



QUALITY OF LIFE, QUALITY OF CARE, AND PATIENT SAFETY

PALMOPLANTAR KERATODERMA: CREATING A DISEASE BURDEN QUESTIONNAIRE

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Background: Palmoplantar keratoderma (PPK) constitutes a heterogeneous group of disorders that may be further subdivided into hereditary and acquired forms, characterized by hyperkeratosis of the palm and sole skin.

Objectives: This study sought to develop a self-administered questionnaire in French designed to assess the burden of PPK (BoPPK), then translate and linguistically and cross-culturally validate the BoPPK into American English.

Methods: Standardized methodology was applied, comprising exploratory, development, and validation phases, followed by translation, cross-cultural adaptation, and cognitive debriefing using a rigorous 9-step procedure.

Results: Based on several discussions with 10 PPK patients, a 56-item conceptual questionnaire was first generated by the authors. Among the adult patients who then responded to this questionnaire, 53 were accessible. Subsequent confirmatory analyses generated a 20-item questionnaire grouped into four domains. The Cronbach's alpha coefficient for the entire 20-item questionnaire was 0.95, demonstrating its excellent internal consistency, while consistency within the dimensions indicated good reliability ($\alpha > 0.79$). The BoPPK proves to be the first instrument able to specifically assess the individual burden of PPK. With its 20-item structure, it is relatively short, simple, and easy to use. Its simple questions can be answered by anyone. Building on our research, the BoPPK has been proven a robust tool, its internal consistency exceeding the minimum reliability criterion of 0.90 for individual patient analysis. Besides its internal consistency, BoPPK was likewise shown to exhibit external validity, owing to the good correlations between the BoPPK and other previously-validated questionnaires, such as SF12, DLQI, and PSS.

Conclusions: BoPPK is the first specific instrument available for assessing individual disease burden in adult PPK patients. Considering the increasing relevance that regulatory authorities attribute to patient-reported outcomes, the BoPPK questionnaire by accounting for the PPK burden in the broadest sense most likely provides this supplementary information.

