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The Burden of Pediatric Psoriasis: A Systematic Review

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Abstract

Background The approach to pediatric psoriasis requires special considerations, given the potential for negative consequences on overall physical and psychosocial health.

Objective The aim of this study was to systematically review the literature to characterize the burden of pediatric psoriasis.

Methods Papers assessing associations between pediatric psoriasis (in children <18 years old) and quality of life, physical symptoms (e.g., skin pain, itch, sleep disruption), and adverse psychological, social, and financial effects were searched with no date restrictions through July 2023. Databases searched included Ovid MEDLINE[®], CENTRAL, the Cochrane Database of Systematic Reviews, and PsycInfo. Articles were excluded if they focused on comorbidities (including psoriatic arthritis/enthesitis), were of low quality, or were not in English.

Results 64 publications met eligibility criteria. Composite quality of life was the most frequently reported domain (40 publications) and was negatively impacted by psoriasis as a function of severity. Physical burdens, especially itch, occurred in 44.1–96.3% of children with psoriasis, while skin pain was less common. Psychosocial and family burdens were less frequently assessed and often with non-validated tools. Children with psoriasis participated less in social activities, but there were no clear associations between psoriasis and school performance or interpersonal relationships. Psoriasis was associated with a higher mental health burden on caregivers and greater family financial burden.

Conclusions Psoriasis leads to high burden for pediatric patients and caregivers. Evaluation and management decisions should include and incorporate a thorough assessment of burden. Additional studies using validated tools are necessary to fully assess psychosocial and family burdens of psoriasis.

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Key Points

Psoriasis is associated with a decreased quality of life and burdensome physical symptoms in pediatric patients, along with financial and mental health burdens in patients' caregivers and families.

Future studies using validated, easily interpreted tools would be useful in assessing psychosocial and family burdens.

1 Introduction

The prevalence of psoriasis in children ranges from 0.1% to 1% of the pediatric population [1–4], with 64% of cases beginning during adolescence [5] and up to 19% with moderate-to-severe disease [2, 6, 7]. Pre-adolescence and

adolescence are critical periods for psychosocial development. Chronic illness is recognized to negatively impact educational, behavioral, psychological, and quality of life (QoL) metrics in children [8, 9], as well as the risk of depression and anxiety in adulthood [10]. Children with psoriasis have more facial and scalp involvement than adults, increasing disease visibility [6] and potential stigma [2, 6, 7]. In addition, 61% experience itch, with 72% of patients with moderate-to-severe psoriasis having at least moderate itch based on the Peak Pruritus (Itch) Numeric Rating Scale score [11, 12], while 39% complain of skin pain [12]. Embarrassment and discomfort may reduce participation in sports.

Children with psoriasis show QoL impacts comparable to other chronic diseases. In one study, the mean Children's Life Quality Index for children and adolescents with psoriasis was 9.6, worse than the score for children with diabetes and epilepsy [13]. In addition, Children's Dermatology Life Quality Index (CDLQI) scores in this same study showed children with psoriasis had levels of impairment comparable to atopic dermatitis (9.14 vs 9.17, respectively), a moderate impact [13]. In a recent cross-sectional study of children with chronic skin diseases, including 123 children and adolescents with psoriasis, stigma correlated with poor QoL, depression, and anxiety. Stigma T scores in children with psoriasis were similar to those of both atopic dermatitis and alopecia (44.0, 44.4, and 44.2, respectively, with an overall mean for children with chronic skin disorders of 43.8) [14]. Bullying and stigmatization have been reported in 50% and 65%, respectively, of school-aged children with mild psoriasis [15].

Chronic diseases can reduce the QoL of family members, particularly caregivers [16]. The chronic nature of psoriasis, need for frequent office visits, and cost of therapies can impose substantial financial burdens. Caregivers in the US have higher rates of psychiatric disorders, including anxiety and depression, than the general population [17, 18]. However, the burdens on overall QoL and physical, psychological, and social impacts of pediatric psoriasis, including on the family, have not been analyzed systematically. We critically evaluated the literature to probe the association between pediatric psoriasis and QoL, burdensome physical symptoms, psychological conditions, aspects of social well-being and functioning, and the adverse social, psychological, and financial effects on the family.

2 Materials and Methods

2.1 Topic Development and Refinement

The methods and scope for this review were developed and refined with guidance from a pediatric psoriasis working group of the International Psoriasis Council. The

initial search was conducted with no search date restrictions through June 2022 by a team at Oregon Health Sciences University (OHSU) and subsequently amplified and extended to July 2023 by a team at Northwestern University (NU). Ovid MEDLINE®, the Cochrane Central Register of Controlled Trials, the Cochrane Database of Systematic Reviews, and PsycInfo databases were searched for relevant English language primary studies and systematic reviews. Search terms and search strategies are included in the Supplementary Information (see electronic supplementary material [ESM]). Reference lists of primary articles were also reviewed.

Using an explicit list of inclusion/exclusion criteria based on key questions and the Populations, Interventions, Comparators, Outcomes, Timing, Settings/Study (PICOTS) design (Supplementary Table 1, see ESM) [19], each title and abstract identified through the search, and then full-text articles for each, were reviewed independently by two team members and assessed for eligibility. Systematic reviews were used to identify additional primary studies. To assure adequate agreement regarding eligibility, initial disagreements between reviewers were resolved by discussion and consensus and were adjudicated by a third reviewer if needed. All results were tracked in EndNote®, including the reasons for exclusion of full-text publications. Given a discovered paucity of evidence, we included studies of any design that provided baseline prevalence information on the burdens of interest. Randomized trials and observational studies in which relevant burden factors were not defined as incident outcomes of the study were included if applicable, solely for their baseline data; their results data were outside the scope of this review and therefore not abstracted. If applicable, a 'best evidence approach' [20, 21] was used to make final inclusion determinations for each key question. Studies of lower quality or directness were included when studies of higher quality and/or studies that used preferred methods were lacking.

2.2 Data Abstraction and Risk of Bias/Quality Assessment

Supplementary Table 2 summarizes the various instruments used in studies (see ESM). The quality of individual studies was assessed by two team members (BC and AY) using the Oxford Centre for Evidence-Based Medicine: Levels of Evidence scoring tool as level of evidence (1a through 5) and grade of recommendation (A through D) [22]. Cross-sectional studies, the majority, were classified as case-controls (level 3b), given that they represent a single time point in contrast with cohort studies (level 2b) and are not otherwise categorized through the Oxford Levels of Evidence tool. However, these cross-sectional studies were often large and always prospective, despite their assigned level. Disagreements between reviewers were resolved by

discussion and consensus and, if necessary, adjudication by a third reviewer (AP).

3 Results

In total, 855 publications were identified and 375 eligible for full-text review, of which 64 met inclusion criteria (Fig. 1; Supplementary Table 1, see ESM). Among these papers, demographic data and the tools used to determine psoriasis severity and disease burden were highly variable. Tables 1, 2, 3, 4, and 5 summarize the key findings about each domain probed, while Supplementary Tables 3–7 provide details from individual studies and provide levels of evidence. All reported data were abstracted from original papers.

3.1 Quality-of-Life Burden

QoL was the most studied burden, with 40 articles (Table 1, Supplementary Table 3, see ESM). Psoriasis in pediatric patients negatively influences QoL, and in many cases, correlates with severity measures such as Psoriasis Area and Severity Index (PASI) (range, $\rho = 0.382$ [weak] to 0.653 [strong]) [11, 13, 15, 16, 23–39]. In one study, CDLQI scores in children with psoriasis were worse than other chronic skin diseases, including (in descending order of scores) atopic dermatitis, urticaria, acne, alopecia, pigmentary abnormalities, nevi, and vascular anomalies [13].

3.2 Physical Burden

While arthritis is a known comorbidity of psoriasis with impact on physical function, our focus was on data specifically related to skin-specific itch, pain, and sleep disruption (Table 2, Supplementary Table 4, see ESM). Of the 30 articles included, 29 were observational studies and one was a clinical trial. Twenty-one studies evaluated itch in children with psoriasis. Eight studies reported only the presence or absence of itch among subjects (44.1–96.3%) [40–47]. In three studies using a (0–10 range) Numerical Rating Scale (NRS) or Visual Analog Scale (VAS) to measure itch severity, moderate itch was noted (4.89–6.61) across mean PASI scores ranging from 4.78 to 19.8 [11, 48–51]. In a study of severe psoriasis (median PASI: 24), 83% of subjects reported itch [52]. Overall, itch is a common symptom associated with psoriasis, the intensity of which may correlate with disease severity [26, 31, 48, 49, 52–55]. Eight studies measured sleep disruption using the non-validated CDLQI sleep subscale, reporting low scores. Patients in these studies predominantly had mild disease (PASI: 1.8–7.0) [23, 25, 27, 52, 56–60]. Psoriasis-related itch had an inconsistent influence on sleep, disturbing sleep in roughly 9% to 45% of psoriasis patients who reported itch [42, 44, 54]. When parents of

children aged 2–18 years were interviewed using the Pittsburgh Sleep Quality Index (PSQI), no sleep differences were noted for parents of patients with psoriasis overall compared with healthy, age-matched controls or mild versus moderate-to-severe disease (based on the requirement for phototherapy, systemic medication, or hospitalization) [61]; moderate-to-severe psoriasis versus controls was not evaluated. Four studies described genital region skin or specifically vulvar pain associated with pediatric psoriasis, generally linking the level of pain to the severity of the psoriasis [43, 46, 47, 62].

3.3 Psychological Burden

All studies were evidence level 3b (Table 3, Supplementary Table 5, see ESM). Five database studies found that the prevalence of depression and depressive episodes, as well as the incidence of depression, were significantly higher in children with psoriasis compared with those without [18, 63–66]. The largest was a cross-sectional database study with 7404 psoriasis patients that found an increased risk of depression in comparison with pediatric patients without psoriasis based on incidence (3.01% vs 2.42%; $p = 0.0036$) and time to depression diagnosis (hazard ratio 1.25; $p = 0.0053$) [18]. One study ($n = 61$) found the prevalence of depression in children with psoriasis to be 6.6% [67]. Direct screening for depression using the Children's Depression Inventory (CDI) showed a higher score for the 22 children with psoriasis (8–12 years old) versus age-matched healthy controls. In contrast, the 26 adolescents (13–18 years old) with psoriasis in the same study did not show a higher risk of depression than their age-matched controls [68], despite higher mean PASI scores (9.8 for adolescents vs 6.4 for the children). Two other studies [59, 69] found no association of pediatric psoriasis with depression. These three studies varied in their participant baseline characteristics (including disease severity) and utilized different statistical methods.

Odds ratios (ORs) for anxiety were greater in pediatric psoriasis patients compared with healthy controls in three large database studies [18, 65, 66]. One study used first prescription for psychotropic medication as a proxy for psychiatric disorders, as these disorders may be underdiagnosed in children; children with psoriasis received more psychotropic prescriptions (4.1% for psoriasis vs 1.5% for children without psoriasis) and had shorter time to first prescription than non-psoriasis controls (HR 2.44) [18]. Another study used ICD-10 codes to identify all anxiety-related disorders in Israeli Defense Forces recruits (all 16- to 18-year-olds) prior to military service (generalized anxiety disorder, phobias, and obsessive-compulsive disorder) with an OR of 2.02 for the overall psoriasis versus non-psoriasis cohort (OR 1.40 for mild psoriasis; OR 2.91 for moderate-severe cases) [66]. The third database study, sourced from the National Inpatient Sample, includes 20% of all US inpatient admissions

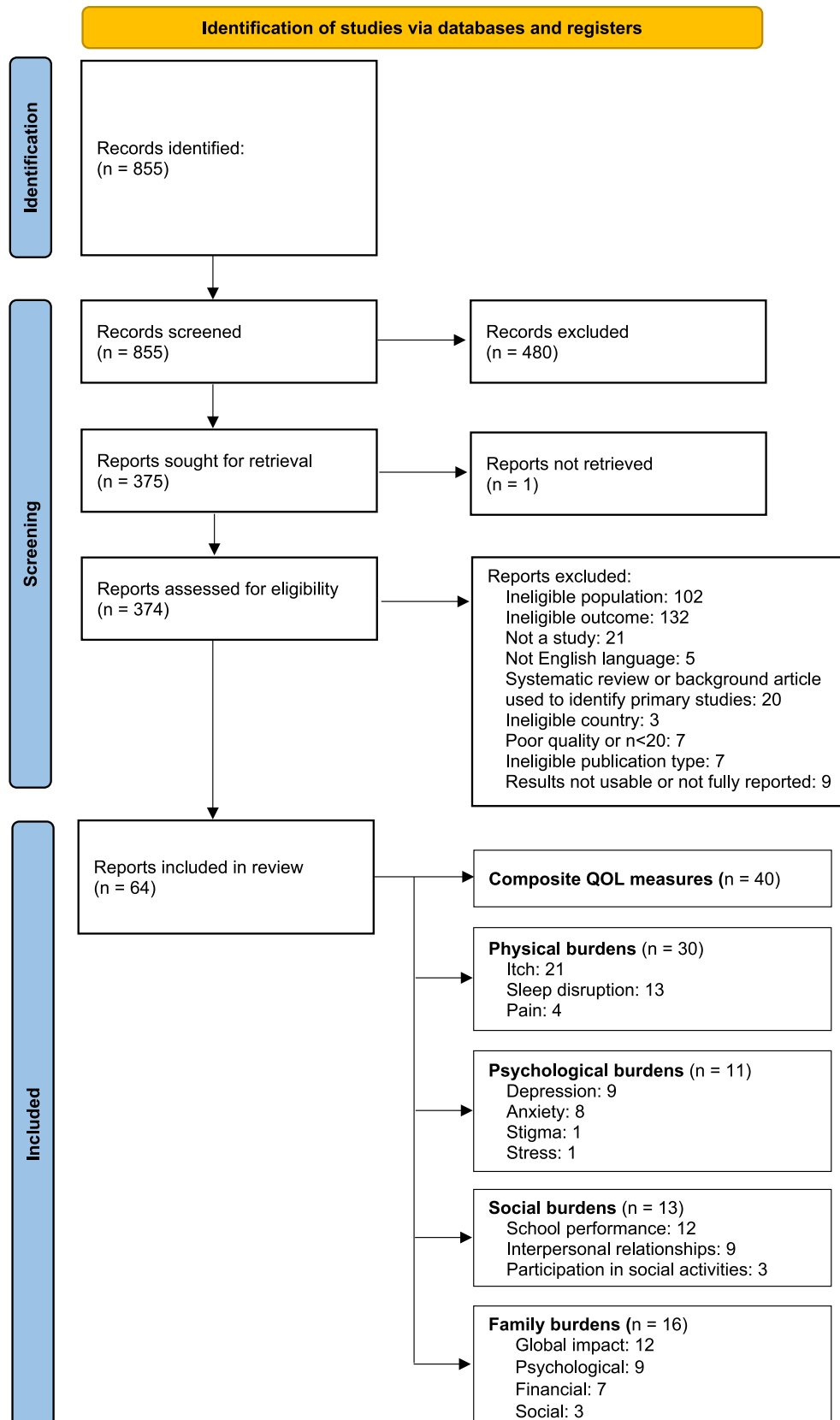


Fig. 1 Flow diagram of systematic literature review. The sum of articles included in the five domains may be greater than the total, given that individual articles may address multiple domains or subdomains

Table 1 Summary of quality of life burden in children and adolescents with psoriasis (see Suppl. Table 3 in the ESM for details)

Evidence type and comments	Key findings
Comparison with healthy controls Worse QoL	One study ($n = 94$) compared QoL between children with Pso and healthy controls using the PedQL [68]: – Children: PedQL-Parent, not PedQL-Child lower in Pso than controls ($p < 0.01$) – Adolescents: no significant differences in PedQL-Parent or PedQL-Child Another study ($n = 48$) used the CDLQI (out of 30, higher is worse) to compare Pso and controls [60]: – Median (range), Pso vs controls: 5.0 (0.0–14.0) vs 2.0 (0.0–10.0)
Comparison with other diseases Worse QoL than vitiligo and overall pediatric skin disease Worse if Pso with musculoskeletal pain	CDLQI to compare QoL between Pso and other skin diseases ($n = 29$) [13]: – Mean, Pso vs other skin disease: 9.17 vs 5.45 Children with Pso ($n = 25$): 2.7 times more likely to have CDLQI ≥ 6 , compared with vitiligo [57, 58] QoL in children with Pso with no pain vs Pso with musculoskeletal pain ($n = 43$) [79]: – CDLQI, median (range): 1 (0–13) vs with musculoskeletal pain, 6 (1–21); $p < 0.001$ • PedsQL, median (range) (out of 100, higher is better): 85 (64–100) vs 70 (11–94); $p < 0.001$
Association with severity Poor QoL is moderately to strongly associated with disease severity in most studies, but there is variability	10 studies assessed the correlation between QoL and disease severity: – Correlation strength for studies that used the CDLQI ranged from weak to strong: • CDLQI correlation with PASI: $\rho = 0.471$, $p < 0.001$ ($n = 50$) [27]; strength NR, $p < 0.001$ ($n = 110$) [28]; 0.47 , $p = 0.003$ ($n = 39$) [15]; $r = 0.653$, $p < 0.001$ ($n = 40$) [24]; $r = 0.48$, $p = 0.00$ ($n = 125$) [25]; $r = 0.382$, $p < 0.001$ ($n = 255$) [23] • CDLQI correlation with BSA: $r = 0.428$, $p < 0.001$ ($n = 25$) [57, 58] – One study ($n = 208$): PedsQL very weakly correlated with PASI: $r = -0.13$, $p = \text{NR}$ [78] – One study of scalp Pso severity (correlation strength NR, $n = 94$) [29] • CDLQI and Parent Global Assessment Scalp: $p = 0.004$ • CDLQI and Physician Global Assessment Scalp: $p = 0.05$ – One study ($n = 94$): PedQL-C or PedQL-P did not correlate with disease severity, except when using PedQL-P in adolescents: $r = -0.51$, $p \leq 0.01$ [68] Two studies: generally, stratified CDLQI scores increased/worsened with greater severity: – CDLQI per severity category, median (IQR) ($n = 319$) [56]: • PASI = 0.0–4.9 ($n = 126$): CDLQI 6.0 (6.0), 0–25 • PASI = 5.0–9.9 ($n = 143$): CDLQI 8.0 (7.0), 0–23 • PASI ≥ 10.0 ($n = 49$): CDLQI 9.0 (7.0), 2–22 – CDLQI, mean (SD), by PASI score ($n = 40$) [24]: • PASI score 0–7.5 ($n = 19$): CDLQI 6.3 (7.4) • PASI score 7.5–15 ($n = 14$): CDLQI 8.9 (7.2) • PASI score 15–22.5 ($n = 5$): CDLQI 17.9 (9.5) • PASI score 22.5–30 ($n = 2$): CDLQI 26.4 (8.2)
No control group/comparisons Most of populations of children with Pso have moderate to large impact on QoL	25 studies (n ranging from 25 to 448) reported CDLQI scores for entire study cohort (out of 30, higher is worse), although disease severity in the subject included in each study varied greatly: – CDLQI, mean (SD): 11.2 (5.4) [30], 7.5 (4.0) [27], 4.20 (3.73) [28], 5.05 (5.0) [26], 9.9 (6.7) [32], 8.75 (7.14) [81], 9.6 (6.5) [33, 34], 5.4 (5.0) [71], 18.87 (8.15) [24], 7.5 (5.0) [25], 8.1 (5.3) [11, 50, 51], 8.1 (5.69) [36], 7.6 (6.1) [23], 6.61 (5.74) [76], 11.2 (6.3) [52] – CDLQI, median (range): 1 (0–17) [69], 7.0 (0–25) [56], 9.0 (2.0–20.0) [37], 4.0 (0–23) [38] – CDLQI, median (IQR): 7 (5.0–11) [77], 6 (5–9) [15], 7 (3–14.5) [57, 58], 5 (2–8.25) [59], 5.5 (3.0–9.0) [62] Two studies reported CDLQI scores stratified by effect significance*: – No effect 46.4%, small 33.9%, moderate 10.7%, large 8.9%, extremely large 0% ($n = 69$) [31] – No effect 17%, small 47%, moderate 24%, large 8.6%, extremely large 3.4% ($n = 58$) [59] Four studies reported DLQI scores (out of 30, higher is worse): – Median (IQR): 8 (6.0–11.8) ($n = 448$) [77] – Mean (SD): 9.7 (4.9) ($n = 134$) [32], 9.4 (4.9) ($n = 171$) [11, 50, 51], 5.41 (5.20) ($n = 56$) [76] One study ($n = 45$) reported IDQOL scores for affected infants (out of 30, higher is worse): – Mean (SD): 6.0 (5.3) [26] Three studies did not differentiate reported combined CDLQI and DLQI scores: – Mean (SD): 8.4 (4.8) ($n = 120$) [49], 8.1 (4.9) ($n = 65$) [16] – Mean (SD): all, 8.16 (4.85); girls, 7.74 (4.81); boys, 9.07 (4.98) ($n = 45$) [39] Four studies used other QoL measures: – KINDL-R (out of 100, higher is better), mean (95% CI): 69.85 (67.28–72.41) ($n = 108$) [75] – CSP, median (IQR) (out of 100, higher is worse): 79.0 (82.9) ($n = 73$) [35] – SPI-p, median (range) (out of 10, higher is worse): 3.0 (0–10) ($n = 113$) [38] – PedsQL 4.0, mean (SD) (out of 100, higher is better): 75.5 (17.4) ($n = 208$) [78]

Table 1 (continued)

*Stratifications for CDLQI: 0–1 no effect; 2–6 small; 7–12 moderate; 13–18 large; 19–30 extremely large

BSA body surface area, *CDLQI* Children's Dermatology Life Quality Index, *CLQI* Children's Life Quality Index, *CSP* Children's Scalpdx in Psoriasis, *DeFIS* Dermatological Diseases Family Impact Scale, *DLQI* Dermatology Life Quality Index, *FDI* Dermatitis Family Impact Questionnaire, *IDQOL* Infants' Dermatitis Quality of Life Index, *IQR* interquartile range, *KINDL-R* Quality of Life in Children – Revised, *NR* not reported, *PASI* Psoriasis Area and Severity Index, *PedsQL* Pediatric Quality of Life Inventory, *PedsQL-C* Pediatric Quality of Life Inventory—Child, *PedsQL-P* Pediatric Quality of Life Inventory—Parent, *PFI-14* Psoriasis Family Index-14, *Pso* psoriasis, *QoL* quality of life, *SD* standard deviation, *SIFS* Stein Impact on Family Scale, *SPI-p* Simplified Psoriasis Index—Psychosocial Domain

and revealed an increased OR (1.98) for any anxiety disorder diagnosis compared with non-psoriasis controls and a non-significant increase in hospitalizations due to an anxiety disorder (2.33, 95% CI 0.97–5.56) [65].

Screening studies were performed for detecting anxiety using two validated instruments, the State-Trait Anxiety Inventory for Children (STAI-C) [59, 68] (validated for adolescents) and Generalized Anxiety Disorder-7 (GAD-7) [69] (validated for children and adolescents). As for depression, anxiety was not greater in psoriasis versus controls [68, 69]. However, sample sizes were small. Only one study assessed stigma, using the Psoriasis Internalized Stigma Scale (PISS), which has never been validated [70]. This study evaluated 125 pediatric patients (mean age 14.6 years old, range 10–18 years), as well as 1235 adults, and used the Dermatology Life Quality Index (DLQI) for all ages, despite its lack of validation under 17 years of age. PISS scores correlated moderately with DLQI but not with disease severity. PISS total scores were not different between children and adults (older vs younger children not compared), but children showed less stigmatization than adults [70].

3.4 Social Burden

Thirteen observational studies assessed social wellbeing and functioning of children with psoriasis (Table 4, Supplementary Table 6, see ESM). Subdomains included interpersonal relationships, participation in social activities, and school performance. Most studies reported CDLQI subscale data, despite the lack of validation of subscales [71]. One used KINDL-R (Quality of Life in Children—Revised) subscales and two Pediatric Quality of Life (PedsQL) subscales, which have been separately validated, but are not skin-specific [72, 73].

Twelve studies discussed the impact of pediatric psoriasis on school performance, with most finding little effect. In a cross-sectional database study, psoriasis was not associated with chronic school absenteeism, even when adjusted for severity [74]. This study also reported data on atopic dermatitis, which had a statistically significant rate of absenteeism [74]. KINDL-R school subscale scores between children with versus without psoriasis were similar [75].

Although using poor quality data, eight studies reported low CDLQI subscores for school attendance, suggesting little impact [23, 25, 27, 52, 56–59, 76, 77]. Two of these studies reported atopic dermatitis data and also showed little impact [57, 58]. In contrast, two studies found lower school functioning in children with psoriasis ($n = 211$) compared with healthy controls ($n = 5079$) using the PedsQL school functioning subscale score [78, 79]. Although only three studies reported data on atopic dermatitis, the limited data appear to show a lower rate of absenteeism in children with psoriasis but no other difference beyond this [57, 58, 74].

Ten studies reported data on interpersonal relationships in children with psoriasis versus controls, showing little impact on social functioning in the nine using the unvalidated CDLQI personal relationships subscale [23, 25, 27, 52, 56–59, 76] and the tenth using the eight 'friends' and 'family' questions of the KINDL-R [75]. For participation in social activities, one cohort and two cross-sectional studies were identified (all evidence level 3b). Using a validated set of 23 questions [80], 16- to 18-year-old Israeli military recruits had social function scored as 0 (very poor) to 5 (excellent) [66]. Those with low scores were referred for further psychosocial evaluation to confirm impaired social adjustment skills. Adolescents with psoriasis had an increased prevalence of impaired social adjustment skills compared with those without and prevalence was higher in patients with moderate-to-severe psoriasis [66]. Two additional studies utilized the PedsQL social functioning subscale, for which higher scores indicate better function. One showed lower mean social function scores in children with psoriasis (80.7) compared with healthy controls (85.0) ($p < 0.001$) [78]. The other study included only psoriasis patients and reported better function in those children without (92.5) versus with musculoskeletal pain (85) ($p = 0.04$) [79]. Two studies also compared psoriasis and atopic dermatitis using the same CDLQI personal relationships subscale, which showed median scores of 1 and 0, respectively [57, 58].

3.5 Family Burden

Sixteen studies investigated the impact of pediatric psoriasis on families (Table 5; Supplementary Table 7 see ESM). Burdens were divided into global impact and psychological,

Table 2 Summary of physical burdens in children and adolescents with psoriasis (see Suppl. Table 4 in the ESM for details)

Domain and comments	Type of evidence	Key findings
<p>Itch</p> <p>Majority of children with Pso in most studies have itch</p> <p>Itch prevalence is less in Pso vs AD</p> <p>Itch prevalence is higher in moderate-to-severe Pso vs mild Pso</p> <p>Itch improves with efficacious therapy</p>	<p>Prevalence/incidence</p> <p>Direct assessment</p>	<p>Prevalence of itch varied greatly; most studies failed to report disease severity or correlate itch and severity</p> <p>Prevalence of itch by study location:</p> <ul style="list-style-type: none"> – Netherlands 80% [40] – Singapore 14% [40] – Turkey 56% (78–80% of subjects with mild Pso, 20–22% with severe) [41] – Australia: 96.3% [43] – Kuwait: 72% [45] – China: 60.6% [47] <p>Two studies compared prevalence of itch in Pso vs AD:</p> <ul style="list-style-type: none"> – 24% vs 71%, $p < 0.0001$ ($n = 109$) [42] – 73.4% vs 93.5% ($n = 64$ with Pso vs $n = 62$ with AD) [44] <p>One larger study ($n = 2,379$) stratified prevalence of itch by disease severity [46]:</p> <ul style="list-style-type: none"> – 44.1% with mild Pso (mean PASI: 3.3) – 75.9% with moderate Pso (mean PASI: 12) – 67.7% with severe Pso (mean PASI: 28) <p>Itch stratified into groups by itch intensity in four studies, with varying Pso disease severity:</p> <ul style="list-style-type: none"> – No itch 40.6%; mild 27.5%; moderate 23.2%; severe 8.7% ($n = 69$; 72.5% of children with Pso had PASI <10) [31] – No itch ~10%; mild ~55%; moderate ~32%; severe ~3% ($n = 31$ with 74% moderate to severe Pso) [53] – No itch 20.7%; mild 47.8%; moderate 22.3%; severe 9.2% ($n = 358$ with mean PASI: 21 for children and 16 for adolescents) [54] – Mild itch 14.3%; severe 83% ($n = 120$, with median PASI: 24) [52] <p>Itch intensity was quantified in 5 studies with varying disease severity; no controls were studied.</p> <ul style="list-style-type: none"> – Itch VAS (0–10) mean (SD); median: 6.6 (1.7); 7.0 ($n = 23$; mean PASI: 4.8 and median PASI: 7.0) [48] – Itch VAS (0–100): median (range) 19 (0–74) ($n = 45$; PASI: 3.3 [0.5–12]) [26] – Itch VAS (0–100): mean (SD) 39.3 (26.8) ($n = 106$; PASI: 8.6 with 14.2% mild, 76.4% moderate, and 1.9% severe based on PGA) [55] – Itch VAS (0–100): median (IQR) 33.0 (15.0–60.0) ($n = 73$; mean PASI [range]: 5.2 [0–11.5]) [62] – Itch NRS (0–10): mean (SD) 4.9 (2.7) ($n = 109$; mean PASI [SD]: 7.1 [5.9]) [49] <p>One study compared Itch VAS (0–10) in Pso vs AD [81]:</p> <ul style="list-style-type: none"> – Mean (SD): 5.3 (2.8) vs 6.6 (2.6) ($n = 55$ with Pso [15% mild; 44% moderate, and 41% severe based on parental global assessment] and $n = 125$ with AD) <p>Itch intensity (Itch NRS 0–10) in patients with Pso (6–17 years old with moderate-to-severe Pso) receiving ixekizumab vs placebo in a clinical trial ($n = 171$) [11, 50, 51]:</p> <ul style="list-style-type: none"> – 72% had peak Itch NRS of ≥ 4 at baseline with mean overall for PsO patients of 5.3 – Mean baseline Itch NRS (SD): 5.4 (2.8) vs 5.0 (2.5) and mean PASI: 19.8 (7.5) vs 19.7 (8.0) for ixekizumab vs placebo – Mean Itch NRS (SD) after 12 weeks of 2.2 (2.4) and 4.6 (2.1) for ixekizumab-treated vs placebo; 71% of those treated with ixekizumab achieved reduction in Itch NRS ≥ 4 vs 20% treated with placebo
<p>Sleep disruption</p> <p>Minimal to no effect on sleep but did not use validated scales to measure sleep</p>	<p>Prevalence/incidence</p>	<p>Two studies of prevalence of itch disturbing sleep between Pso vs AD:</p> <ul style="list-style-type: none"> – 29% vs 76%, $p < 0.0001$ ($n = 109$) [42] – 45.3% vs 82.3% ($n = 64$) [44] <p>One study without controls ($n = 358$): prevalence of itch disturbing sleep of 9.2% [54]</p> <p>PASI, mean (SD): children 21 (15), adolescents 16 (11)</p>

Table 2 (continued)

Domain and comments	Type of evidence	Key findings
	Direct assessment	<p>One study showed no difference in stratified sleep disruption using PSQI (range 0–21, higher is worse) based on severity or vs controls ($n = 151$ with Pso and 150 controls) [61]:</p> <ul style="list-style-type: none"> – All Pso: 5.9; mild Pso: 5.6; moderate-severe Pso: 6.5; control: 5.6; mild vs moderate-severe: $p = 0.214$ – All Pso vs control $p = 0.683$ <p>Two studies using CDLQI sleep subscore (0–3; higher is worse) had comparison groups:</p> <ul style="list-style-type: none"> – Score trended to be lower in children with Pso treated with systemics vs only topicals: 27.8% vs 14.4%, $p = 0.23$ ($n = 50$) [27] – Pso vs atopic dermatitis vs vitiligo, median (IQR): 0 (0–1) vs 0 (0–3) vs 0 (0–0) ($n = 25$) [57, 58] <p>Six studies using CDLQI sleep subscore had no control group:</p> <ul style="list-style-type: none"> – Median (IQR): 1.0 (2.0) ($n = 319$) [56], 0 (0–1) ($n = 58$) [59] – Mean (SD): 0.71 (0.93) ($n = 56$) [60], 0 (2.0) ($n = 42$) [52] – Mean inferred from figure: 0.85 ($n = 125$) [25], 23% of maximum score ($n = 129$) [23] – Sleep loss, median (range) (out of 100): 2 (0–99) [26]
Pain Pain prevalence is higher in moderate-to-severe Pso vs mild Pso	Prevalence/incidence	<p>Irritation or pain in 43.1% of children with vulvar Pso ($n = 58$) [43]</p> <p>Larger study ($n = 2379$) stratified prevalence of skin pain by disease severity [46]:</p> <ul style="list-style-type: none"> – Tender/painful skin: <ul style="list-style-type: none"> • Mild Pso: 12.2% (mean PASI: 3.3) • Moderate Pso: 34.0% (mean PASI: 12) • Severe Pso: 45.2% (mean PASI: 28) – Burning skin: <ul style="list-style-type: none"> • Mild Pso: 14.5% • Moderate Pso: 30.1% • Severe Pso: 38.7% <p>Burning in 6.6% and irritation in 8.0% overall (severity not reported) ($n = 137$) [47]</p>
	Direct assessment	<p>Pain intensity median (IQR) (0–100): 2.0 (0–15.5) ($n = 73$) [62]</p> <ul style="list-style-type: none"> – PASI, mean (range): 5.2 (0–11.5)

AD atopic dermatitis, *CDLQI* Children's Dermatology Life Quality Index, *IQR* interquartile range, *NR* not reported, *NRS* Numerical Rating Scale, *PASI* Psoriasis Area and Severity Index, *PedsQL* Pediatric Quality of Life Inventory, *PGA* Physician's Global Assessment, *Pso* psoriasis, *PSQI* Pittsburgh Sleep Quality Index, *SD* standard deviation, *VAS* Visual Analogue Scale

financial, and social burdens. Validated instruments were used (Family Dermatology Life Quality Index [FDLQI], Dermatitis Family Impact [DFI], Dermatological Family Impact Scale [DeFIS], or Psoriasis Family Index [PFI-14]). Mean scores were reported for FDLQI (9.53–13.6, maximum possible score 30 for greatest impact) [16, 39, 81], but strata have not been defined for FDLQI, DeFIS, DFI, and PFI-14 [23, 26, 27, 48]. In five studies evaluating the relationship between psoriasis severity and family impact, very weak to strong relationships between severity in the child and QoL of the family were noted [16, 82, 83].

Studies of the psychological burden in the family primarily used tools to assess caregiver depression or anxiety. Hamilton Anxiety Scale (HAS) and Beck's Depression Inventory (BDI) scores were both high (defined as HAS >17 and BDI >10) in 36% of parents of children with psoriasis, similar to parents of children with atopic dermatitis [58]. In another study, parental depression was higher for pediatric psoriasis than nevi (23% vs 5%) [49]. Financial burden was only measured by the non-validated subscores of the FDLQI

[16, 39, 83], DeFIS [23], or DFI [26], and thus conclusions may not be valid. However, these subscores suggested a moderate burden on the family, a greater burden perceived by the mother compared with the father [39], and similar rates of work absenteeism in parents of children with versus without psoriasis [74]. Non-validated relationship and social life subscores of FDLQI were used to examine social family burdens and were minimally impacted [16, 39, 83].

4 Discussion

Although the medical comorbidities of pediatric psoriasis have been well characterized, there is less clarity about burdens for patients and families. Interpretation of data about burden is challenging, because many studies use unvalidated tools and poorly characterized patient populations. Numerous small studies and clinical trials confirmed a negative impact of pediatric psoriasis on QoL, which may improve

Table 3 Summary of psychological burdens in children and adolescents with psoriasis (see Suppl. Table 5 in the ESM for details)

Domain and comments	Type of evidence	Key findings
Depression Generally, higher prevalence and incidence of depression in pediatric Pso No to little difference in depression scores when directly measured	Prevalence/incidence	3 large insurance claims database studies using ICD diagnostic codes in Pso vs no Pso: – Prevalence 1.3% vs 0.8%, prevalence ratio 1.69 (95% CI 1.05–2.73) ($n = 1313$) [63] – Adjusted OR 2.54 (95% CI 2.04–3.17), $p < 0.0001$ ($n = 3112$) [65] – Prevalence of depressive episodes: 0.7% vs 0.2%, $p < 0.002$ ($n = 4449$) [64] Incidence of depression in Pso vs no Pso: large database study ($n = 7404$) [18] – 3.1% vs 2.4%, $p = 0.0036$; adjusted HR 1.23, 95% CI 1.06–1.43, $p = 0.0053$ Database study of Israeli Defense Forces 16- to 18-year-olds ($n = 3112$): no difference in prevalence of affective disorders in Pso (0.18%) vs no Pso (0.23%) [66] Prevalence of depression in children with Pso: 6.6% ($n = 61$) [67]
	Direct assessment	Two studies compared depression scores using validated tools in Pso vs no Pso: – CDI scores (range 0–54; higher is worse) higher in children but not adolescents with Pso vs no Pso ($n = 48$) [68] – No difference in MDI scores (0–50, higher is worse) (median score 4–5) ($n = 315$) [69] One study of CDI ($n = 58$) without control group had median (IQR) score of 6 (range 3–12) [59]
Anxiety Generally higher prevalence of anxiety No to little difference in anxiety scores when directly measured	Prevalence/incidence	Prevalence of anxiety in three large insurance database studies based on ICD diagnostic codes of Pso vs no Pso: – Anxiety disorders: 1.5% vs 0.75%, crude OR 2.02 (95% CI 1.25–3.27); higher levels of anxiety were also found with moderate-to-severe psoriasis vs no psoriasis, OR 2.91 (95% CI 1.57–5.46) ($n = 3112$) [66] – Incidence of anxiety: 1.8% vs 1.4%, adjusted HR 1.32 (95% CI 1.09–1.61) ($n = 7404$) [18] – Anxiety disorders: Adjusted OR 1.98 (95% CI 1.49–2.62) ($n = 1787$) [65] Two studies reported prevalence of anxiety of 1.4% ($n = 69$) [31] and 1.6% ($n = 61$) [67]; the latter study was of hospitalized children in Turkey
	Direct assessment	No difference in anxiety scores in Pso vs no Pso when directly measured: – No difference in STAI-C scores; no correlation with severity ($n = 94$) [68] – No difference in GAD scores (median score 2–3) ($n = 315$) [69] One study ($n = 58$) with no control group: median STAI-C scores of 28 (state-anxiety) and 33 (trait-anxiety) (possible score range: 20–60); mean PASI: 1.8 [59]
Stigma Moderate stigma correlated with QoL but weakly with severity	Prevalence/incidence	None
	Direct assessment	Internalized stigma score ($n = 125$), PISS (out of 4–91, higher is worse) [70]: – Mean (SD): 58.48 (14.9), range: 32–91 – Internalized stigma correlated moderately with DLQI ($r = 0.42$) and weakly with PASI ($r = 0.12$)
Stress	Prevalence/incidence	Post-traumatic stress disorder prevalence in older adolescents in the Israeli Defense Forces similar in Pso regardless of severity (0.13%) vs healthy (0.06%), adjusted OR 1.73 (95% CI 0.64–4.64), $n = 3112$ [66]
	Direct assessment	None

CDI Children's Depression Inventory, CI confidence interval, GAD generalized anxiety disease, HR hazard ratio, ICD-10 International Classification of Diseases-10, MDI Major Depression Inventory, NR not reported, OR odds ratio, PASI Psoriasis Area and Severity Index, PISS Psoriasis Internalized Stigma Scale, Pso psoriasis, QoL quality of life, STAI-C State-Trait Anxiety Inventory—Children

with successful intervention. Psoriasis severity may not be the only factor that impacts quality of life [68, 78]; therefore, there is high value in assessing skin-specific QoL scores for patients with psoriasis.

Itch is a major physical burden of pediatric psoriasis, but studies of itch quality, itch impacts, and the effect of successful therapy on itch are limited [11, 84]. Psoriasis-related skin

pain in children has been understudied [85] but available data suggest strong association with vulvar involvement, palmoplantar fissures, and erythroderma. Clinical care of patients should include formal or informal assessments of skin itch and pain, and if present, managed accordingly.

Although data are mixed, it is clear that a subset of patients with psoriasis experience comorbid anxiety and

Table 4 Summary of social burdens in children and adolescents with psoriasis (see Suppl. Table 6 in the ESM for details)

Domain and comments	Type of evidence	Key findings
School performance Studies suggest limited impact on school performance	Prevalence/incidence	None
	Direct assessment	<p>Six studies had comparison groups:</p> <ul style="list-style-type: none"> – KINDL-R subscale, school (score out of 100, higher = better) • Mean (95% CI), Pso vs no Pso: 65.1 (60.9–69.4) vs 66.6 (66.0–67.2), $p = 0.49$ ($n = 108$) [75] – CDLQI subscale, school or holiday (score out of 3, higher = worse) • Pso vs atopic dermatitis vs vitiligo, median (IQR): 0 (0–1) vs 0 (0–1) vs 0 (0–0) ($n = 25$) [57] • Systemic vs topical agents: 33.3% vs 18.9% (of max score), $p = 0.25$ ($n = 50$) [27] – PedsQL subscale, school functioning (score out of 100, higher = better) • Pso with no pain, median (range): 80 (50–100) vs Pso with musculoskeletal pain: 65 (5–90) ($n = 43$) [79] • Pso vs healthy, mean (SD): 70.2 (19.7) vs 81.3 (16.1), $p < 0.001$ ($n = 208$) [78] – Association with chronic school absenteeism, adjusted OR (95% CI) ($n = 200$) [74]: • Pso vs healthy: 1.28 (0.52–3.15); no association by severity of Pso • Atopic dermatitis vs healthy: 1.42 (1.13–1.78) <p>Six studies (n ranging 42–319) did not have control groups:</p> <ul style="list-style-type: none"> – CDLQI subscale, school or holiday (score out of 3, higher = worse) • Median (IQR): 1.0 (2.0) [56], 0 (0–1) [59], 1.0 (1.0) [52] • Mean, inferred from figure: 0.75 [25] or 28% (of max score) [23] • Mean (SD): 0.86 (0.88) [76] – DLQI subscale, work/school (score out of 3, higher = worse) • Mean (SD): 0.45 (0.87) [76]
Interpersonal relationships Little impact suggested by direct assessment	Prevalence/incidence	None
	Direct assessment	<p>Three studies had comparison groups:</p> <ul style="list-style-type: none"> – CDLQI subscale, personal relationships (score out of 6, higher is worse) • Systemic vs topical agents: 13.9% vs 13.3%; $p = 0.67$ ($n = 50$) [27] Pso vs AD vs vitiligo, median (IQR): 1.0 (0–3) vs 0 (0–2) vs 0 (0–1) ($n = 25$) [57] – KINDL-R subscales, Pso vs no Pso ($n = 108$) [75] • Friends, mean (95% CI): 73.8 (69.8–77.7) vs 77.5 (77.0–77.9); $p = 0.064$ • Family, mean (95% CI): 80.2 (76.6–83.9) vs 82.0 (81.6–82.4); $p = 0.351$ <p>Six studies (n ranging 42–319) had no control group:</p> <ul style="list-style-type: none"> – CDLQI subscale, personal relationships (score out of 6, higher is worse) • Median (IQR): 1.0 (2.0) [56], 0 (0–1) [59], 1.0 (1.0) [52] • Mean (SD): 0.18 (0.52) [25], 0.07 (0.26) [76] • Mean, inferred from figure: 17% (of max score) [23] – DLQI subscale, personal relationships (score out of 6, higher is worse) • Mean (SD): 0.30 (0.60) [76]
Participation in social activities Impaired social skills in moderate-to-severe Pso	Prevalence/incidence	<p>Impairment of social adjustment skills in Pso vs no Pso ($n = 1135$) [66]:</p> <ul style="list-style-type: none"> – Prevalence: 6.3% vs 4.2%; Crude OR 1.53 (95% CI 1.20–1.94); $p < 0.001$ – By severity, adjusted OR (95% CI): mild Pso vs control: 1.30 (0.93–1.82); moderate-severe Pso vs control: 1.86 (1.31–2.62); $p < 0.001$
	Direct assessment	<p>PedsQL subscale, social functioning (score out of 100)</p> <ul style="list-style-type: none"> – Pso with no pain, median (range): 92.5 (70–100) vs Pso with musculoskeletal pain: 85 (20–100); $p = 0.04$ ($n = 43$) [79] – Pso vs controls, mean (SD): 80.7 (18.8) vs 85.0 (16.7); $p < 0.001$ ($n = 208$) [78]

AD atopic dermatitis, CDLQI Children's Dermatology Life Quality Index, CI confidence interval, DLQI Dermatology Life Quality Index, KINDL-R Quality of Life in Children, Revised, NR not reported, OR odds ratio, PASI Psoriasis Area and Severity Index, PedsQL Pediatric Quality of Life Inventory, Pso psoriasis, SD standard deviation

depression. However, social burdens, such as stigma, bullying and isolation, are not well studied. Although evidence from large studies is lacking, real world experience emphasizes the importance of measuring social and psychological distress related to psoriasis and considering the individual impact when formulating treatment plans. Medical therapies, as well as resources and referrals for social support and counseling, are key.

The few existent studies of disease burden on families largely used unvalidated single questions from composite validated tools (FDLQI, DFI, or DeFIS). Strata have not been established to interpret composite scores, including the

FDLQI, rendering data difficult to interpret. Financial burden affected a subset of families, but how psoriasis severity affects financial burden is unclear. Economic burden may depend in part on regional access and coverage of medications, insurance and tax policies, availability of co-pay assistance cards and other considerations in countries without governmental reimbursement. Incorporating financial considerations into management approaches via shared decision making is a strategy that may be of value to families.

A recurring issue that limited interpretation of many studies was the use of unvalidated tools or tools without well-defined cutoffs. An example was the frequent use

Table 5 Summary of family burdens in children and adolescents with psoriasis (see Suppl. Table 7 in the ESM for details)

Domain and comments	Type of evidence	Key findings
Global impact	Prevalence/incidence	None
Impact on QoL of family appears to be moderate, but strata are not available for any family impact scales	Direct assessment	Nine studies ($n = 45\text{--}255$) used four tools to assess global QoL impact on family members: <ul style="list-style-type: none"> – FDLQI (out of 30, higher is worse, but not linked to strata) <ul style="list-style-type: none"> • Mean (SD): 10.8 (6.7) [81], 13.6 (6.2) [16] • Median (IQR): 12 (7–17) [83], 10 (6.8–15) [59] • Median (range): 12 (2–30) [16] • Mean (SD): mothers: 13.44 (6.46); fathers: 9.53 (6.12) [39] – DeFIS (out of 60, higher is worse) <ul style="list-style-type: none"> • Mean (SD), median (range): 20.8 (11.9), 19 (0–52) [23] – DFI (out of 30, higher is worse) <ul style="list-style-type: none"> • Mean (SD): 18.4 (4.9) [48], 5.6 (5.8) [26] – PFI-14 (out of 42, higher is worse) <ul style="list-style-type: none"> • Mean (SD), median: 11.2 (6.9), 9 [27]
Limited studies of impact of intervention		Five studies correlated disease severity and family impact (very weak to strong): <ul style="list-style-type: none"> – FDLQI of mother vs PASI: $r = 0.615$, $p = 0.001$ ($n = 100$) [82] – FDLQI of caretaker vs PASI: $r_s = 0.44$, $p < 0.001$ ($n = 157$) [83] – DeFIS vs PASI: $r = 0.350$; $p < 0.001$ ($n = 255$) [23, 41] – DeFIS vs physician-rated disease severity: $r = 0.362$, $p < 0.001$ ($n = 255$) [23] – FDLQI vs PASI: $r = 0.17$; $p = 0.17$ ($n = 65$) [16] – BSA vs PASI: $r = 0.19$; $p = 0.13$ ($n = 65$) [16] – DFI vs PASI: $p = 0.0001$ (correlation strength not reported) ($n = 45$) [26] <p>One clinical trial ($n = 211$) compared family impact in patients receiving etanercept vs placebo using SIFS (range 15–60, higher = better) [34]:</p> <ul style="list-style-type: none"> – Etanercept, mean (range): 46 (10) vs placebo, mean (range): 46 (8) <p>One study implemented a 10-week multidisciplinary training program for patients (6–18 years old) and family members, then assessed family impact at baseline and end of program in participants ($n = 25$) vs controls ($n = 23$), who did not undergo this training [60]:</p> <ul style="list-style-type: none"> – Baseline DFI, median (range): participants: 3.0 (0.0–19.0); controls: 2.0 (0.0–17.0); end of program DFI, median (range): participants: 3.0 (0.0–15.0); controls: 1.0 (0.0–9.0) – Baseline SIFS, median (range): participants: 58.0 (41.0–60.0); controls: 60.0 (39.0–60.0); end of program SIFS, median (range): participants: 58.0 (47.0–60.0); controls: 60.0 (50.0–60.0)
Psychological	Prevalence/incidence	One study ($n = 25$) reported rates of anxiety and depression in caregivers of children with Pso vs AD vs vitiligo [57, 58]: <ul style="list-style-type: none"> – Anxiety: 36% vs 36% vs 42% – Depression: 36% vs 36% vs 26%
Higher rates of anxiety and depression in caregivers than general population		
Variable relationship of parental mental health with disease severity		
Less for parents of children with Pso vs AD		

Table 5 (continued)

Domain and comments	Type of evidence	Key findings
	Direct assessment	<p>FDLQI subscale, emotion (out of 3, higher = worse):</p> <ul style="list-style-type: none"> – Mean: 1.54 ($n = 157$) [83] – Mean (SD): 1.78 (0.96) ($n = 65$) [16] – Mean, mothers (1.7, SD 1.0) and fathers (1.2, SD 1.0) ($n = 45$) [39] <p>DeFIS subscale, emotions, mean (SD): 8.7 (4.1) ($n = 255$) [23]</p> <p>One study ($n = 45$): DFI-emotional distress in caregiver subscale: top 3 scoring items [26]</p> <p>Psychological outcomes for parents of children with Pso vs AD ($n = 55$) [81]:</p> <ul style="list-style-type: none"> – Stress, PIP frequency, mean (SD): Pso 90.3 (32.9) vs AD 97.2 (33.4) – Stress, PIP difficulty, mean (SD): 88.6 (34.2) vs 96.0 (37.5) – General stress, DASS-21, mean (SD): 7.1 (4.9) vs 9.0 (6.6) – Depression, DASS-21, mean (SD): 4.7 (5.6) vs 6.6 (6.6) – Anxiety, DASS-21, mean (SD): 4.9 (5.05) vs 5.8 (5.58) – Association of parent outcome with child's skin condition severity: <ul style="list-style-type: none"> • Stress, PIP frequency: $p = 0.19$ Pso vs $p < 0.001$ AD • Stress, PIP difficulty: $p = 0.24$ vs $p < 0.001$ • Stress, DASS-21: $p = 0.97$ vs $p = 0.06$ • Depression, DASS-21: $p = 0.956$ vs $p = 0.053$ • Anxiety, DASS-21: $p = 0.90$ vs $p = 0.07$ <p>Psychological outcomes for caregivers of children with psoriasis vs with nevi ($n = 120$) [49]:</p> <ul style="list-style-type: none"> – BDI, mean (SD): 7.3 (6.9) vs 2.8 (3.5); $p < 0.0001$ – BDI score > 10 (concern for depression): 23% vs 5%; $p = 0.009$ – No effect of child's severity or age vs maternal BDI scores
Financial	Prevalence/incidence	None
Moderate impact of Pso on family finances	Direct assessment	<p>FDLQI subscale, expenditure (out of 3, higher = worse)</p> <ul style="list-style-type: none"> – Mean: 1.35 ($n = 157$) [83] – Mean (SD): 2.08 (0.67) ($n = 65$) [16] – Mean, mothers (2.02, SD 0.66) and fathers (1.8, SD 0.81) ($n = 45$) [39] <p>DeFIS subscale, financial burden, median (IQR) (out of 4, higher = worse): 2 (1–3) ($n = 255$) [23]</p> <p>Two studies reported results without numerical values:</p> <ul style="list-style-type: none"> – “Parents of children with psoriasis had similar rates of work absenteeism versus those of children without psoriasis” ($n = 124,267$) [74] – One study utilized the DFI and found that the expenditure subscale was “one of the three highest scoring DFI items” ($n = 45$) [26]
Social	Prevalence/incidence	None
Small impact on family social relationships	Direct assessment	<p>FDLQI subscale, relationships (out of 3, higher = worse)</p> <ul style="list-style-type: none"> – Mean: 0.57 ($n = 157$) [83] – Mean (SD): 0.72 (0.89) ($n = 65$) [16] – Mean (SD), mothers vs fathers: 0.62 (0.86) vs 0.56 (0.72) ($n = 45$) [39] <p>FDLQI subscale, social life (out of 3, higher = worse)</p> <ul style="list-style-type: none"> – Mean: 0.65 ($n = 157$) [83] – Mean (SD): 0.75 (0.85) ($n = 65$) [16] – Mean (SD), mothers vs fathers: 0.84 (0.08) vs 0.53 (0.66) ($n = 45$) [39]

AD atopic dermatitis, BDI Beck Depression Inventory, BSA body surface area, DASS-21 Depression Anxiety and Stress Scale-21, DeFIS Dermatological Diseases Family Impact Scale, DFI Dermatitis Family Impact Questionnaire, FDLQI Family Dermatology Life Quality Index, IQR interquartile range, NR not reported, PASI Psoriasis Area and Severity Index, PFI-14 Psoriasis Family Index, PIP Pediatric Inventory for Parents, PSF-SF-4 Parenting Stress Index Short Form, Pso psoriasis, QoL quality of life, SD standard deviation, SIFS Stein Impact on Family Scale

of unvalidated subscales (especially of the CDLQI and FDLQI), which do not provide high quality evidence. Similarly, single question queries about sleep, unvalidated in children, were used to show a limited impact of pediatric psoriasis on sleep disturbance. Although articles about

psoriatic arthritis were excluded, it is possible that a small percentage of the children and adolescents with psoriasis had arthritis, which could have confounded responses about pain and other domains. Furthermore, interpretation of differences between age groups, including between

children and adolescents, was limited by the wide variability in defining age groups among different studies.

5 Conclusions

The increasing availability of validated tools for child self-report and proxy report will enable testing of physical, social, and psychological health in large enough numbers of children and adolescents for statistical significance. Most widely used are the Patient-Reported Outcomes Measurement Instrumentation System (PROMIS) instruments, which have been used widely for adults and children with a variety of chronic disorders and are normalized to a control group, obviating the need to enroll healthy controls for comparison [86]. Using these tools, recent studies correlated itch with sleep disturbance in children with atopic dermatitis ($\rho = 0.63$; $p < 0.0001$) [50] and found that 73% of 1671 children with chronic skin disorders experienced stigma. The future use of well validated, easily interpretable tools, such as the CDLQI or various global or domain-specific PROMIS tools, as standard for assessment of burdens during therapeutic interventions, would increase our understanding and decision making about burdens in children with psoriasis.

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Declarations

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Conflicts of Interest MMBS received grant from the IPC on definitions for severity of pediatric psoriasis; payments were made to the institution. She served as a consultant for Janssen, BMS, and Novartis; fees were paid directly to the institution. She participated on a DSMB or Advisory Board for Janssen, Eli Lilly, and BMS; payments were made to the institution. She is a Councilor of the IPC. RM is a Councilor of the IPC but has no other conflicts. MLS received payment for events sponsored by the Spondyloarthritis Research and Treatment Network (SPARTAN) and is Chair of SPARTAN. KC is a Councilor of the IPC but has no other conflicts. PvdK received fees for consultancy service or lectureships from Almirall, Eli Lilly, Janssen Pharmaceutica, UCB, and Boehringer Ingelheim. PvdK received honoraria for participating on a DSMB or Advisory Board for BMS and Celtrion. PvdK is Chief Medical Officer of the International Psoriasis Council. AP has been an investigator for AbbVie, Dermavant, Eli Lilly, Johnson & Johnson Innovative Medicine, UCB; a consultant for AbbVie, Arcutis, Boehringer-Ingelheim, Dermavant, LEO, UCB; and participated on a DSMB for AbbVie. AP is on the Board of Directors of the International Psoriasis

Council. AP (Amy Paller) is an Editorial Board member of The American Journal of Clinical Dermatology. Professor Paller was not involved in the selection of peer reviewers for the manuscript nor any of the subsequent editorial decisions. AY and BC have no conflicts of interest to declare but received monetary support from the IPC for their role in curating data for this review.

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Consent for publication Not applicable.

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Protocol Contact Dr Amy Paller for access.

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Code availability Not applicable.

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