burden. The higher the HFB score, the higher the burden of IH for a family.

For reliability, the homogeneity of the items of module 1 was evaluated using Cronbach's α coefficient. Coefficient scores > 0.7 generally indicate good internal reliability (30).

The concurrent validity of the questionnaire was determined by calculating Spearman's rank correlation coefficient (ρ) between the HFB score and each component of the SF-12 and the PGWBI.

Discriminant validity (known-group validity) was analysed according to the size of IH and its localization. Wilcoxon or Kruskal-Wallis tests and *post-hoc* multiple comparisons with corrected α tests were used, since the parameters studied did not show a normal distribution.

Data were analysed using SAS® software version 9.3 (SAS Institute Inc., Cary, USA) for Windows. A significance level of 0.05 was set for all tests.