

International Alliance of Dermatology Patient Organizations

Dermatological conditions impact physical, psychological, social, financial and daily functioning



Global Research on the Impact of Dermatological Diseases



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Development of the Patient-Reported Impact of Dermatological Diseases (PRIDD) measure: a concept elicitation study

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INTRODUCTION

Dermatological conditions can cause substantial pain, disfigurement, disability, and stigma, associated with psychological, social and financial burdens. Our systematic review of dermatology patient-reported outcome measures (PROMs) found that none comprehensively captured the full impact of living with dermatological conditions. The current qualitative concept elicitation study aimed to develop a conceptual framework on which to build a new measure of the impact of living with a dermatological condition, called PRIDD (Patient-Reported Impact of Dermatological Diseases).

METHODS

Face-to-face focus groups and online synchronous individual semi-structured interviews were conducted with adults (≥ 18 years) living with a dermatological condition and/or dermatology patient organization representatives. Patients were recruited through the International Alliance of Dermatology Patient Organizations' membership network. Interview questions were theoretically informed by the Conceptual Model of Health-Related Quality of Life and the Common-Sense Self-Regulatory Model. Thematic analysis was conducted following a combined inductive-deductive approach guided by these models.

RESULTS

Sixty-three people (68% female) across 29 dermatological conditions and countries participated. Key themes were: 1) Impacts at the individual, organizational and societal levels; 2) Impact on life can be both point-in-time and cumulative; 3) Impact is a multifaceted construct. The final theme further divided into two subthemes: a) *Common impacts* and b) *Psychological and social impacts* are most significant. The conceptual framework depicts a reflective model of impact:



DISCUSSION

Life impact is a multifaceted concept presenting across physical, psychological, social, and financial and daily functioning. The breadth of impact has not previously been captured as a unified construct or by a single instrument. These data provide a basis for developing PRIDD's content and have subsequently been validated in Delphi study (n=1154). PRIDD is currently being pilot-tested with patients.



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