

This is an Open Access document downloaded from ORCA, Cardiff University's institutional repository: <https://orca.cardiff.ac.uk/id/eprint/155447/>

This is the author's version of a work that was submitted to / accepted for publication.

Citation for final published version:

Chernyshov, Pavel V., Tomas-Aragones, Lucia, Linder, Dennis, Bewley, Anthony, Salavastru, Carmen Maria, Marron, Servando E., Manolache, Liana, Pustisek, Nives, Evers, Andrea W. M., Koumaki, Dimitra, Abeni, Damiano, Suru, Alina, Salek, Sam S. and Finlay, Andrew Y. 2023. Further insights into the wider impact of childhood atopic dermatitis - Comment on "Burden of childhood atopic dermatitis on parents: Fathers' and mothers' respective feelings" by Mahé et al. [Letter to the editor]. *Journal of the European Academy of Dermatology and Venereology* 37 (4) , e491-e492. 10.1111/jdv.18687

Publishers page: <http://dx.doi.org/10.1111/jdv.18687>

Please note:

Changes made as a result of publishing processes such as copy-editing, formatting and page numbers may not be reflected in this version. For the definitive version of this publication, please refer to the published source. You are advised to consult the publisher's version if you wish to cite this paper.

This version is being made available in accordance with publisher policies. See <http://orca.cf.ac.uk/policies.html> for usage policies. Copyright and moral rights for publications made available in ORCA are retained by the copyright holders.



**Further insights into the wider impact of childhood atopic dermatitis. Comment on “Burden of childhood atopic dermatitis on parents: fathers’ and mothers’ respective feelings” by Mahé et al.**

**Chernyshov PV, Tomas-Aragones L, Linder D, Bewley A, Salavastru CM, Marron SE, Manolache L, Pustisek N, Evers AWM, Koumaki D, Abeni D, Suru A, Salek SS, Finlay AY.**

Dear Editor,

Skin diseases have a major impact on the lives of patients and their families.<sup>1</sup> Additional factors such as the recent COVID-19 pandemic may exacerbate this impact.<sup>2</sup> The European Academy of Dermatology and Venereology (EADV) Task Force on Quality of Life and Patient Oriented Outcomes published a position paper on measuring the impact of dermatological conditions on family and caregivers.<sup>3</sup> We therefore read with interest the letter by Mahé et al<sup>4</sup> and congratulate them on drawing further attention to the major burden experienced by parents of children with atopic dermatitis (AD). The authors present data from 282 mother/father dyads, and conclude that the burden experienced by mothers and by fathers is similar: this confirms our 2009 study<sup>5</sup> using the Dermatitis Family Impact (DFI) questionnaire. However, Mahe et al.<sup>4</sup> reported that data collection in spouses was not necessarily happening simultaneously (a maximum interval of three days was allowed). It is possible therefore that various aspects of the completed questionnaires were discussed by the couples, which may have biased the answers of those spouses who were interviewed later. This approach could have in turn led to the similarity of the impact observed. It is not clear how the authors interpreted the results of the versions of the generic EQ-5D for assessment of family impact or children’s quality of life (QoL). The EQ-5D is a utility index and thus considering the context of the study it would have been prudent to use a generic family reported outcome measure such as FROM-16. Mahe et al. incorrectly described the DFI as a “dermatology-specific” instrument, but the DFI was developed specifically as an

instrument for use in childhood AD.<sup>1</sup> There is a dermatology-specific (for use across all skin diseases) family QoL instrument: the Family Dermatology Life Quality Index (FDLQI).<sup>6</sup> The FDLQI may be effectively used in parents of children with atopic dermatitis. Perhaps the authors had meant to use the FDLQI.

The authors claimed that their study<sup>4</sup> evaluates for the first time since 1986 the impact of AD on the mother/father dyad of the same child in a unity of time, perhaps unaware of our 2009 study using the DFI questionnaire.<sup>5</sup> In our study both the mother and father of 21 children with AD simultaneously filled in the DFI questionnaire to assess the family impact, and the AD-specific proxy instrument, the Infants' Dermatitis Quality of Life Index (IDQoL) questionnaire, to assess the quimp (the EADV Task Force on QoL and Patient Oriented Outcomes recommends using the word "quimp"<sup>7</sup> (quality of life impairment) in routine clinical work and research<sup>8</sup>) in their children. No significant differences between mothers' and fathers' answers were found. The conclusion of that study<sup>5</sup> was that the choice of which parent should fill in the IDQoL and the DFI cannot significantly influence the results of clinical studies. However at an individual family level the DFI and the IDQoL scores may differ. It may be therefore be better to collect data from both parents, even though this may be sometimes difficult.

The study by Mahé et al.<sup>3</sup>, despite the variable use of the EQ-5D and the non-synchronous collection of data from mothers and fathers, showed no significant differences in the impact of children's AD on the QoL of mother or father, confirming our previously published study<sup>5</sup>. Other approaches to assess the impact of childhood AD on the lives of parents' have included the initial validation and use of a visual instrument "Caregiver-PRISM".<sup>9</sup> Another aspect of the burden, the impact of childhood AD on the major life changing decisions of the child's caregivers has recently been explored.<sup>10</sup> This has demonstrated a great influence on major decisions, altering the trajectory of the lives of caregivers. These various insights into the QoL issues experienced by carers of children with AD pose important challenges to clinicians over how best to respond with appropriate support.

In conclusion, the study reported by Mahe et al. leaves the option open for conducting another large study in which both parents complete the study instruments at the same time as well as employing a more appropriate family reported outcome measure such as the FDLQI or the FROM-16.

## References

1. Lawson V, Lewis-Jones MS, Finlay AY, Reid P, Owens RG. The family impact of childhood atopic dermatitis: the Dermatitis Family Impact Questionnaire. *Br J Dermatol* 1998;**138**:107-113.
2. Chernyshov PV, Tomas-Aragones L, Augustin M et al. Position statement of the European Academy of Dermatology and Venereology Task Force on Quality of Life and Patient Oriented Outcomes on quality of life issues in dermatologic patients during the COVID-19 pandemic. *J Eur Acad Dermatol Venereol* 2020;**34**:1666-1671.
3. Sampogna F, Finlay AY, Salek SS et al. Measuring the impact of dermatological conditions on family and caregivers: a review of dermatology-specific instruments. *J Eur Acad Dermatol Venereol* 2017;**31**:1429-1439.
4. Mahé E, Ezzedine K, Thenie C, Merhand S, Taïeb C. Burden of childhood atopic dermatitis on parents: fathers and mothers' respective feelings. *J Eur Acad Dermatol Venereol* 2022 Jul 20. doi: 10.1111/jdv.18444. Epub ahead of print.
5. Chernyshov PV. May the gender of a parent influence assessment of health-related quality of life, family impact and severity of atopic dermatitis in children. *Pediatr Dermatol* 2009;**26**:99-100.
6. Basra MK, Sue-Ho R, Finlay AY. The Family Dermatology Life Quality Index: measuring the secondary impact of skin disease. *Br J Dermatol* 2007;**156**:528-538.

7. Finlay AY. Quimp: A Word Meaning "Quality of Life Impairment". *Acta Derm Venereol* 2017;**97**:546-547.
8. Chernyshov PV, Linder MD, Pustišek N et al. Quimp (quality of life impairment): an addition to the quality of life lexicon. *J Eur Acad Dermatol Venereol* 2018;**32**:e181-e182.
9. Marinello E, Linder D, Spoto A et al., Assessing the Impact of Atopic Dermatitis on the Patients' Parents with the Visual Instrument 'Caregiver-PRISM'. *Dermatology* 2016;**232**:490-495.
10. Capozza K, Schwartz A, Lang JE et al. The Impact of Childhood Atopic Dermatitis on Life Decisions for Caregivers and Families. *J Eur Acad Dermatol Venereol* 2022;**36**:e451-e454.