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Please cite the final published version:

Randa, H., Lomholt, J. J., Skov, L., & Zachariae, R. (2018). Health-related quality of life in adolescents with psoriasis: an interview-based study. *British Journal of Dermatology*, 178(6), 1404-1411. DOI: [10.1111/bjd.16326](https://doi.org/10.1111/bjd.16326)

Publication metadata

Title:	Health-related quality of life in adolescents with psoriasis: an interview-based study
Author(s):	Randa, H.; Lomholt, J. J.; Skov, L.; Zachariae, R.
Journal:	British Journal of Dermatology
DOI/Link:	https://doi.org/10.1111/bjd.16326
Document version:	Accepted manuscript (post-print)

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Health-Related Quality of Life in adolescents with psoriasis: an interview-based study

Short title: HRQoL in adolescents with psoriasis

Word count: 3 580 (after revision: 4113)

Table count: 3

Figure count: 0

(Appendix: 6 tables)

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Funding statement and disclosures:

Hilde Randa is an industrial PhD-student situated at the Department of Psychology and Behavioural Science, Aarhus University, Aarhus C, Denmark. Her work is financed by LEO Pharma A/S, Ballerup, Denmark, and the Innovation Fund Denmark. The remaining authors state no conflict of interest. The funding source had no influence on study design, data collection, data analysis, manuscript preparation and/or publication decisions.

What's already known about this topic?

- HRQoL is impaired in both adult and pediatric psoriasis patients.
- Studies using generic or dermatology-specific instruments have found a moderate impact of psoriasis on HRQoL in pediatric patients, but no studies have used psoriasis-specific instruments and qualitative research is very limited.
- A qualitative study revealed substantial, negative HRQoL-impact on parents of children with psoriasis, but comparable in depth-data on HRQoL in adolescent patients themselves has only briefly been described in the literature

What does this study add?

- The present study is the first to provide in-depth knowledge about factors influencing adolescent psoriasis patients' HRQoL from a qualitative perspective.
- The results provide a conceptual framework to understanding HRQoL in adolescents with psoriasis.

What are the clinical implications of this work?

- The results contribute to increased awareness among dermatologists about the specific HRQoL issues experienced by adolescents with psoriasis.
- The conceptual model presented support a patient-centered approach by inspiring dermatologists and other health professionals with regard to relevant questions and topics to address in the clinical interview.

Abstract

Background: Psoriasis is a common skin disease affecting the physical, psychological and social well-being of patients and their families. Most research so far has been limited to adults, and little is known about the qualitative experiences of young people with psoriasis.

Objectives: To provide an in-depth understanding of the impact of psoriasis on adolescents' Health-related Quality of Life (HRQoL).

Methods: Patients and their parents were recruited from a dermatology outpatient clinic, the Danish National Birth Cohort, and the Danish Psoriasis Association. A total of 36 semi-structured interviews were conducted with adolescents with psoriasis 12-17 years old (n=18), their parents (n=14) and health professionals working with psoriasis (n=4). Interviews were digitally recorded, transcribed verbatim, and analyzed using inductive thematic analysis.

Results: The participants reported psoriasis-related HRQoL challenges within six main themes: physical symptoms, feeling different, psoriasis-related worry about the future, increased attention, attempts to conceal, and treatment-related frustrations and worry. Taken together, a broad range of the reported difficulties appeared to arise from appearance-related concerns. There was considerable variance regarding how much psoriasis and its treatment affected the adolescents' daily lives.

Conclusions: This first in-depth, qualitative study of HRQoL in adolescents with psoriasis provides a conceptual framework for understanding the impact of psoriasis and its treatment on physical, psychological and social aspects of their daily life.

Introduction

About one-third of psoriasis patients are diagnosed by the age of 20¹⁻³, and most young people diagnosed with psoriasis will live with the condition throughout their adult lives². The main objective of psoriasis treatment is therefore to minimize the extent and severity of the disease and to reduce its impact on patients' Health-Related Quality of Life (HRQoL)⁴, a multidimensional construct reflecting patients' physical, psychological and social function and well-being⁵. The subjective construct of HRQoL has been viewed by the World Health Organization (WHO) as a major determinant of health⁶, and has received increased attention during the last decades, especially within chronic diseases,.

Although most psoriasis-related HRQoL research has been focused on adult patients, there is increased interest in HRQoL in pediatric patients⁷. Two recent meta-analyses indicate moderate HRQoL-impairment in pediatric psoriasis patients, with greater impairment than found in most pediatric skin diseases and comparable to that found for pediatric eczema patients^{7,8}. As no psoriasis-specific instrument currently exists for this population, studies have relied on generic or dermatology-specific instruments. For the most commonly used HRQoL instrument in pediatric psoriasis, the Children's Dermatology Life Quality Index (CDLQI)⁷, only 5 % of the patients contributing with information to item development had psoriasis. It is therefore unknown whether dermatology-specific measures of HRQoL accurately capture all relevant aspects of HRQoL in pediatric psoriasis. Qualitative data, based on direct input from an adequate sample of patients from the targeted population, are essential for establishing the content validity of HRQoL instruments^{9,10}.

Currently, qualitative research on how psoriasis affects adolescents in their daily life is very limited. Psoriasis in children is characterized by well-defined erythematous papules and plaques of varying size with silvery scales, most common in visible areas such as the scalp and face, and on elbows and knees^{2,11}. While research in adult populations confirm that appearance-related issues are important for understanding HRQoL in psoriasis in general^{12,13}, such difficulties may be particularly salient in adolescents, where peer pressure and the desire to "fit in" often play a highly significant role in their everyday life and psychosocial development¹⁴⁻¹⁶. The results of an online focus group study of 11-18 year olds with psoriasis confirmed that appearance-related issues were experienced as central for their well-being¹⁵. This study, however, focused specifically on young people's appearance-related concerns, rather than the broader HRQoL concept. HRQoL has been the topic of two

previous qualitative studies of pediatric patients with psoriasis; one pilot study of 15 children with psoriasis, with results only briefly presented in a published conference abstract ¹⁷, and another investigating the general impact of skin disease in adolescents ¹⁸. Although only two psoriasis patients were included in this study, they appeared to be affected by the largest number of HRQoL issues compared to the other skin diseases covered, e.g., acne and eczema. Finally, a qualitative study investigating parents of children with psoriasis revealed a substantial, negative impact on parents' health and self-care, emotional well-being, family and social function, personal well-being and life pursuits ¹⁹.

Taken together, our knowledge about these and other HRQoL-related issues in adolescents with psoriasis is limited. Therefore, as part of a larger study aimed at developing a psoriasis-specific measure of HRQoL in adolescents, the present study collected in-depth qualitative data to identify HRQoL issues of importance to adolescents with psoriasis.

Patients and methods

The present interview study explored the daily life and HRQoL of adolescents living with psoriasis using grounded theory data collection methods ^{10,20} and inductive thematic analysis ²¹.

Sample and recruitment

Study participants were adolescents with psoriasis (age 12-17 years), their parents, and health professionals within the field. To ensure maximum variation in age, sex, and disease severity, we recruited adolescents and parents from three sources: a specialized dermatology hospital clinic, the Danish National Birth Cohort ²², and a Summer School, sponsored by the Danish Psoriasis Association. Adolescents and parents were approached either by the first author and interviewer (HR) or asked to participate by their dermatologist during scheduled consultations. Psoriasis severity was evaluated by a dermatologist with the Psoriasis Area and Severity Index (PASI) ²³ upon recruitment. Health professionals were recruited either from the hospital clinic or the psoriasis association.

Data collection

Separate interview guides were developed for adolescents, parents, and health professionals. Participants were informed that we did not search for correct answers, but were interested in their personal experiences and thoughts. They were encouraged to bring up new topics whenever they felt like. To build rapport, adolescent and parent interviews included a warm-

up question urging them to tell a little bit about themselves, such as their family and hobbies, and professionals were asked to describe their experiences from working with pediatric psoriasis patients. The interview guide for health professionals included a list of discussion points, while adolescents and parents were asked to describe their/their child's daily routine by describing a typical day. We hoped this would allow them to explore in more detail how psoriasis influenced their daily lives,

As our design was based on grounded theory and inductive reasoning – as opposed to pre-formulated hypotheses or theory¹⁰ -, our interview guide included additional broad, open-ended questions asking about different life domains (i.e. physical, emotional and social), rather than specific issues previously addressed in existing research (i.e. questionnaires). However, when participants spontaneously raised issues previously described or addressed in existing questionnaires, we prompted them to provide more information on these issues, to allow for closer scrutinization of their face validity in this specific population. Additional probing techniques were used to invite participants to reflect upon issues in broader context or detail.

Data analysis

All interviews were transcribed verbatim and analyzed based on inductive thematic analysis²¹ facilitated by the NVivo version 11 software. The adolescent interviews were the main focus of the analysis. Parent and health professionals data were used to contrast, highlight or elaborate on adolescent perspectives. When applying inductive thematic analysis, interview transcripts were read multiple times by the primary coder (HR) to maximize familiarity with the data, and an initial list of themes and codes was developed based on the transcripts themselves. In the next step, data transcripts were systematically coded based on the initially identified issues or new codes were constructed. When relevant, individual data extracts were given several codes. Then, the focus shifted to the broader level of themes, including interpretation of initial codes and considering how different codes might combine to form overarching themes. From this stage and onwards, an iterative and interpretive process of continuous comparison supported the development of the conceptual model. Data extracts were compared and contrasted in several ways, e.g., across i) earlier and later interviews and concepts/themes/subthemes, ii) subgroups of patients with different disease characteristics, and iii) informant groups (adolescents; parents; and health professionals). As recommended⁹, interviews were conducted and analyzed in smaller chunks of 5-7 interviews, allowing for

continuous evaluation of the interview guide and possible data saturation. Saturation of data occurs when no new information is obtained or uncovered in the ongoing analysis²⁰. To ensure reliability, the first chunk of adolescent interviews (n=5) and the initial coding scheme were reviewed in full length by an independent researcher (JLL), discussed, and finally agreed upon by the full research team (HR; JLL; RZ) before moving to the next step. When all interviews had been analyzed and the thematic map had been developed, all transcripts were reviewed again in full length. This was done to code any additional data within themes that had been missed in earlier coding stages, and to evaluate whether the conceptual model required revisions to accurately reflect the dataset as a whole²¹.

Ethics

Following the Danish Data Protection Agency guidelines, all personal identifiers in the data were removed, and no subject code identifiers were linked back to specific individuals. Under the rules of the Danish National Committees on Biomedical Research Ethics, the study was approved under exempt status.

Results

Adolescents (n=18; see Table 1) and parents (n=14, of which 12 were mothers) were interviewed between June 2015 and November 2016. All adolescents agreed to be interviewed alone by the first author (HR), a psychologist whom they had not met before. Patient and parent interviews were conducted in a quiet meeting room at the hospital or summer camp. Interviews with health professionals (2 dermatology nurses; 1 clinical dermatologist; 1 hotline counsellor) were conducted face to face (n=3) or by telephone (n=1).

The analysis identified six overarching themes and subthemes reflecting physical, psychological and social aspects (see Table 2 and 3). In general, social support, especially from family and close friends, being able to speak openly about psoriasis, and mechanisms of normalization, e.g., meeting others with psoriasis, appeared to be protective mechanisms. The localization of plaques appeared especially important, with adolescents with psoriasis on visible parts of the body generally reporting more impairment. Older patients (15-17 years) generally described more impairment of their daily lives than younger (12-14 years).

[Insert Tables 1-3 around here].

Theme 1: Physical symptoms

The negative impact of physical symptoms varied considerably and was complicated by their unpredictable nature (see Table 4). The most commonly reported physical symptoms were itch and flaking, influencing a broad range of daily activities. According to both adolescents and parents, adolescents' thoughts often focused on itch, leading to scratching of the skin, bleeding, discomfort, and avoidance of certain activities. Some adolescents explained how they had to be extra careful during play or sports to protect their skin. Although many adolescents described itch as the most disabling aspect of having psoriasis, some of the health professionals generally did not regard itch as a particularly important symptom in pediatric psoriasis.

When describing their physical symptoms, the adolescents more often used words such as “irritating” or “annoying” than “painful”, viewing them either as distractors or reminders of their different or distorted looks. Psoriasis on the scalp was associated with negative thoughts and feelings and having to take precautions to prevent flakes on clothing or furniture. The peeling of skin and, sometimes, bleeding increased the need to clean the home. This was mostly reported by parents, but also by some adolescents. The adolescents described how fluctuations in their symptoms affected their daily life. Not knowing when their psoriasis would flare up challenged their desire and ability to plan activities ahead of time. Some, for example, described that when experiencing flares, they preferred to stay at home to avoid exposing their psoriasis or to prevent worsening of their symptoms by reducing exposure to stressors.

Theme 2: Feeling different

Adolescents described a broad range of psychological concerns related to feeling different due to psoriasis (see Table 5). The majority described having psoriasis as a lonely experience. They felt great relief by seeing other people with psoriasis, assuring them that they were not the only ones to be “different”. Talking to psoriatic peers was highly valued, as other people – even their best friends – could not truly understand what living with psoriasis felt like. Adolescents also reported spending considerable energy considering when and how to tell others about their disease. Some feared that if they waited too long, people would reject them or treat them differently once they found out, and some felt too insecure to tell new

acquaintances at all. However, those who spoke openly about their psoriasis, generally experienced understanding from others and felt relief when telling others about their disease.

The majority of adolescents held negative views about their own appearance, using words such as “different”, “dirty” or “unattractive”, and worried about what others might think when seeing their psoriasis. While the prevalence of these thoughts varied, body image concerns were raised spontaneously by most adolescents during the interviews. For some, the negative thoughts could become almost obsessive, leading to social interactions becoming emotionally draining and therefore avoided. Some, especially boys, expressed anger towards their psoriasis, often stemming from feelings of hopelessness and the unfairness of the diagnosis, and could be directed towards themselves, their parents and others, e.g., people commenting on their looks.

Theme 3: Psoriasis-related worry about the future

Several adolescents reported periods with emotional difficulties, struggling to accept that psoriasis would compromise their looks, require life-long treatment, and probably make them dependent on others applying treatments for the rest of their lives (see Table 6). Adolescents with older family members with psoriasis often worried that they might end up looking like them or worse. Others worried that the effectiveness of their treatments would diminish over time, and that they would run out of treatment options, forcing them to live with more severe disease or develop comorbid diseases. The fear of developing comorbidities was primarily raised by parents.

Several adolescents mentioned dating experiences that had been challenging due to their psoriasis, or had worries regarding future romantic experiences. Most concerns were appearance-related, and several worried that potential dates would find them unattractive or judge them as “filthy”. Some adolescents worried they might never be able to find a life partner, while others felt confident that they one day would find a partner who focused on inner values and not their looks. A concern mentioned only by few adolescents, but prevalent in the interviews with parents and health professionals, was that the adolescents would be too “avoidant”, “shy” or “low in self-confidence” to seek out romantic and/or intimate experiences at all. Several adolescent also were unsure whether they would risk having children, knowing that their offspring would be at risk of developing psoriasis.

Thoughts about the impact of psoriasis on education and career prospects were also reported. All three informant groups reported that some adolescents, because of time-consuming treatments or appearance-related/psychological concerns, were challenged by high school absenteeism threatening their educational goals. Adolescents primarily mentioned challenges related to appearance, ranging from not being able to become models or movie stars, to more general consequences, such as whether they would be able to cope with adult work life with psoriasis, fearful that job-related challenges and stress could lead to lower self-esteem and more psychological problems. Parents and health professionals also endorsed these concerns.

Theme 4: Increased attention

Negative experiences of getting increased attention because of how they looked was reported by most adolescents (see Table 7). Several described how being stared at or even pointed at made them feel like being constantly “on display”, and reported a wide range of negative thoughts when being looked at. While comments and questions regarding their looks were common, adolescents differed in how they reacted to the increased attention. Some felt different and sad; some felt annoyed or even angry by always having to explain; while others were appreciative, as neutral comments and questions were regarded as opportunities for them to explain that psoriasis is a hereditary, non-contagious, chronic disease that “makes your skin look nasty”. While most adolescents reported that the majority of comments stemmed from ignorance about psoriasis, some reported being teased, or even bullied, because of their appearance.

Theme 5: Attempts to conceal

The adolescents used a wide range of strategies to conceal their psoriasis-affected skin affecting their daily lives (see Table 7). Several explained that their attempts at concealing not only was to keep people from staring, commenting, or withdrawing from them due to fear of contagion, but also a self-protective strategy keeping them from worrying too much about what others might think. Several adolescents admitted “it was all in their heads”, but that they “just couldn’t let it show”. Developmental aspects appeared to play a role, as some adolescents explained how they as children had been less concerned or even unaware of their different appearance. Others described that being able to display their psoriasis had required several years of adaptation, while a third group found it much more difficult when entering the teenage years. Strategies ranged from concealment actions, e.g., selecting certain clothes or hairstyles, even if it was inconvenient, to more pronounced avoidance behaviors, e.g.,

avoiding going to the beach or swimming pool. To some, showing their skin to people who knew about their psoriasis did not pose problems, while putting oneself at display at a public beach filled with strangers was avoided. Furthermore, although only expressed by a few adolescents, parents and health professionals shared the general concern that psoriasis made some adolescents shyer and more avoidant.

Theme 6: Treatment-related frustrations and worry

In addition to commonly reported side-effects of treatments, e.g., nausea, pigmental changes, burning/stinging sensations when applying treatments, itch, dry lips and disrupted sleep, more subtle negative effects and frustrations were also prevalent (see Table 9), including greasy skin, hair, clothing and bedsheets, being unable to drink alcohol at parties, and continuous arguments with parents related to psoriasis care. For example, several mothers explained how their child could not stand the greasiness of topical treatments, leading to repeated arguments with their child. Furthermore, treatments were often time-consuming, resulting in increased school absence, failure to follow prescribed procedures, and frustrations over the effort required by treatments. Several explained how time consuming treatments, combined with delayed treatment response, was especially challenging.

Some older adolescents and their parents worried about possible harmful side effects of treatments, e.g., immunosuppressive effects, liver damage, hormonal disturbances, and weakening of the skin. However, most adolescents raising these issues acknowledged that their wish to make their psoriasis go away outweighed the potential harmful effects; a prioritization that was less clear cut among parents. The health professionals expressed concerns that parent's worries about treatments might result in patients not receiving optimal care. Several adolescents had experienced having to change medication, either due to excessive side effects or because the effectiveness had diminished, and worried that they one day would end up with flares all over their body and no available treatments left.

Discussion

To our knowledge, ours is the first in-depth, qualitative study to explore adolescents' experiences of living with psoriasis (HRQoL), based on interviews with the adolescents, their parents, and health professionals with different backgrounds. Among the aspects reported to affect adolescents' daily life, we identified six main themes; physical symptoms, feeling different, psoriasis-related worry about the future, increased attention, attempts to conceal,

and treatment-related frustrations and worry. Combined, the themes represent a conceptual model for understanding HRQoL in 12-17 year-old adolescents with psoriasis, reflecting a range of physical, psychological and social concerns. While previous qualitative studies have touched upon several of the identified issues in adult ^{12,24-28} and pediatric ^{15,17,18} psoriasis, our study goes further by providing an integrated conceptual model of HRQoL, which is both psoriasis- and adolescent-specific. Some issues are worth highlighting.

Although there has been an increased research interest on itch in psoriasis, some health professionals in our study appeared to compare their pediatric psoriasis patients with eczema patients or psoriasis in adults, reaching the conclusion that itch is less relevant in childhood psoriasis. In contrast, several adolescents reported, that their itch caused considerable impairment. This apparent paradox has also been identified in a previous qualitative study ²⁴. Unfortunately, no information on age and other demographic characteristics has been published for this study. While previous quantitative and qualitative studies support the prevalence of itch in pediatric psoriasis ^{2,17,18}, our data provide a richer understanding of adolescents' experiences with itch and the many ways it may impact the daily lives. Dermatologists are recommended to pay attention to itch-related concerns when treating pediatric psoriasis patients, regardless of how it compares with other patient groups.

We found that the adolescents' social life was influenced by increased attention, i.e., being stared at and asked questions about their appearance. While previous qualitative studies have highlighted the importance of teasing and bullying in psoriasis ^{18,29}, most adolescents in our study attributed comments made by others to ignorance rather than intentional hurtful comments. Still, such comments often resulted in feelings of "being on display" causing them to feel different, self-conscious or sad about their looks. We do not wish to underestimate the importance of teasing and bullying in adolescent psoriasis, but rather emphasize that comments perceived as neutral could also be experienced as negative. Although only briefly reported in previous studies ³⁰, neutral comments were very common, and seemed important for our understanding of the more subtle psychological and social consequences of living with psoriasis.

The experiences related to treatments for skin diseases in children have previously been studied, especially with regard to topical treatments with poor treatment adherence ³¹. Our data provide a more thorough understanding of the underlying mechanisms of nonadherence,

not only in topical treatments, but also phototherapy and oral/injected medications, which are less well described in this population. Furthermore, treatment-related concerns, along with more general worries about the future with psoriasis, appear to significantly affect adolescents' psychological well-being.

While our study has several strengths, some limitations should be mentioned. It is, for example, difficult to disentangle the more general developmental struggles experienced by adolescents from the psoriasis-related difficulties reported in our study. Several parents had difficulties ascertaining whether psoriasis itself or typical adolescent struggles were the main cause of their children's difficulties. The adolescents themselves, however, mainly attributed their difficulties to psoriasis. A hypothesis could be that psoriasis may amplify developmental difficulties, making them even more challenging. Furthermore, most themes and subthemes in our conceptual model were drawn mainly from interviews with the older adolescents (≥ 15 years) in our sample. Whether this reflects that adolescents in this age group experience more struggles than their younger counterparts, or whether it is related to higher abstraction levels due to age-related maturation, is uncertain.

Moreover, as HRQoL per definition³² is a subjective construct, i.e. based on patient self-report, we prioritized adolescent participants and data. Hence, the generalizability of our parent and health professionals data is limited by the fact that only 2 of 14 parents were fathers (as most adolescents were accompanied by their mothers when approached), and that we only included a small number of health professionals. Furthermore, although all approached health professionals and parents agreed to participate in our study, a few adolescents declined to do so. For example, one patient declined as he described simply being too burdened by his psoriasis. Unfortunately, we did not collect systematic data on reasons for not wanting to participate, and our results could be biased i.e. by our sample consisting mostly of patients willing or able to share – as opposed to adolescents more troubled and/or shy about their psoriasis. This may imply, that the true burden across all psoriasis patients is actually higher than perceived from the interviews, and that even mild psoriasis affect the HRQoL of adolescents substantially, as reflected in our conceptual model. This assumption could be further supported by the fact that although patients in our study were recruited broadly from the general population as well as from specialized dermatology hospitals, the mean severity of psoriasis in our sample fell within the mild-to-moderate range. However, as participants were asked to elaborate not only on current, but also earlier experiences of living

with psoriasis, the true range in disease severity covered during the interviews was broader, as several patients reported currently being in remission thanks to effective medications.

Despite such limitations, by using qualitative methods, the present study provides additional insights to questionnaire-based studies, enabling a richer understanding of HRQoL in adolescent psoriasis. In contrast to most previous research^{7,15,18}, we, in addition to patients recruited from dermatology clinics and patient organisations^{7,15,18}, also included participants from a general population birth cohort. We believe this data, being more representative of the general population of adolescent psoriasis patients, offer a more nuanced view. The conceptual model, as well as additional data from these interviews, will be used to develop the first age-appropriate, psoriasis-specific instrument to measure HRQoL in adolescents, and thus will be further evaluated and possibly extended during later stages of the instrument development process.

To provide optimal care for adolescent psoriasis patients, dermatologists should focus not only on physical symptoms, but also pay attention to the psychosocial aspects of living with psoriasis^{4,33}. The degree to which dermatologists succeed in this is debated^{25,27} and challenged by the scarcity of research on the specific content and importance of such impairments in daily life. We hope that the conceptual model presented in our study will support dermatologists in providing optimal care for adolescents with psoriasis, by inviting them to stay alert regarding the many specific HRQoL-aspects identified in the present study. Based on our study, it is our impression that dermatologists during consultations could alleviate this burden significantly not only by including patient's HRQoL-concerns in treatment planning, but also by simply asking about, and showing interest in and acknowledging, potential multifaceted influences – as the ones described in our conceptual model - psoriasis might have on the patient sitting in front of them. For more complicated cases, referral to psychologists or counselling might be necessary.

Acknowledgements

The authors would like to thank all individuals who took part in our study, as well as Tilde Elkjær Nielsen (MSc), Christoffer Blegvad (MD), dermatologist Hans-Henrik Horsten, and the Danish Psoriasis Association for help with recruitment and data collection.

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Supporting information

For more detailed data extracts representing each theme and subtheme, see Appendix Tables 4-9.

Table 1. Characteristics of adolescent sample

Demographic characteristics	12 to 14 years	15 to 17 years	Total sample
Number of participants	7	11	18
Gender			
Female	3	7	10
Male	4	4	8
Living arrangements			
Living with both parents	5	9	14
Living with one of the parents ¹	1	1	2
Shared between two families (50/50%) ¹	1	0	1
Moved away from home ¹	0	1	1
Disease characteristics			
Mean age at onset (range in years)	7 (1-10)	9 (3-14)	
Mean duration of psoriasis (range in years)	6 (3-8)	7 (1-14)	
Mean disease severity; PASI (range)	3.1 (0-7.4)	3.3 (0-9.8)	
Current treatment			
Topical	6	7	13
Systemic	0	2	2
Biological	1	2	3
Recruitment setting			
Outpatient clinic	2	6	8
Summer School/Danish Psoriasis Association	2	2	4
National Birth Cohort	3	3	6

Abbreviations: PASI; Psoriasis Area Severity Index.

¹Separated or divorced parents.

Table 2. Themes and subthemes

Theme	Subtheme
1: Physical symptoms	1.1 Itch
	1.2 Flaking
	1.3 Fluctuations in symptoms
2: Feeling different	2.1 Feeling alone
	2.2 Telling others about one's disease
	2.3 Body image issues
	2.4 Why me?
3: Psoriasis-related worry about the future	3.1 Worsening of psoriasis or comorbidities
	3.2 Living with chronic disease
	3.3 Starting a family
	3.4 Education and work
4: Increased attention	4.1 Comments and questions
	4.2 Others staring or pointing
	4.3 Teasing and bullying
5: Attempts to conceal	5.1 Avoidance behavior
	5.2 Concealment issues
6: Treatment-related frustrations and worry	6.1 Worry and limitations
	6.2 Time consuming and frustrating
	6.3 Inconvenient and unpleasant

Table 3 Themes and data extracts¹

Themes	Data extracts²
1: Physical symptoms	<p>‘It itches and can be intense [Interviewer: Intense - how?] Well, when I can't do anything else than just stand there and scratch, scratch, scratch, and...' (P13; m, 14 yrs)</p> <p>‘It keeps flaking just by the look of it. If I touch it just slightly, it simply pours down. In fact, the state of my scalp actually determinates how good or bad a day is for me.' (P11; m, 16 yrs)</p> <p>‘Once I get it, like now, when I've got a lot on my hands, it makes me even more stressed, like "argh, now I'll get it on visible places again" and stuff (...) So, it affects everything when my psoriasis is behaving like crazy. Because then I don't want to do anything'. (P2; f, 16 yrs)</p>
2: Feeling different	<p>‘To start a new school [was tough due to psoriasis], because everybody asked questions about it, and everybody wanted to know who I was, and what made me look like that, so I had to tell everyone, and...' (P10, m, 12 yrs)</p> <p>‘I shouldn't really care when it's other people and my friends, they know that I have it, but it's psychological, I just can't (...) It affects that, I can't... I can't be myself, when I'm out with others. I can't... I always need to think about, whether people can see my psoriasis and what they would think if they notice it. Stuff like that. So it affects me a lot; I can't be myself, I can't wear a t-shirt, I can't show who I really am.' (P2; f, 16 yrs)</p> <p>‘You can do anything, but it's just, if you're to walk around not wearing a t-shirt, by the swimming pool, for example, then... You can do anything, but it all boils down to your own thoughts about what people think about you.' (P13; m, 14 yrs)</p> <p>‘I've just, several times I've just been like why me? <i>Why?! Because...</i> it makes my body look so nasty!' (P10; m, 12 yrs)</p>
3: Psoriasis-related worry about the future	<p>‘I'm also afraid of... See, my mum was diagnosed with psoriasis on 80% of her body, and my dad had it as well, like, it covered his full body; it was almost as bad as my mums'. And I'm very afraid, because I'm their child, so I'm terrified I might get as much as them when I get older.' (P8; f, 15 yrs)</p> <p>‘It bothered me a lot when the two medications I was on all of a sudden stopped working, because then you feel kind of "Argh, are there even anything else for me to try, or was this the last option?", right. And then, luckily, there was something I could try, but... you know, like I said previously, there is only a limited number of</p>

medicines out there, that are tested and stuff (...) And I might end up having to live with severe psoriasis. Because that's what I used to have, you know.' (P3; f, 17 yrs)

'The hardest thing about having psoriasis is that you need to settle with the fact that you're actually going to live with it for the rest of your life.' (P7; f, 16 yrs)

'I know that it's a relative big risk, for example if I decide to have my own children, that I will pass it on to them, and that would make me feel really sorry for them. Because I've been through it myself, and my mum has as well.' (P3; f, 17 yrs)

'[Whether] I'll manage to get a decent job, if I end up getting low self-worth again, and don't take my schoolwork seriously and stuff. I'm really, truly fearful of that. I hope it won't happen.' (P12; m, 15)

4: Increased attention

'People ask "Why are you always wearing long sleeves?" and such (...) And whether it's contagious and stuff. That's a question I get a lot.' (P2; f, 16 yrs)

'They just come and they're like "What's *thaaaat*?!" (P10; m, 12 yrs)

'I don't like it when people stare but don't ask about it. Maybe they think it's something contagious, and I just want to let them know, that it isn't, but... (...) A good day is when I can walk around wearing a t-shirt, and all the others they're just, like... they don't look and point at me.' (P8; f, 15 yrs)

'I had a lot of problems at my first, no, my second school. And then, because I was teased about my disease, my self-worth got really low, and I ended up in a lot of fights and stuff like that (...) I had a really tough time at that school (...) I stayed home from school for three months, before moving to another school' (P12; m, 15 yrs)

5: Attempts to conceal

'I don't want to go swimming or to the beach or stuff like that. And that's all because of my psoriasis. I don't mind showing it to people I know, but when it's like on public beaches, I'm not too happy about it,' (P11; m, 16 yrs)

'When we're hanging out they [my friends] always wear t-shirts and skirts or stuff like that when we're going out and stuff, but I always cover myself up and stuff. People probably think I'm weird or something.' (P8; f, 15 yrs)

6: Treatment-related frustrations and worry

'It was very uncomfortable... I had to take 8 pills once a week, and I just couldn't swallow them. I got anxious about taking them. They're not particularly big or anything, it's just really uncomfortable, and I get thoughts about "What will it do to my body?", and "Will I die of this?" or stuff like that.' (P2; f, 16 yrs)

'It wasn't until very late the effects [of the treatment] started showing. In addition, it took a lot of my time. I had to go there twice a week, so it took quite some [time] (...) about 25 minutes by bus, but normally my mother would drive me.' (P11; m, 16 yrs)

'At least once a month I have to grab a hold of him, and he simply hates it, because he finds it annoying when I put olis in his hair [takes a deep breath], and he gets totally hysterical if it starts running down his neck and stuff. He simply can't take it.' (Mother of P15)

Abbreviations: f, female; m, male; yrs, years.

¹For more detailed data extracts representing each theme and subtheme, see Appendix Tables 4-9.

²All data extracts have been translated from Danish to English for illustrative purposes.