Review paper

Chronic dermatoses affect not only sick individuals: a review of family and caregiver burden assessment tools

Ewa Wójcik, Piotr K. Krajewski, Jacek C. Szepietowski

Department of Dermatology, Venereology, and Allergology, Wroclaw Medical University, Wroclaw, Poland

Adv Dermatol Allergol 2024; XLI (5): 433–445
DOI: https://doi.org/10.5114/ada.2024.141685

Abstract

Introduction: The focus in dermatology has shifted from solely treating skin conditions to considering the quality of life (QoL) of patients and their family members.
Aim: To identify and categorise instruments that assess the impact of chronic skin diseases on the QoL of family members and caregivers.
Methods: A narrative review was conducted using the Scopus and Medline databases, with search terms related to QoL, dermatology, and family/caregivers. Articles published up to January 2024 were reviewed, and relevant instruments were categorised.
Results: The search yielded 2799 papers, of which 153 were reviewed in detail. Twenty instruments were identified and categorised into generic, dermatology-specific, and disease-specific tools.
Conclusions: The review highlights the importance of assessing family QoL in dermatology. Integrating these tools into clinical practice can enhance support for family members, improving overall patient care. Further development and refinement of these tools are necessary to capture the full impact on family QoL.

Key words: burden, quality of life, chronic dermatoses, questionnaires.

Introduction

With the advancement of dermatology, the condition of the skin ceased to be the only criterion for the severity of the disease, and its improvement ceased to be the sole indicator of the effectiveness of treatment. Increasing significance of patients' quality of life (QoL) as an outcome measure across medicine resulted in the creation of various tools to determine the impact of the disease on different aspects of the patients' life and general functioning. Over the years, the QoL in dermatology has gained importance as an aspect significantly effecting therapeutic decisions and the assessment of its satisfactoriness [1].

For a long time, attention was focused almost exclusively on the influence of diseases on patients' lives, but finally, due to changes in the health care system and the increased contribution of outpatient care in the dermatological therapeutic process, the consideration was made on the impact of diseases on caregivers and other members of the patients' close social group [2]. It has been noticed that the QoL of patients and the QoL of people around them largely depend on each other, and thus the evaluation of the emotional, physical, or even financial burden resulting from having a child, partner, or other family member with chronic skin disorder should be taken into account when guiding management decisions [3]. However, the different symptoms and difficulties associated with them, the type and condition of the relationship, and the multitude of factors affecting one's life situation and well-being, imply confusion in recognising the problems and needs of patients' relatives [4].

Objective

The aim of this study was to reveal, present, and summarise the instruments that can be used to evaluate the impact of a chronic skin diseases on the QoL of those living with the patients. To facilitate the selection of the appropriate instrument for a specific clinical situation, the identified tools were briefly characterised and categorised as either for the use across all medicine, dermatology-specific, or disease-specific questionnaires.

Methods

A comprehensive narrative review of existing instruments for assessing the quality of life (QoL) of caregiv-

Address for correspondence: Prof. Dr. Jacek C. Szepietowski, Department of Dermatology, Venereology, and Allergology, Wroclaw Medical University, Wroclaw, Poland, e-mail: Jacek.szepietowski@umw.edu.pl
Received: 17.06.2024, **accepted:** 22.06.2024, **online publication:** 22.07.2024.

ers, family members, or partners of patients in dermatology was conducted through a literature search in the Scopus and Medline databases. Articles published up to 31 January 2024 were examined by combining search terms such as 'quality of life' or 'life quality' and 'Dermatol*', or 'skin' with terms like 'family', 'partner', 'proxy', 'parent', 'caregiver', 'carer', and 'sibling'.

The search results were filtered based on relevance, considering the titles and abstracts. Articles that did not address the specified topics were excluded. English language articles discussing the development or application of any tool with the potential for QoL assessment in dermatology were then thoroughly reviewed in full text.

Results

The database search revealed 2799 papers. After screening the titles and abstracts of the articles, 153 papers were selected for further examination, from which 20 instruments were identified as useful tools for assessing QoL in family members, partners, or caregivers of patients with chronic dermatoses. All tools were categorised as universal, specific for dermatology, and specific for skin diseases. The presented categorisation does not encompass other features of the questionnaires. Some of them focus solely on a selected aspect of quality of life, while others are intended for family members of patients within a certain age range or can only be completed by individuals holding a particular role.

Questionnaires for use across all medicine

Each disease presents distinct challenges and complications, but certain issues are commonly experienced by family members of patients throughout the medical field. To evaluate and compare the QoL of relatives and partners of patients with chronic skin conditions and other diseases, it is essential to use universal, generic assessment tools. They are presented in Table 1.

Family Reported Outcome Measure (FROM-16)

FROM-16, developed by Beasara *et al.* [5], is the most versatile measurement tool currently available. It is designed to estimate the impact of any disease on the QoL of any adult member within the patient's immediate social group. It was created based on extensive interviews conducted with family members of patients across 26 medical specialties. The questionnaire is structured into 2 distinct sections: emotional life, and personal and social life. Responses are evaluated on a scale ranging from 0 to 3 points, reflecting the current moment in time. A higher score indicates a greater impact on the respondent's QoL. Transparency and short implementation time stand out as undeniable strengths of this instrument [6]. A Polish language version of this questionnaire was created and validated [7].

The Family Quality of Life Survey – General Version 2006

This instrument was created within the framework of the Family Quality of Life Project, with the goal of defining the concept of "family quality of life" and formulating a tool for its evaluation. Initially, the FQoLS-2000 was derived for family members of people with intellectual or developmental disabilities [8]. In 2006, a general version of the FQoLS questionnaire was created by Brown *et al.* [9] for families without intellectual disabilities. The questionnaire was designed

Table 1. The summary of family and caregiver quality of life assessment tools

Generic questionnaires	Dermatology-specific questionnaires	Disease-specific questionnaires
• Family Reported Outcome Measure (FROM-16) • The Family Quality of Life Survey – General Version 2006 • Family Strain Questionnaire – Short Form (FSQ-SF) • Revised Impact on Family Scale (IOF) • Paediatric Quality of Life Inventory™ Family Impact Module (PedsQL™ Family Impact Module) • The Beach Center Family Quality of Life Scale • The CarerQol	• Family Dermatology Life Quality Index (FDLQI)	• Dermatitis Family Impact (DFI) • Parents' Index of Quality of Life in Atopic Dermatitis (PIQoL-AD) • Measure of quality of life in primary caregivers of children with atopic dermatitis (QPCAD) • Childhood Atopic Dermatitis Impact Scale (CADIS) • Atopic dermatitis Burden Scale – Family (ABS-F) • Psoriasis Family Index (PFI) • FamilyPso • Epidermolysis Bullosa Burden of Disease (EB-BoD) • Family Burden Ichthyosis (FBI) • Haemangioma Family Burden (HFB) • Family vitiligo impact scale • Erlanger Quality of Life questionnaire for Woundcare-Attached family members (ELWA)

to assess the degree to which family life is fulfilling and significant, along with the level of support from essential resources. Additionally, it explores the challenges families encounter. The survey consists of open and closed questions divided into 3 parts: an introduction of family members, an assessment of 9 different aspects of family life (family relationships, health, leisure and recreation, finances, careers, support from other people, support from institutions, influence of values, and community interaction), and an overall impression of family quality of life. While the questionnaire is time-consuming – it typically requires about an hour for completion – it offers a substantially more comprehensive understanding of the emotions, obstacles, and requisites experienced by family members compared to other tools available.

Family Strain Questionnaire – Short Form (FSQ-SF)

The Family Strain Questionnaire (FSQ) was introduced in 2004 by Rossi Ferrario *et al.* [10] as a valuable tool for comprehensive assessment of caregiver QoL, irrespective of the specific medical condition afflicting the adult patient. This instrument comprised a semi-structured clinical interview and 44 dichotomous questions organised into 5 distinct domains: emotional burden, problems in social involvement, need for knowledge about the disease, satisfaction with family relationships, and thoughts about death, alongside experiences of embarrassment or discomfort. Limitations of the FSQ included the requirement for a healthcare professional to conduct the interview and the considerable time needed for completion. Consequently, in 2010, Vidotto *et al.* [11] proposed a condensed version of the questionnaire, reducing the number of questions to 30 and eliminating the need for an interview. This modification resulted in the development of the Family Strain Questionnaire – Short Form (FSQ-SF), enabling caregivers to independently complete the assessment within 5 min. Despite its brevity, the FSQ-SF remains an effective and easily interpretable tool for monitoring caregivers' psychological well-being over time.

Revised Impact on Family Scale (IOF)

The Family Impact Scale was devised in 1978 by Stein and Riessman [12] as an instrument for evaluating the consequences of diverse chronic illnesses in children on their families. During the questionnaire development process, an extensive analysis of the literature and interviews with mothers and caregivers was conducted. This endeavour led to the identification of 4 impact dimensions: financial burden, family/social impact, personal strain, and mastery, all of which were linked to coping strategies. The original 24-item version remained in use until 2003, when Stein and Jessop [13] conducted a comprehensive analysis of its psychometric properties. This scrutiny led to a reduction in the number of questions to 15 and adjustments in scoring, enhancing the questionnaire's ease of use and reliability. Notably, questions regarding financial impact and impact on siblings were removed from the core version and organised into 2 supplementary sets for optional use. Importantly, subsequent revision of the tool demonstrated consistent characteristics across respondents' socioeconomic statuses and backgrounds, underscoring its universal applicability and broad utility [14].

Paediatric Quality of Life Inventory™ Family Impact Module (PedsQL™ Family Impact Module)

The PedsQL™ Family Impact Module serves as a valuable tool for evaluating the influence of chronic childhood diseases on parental quality of life and family dynamics. Developed by Varni *et al.* [15] through cognitive review sessions with parents and focus group discussions, the questionnaire comprises 36 items. Of these, 20 items concern Parents' Health-Related Quality of Life (HRQOL), evaluating the disease's impact on social, emotional, physical, and cognitive functioning. Additionally, 8 items assess family functioning within the context of daily activities and intra-family relationships, while the remaining items address communication and fears. Higher scores indicate enhanced family functioning. The module can be utilised independently or in conjunction with other PedsQL™ Measurement Model instruments to provide a comprehensive understanding of the patient's overall condition [16].

The Beach Center Family Quality of Life Scale

The Beach Center Family Quality of Life Scale, introduced by Hoffman *et al.* in 2005 [17], was developed to evaluate the immediate impact of family support and services on overall quality of life. Developed through qualitative investigations involving interviews and focus groups to understand families' perspectives on raising children and youths with disabilities, the scale was subsequently constructed within a statistical framework [18–20]. Analysis identified five key factors, resulting in the creation of a 25-item scale covering various dimensions of family quality of life: physical and material wellbeing, emotional wellbeing, family interaction, parenting, and disability-related support. This widely used questionnaire, particularly prevalent in research among parents of children with intellectual and neurological disorders, is applicable to any family member of a child with any health impairment. It functions as a reliable, genuine, and effective instrument for evaluating the influence of services on families [21].

The Care-related Quality of Life instrument (CarerQol)

The objective behind developing CarerQol was to provide a tool for estimating the impact of caring for

a chronically ill person in economic evaluations. To gain insight into the challenges faced by informal caregivers and their effect on happiness, Brouwer *et al.* [22] proposed a questionnaire comprising 2 parts: the CarerQol-7D and the CarerQol-VAS. Dimensions of care-related quality of life were determined following a review of existing caregiver burden measures. Each identified aspect of caregiver burden was integrated into one of 7 statements covering social, relational, mental health, financial, and physical dimensions, as well as received support and sense of fulfilment. Respondents evaluate these aspects relative to their life situation on one of 3 levels. Moreover, a visual analogue scale was included for caregivers to indicate their happiness level, ranging from 0 ('completely unhappy') to 10 points ('completely happy'). The resulting tool combines the simplicity of use with the informational density of a burden measure, making it a comprehensive assessment tool.

Dermatology-specific questionnaires

In recent years, various QoL questionnaires have been developed for carers, partners, and relatives of patients suffering from different dermatoses. Nevertheless, there remain numerous dermatoses for which dedicated assessment instruments have not yet been developed [18, 23, 24]. Moreover, numerous research endeavours aimed at comparing the QoL among family members of patients with various dermatoses necessitate a universal tool that transcends specific dermatological conditions. To the best of our knowledge, the Family Dermatology Life Quality Index (FDLQI) is the only available instrument in this group (Table 1).

Family Dermatology Life Quality Index (FDLQI)

The FDLQI, introduced by Basra *et al.* [23] in 2006, serves as an outcome measure for adult family members or partners of individuals with any dermatological condition. During its development, key aspects of quality of life were discerned through detailed semi-structured interviews with relatives and partners of patients. Subsequently, the most representative aspects were selected based on analysis of results obtained from the preliminary version of the instrument. Ultimately, a succinct and user-friendly 10-item questionnaire was devised, typically requiring about 3 min for completion. Respondents recall their experiences over a 1-month period when answering the questions, enabling the observation and exploration of changes over time. Responses are scored from 0 to 3 points for each question, with higher scores indicating greater impairment of the respondent's quality of life [25]. This questionnaire was prepared and validated for Polish patients by our group [26].

Disease-specific questionnaires

Dermatological diseases often entail specific challenges, such as intensive care requirements, lifestyle adjustments, or frequent medical consultations. Beyond directly affecting the patient's quality of life, these drawbacks also extend to their caregivers and family members. Recognising the distinct quality of life aspects tied to caring for individuals with specific dermatoses, disease-specific questionnaires have been devised to address these unique concerns. They are grouped in Tables 1 and 2.

Dermatitis Family Impact (DFI)

Lawson *et al.* [24] presented the DFI questionnaire in 1995 as the first tool designed to evaluate the impact of skin disease on family QoL. Tailored specifically to measure the influence of atopic dermatitis in children on the QoL of adult family members, the questionnaire underwent meticulous development. Using open interviews with minimal formal questioning, researchers engaged 61 participants from 34 families with children diagnosed with atopic dermatitis, enabling the identification of 11 pivotal problem areas. The final version of the questionnaire comprises 10 items, addressing lifestyle, expenditures, relationships, and both physical and men-

Table 2. Summary of disease-specific questionnaires among different skin diseases

Disease	Disease-specific questionnaires
Atopic dermatitis	Dermatitis Family Impact (DFI) Parents' Index of Quality of Life in Atopic Dermatitis (PIQoL-AD) Measure of quality of life in primary caregivers of children with atopic dermatitis (QPCAD) Childhood Atopic Dermatitis Impact Scale (CADIS) Atopic Dermatitis Burden Scale – Family (ABS-F)
Psoriasis	Psoriasis Family Index (PFI), FamilyPso
Epidermolysis bullosa	Epidermolysis Bullosa Burden of Disease (EB-BoD)
Ichthyosis	Family Burden Ichthyosis (FBI)
Haemangiomas	Haemangioma Family Burden (HFB)
Vitiligo	Family vitiligo impact scale
Chronic wounds	Erlanger Quality of Life questionnaire for Woundcare-Attached family members (ELWA)

tal well-being, with a one-week recall period. Responses are scored from 0 to 3 for each item, with higher scores indicating a greater impact of the disease on family life. Subsequent investigations into the psychometric properties of the tool revealed its responsiveness to change, rendering it valuable for assessing the efficacy of diverse interventions [27].

Parents' Index of Quality of Life in Atopic Dermatitis (PIQoL-AD)

The PIQoL-AD is a tool designed to evaluate the secondary impact of childhood atopic dermatitis on caregivers of affected children up to 8 years old. It originated from in-depth interviews with parents of children diagnosed with atopic dermatitis, and its development spanned multiple countries to minimise the influence of cultural differences on its content. Initially comprising 45 questions, some were excluded after thorough analysis. The final version, with 28 dichotomous items, was introduced by McKenna *et al.* in 2005 [28]. Clinical trials utilising the PIQoL-AD demonstrated its high level of measurement precision and its ability to differentiate between severity groups, indicating its potential usefulness in detecting improvements in quality of life associated with effective treatment [29, 30].

Measure of quality of life in primary caregivers of children with atopic dermatitis (QPCAD)

The QPCAD is a questionnaire developed in Japan by Kondo-Endo *et al.* [31] specifically to assess the impact of atopic dermatitis in children on the quality of life (QoL) of their primary caregivers. Derived from semi-structured interviews, the preliminary version consisted of 67 items covering various QoL issues over the past week across 7 categories. Following pilot testing and validation, 19 items were selected for the final version, categorised into domains such as 'exhaustion', 'worry about atopic dermatitis', 'family cooperation', and 'achievement'. Responses are provided on a 5-point scale, and the questionnaire can typically be completed in 1–2 min. Notably, 6 items out of the 19 address positive influences of atopic dermatitis on caregiver QoL, distinguishing it from other AD-specific questionnaires like the DFI and PIQoL-AD, which focus solely on the negative impact of the children's disease on family life. Responsiveness analysis indicated that the QPCAD is sensitive to improvements in disease severity to a sufficient extent. Additionally, an abbreviated version of the QPCAD, known as QP9, has been devised to lessen the load on respondents and promote the assessment of QoL in clinical settings [32].

Childhood Atopic Dermatitis Impact Scale (CADIS)

The CADIS was designed to assess the impact of atopic dermatitis on children aged 6 years or younger, as well as on their parents' QoL. Developed through an extensive review of published literature and direct interviews with families, along with consultations with medical experts [33], the questionnaire initially comprised 62 questions across 5 domains: child dimensions (symptoms and activity limitation/behaviour), and parent dimensions (family/social function, sleep, and emotions). In its final version introduced in 2005 by Chamlin *et al.* [34], the number of items was reduced to 45, with responses categorised into 5 frequency-based options reflecting parents' perceptions over the last 4 weeks. Notably, 17 items of the questionnaire were dedicated to assessing parents' emotions, highlighting the significance of this aspect. Additionally, subsequent assessments of the instrument have shown that the CADIS effectively captures changes in patients whose condition improves [35].

Atopic Dermatitis Burden Scale – Family (ABS-F)

The ABS-F is a self-administered questionnaire designed to assess the burden experienced by parents of children with atopic dermatitis. Developed by a working group under the leadership of Meni [36], the initial items of the instrument were formulated through a process involving literature review, feedback from parents of children with atopic dermatitis, and input from healthcare professionals. A total of 29 items were initially generated, with 14 deemed most relevant and retained in the final version. These items were categorised into 4 dimensions: family life, budget and work, daily life, and treatment. Responses to each item were scored on a scale from 0 to 3. The original version of the ABS was in French, with additional versions in English (US) and 6 other European languages simultaneously proposed by the author.

Psoriasis Family Index (PFI)

The PFI is a pioneering disease-specific tool designed by Eghlileb *et al.* [37] in 2006 to measure the quality of life (QoL) of family members of psoriasis patients. Originating from postal surveys and exhaustive qualitative interviews with family members and partners of patients, the conceptual framework of the questionnaire was built, elucidating significant secondary QoL concerns. A preliminary 20-item version of the tool was then developed through further analysis of the obtained results. Following initial psychometric evaluation, a final 15-question version was established, focusing on the respondent's perception of current life impairment. Each question was assessed using a 4-point scale ranging from 0 to 3, with higher overall PFI-15 scores reflecting a more significant influence on the quality of life of the respondent. The questionnaire exhibited notable correlations between its score, the severity of the disease quantified by the PASI, and the patients' QoL estimated by the DLQI. Subsequent evaluation indicated the questionnaire's ability to distinguish between clinical groups and its specificity

to the effects of psoriasis. After further validation, one question was eliminated, culminating in the publication and endorsement of the 14-item version of the questionnaire [38].

FamilyPso

Mrowietz *et al.* [39] introduced the FamilyPso in 2017, adopting a family-centric approach to assess the disease-specific burden on family members residing with psoriasis patients. The questionnaire's content was derived from interviews conducted with family members of patients and thorough research of existing literature. Following this, a panel of experts convened to deliberate on the identified concerns and developed the 29 items for the FamilyPso questionnaire. These items underwent preliminary psychometric assessment, resulting in the removal of certain questions based on low statistical agreement. Additionally, therapy-related questions were excluded due to their emphasis on treatment logistics rather than the impact of psoriasis. The ultimate version of FamilyPso consists of 15 items, each rated on a 5-point Likert scale, categorised into 3 domains: emotional, social, and leisure. FamilyPso also provides a total score, serving as a comprehensive measure of overall strain. Significantly, the instrument stands out for its particular emphasis on the emotional dimensions of coping with family members affected by psoriasis, addressing aspects such as the impact of psoriasis on sexual life and the necessity of explaining the disease to others. FamilyPso was originally developed in German and has been translated and validated into English.

Epidermolysis Bullosa Burden of Disease (EB-BoD)

Dufresne *et al.* [40] introduced the EB-BoD questionnaire in 2015 with the aim of providing a specific and informative measure of the disease's impact on families of patients. During the conceptual phase, alongside a literature review, discussions were held with 23 parents of children suffering from various epidermolysis bullosa variants to elucidate their challenges and dysfunctions associated with the disease. Major concerns identified by parents encompassed daily life, family dynamics, the child's well-being, the disease itself, treatment modalities, economic consequences, and social impact. At the outset, a total of 54 items were identified, of which 20 were selected and organised into 4 distinct domains: family dynamics, the child's well-being, the disease and its treatment, and economic and social impact. Each question was associated with responses indicating the degree to which a specific issue affects a particular family, measured on a 6-point Likert scale. The score acquired represents the burden of the disease, with a higher score indicating a more significant disruption to the family's quality of life. It was revealed that the questionnaire effectively captures distinctions arising from various clinical subtypes of EB. The original version of the tool was generated in French and subsequently translated, undergoing linguistic and cultural adaptation into US English.

Family Burden Ichthyosis (FBI)

The introduction of the FBI by a team led by Dufresne [41] in 2013 followed a systematic data collection process from July 2005 to December 2010, focusing on the experiences of patients with autosomal recessive congenital ichthyosis and the concerns expressed by them and their parents. From this data, 96 relevant issues were identified and condensed into 40 questions across 5 dimensions of QoL: family and personal relationships, psychological impact, pain, daily life, and work impact. Scores ranging from 0 to 3 were assigned to each response. During the validation phase, it was demonstrated that the total score exhibits a strong correlation with disease severity. Additionally, it encompasses aspects such as QoL, life organisation, integration within the community, and medical resource utilisation, thereby facilitating the assessment of various management strategies and their impact on mitigating the burden. Originally developed in French, the FBI questionnaire underwent adaptation for English usage following good practice standards.

Haemangioma Family Burden (HFB)

Throughout the development of the HFB, a thorough exploration of the literature and interviews with healthcare practitioners and parents of affected children uncovered significant issues. This led to the creation of the initial questionnaire, which comprised 36 questions grouped into 3 modules. The first module focused on assessing the daily burden experienced by the family (scored on a scale of 0–3 points), while the second module aimed to evaluate the severity of the disease's impact on the quality of life (scored as –1, 0, 1, 0), and the third module concerned the affected child's daily life (scored from 0 to 3 points). Following a pilot study, it was observed that questions in the third module predominantly reflected the patient's attitude rather than the impact on the family QoL. Consequently, these questions were removed entirely, while items in other modules were adjusted or reduced as necessary. The final version of the HFB comprised 20 questions organised into 5 categories: 'family life', 'relationships and work', 'emotions/feelings', 'psychological', and 'disease management'. Originally developed in French by Boccara *et al.* [42] in 2015, the questionnaire underwent translation and validation into Spanish, American English, and British English.

Family vitiligo impact scale

The Family Vitiligo Impact Scale was developed in India by a team led by Agrawal *et al.* [43], in 2020. The basis for generating questionnaire items was 23 detailed

semi-structured interviews with 8 family members of vitiligo patients. Based on this, 116 items were generated, from which experts created 32 questions for the initial version of the questionnaire after numerous analyses. The establishment of the final version of the tool was preceded by pilot testing involving a group of 30 relatives and partners of patients. The scale, consisting of 16 questions related to 12 domains of quality of life, was simultaneously published in Hindi and English, demonstrating excellent psychometric properties.

Erlanger Quality of Life questionnaire for Woundcare-Attached family members (ELWA)

Erlanger *et al.* [44] developed the ELWA questionnaire in 2019 as part of a project focusing on evaluating the QoL among caregivers of patients with chronic wounds. Recognising the relevance of chronic wounds across various professional fields beyond dermatology, the necessity for a disease-specific questionnaire was acknowledged. Guided by an interprofessional team, existing instruments were reviewed, and relevant questions were adapted to address wound-specific topics. The original questionnaire included 5 sections: gathering epidemiological data, self-evaluation regarding familiarity with the disease and its treatment, exploration of wound-related factors contributing to personal stress, evaluating provided statements regarding QoL, and additional space to include written comments. In total, the questionnaire comprised 48 items and underwent testing on a sample of 30 family members of patients in a pilot study. While further validation should be performed to evaluate its psychometric properties fully, the results obtained showed that the questionnaire could be a practical instrument for assessing the current status and tracking changes in the QoL of caregivers of patients with chronic wounds.

Discussion

According to the World Health Organisation definition, 'Health is a state of complete physical, mental, and social well-being and not merely the absence of disease or infirmity.' [45]. Nevertheless, for decades, the goal of treatment across medicine was to achieve remission of the illness or the greatest possible reduction of accompanying symptoms. However, the second half of the 20th century brought many changes to the health care system. The holistic model of medicine was gaining in popularity and began to gradually replace the approach focused exclusively on the results of instrumental or laboratory findings.

In 1966, Elkington [46] first considered the issue of quality of life (QoL) in medicine. In the following years, interest in this topic increased, especially among dermatologists, oncologists, and psychiatrists, which was reflected in the dynamically growing number of reports concerning the QoL in various diseases [47, 48].

With the development of medicine and the social sciences at the end of the 20th century, a new QoL problem was recognized. The aging of society and the extension of life expectancy resulted in the need to provide care for the elderly and chronically ill. It was then that the first studies on the burden of caregivers appeared. In their landmark publication Zarit *et al.* [49], based on the clinical experience and previous scientific reports, proposed the Zarit Burden Interview, which addressed the problems of the physical and psychological condition of caregivers, as well as financial issues, their social life, and relationships.

The first dermatology-specific measure designed to determine the impact of the disease on the family members of patients with atopic dermatitis was the Dermatitis Family Impact questionnaire [27]. Further exploration in this field in the following years resulted in the presentation of the "Greater Patient" concept by Basra and Finlay [2] in 2006 and subsequent creation of the Family Dermatology Life Quality Index [22]. To date, several tools have been developed that are used in various clinical situations and are intended for different respondents [50]. Over the years, existing questionnaires have been modified, translated, and validated, but they have not been widely used in clinical practice.

The presented review was intended to provide information on the usefulness of available tools for assessing the QoL of family members of patients with skin diseases. Since the psychosocial needs of this group are still inadequately understood and often ignored, this concern requires further exploration. Based on the "greater patient" concept, it should be noted that the patients and people around them mutually influence the quality of their lives [2]. Thus, following the holistic model of medicine, more attention should be paid not only to the QoL of patients but also to their family or partner. This implies an urgent need for clinicians to investigate how to use measures for assessing the QoL of family members to better recognise their needs and help in making informed decisions.

This review identified QoL assessment instruments suitable for various members of the close social group of dermatological patients. The presented measures are categorised into 3 sections: questionnaires for general use across medicine, questionnaires specific to dermatology, and questionnaires specific to particular diseases.

The selection of an appropriate measure depends on the intended purpose of evaluation, emphasising the importance of establishing the rationale for assessment initially. Other considerations include the psychometric properties of the questionnaire, potential methods of administration, and characteristics of the respondent group [51, 52]. Disease-specific questionnaires provide insights into issues, impairments, and difficulties particularly rel-

evant to family members of specific patients. However, unlike generic measures, the results obtained from these instruments are not conducive to comparing groups affected by different diseases [53]. Research evidence suggest that individuals providing care to family members with various health conditions experience comparable effects, thereby supporting the use of universal assessment tools [4]. Nonetheless, the detailed information garnered from disease-specific questionnaires appears to better reflect nuanced changes in QoL aspects over time and is less susceptible to confounding factors unrelated to the disease [54]. It is noteworthy that in validation processes, disease-specific questionnaires' results often exhibit strong correlations with generic questionnaire outcomes; therefore, these tools can be considered equally reliable. In many instances, integrating dermatology-specific and disease-specific instruments would represent the optimal strategy for obtaining a thorough understanding of the effects of a dermatological condition on family members [55].

The number of tools presented, as well as reports of ongoing projects to create new ones, underscores the growing awareness of the problem of the influence of a patient's disease on family QoL. The significance of this issue is confirmed by findings from various studies conducted among relatives of individuals with diverse dermatoses. A study in Spain revealed that merely a minor fraction (10.6%) of those cohabiting with acne patients reported no decline in their QoL, whereas more than half (51.5%) declared a significant QoL decrease [56]. Similarly, a study from Saudi Arabia disclosed that 91.5% of family members experienced QoL deterioration due to a relative or partner's vitiligo [57]. A comparable proportion of cohabitants in the United Kingdom acknowledged the impact of a family member's psoriasis on their QoL [55]. Furthermore, in a study conducted in Greece, over 96% of family members of patients with leg ulcers reported a large QoL impairment due to the illness of their loved one [58].

Undoubtedly, there is a correlation between the effects of chronic disease on the quality of life (QoL) of individuals within the patient's close social group and the nature of their relationships with one another. Studies conducted across various medical fields, involving partners of chronically ill individuals, demonstrate that the burden of caregiving significantly diminishes the quality of life, exacerbates anxiety and depression, disrupts social life, and adversely affects health [59]. Surprisingly, research involving partners of cancer patients revealed that their QoL was even lower than that of the affected spouses [58, 60]. These challenges stemmed from feelings of isolation, difficulties in fulfilling familial and household responsibilities, financial repercussions of the disease, and fears regarding the treatment process and the suffering of the partner [61].

A distinct aspect of quality of life for partners and spouses, which can be significantly compromised by the onset of skin conditions, is sexual satisfaction. Research has shown that in various diseases like hidradenitis suppurativa, chronic urticaria, or alopecia areata, partners often experience a decline in sexual satisfaction, leading to strain in the relationship [62–66].

It is also worth noting that there are often significant differences in the QoL between female and male partners, which stem from the social roles attributed to them. For example, women in relationships tend to experience greater stress related to household cleaning duties compared to men. This observation reflects traditional gender norms where women are predominantly tasked with domestic chores [40].

However, the positive impact of illness on a partner or spouse should not be overlooked. Research conducted among caregivers of dementia patients has shown that they perceive benefits such as personal growth, experiencing a sense of personal fulfilment and satisfaction, and improved relationship with their partner [67]. These positive experiences can enhance their well-being and can be associated with a decreased sense of burden [68, 69]. Understanding factors related to positive caregiving experiences is crucial for optimising interventions for caregivers. However, dermatologic questionnaires largely neglect positive aspects, thereby limiting insights into these issues.

Meanwhile, research on siblings of sick children has shown that growing up in a family burdened by another child's chronic illness can be a source of long-term developmental effects [70, 71]. Sometimes, the illness of a sibling contributes to a reduction in the time parents spend with the healthy child, and in particular cases, even their complete separation, for example, during the hospitalisation of the sick child [72]. Additionally, the family member's focus on fulfilling the specific needs of one child may lead to neglect or disregard for the needs of their healthy offspring [73]. As a result, the patient's brother or sister may experience jealousy, envy, or loneliness [74, 75]. Research indicates that there is also an increased risk of declining academic performance, difficulties in peer relationships, feelings of stress or anxiety, as well as introversion and problems internalisation among healthy siblings [71, 72]. It has been noted that a sibling's illness, as a source of parental stress, limitations, and changes in family functioning, can significantly lower the QoL of brothers and sisters [76]. Importantly, it has been shown that the impact of illness on the life of a patient's sibling is greatest shortly after diagnosis, but the quality of life of siblings stabilises over time [77]. The gender and age of siblings are significant factors, as it has been found that older sisters are more vulnerable to the negative impact of illness on their quality of life [78]. Research findings also suggest that diseases requiring repetitive treatment regimens implies less burden on the quality of life of siblings, probably due to a greater sense of control and stability arising from establishing medical routines [79].

As shown, chronic illness impacts the entire family unit, but when a child is ill, the greatest burden typically falls on the parents. They must deal not only with emotional aspects but also provide care, make decisions, and manage the whole family. They are responsible for the often time-consuming care of the child, administering medications, providing transportation, attending medical appointments, and adjusting diet and environment to meet the patient's needs. Such responsibilities result in many parents experiencing stress and anxiety, depression, feelings of being overwhelmed or helpless, fatigue, and difficulty concentrating [80–85]. For example, an Australian study conducted among 157 paediatric patients with psoriasis and their families found that only one reported no impact of the child's disease on the FDLQI. Meanwhile, in a study among families of adult patients with psoriasis, as many as 10% of respondents reported no impact of the family member's disease on their QoL [86]. Studies conducted among parents of children with atopic dermatitis revealed that parents face challenges in finding competent and willing caregivers for their children [33, 87, 88]. Consequently, they are more frequently absent from work or require adjustments to their work hours and professional duties to fulfil parental responsibilities, and their productivity at work may be reduced [2, 83, 89]. This can negatively impact the family's economic situation, while maintaining a sick child already involves significant costs associated with disease management [81, 83, 90].

Furthermore, caregivers of chronically ill children experience more limitations than other parents in spending leisure time away from their children, which adversely affects their social lives, friendships, and intimate relationships with partners [80, 87, 88]. It has been reported that parents of children with various skin diseases withdraw from social life, not only due to time constraints but also because of feelings of isolation, lack of understanding, and being unfairly criticised by relatives and society, or the need to avoid unwanted attention [33, 81, 83, 87–89, 91].

Lack of time and fatigue also sometimes contribute to the deterioration of relationships between parents [80, 88, 90, 92]. This phenomenon is often described among parents of children with atopic dermatitis, who, during disease flare-ups, often sleep with the child to prevent scratching during sleep, resulting in chronic sleep deprivation and lack of intimacy [2, 80, 89, 93–95]. Additionally, the need to make difficult decisions regarding treatment or parenting methods increases the risk of conflicts and differences of opinion between parents [94, 96]. In a study conducted among parents of children with various subtypes of epidermolysis bullosa, a significant proportion of parents reported that having a sick child negatively impacted their sexual life, with their relationship primarily revolving around caring for the child and managing disease-related concerns. In this group, frequent occurrences of divorce were noted, and many parents stated that the disease significantly contributed to the breakdown of their marriage [97]. Similarly, about one-third of divorced parents of children with atopic dermatitis acknowledged that the child's disease influenced their decision to separate, and one-third of single parents declared that due to the child's illness, they decided not to start romantic relationships [98].

In the case of genetically inherited diseases, a parent may also blame their partner or themselves for the child's disability [80, 87]. In such a situation, previous plans of having another child may change, fearing that the next child could also be affected by the disease [80, 87, 92, 98].

Blaming oneself for the child's suffering and the desire to compensate for the child's difficulties and stress affect the parenting style. Parents of chronically ill children often become overprotective, lenient, and unable to maintain discipline [89, 99].

Analyses conducted among families of children with atopic dermatitis and psoriasis have shown that the degree of impairment in parents' QoL depends on the severity of the disease, and a good response to treatment results in an improvement in the family's QoL [86, 91, 100–105]. At the same time, it is suspected that stress among parents causes an increase in inflammatory markers in both children with asthma and healthy children. Therefore, low QoL of parents may negatively impact the treatment process of patients [106, 107].

The family is a complex and delicate network of connections, with its members complementing and influencing each other. Difficulties experienced by the family affect all its members to varying degrees, and a problem faced by one member impacts the stability of the entire unit. Different individuals engage in the issues related to a relative's illness in various ways, but caregiving responsibilities are often largely delegated to one person. This additional burden, anxiety, and responsibility can lead to a significant reduction in QoL and even the development of somatic symptoms. Maintaining a high QoL life is crucial for providing good home care for the patient and contributes to better adherence to medical recommendations. Therefore, it is essential to incorporate the assessment of family QoL into standard practice.

Physicians providing care for a patient cannot resolve all family problems during brief office visits, but they should recognise these issues and offer appropriate support to the patient's relatives. This may include referring them for therapy to learn stress reduction techniques or coping strategies for anxiety, educational programs to gain knowledge to help manage the illness [18, 80, 108], or identifying social problems and directing them to government institutions or foundations that can provide financial support. Simply acknowledging the problem and showing concern for the family's situation can enhance the physician-patient and physician-caregiver relationships, positively affecting

the patient's compliance and attitude towards treatment. Moreover, understanding the family's situation can help the physician choose the most appropriate therapy by accurately assessing the likelihood of following recommendations, considering the family's lifestyle and resources [109].

QoL questionnaires can be valuable tools for physicians, improving communication and providing deeper insights into issues that might not spontaneously be disclosed by the patient's relatives. This attention increases satisfaction with healthcare and the feeling of being acknowledged and considered in the disease management process [43]. The advantage of standardised questionnaires is that, within the short time available during consultations, they allow for the review of various aspects of family members' lives while significantly reducing the discomfort respondents might feel regarding sensitive or intimate issues. The scoring system of these questionnaires also enables the assessment of changes over time between visits and the potential impact of interventions, thereby informing the physician about the effectiveness of different support strategies. However, the fixed structure of these tools carries the risk of overlooking or neglecting issues that are important to the individual. Therefore, physicians should always show empathy and encourage patients and their family members to share their thoughts about the disease and the challenges they face in everyday life. It is also important to remember that questionnaires undergo validation and cultural adaptation, and they may sometimes fail to address issues relevant to cultural minorities.

Previous studies have demonstrated that educational programs contribute to an improved QoL for families. Increasing knowledge about the disease and available coping strategies enhances the sense of empowerment and self-confidence, thereby reducing anxiety and feelings of helplessness. This improvement positively affects both the QoL of the patient's relatives and the quality of care provided. The beneficial effects of such educational programs for parents have been shown in studies involving families of patients with atopic dermatitis and epidermolysis bullosa [110].

Conclusions

Currently, dermatology is evolving to reduce hospitalisation rates and enhance the role of outpatient care in treating skin conditions. Consequently, more patients now rely on family members for support and care. However, these relatives often lack the necessary knowledge and skills, and having a loved one with a skin condition significantly disrupts their lives, presenting challenges across various aspects of their daily routines.

Therefore, it is essential for clinicians to enhance their understanding of the psychosocial implications of skin diseases, enabling them to recognise the challenges and needs of caregivers and family members, and to be familiar with available support resources and programs. There is an urgent need to acquaint physicians with existing QoL assessment tools and to promote their use in daily practice.

The presented summary reveals the absence of a perfect questionnaire to date, indicating the need for further updates of existing instruments and the development of new, more effective tools providing comprehensive insights into all aspects of patients' family members' QoL, while ensuring the best possible psychometric properties. Importantly, the creation of new tools should prioritise practicality and accessibility for both clinicians and respondents. This would promote broader utilisation in daily clinical practice, thereby expanding understanding of the secondary impacts of skin diseases and, ideally, facilitating the implementation of this knowledge into the development of support programs for family members of patients with chronic dermatoses.

Funding

SUBZ.C260.24.003.

Ethical approval

Not applicable.

Conflict of interest

The authors declare no conflict of interest.

References

1. Finlay AY. Quality of life assessments in dermatology. Semin Cutan Med Surg 1998; 17: 291-6.
2. Basra MKA, Finlay AY. The family impact of skin diseases: the greater patient concept. Br J Dermatol 2007; 156: 929-37.
3. Golics CJ, Basra MKA, Salek MS, Finlay AY. The impact of disease on family members: a critical aspect of medical care. J R Soc Med 2013; 106: 399-407.
4. Golics CJ, Basra MKA, Salek MS, Finlay AY. The impact of patients' chronic disease on family quality of life: an experience from 26 specialties. Int J Gen Med 2013; 6: 787-98.
5. Salek S, Finlay AY, Basra MKA, Golics CJ. The development and validation of the Family Reported Outcome Measure (FROM-16)© to assess the impact of disease on the partner or family member. Quality Life Res 2014; 23: 317-26.
6. Shah R, Finlay AY, Salek SM, et al. Meaning of Family Reported Outcome Measure (FROM-16) severity score bands: a cross-sectional online study in the UK BMJ Open 2023; 13: e066168.
7. Wójcik E, Reszke R, Otlewska A, et al. Family Reported Outcome Measure-16 (FROM-16): creation, reliability and reproducibility of the Polish language version. Acta Derm Venereol 2020; 100: adv00219.

8. Isaacs BJ, Brown I, Brown RI, et al. The International Family Quality of Life Project: Goals and Description of a Survey Tool. J Policy Pract Intell Disab 2007; 4: 177-85.
9. Brown I, Brown RI, Baum NT, et al. Family Quality of Life Survey: General Version. Toronto, ON, Canada: Surrey Place Centre 2006.
10. Rossi Ferrario S, Baiardi P, Zotti AM. Update on the Family Strain Questionnaire: a tool for the general screening of caregiving-related problems. Qual Life Res 2004; 13: 1425-34.
11. Vidotto G, Ferrario SR, Bond TG, Zotti AM. Family Strain Questionnaire – Short Form for nurses and general practitioners. J Clin Nurs 2010; 19: 275-83.
12. Stein REK, Riessman CK. The development of an Impact-on-Family Scale: preliminary findings. Med Care 1980; 18: 465-72.
13. Stein REK, Jessop DJ. The Impact on Family Scale revisited: further psychometric data. J Dev Behav Pediatr 2003; 24: 9-16.
14. Williams AR, Piamjariyakul U, Williams PD, et al. Validity of the revised Impact on Family (IOF) scale. J Pediatr 2006; 149: 257-61.
15. Varni JW, Seid M, Rode CA. The PedsQL: measurement model for the pediatric quality of life inventory. Med Care 1999; 37: 126-39.
16. Varni JW, Sherman SA, Burwinkle TM, et al. The PedsQL Family Impact Module: preliminary reliability and validity. Health Qual Life Outcomes 2004; 2: 55.
17. Hoffman L, Marquis J, Poston D, et al. Assessing family outcomes: psychometric evaluation of the Beach Center Family Quality of Life Scale. J Marriage Fam 2006; 68: 1069-83.
18. Park J, Hoffman L, Marquis J, et al. Toward assessing family outcomes of service delivery: validation of a family quality of life survey. J Intellect Disabil Res 2003; 47: 367-84.
19. Poston D, Turnbull A, Park J, et al. Family quality of life: a qualitative inquiry. Mental Retardation 2003; 41: 313-28.
20. Wang M, Turnbull AP, Summers JA, et al. Severity of disability and income as predictors of parents' satisfaction with their family quality of life during early childhood years. Res Pract Persons Sev Disabil 2004; 29: 82-94.
21. Summers JA, Poston DJ, Turnbull AP, et al. Conceptualizing and measuring family quality of life. J Intellect Disabil Res 2005; 49: 777-83.
22. Brouwer WB, van Exel NJ, van Gorp B, Redekop WK. The CarerQol instrument: a new instrument to measure care-related quality of life of informal caregivers for use in economic evaluations. Qual Life Res 2006; 15: 1005-21.
23. 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: 528-38.
24. Lawson V, Lewis-Jones MS, Finlay AY, et al. The family impact of childhood atopic dermatitis: the Dermatitis Family Impact Questionnaire. Br J Dermatol 1998; 138: 107-13.
25. Basra MKA, Edmunds O, Salek MS, Finlay AY. Measurement of family impact of skin disease: further validation of the Family Dermatology Life Quality Index (FDLQI). J Eur Acad Dermatol Venereol 2008; 22: 813-21.
26. Marciniak J, Reich A, Szepietowski J. The Family Dermatology Life Quality Index – formulation and validation of the Polish version. Forum Dermatologicum 2016; 2: 24-8.
27. Dodington SR, Basra MK, Finlay AY, Salek MS. The Dermatitis Family Impact questionnaire: a review of its measurement properties and clinical application. Br J Dermatol 2013; 169: 31-46.
28. McKenna SP, Whalley D, Dewar AL, et al. International development of the Parents' Index of Quality of Life in Atopic Dermatitis (PIQoL-AD). Qual Life Res 2005; 14: 231-41.
29. Meads DM, McKenna SP, Kahler K. The quality of life of parents of children with atopic dermatitis: interpretation of PIQoL-AD scores. Qual Life Res 2005; 14: 2235-45.
30. Whalley D, Huels J, McKenna SP, van Assche D. The benefit of pimecrolimus (Elidel, SDZ ASM 981) on parent's quality of life in the treatment of paediatric atopic dermatitis. Pediatrics 2002; 110: 1133-6.
31. Kondo-Endo K, Ohashi Y, Nakagawa H, et al. Development and validation of a questionnaire measuring quality of life in primary caregivers of children with atopic dermatitis (QPCAD). Br J Dermatol 2009; 161: 617-25.
32. Katsunuma T, Tan A, Ohya Y. [Short version of a quality-of-life questionnaire in primary caregivers of children with atopic dermatitis (QPCAD): development and validation of QP9]. Arerugi 2013; 62: 33-46.
33. Chamlin SL, Frieden IJ, Williams ML, Chren MM. Effects of atopic dermatitis on young American children and their families. Pediatrics 2004; 114: 607-11.
34. Chamlin SL, Cella D, Frieden IJ, et al. Development of the Childhood Atopic Dermatitis Impact Scale: initial validation of a quality-of-life measure for young children with atopic dermatitis and their families. J Invest Dermatol 2005; 125: 1106-11.
35. Chamlin SL, Lai JS, Cella D, et al. Childhood Atopic Dermatitis Impact Scale: reliability, discriminative and concurrent validity, and responsiveness. Arch Dermatol 2007; 143: 768-72.
36. Méni C, Bodemer C, Toulon A, et al. Atopic dermatitis burden scale: creation of a specific burden questionnaire for families. J Eur Acad Dermatol Venereol 2013; 27: 1426-32.
37. Eghlileb AM, Basra MK, Finlay AY. The psoriasis family index: preliminary results of validation of a quality of life instrument for family members of patients with psoriasis. Dermatology 2009; 219: 63-70.
38. Basra MK, Zammit AM, Kamudoni P, et al. PFI-14©: a rasch analysis refinement of the Psoriasis Family Index. Dermatology 2015; 231: 15-23.
39. Mrowietz U, Hartmann A, Weißmann W, Zschocke I. FamilyPso – a new questionnaire to assess the impact of psoriasis on partners and family of patients. J Eur Acad Dermatol Venereol 2017; 31: 127-34.
40. Dufresne H, Hadj-Rabia S, Taieb C, Bodemer C. Development and validation of an epidermolysis bullosa family/parental burden score. Br J Dermatol 2015; 173: 1405-10.
41. Dufresne H, Hadj-Rabia S, Méni C, et al. Family burden in inherited ichthyosis: creation of a specific questionnaire. Orphanet J Rare Dis 2013; 8: 28.
42. Boccara O, Méni C, Léauté-Labreze C, et al. Haemangioma family burden: creation of a specific questionnaire. Acta Derm Venereol 2015; 95: 78-82.
43. Agrawal S, Satapathy S, Gupta V, et al. Family vitiligo impact scale: a scale to measure the quality-of-life of family members of patients with vitiligo. Indian J Dermatol Venereol Leprol 2021; 88: 32-9.
44. Erfurt-Berge C, Ronicke M, Richter-Schmidinger T, et al. Quality of life assessment in family members of patients with chronic wounds. Eur J Dermatol 2019; 29: 484-9.
45. World Health Organization. WHO Constitution. Geneva WHO 1948.
46. Elkington JR. Medicine and the quality of life. Ann Intern Med 1966; 64: 711-4.
47. Albrecht GL. Subjective health assessment. In: Measuring Health and Medical Outcomes. Jenkinson C ed. UCL London 1994; 7–26.

48. The World Health Organization Quality of Life assessment (WHOQOL): position paper from the World Health Organization. Soc Sci Med 1995; 41: 1403-9.
49. Zarit SH, Reever KE, Bach-Peterson J. Relatives of the impaired elderly: correlates of feelings of burden. Gerontologist 1980; 20: 649-55.
50. Sampogna F, Finlay AY, Salek SS, et al.; European Academy of Dermatology and Venereology TaskForce on Quality of Life. Measuring the impact of dermatological conditions on family and caregivers: a review of dermatology-specific instruments. J Eur Acad Dermatol Venereol 2017; 31: 1429-39.
51. Guyatt GH, Feeny DH, Patrick DL. Measuring health related quality of life. Ann Intern Med 1993; 118: 622-9.
52. Lohr KN. Assessing health status and quality of life instruments: attributes and review criteria. Qual Life Res 2002; 11: 193-205.
53. Aaronson NK. Quantitative issues in health-related quality of life assessment. Health Policy 1988; 10: 217-30.
54. Wood-Dauphinee S. Assessing quality of life in clinical research. J Clin Epidemiol 1999; 52: 355-63.
55. Chernyshov PV, Kaliuzhna LD, Reznikova AA, Basra MK. Comparison of the impairment of family quality of life assessed by disease-specific and dermatology-specific instruments in children with atopic dermatitis. J Eur Acad Dermatol Venereol 2015; 29: 1221-4.
56. Martínez-García E, Arias-Santiago S, Herrera-Acosta E, et al. Quality of life of cohabitants of people living with acne. Acta Derm Venereol 2020; 100: adv00290.
57. Bin Saif GA, Al-Balbeesi AO, Binshabaib R, et al. Quality of life in family members of vitiligo patients: a questionnaire study in Saudi Arabia. Am J Clin Dermatol 2013; 14: 489-95.
58. Kouris A, Christodoulou C, Efstathiou V, et al. Quality of life in Greek family members living with leg ulcer patients. Wound Repair Regen 2015; 23: 778-80.
59. Jones DA, Peters TJ. Caring for elderly dependants: effects on the carer's quality of life. Age Ageing 1992; 21: 421-8.
60. Eghlileb AM, Davies EE, Finlay AY. Psoriasis has a major secondary impact on the lives of family members and partners. Br J Dermatol 2007; 156: 1245-50.
61. Kornblith AB, Herr HW, Ofman US, et al. Quality of life of patients with prostate cancer and their spouses. Cancer 1994; 73: 2791-802.
62. Axelsson B, Sjoden P. Quality of life of cancer patients and their spouses in palliative home care. Pall Med 1998; 12: 29-39.
63. Rees J, O'Boyle C, MacDonagh R. Quality of life: impact of chronic illness on the partner. J R Soc Med 2001; 94: 563-6.
64. Włodarek K, Głowaczewska A, Matusiak Ł, Szepietowski JC. Psychosocial burden of hidradenitis suppurativa patients' partners. J Eur Acad Dermatol Venereol 2020; 34: 1822-7.
65. Sánchez-Díaz M, Salazar-Nievas MC, Molina-Leyva A, Arias-Santiago S. The burden on cohabitants of patients with chronic spontaneous urticaria: a cross-sectional study. J Clin Med 2022; 11: 3228.
66. Sánchez-Díaz M, Díaz-Calvillo P, Ureña-Paniego CA, et al. Quality of life and mood status disturbances in cohabitants of patients with alopecia areata: a cross-sectional study in a Spanish population. Int J Environ Res Public Health 2022; 19: 16323.
67. Yu DSF, Cheng ST, Wang J. Unravelling positive aspects of caregiving in dementia: an integrative review of research literature. Int J Nurs Stud 2018; 79: 1-26.
68. Rapp SR, Chao D. Appraisals of strain and of gain: effects on psychological wellbeing of caregivers of dementia patients. Aging Ment Health 2000; 4: 142-7.
69. Quinn C, Toms G. Influence of positive aspects of dementia caregiving on caregivers' well-being: a systematic review. Gerontologist 2019; 59: e584-96.
70. Vermaes IP, van Susante AM, van Bakel HJ. Psychological functioning of siblings in families of children with chronic health conditions: a meta-analysis. J Pediatr Psychol 2012; 37: 166-84.
71. Gan LL, Lum A, Wakefield CE, et al. School experiences of siblings of children with chronic illness: a systematic literature review. J Pediatr Nurs 2017; 33: 23-32.
72. Pilowsky T, Yirmiya N, Doppelt O, et al. Social and emotional adjustment of siblings of children with autism. J Child Psychol Psychiatry 2004; 45: 855-65.
73. Opperman S, Alant E. The coping responses of the adolescent siblings of children with severe disabilities. Disabil Rehabil 2003; 25: 441-54.
74. Knecht C, Hellmers C, Metzing S. The perspective of siblings of children with chronic illness: a literature review. J Pediatr Nurs 2015; 30: 102-16.
75. Lapidus CS, Kerr PE. Social impact of atopic dermatitis. Med Health RI 2001; 84: 294-5.
76. O'Brien I, Duffy A, Nicholl H. Impact of childhood chronic illnesses on siblings: a literature review. Br J Nurs 2009; 18: 1358-65.
77. Alderfer MA, Long KA, Lown EA, et al. Psychosocial adjustment of siblings of children with cancer: a systematic review. Psycho-Oncology 2010; 19: 789-805.
78. Houtzager BA, Grootenhuis MA, Last BF. Supportive groups for siblings of pediatric oncology patients: impact on anxiety. Psycho-Oncology 2001; 10: 315-24.
79. Havermans T, Croock ID, Vercruysse T, et al. Belgian siblings of children with a chronic illness. J Child Health Care 2013; 19: 154-66.
80. Yang EJ, Beck KM, Sekhon S, et al. The impact of pediatric atopic dermatitis on families: a review. Pediatr Dermatol 2019; 36: 66-71.
81. Caicedo C. Families with special needs children. J Am Psych Nurses Assoc 2014; 20: 398-407.
82. Lin VW. Tough-skinned kids: identifying psychosocial effects of psoriasis and helping pediatric patients and families cope. J Pediatr Nurs 2012; 27: 563-72.
83. Neri I, Galli E, Baiardini I, et al. Implications of Atopic Dermatitis on the Quality of Life of 6-11 Years Old Children and Caregivers (PEDI-BURDEN). J Asthma Allergy 2023; 16: 383-96.
84. Pauli-Pott U, Darui A, Beckmann D. Infants with atopic dermatitis: maternal hopelessness, child-rearing attitudes and perceived infant temperament. Psychother Psychosom 1999; 68: 39-45.
85. Lewis-Jones S. Quality of life and childhood atopic dermatitis: the misery of living with childhood eczema. J Clin Pract 2006; 60: 984-92.
86. Kim E, Fischer G. Relationship between PASI and FDLQI in paediatric psoriasis, and treatments used in daily clinical practice. Austral J Dermatol 2021; 62: 190-4.
87. Elliott BE, Luker K. The experiences of mothers caring for a child with severe atopic eczema. J Clin Nurs 1997; 6: 241-7.
88. Lawson V, Lewis-Jones MS, Finlay AY, et al. The family impact of childhood atopic dermatitis: the Dermatitis Family Impact Questionnaire. Br J Dermatol 1998; 138: 107-13.
89. Ezzedine K, Shourick J, Merhand S, et al. Impact of atopic dermatitis in adolescents and their parents: a French study. Acta Derm Venereol 2020; 100: adv00294.

90. Su JC, Kemp AS, Varigos GA, et al. Atopic eczema: its impact on the family and financial cost. Arch Dis Child 1997; 76: 159-62.
91. Ju HJ, Seo JM, Kim SH, et al. Quality of life in parents of children and adolescents with vitiligo: a qualitative study. Ann Dermatol 2023; 35: 472-5.
92. Fine JD, Johnson LB, Weiner M, Suchindran C. Impact of inherited epidermolysis bullosa on parental interpersonal relationships, marital status and family size. Br J Dermatol 2005; 152: 1009-14.
93. Reid P, Lewis-Jones MS. Sleep difficulties and their management in preschoolers with atopic eczema. Clin Exp Dermatol 1995; 20: 38-41.
94. Koblenzer CS, Koblenzer PJ. Chronic intractable atopic eczema. Its occurrence as a physical sign of impaired parent-child relationships and psychologic developmental arrest: improvement through parent insight and education. Arch Dermatol 1988; 124: 1673-7.
95. McCann D, Bull R, Winzenberg T. Sleep deprivation in parents caring for children with complex needs at home: a mixed methods systematic review. J Fam Nurs 2015; 21: 86-118.
96. Germo GR, Chang ES, Keller MA, et al. Child sleep arrangements and family life: perspectives from mothers and fathers. Infant Child Dev 2007; 16: 433-56.
97. Fine JD, Johnson LB, Weiner M, Suchindran C. Impact of inherited epidermolysis bullosa on parental interpersonal relationships, marital status and family size. Br J Dermatol 2005; 152: 1009-14.
98. Capozza K, Schwartz A, Lang JE, et al. Impact of childhood atopic dermatitis on life decisions for caregivers and families. J Eur Acad Dermatol Venereol 2022; 36: e451-4.
99. Daud LR, Garralda ME, David TJ. Psychosocial adjustment in preschool children with atopic eczema. Arch Dis Child 1993; 69: 670-6.
100. Chernyshov PV, Ho RC, Monti F, et al. An international multi-center study on self-assessed and family quality of life in children with atopic dermatitis. Acta Dermatovenerol Croat 2015; 23: 247-53.
101. Jang HJ, Hwang S, Ahn Y, et al. Family quality of life among families of children with atopic dermatitis. Asia Pac Allergy 2016; 6: 213-9.
102. Marciniak J, Reich A, Szepietowski JC. Quality of life of parents of children with atopic dermatitis. Acta Derm Venereol 2017; 97: 711-4.
103. Balkrishnan R, Housman TS, Carroll C, et al. Disease severity and associated family impact in childhood atopic dermatitis. Arch Dis Child 2003; 88: 423-7.
104. Pustisek N, Vurnek Zivkovic M, Situm M. Quality of life in families with children with atopic dermatitis. Pediatr Dermatol 2016; 33: 28-32.
105. Whalley D, Huels J, McKenna SP, et al. The benefit of pimecrolimus (Elidel, SDZ ASM 981) on parents' quality of life in the treatment of pediatric atopic dermatitis. Pediatrics 2002; 110: 1133-6.
106. Wolf JM, Miller GE, Chen E. Parent psychological states predict changes in inflammatory markers in children with asthma and healthy children. Brain Behav Immun 2008; 22: 433-41.
107. Buske-Kirschbaum A. Treating the parents to heal the child? Brain Behav Immunity 2008; 22: 431-2.
108. Adelman RD, Tmanova LL, Delgado D, et al. Caregiver burden. JAMA 2014; 311: 1052.
109. 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: 490-5.
110. Muzzolon M, Imoto RR, Canato M, et al. Educational intervention and atopic dermatitis: impact on quality of life and treatment. Asia Pac Allergy 2021; 11: e21.