

Impact of childhood psoriasis on parents of affected children

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Background: Childhood diseases, such as atopic dermatitis, have a negative impact on quality of life (QoL) of parents. How pediatric psoriasis affects a parent's QoL is unknown.

Objective: To explore the impact of childhood psoriasis on the lives of the parents.

Methods: Semistructured interviews were conducted with 31 parents of children with psoriasis. Narrative data were analyzed and a conceptual framework of the effects of childhood psoriasis on parents was developed.

Results: All parents reported that their child's psoriasis caused a substantial, negative impact on their own QoL. A conceptual framework showed a negative impact on health and self-care, emotional well-being, family and social function, personal well-being, and life pursuits. Emotional well-being was the most affected domain.

Limitations: It was not possible to correlate psoriasis severity with parental QoL.

Conclusion: Childhood psoriasis alters the QoL of parents in multiple ways. Information from this study can be used to develop a QoL instrument to explore treatment and support strategies for families affected by pediatric psoriasis. (J Am Acad Dermatol <http://dx.doi.org/10.1016/j.jaad.2016.09.014>.)

Key words: emotional well-being; family function; health and self-care; parent; personal well-being; psoriasis; quality of life; social function.

The incidence and prevalence of psoriasis in childhood are steadily increasing: 1.2% of children have psoriasis at age 18, and one-third of psoriasis patients develop the condition in childhood.^{1,2} Psoriasis has a detrimental effect on the quality of life (QoL) of affected children.^{3,4} Children with moderate-to-severe psoriasis have a health-related QoL comparable to children with arthritis and asthma and worse than children with diabetes mellitus.⁵ They commonly experience itching, fatigue, and feelings of stigmatization and are more likely to suffer from anxiety and depression.⁶⁻⁸ The greater patient concept refers to family members whose QoL is affected by the skin disease experienced by their loved ones.⁹ Ninety percent of

Abbreviations used:

AD: atopic dermatitis
QoL: quality of life

family members of adults with psoriasis report a negative impact on their own QoL. As psoriasis severity increases, the impact worsens, and as the patient's QoL decreases, so does that of their family members.¹⁰⁻¹²

Childhood disease, including atopic dermatitis (AD), is known to have a negative impact on the QoL of parents.¹³⁻¹⁷ An understanding of the effect of childhood psoriasis on families is important for tailoring treatment and support strategies. The goal

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of this study was to evaluate how a child's psoriasis can affect the QoL of the parent caregiver.

MATERIALS AND METHODS

Participants

Parents of children aged 17 years or younger with psoriasis were consecutively recruited from the dermatology clinics at Mayo Clinic (Rochester, Minnesota) between May 1, 2014, and May 1, 2015. The diagnosis of psoriasis was confirmed by a pediatric dermatologist. Recruitment was not based on the severity of the skin disease. Parents were excluded if they could not speak English or if their child had comorbid conditions that required intensive daily care. The study was approved by the Mayo Clinic Institutional Review Board.

Qualitative interviews

An oral interview script was developed and reviewed for content by the authors and an additional pediatric dermatologist. Each parent who agreed to participate was interviewed in person without their child present. Semistructured parent interviews were conducted by one of the investigators (MMT). The oral script was generally followed, with additional questioning to expand on any novel issues that emerged. Questions focused on how the parent's life was affected by the child's psoriasis. The interviews were audio recorded and transcribed verbatim. Notes were taken during the interviews to supplement the transcribed, audiotaped sessions.

Data analysis

Qualitative analysis was done on the transcribed data and interviewer notes. A preliminary conceptual framework of emergent issues was developed from an initial review of the first 5 transcripts. This preliminary framework was applied to all of the narrative transcripts. Two study members (MMT and DF) independently reviewed and coded each transcript and met to discuss each one and to arrive at a consensus. Data were entered into NVivo software (QSR International Pty Ltd), and saturation analysis was performed by creating a grid that matched major topics with interview content and compared content from newer interviews with content from the initial interviews. Saturation was determined to occur when no new major topics emerged from the

narrative data. Items that were not identified by codes in the preliminary framework were discussed, and consensus was reached to modify an existing code or add a new code. After coding all interviews, a final review was done, and the conceptual framework was modified accordingly.

RESULTS

Patient characteristics

Thirty-one consecutive parents of affected children were interviewed: 29 mothers and 2 fathers. The patients ranged in age from 18 months to 17 years. No parent declined participation. The children (62% male) were affected by plaque (86%), inverse (7%), guttate (3%), and generalized pustular (3%) psoriasis.

CAPSULE SUMMARY

- Chronic skin disease has a negative impact on quality of life of patients and their families.
- Pediatric psoriasis has a multifaceted, negative impact on the quality of life of parental caregivers.
- Support for families should be part of the treatment plan for children with psoriasis.

Interview results

All parents reported that their child's psoriasis negatively affected their own QoL. Four major themes emerged from the interview data: 1) impact on health and self-care, 2) emotional well-being, 3) family and social function, and 4) personal well-being and life pursuits. The conceptual framework is shown in Fig 1.

Theme 1: health and self-care. Parents reported sleep disruption that resulted in fatigue, difficulty with concentration, and impaired ability to manage personal care (Supplemental Table I, available at <http://www.jaad.org>).

Theme 2: emotional well-being. Emotional well-being was substantially affected for most participants (Supplemental Table II, available at <http://www.jaad.org>). Many parents experienced considerable stress directly related to their child's psoriasis and its treatment, medical concerns for their child and their overall well-being, and sadness and frustration over the child's illness. Many parents had feelings of depression and anxiety that they considered directly related to their child's skin condition.

Theme 3: family and social function. This theme raised multiple talking points for parents (Supplemental Table III, available at <http://www.jaad.org>). Finances were a concern, as was the time it took to treat the psoriasis and travel for appointments. Parents discussed the substantial impact the child's condition had on relationships with family and friends, including their significant other. Many parents felt the need to raise awareness about their child's condition. The burden of caring for the

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