



QUALITY OF LIFE, QUALITY OF CARE, AND PATIENT SAFETY

DEVELOPMENT OF A SCALE TO MEASURE THE PSYCHOSOCIAL IMPACT OF VITILIGO ON FAMILY MEMBERS

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Introduction: The psychosocial impact of vitiligo on the health related quality of life of patients is well known, however, surprisingly little is known about its impact on caregivers and family members. There are several scales to assess the impact of vitiligo on patients, but there is no disease specific scale to measure the impact on family members.

Objective: To develop and preliminarily validate a scale to measure the psychosocial impact of vitiligo on family members

Material and Methods: The scale was developed in three phases: item generation, pre testing and preliminary validation. Qualitative key interviews (23 family members of vitiligo patients) and focused group discussion (8 family members) were carried out to generate items that reflected different aspects of psychosocial burden. Initial items were pre-tested on 30 participants. The revised scale was then tested on 150 family members.

Results: After the key interviews and focused group discussion, 122 items were generated. After expert evaluation and revision, a preliminary scale with 32 items in 13 domains (disease understanding, treatment response, social impact, impact on affect, behavior, financial burden, functionality, familial conflicts, disclosure difficulty, coping mechanisms, spousal relationships, cognition and child's academic functioning) were pre-tested on 30 participants. Preliminary analysis revealed Cronbach's alpha of 0.89-0.91. Based on this, it was further condensed to a final measure of 16 items in 11 domains. The final scale was administered to 150 participants along with two comparator scales, Family Dermatology Life Quality Index (FDLQI) and Family Strain Questionnaire- Short Form (FSQ-SF).

Conclusion: Family Vitiligo Impact Scale (FVIS) will help clinicians to assess the psychosocial impact of vitiligo on family members and can be used as an outcome measure in both clinical and research settings.

