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ARTICLE



## Caring for young people with moderate to severe psoriasis: an interpretive description of parental perspectives

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### ABSTRACT

**Introduction:** Psoriasis often sets on during childhood or adolescence, when parents have great importance for the young people's self-management, well-being, and quality of life. The aim of this study was to understand parents' perspectives on young people's daily life with psoriasis in order to improve adolescents' self-management.

**Method:** Adopting interpretive, description methodology (ID), focus group discussion, and interviews were conducted with eight parents of adolescents with psoriasis. The analysis was inductive with an iterative comparative approach. Main themes conveying participants' perceptions were identified for constructing a coherent narrative of parents' perspectives on their young people's transition with psoriasis through adolescence.

**Results:** Parents initially perceived psoriasis mainly a physical and treatment-related burden and not until late realized its socio-emotional impact. They eventually found themselves balancing between declining treatment due to fear of side effects and acknowledging the impact on their young people's quality of life and their desire for effective treatment.

**Conclusions:** Caring for young people with psoriasis is a stressful process involving experiential learning to understand and manage the complexity of psoriasis and its impact on adolescents' emotional and social life. Future research should consider integration of shared decision-making and self-management support interventions in routine daily care as focus points.

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### KEYWORDS

Psoriasis; self-management; young people; parents; qualitative

### Introduction

Adolescence is characterized by rapid physical, emotional, social, and cognitive changes. It is a demanding developmental stage and can be even more challenging for young people with long-term conditions (1). Psoriasis is common among adolescents, with one-third of all patients being diagnosed before the age of 16 (2). The disease is often mild during childhood but may develop into more widespread involvement during adolescence (3), considerably impacting on quality of life (4). During adolescence, young people struggle with the impact of psoriasis on their appearance and socio-emotional functioning (5). Their vulnerability to cumulative life course impairment due to experiences of more intense stigmatization during adolescence, and longer-term physical and psychosocial comorbidities, is now acknowledged (6).

Research on young people with psoriasis is limited (7). But research across long-term conditions points out that self-management in young people with long-term conditions is a gradual process involving changes in knowledge, attitudes, and behavior when moving from the dependency of parents toward responsibility and capability of self-management (8). Self-management has been defined as an active dynamic process of learning, trying, and exploring the boundaries created by illness, and fluctuates as life and illness itself present new challenges (9,p.265). Self-management involves management of the condition as well as emotional and social implications of illness (10). This process is greatly influenced by parents and healthcare professionals (11).

One of the most important relationships for young people is the one they have with their parents (12). This relationship influences young people's attitudes toward their condition both positively and negatively (13) and affects their self-management and acceptance of the condition (11,14). Collaborative decision-making concerning treatment is beneficial for self-management and young people's psychosocial well-being (15). However, caring for young people with psoriasis can be challenging and parents report heightened emotional distress, worry, and frustrations (16). Parents tend to underestimate the impact of psoriasis on their adolescents' emotions and social life and might unwittingly fail to offer appropriate support (17). Overall, parents are concerned about their child's psychosocial well-being and find it difficult to balance between appropriate management of their child's condition and normal adolescent development (18), as well as the parents' own need for control as opposed to their young people's need for independence.

To manage these tasks successfully, parents may need help from and a positive relationship with health care professionals (HCPs) (19). If a positive relationship between parents and HCPs is not accomplished, parents may resort to their own self-management methods with the risk of ignoring vital information (20). In clinical practice, young people with psoriasis and their parents are often in sporadic contact with the healthcare system, with consequent lack of continuity and frequent drop-out. Furthermore, HCPs may feel uncomfortable dealing with young people with long-term conditions and transition process (21).

Understanding people's illness beliefs, feelings, and attitudes is important when working with self-management support (22). Understanding the parents' beliefs, feelings, and attitudes toward their child's long-term condition is necessary when working with young people with psoriasis, because parents play an important role in the young people's health behaviors and influence adolescent psychosocial and medical outcomes (1). Knowledge of the perspective of parents to young people with psoriasis can inform clinical practice and contribute to better collaboration with less drop-out from consultations (23).

Consequently, the aim of this study was to understand parents' perspectives on young people's daily life with psoriasis with the goal of improving young people's self-management.

## Methodology

The interpretive description methodology (ID) (24) was chosen for this project due to its inductive and explorative nature which allows the researcher to draw on a combination of different data collection methods appropriate for the study. In this study, one focus group discussion, one dyadic interview, and two individual interviews were conducted. ID is particularly suitable for studies of clinical origin and relevance and aims to provide insight beyond the self-evident or superficial understanding of human experiences. A distinct ID characteristic is the iterative process of data collection and analysis meant to extend the analysis to confirm and expand on conceptualizations that begin to form when entering the field (25).

## Sampling

Data were generated from May 2014 to May 2016 at Aarhus University Hospital, Denmark, and in the participants' homes. Participants for this study were, on the one hand, sampled by virtue of their experience of being parents to young people with psoriasis, and, on the other hand, by convenience in the sense that they were the people closest at hand (24). They had been invited to participate by their young people, who had participated in a study concerning their own perspectives (17) comprising 25 young people aged 15–24 years. A total of 12 parents (eight mothers and four fathers) accepted the invitation and were subsequently contacted by phone or e-mail for further information. The first author had no previous clinical contact with any of the participant but was familiar with the clinical setting.

## Data source

Focus group method was chosen as a main method for data generation, as focus groups are suitable for exploring new fields and improve our understanding of how people think, feel, and act in relation to a topic of interest (26–28); in this case being a parent to a young person with psoriasis. The group interaction characteristics facilitate the discovery of perspectives that otherwise would have remained hidden, by participants sharing and comparing perspectives (26,29). Originally, the plan was to conduct focus groups exclusively with four participants in each of three groups. However, four participants (one mother and three fathers) dropped out due to practical reasons related to time, transportation, and family activities. As practical problems with scheduling one of the two remaining planned focus group discussions arose, it was decided to invite the four parents from this group to instead participate either in a dyadic interview (a two-participant setting), where sharing and comparison of perspectives and

opinions is still a characteristic although in the format of a two-person conversation, or in individual interviews, well knowing that this format may result in the interviewer taking more control over the dialog (28).

The focus group discussion lasted two and a half hours and was conducted in a pleasant and welcoming room in the proximity of a university hospital in Denmark. The dyadic interview and the two individual interviews took place in the participants' homes and each lasted 1–2 h. A specialist in group dynamics served as co-moderator in the focus group discussion with the first author as moderator, while the interviews were conducted solely by the first author. A questioning route for the focus group discussion was designed to ensure that topics were focused in accordance with the aim of the study. The form of this questioning route was later adapted to the dyadic and individual interviews, respectively. The scope of the topics was informed by the previous study with the young people as well as the literature. In addition, analytical reflections and preliminary themes from each session informed the following sessions. Focus was on the participants' perception of the disease, the main challenges of integrating psoriasis into daily life including management of condition and socio-emotional burden and experiences, and perspectives of seeking help and support from the health professionals. During the discussion and interviews, participants were encouraged to raise any other issues that they considered important in relation to the topic.

The study was approved by the Danish Data Protection Agency [ID no 1–16-02–376-15] and acts in accordance with the Declaration of Helsinki and UNICEF's notes on children's participation in research (30). The study does not belong under the jurisdiction of the Danish Health Research Act and was, therefore, exempted from approval from the Regional Committee on Health Research Ethics [ID no 1–15-0–72-1–11]. Respecting the young people's integrity, all initial communication with parents went through the young people and potential parental participation was decided by them. All participants received oral and written information about the study from the first author and all provided written consent. Participants were assured that withdrawal from the study would have no impact on their adolescent's treatment program. In the focus group setting, mutual oral contracts about duty of confidentiality were made.

## Data analysis

In accordance with ID methodology (24), analysis began immediately after the first data collection using an inductive and iterative process comprising four interrelated steps (see Figure 1).

1. After focus group discussion and each interview, detailed memos on immediate understandings and reflections were made. These memos were continuously developed during the entire analysis process to support the interpretation of themes and patterns. A carefully trained assistant transcribed all audio recordings verbatim into text based on written instructions. To ensure credibility in this process, each recording was listened to by the main author while reading the transcripts, and errors were corrected. NVivo 10 data analysis software (QSR International, Melbourne, Australia) (31) was used to organize the transcripts, codes, and memos. Data immersion was achieved by listening again to the recordings, rereading the transcripts, and making notes to comprehend each group or interview session.
2. In the next step, data from the focus group discussion and interviews were coded inductively by identifying initial themes and using broad-based codes (24) that were

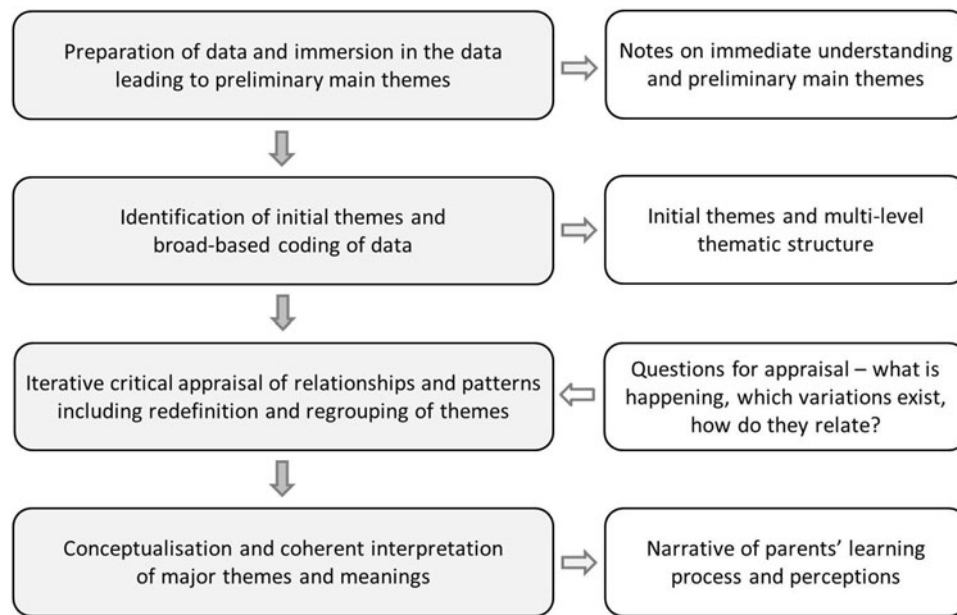


Figure 1. Data analysis process, inspired by interpretive description.

meaningful and relevant to the study purpose. Each coded data bit represented a meaning unit with an extent ranging from a few sentences to several paragraphs. Initial themes used to organize codes were 1) parents perception of psoriasis, 2) parents perception of young people's course of disease, and 3) parental roles and management. The themes and codes were discussed between the first and last author to ensure the representation of different perspectives in the analytical process.

3. In the following step of the analysis, the initial structure was put aside, as more sophisticated themes and codes were developed. These were iteratively compared, and relationships and patterns were critically appraised to identify similarities and differences. Creation of mind map diagrams was widely used to help facilitate this identification process. The process took place over a lengthy period and was facilitated by continuously asking questions to the data. During this process, data were further coded or recoded, and theme groupings were restructured or merged.
4. In the final step of the analysis, the identified patterns and thematic structure were conceptualized into one major theme and three underlying themes. To ensure validity, the identified themes were compared to the originating data. Finally, the themes and patterns were presented in the form of a coherent interpretation as a professional narrative of the ongoing learning process which the participants had been going through.

## Findings

Eight parents of seven young people (15–24 years) participated in this study: seven mothers and one father (44–52 years). Four participants reported a family history of psoriasis and two of them suffered from psoriasis themselves. They described their child's psoriasis as severe or very severe when not treated and the impact on their own quality of life ranged from none to very high. They all had several years of experience with their child's disease, three from childhood and five from early or middle adolescence (see Table 1 for further participant characteristics).

Overall, the analysis revealed that parents perceived caring for their child as an ongoing stressful learning process during adolescent development (see Figure 2). They found themselves balancing between, on the one hand, toning down the impact of psoriasis, and, on the other hand, acknowledging their young people's needs of treatment and support. In the following, we elaborate on the most significant challenges experienced by the participants.

### *Psoriasis – a stressful acquaintance*

Psoriasis disrupted family life and required parents to adapt. Participants unequivocally described their children's psoriasis as being stressful at times for the entire family. However, the stress that they experienced differed depending on age at onset, the individual course of the disease, participants' own beliefs and attitudes regarding psoriasis, and their relationship with their HCPs. Participants with psoriasis themselves experienced the additional emotional burden of having passed psoriasis on to their child. Despite having the disease themselves or knowing about the disease among family members, it made a profound impression to see the disease manifested on their own child's skin:

To see your child like this way, totally spotted all over her body [...], that, I thought, was a rather shattering experience. (Mother 1, Daughter 19 years old)

### *A solo disease*

All participants initially conceptualized psoriasis mainly as a physical and especially treatment-related burden.

The quest for diagnosis and optimal treatment was experienced as extremely stressful, with years spent trying numerous time-consuming treatments with no or little effect, striving to find answers regarding the cause of the disease and exploring alternative methods to ease the physical burden of the disease (food, detergents, special clothes, etc.). The treatment algorithms offered by HCPs were not immediately clear or understandable to the participants.

I know that doctors have their own view on things, but now and then you wonder why you must go through so much to get the right

Table 1. Participant profile.

	Female (44-52 years)	Male (48 years)	Total (44-52 years)
Selected participant characteristics, parents	7	1	8
<b>Psoriasis family history:</b>			
Yes	4	0	4
No	3	1	4
<b>Parent-reported severity of young person's psoriasis without treatment:</b>			
Very severe	4	1	5
Severe	3	0	3
Moderate	0	0	0
Mild	0	0	0
<b>Parent-reported severity of young person's psoriasis with treatment:</b>			
Very severe	0	0	0
Severe	1	0	1
Moderate	3	1	4
Mild	3	0	3
<b>Self-reported impact on parent's lifestyle:</b>			
All the time	1	0	1
Most of the time	1	0	1
Some of the time	1	1	2
Little of the time	3	0	3
None	1	0	1
<b>Rated impact on their young person's lifestyle:</b>			
All the time	2	0	2
Most of the time	2	1	3
Some of the time	3	0	3
Little of the time	0	0	0
None	0	0	0

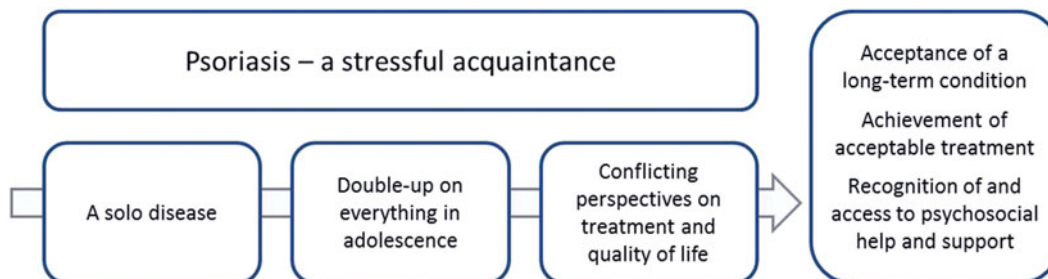


Figure 2. An ongoing learning process for the young people's parents.

medicine. It may be because she is as young as she is, but it might have saved our lives a bit earlier, perhaps. (Mother 5, Daughter 16 years old)

Some participants had experienced being reproached, also by HCPs, for insufficient improvement in their child's skin. It subsequently took years for them to gain confidence in their abilities to help their child achieve the best possible treatment. Psoriasis was described as a 'solo disease' (Father 7), reflecting the general understanding among participants that no treatment exists with equal efficacy on all individuals and the fact that parents found themselves constantly in search of a treatment that would work for their child.

The process of making sense of psoriasis and its treatment, and gradually accepting the futility of expecting recovery, was experienced as very distressing. The dream that psoriasis one day would disappear was constantly at the back of their minds. Some participants stated that although they had been informed of the condition's chronicity by HCPs, they had simply not been ready to accept the fact that their child was suffering from a life-long condition.

It was not until I participated in a psoriasis course that I understood. [...] Not until a person told me: 'Somebody has moved into your house. This is a person you haven't invited, and who has come to stay. This person will not move out again.' [...] Then I understood. Then I was able to accept it and proceed from that outset. (Mother 6, Son 15 years old)

Depending on whether this acceptance was finally acquired, or an acceptable treatment was established, parents could experience psoriasis on a stress continuum from mattering 'not at all' regarding daily life activities to mattering 'completely' when their child suffered emotionally. Participants no longer gave that much thought to physical or practical limitations and additional work imposed on them by the disease, as these burdens had become routine in their everyday lives.

#### *Double up on everything during adolescence*

During adolescence, participants experienced that psoriasis aggravated their child's condition and they became aware of its broader implications. This was unexpected, even for parents who had psoriasis themselves. Although they were aware that their child risked

being teased, they recalled that they had not initially been conscious of the emotional or social impact of psoriasis on their child.

The psychological part of it, I don't think I went much into that [...]. It didn't turn up until much later; I don't think I gave it much thought. (Mother 3, Son 22 years old)

But then, when she went to school, and it wasn't like she was being teased – well, not anything worth mentioning – someone asked her if she had porridge in her hair. [...] Then it [psoriasis] really got to her. Her self-confidence went downhill. (Mother 1, Daughter 19 years old)

Even for those young people who chose to ignore the disease and treatment, parents sensed a constant psychological burden:

It lies within him all the time. (Father 7 and Mother 6, Son 15 years old)

Participants gradually realized that beyond physical suffering, their child was carrying a heavy psychological burden. It was stressful witnessing their child 'getting the elevator eyes' (Mother 2, Son 24 years old) and see people withdrawing from him or her. Particularly when the young people began to develop interest in the opposite sex, the psychological impact of the condition became evident to parents who found that their child was sometimes prevented from living his or her life to the full with friends of the opposite sex, and that their child's sexual development and hopes for the future were affected.

I remember him once saying: 'I will never have a girlfriend.' [...] So, when a 15-years old boy says: 'I will never have a girlfriend', he has sort of ... written off some of the things other young people dream about. (Mother 3, Son 22 years old)

Participants also stated that it was very stressful watching their child focusing so much on the disease that they had no time or energy left for leisure activities or socializing with other young people.

It takes so much energy dealing with the disease and how you look that the focus shifts away from ordinary teenage stuff [...] to trying to avoid being seen and touched. [...] It has been tremendously hard for her. [...] The rest of us can put up with this alright ... but the thing is that this is more than double on top of everything, isn't it? (Mother 1, Daughter 19 years old)

The participants realized that the visibility and extensive effects of the disease were more important to their children than they had themselves realized and that they had reached this awareness too late. The hardest thing was realizing that they had not always been providing sufficient help for their child.

### **Conflicting perceptions of treatment and quality of life**

Participants emphasized that choosing between treatment options for their child was conflictual and complex. Some had chosen to keep their child entirely out of treatment. One reason given for this was the HCPs' lack of compassion and failure to engage in proper, serious dialog about the condition. Another reason was the parents' own experience of insufficient efficacy or side effects of various treatment options. Some did not want to take responsibility for a treatment they did not trust, or simply did not like all those medications.

I have tried to protect my child against ... or, to put it another way, I have not had the courage to take responsibility for saying that, of course, you get treatment because you can't go around looking like that. Well, I had thought that 'it doesn't matter how you look because you are a lovely child', but it doesn't quite work like that when you are a teenager, and somehow, I knew that. (Mother 1, Daughter 19 years old)

The participant quoted above acknowledged that her daughter had achieved a much better life when she herself chose treatment as an 18-year old, upon reaching the age of maturity.

Participants stated that helping their children through adolescence to remain whole human beings was their most important job. However, they acknowledged conflicting perspectives between themselves and their children. They had to consider whether they should follow their own beliefs and disavow treatment for fear of side effects or yield to their child's demand for treatment to improve his/her quality of life.

They must be able to function in their everyday lives, so the dilemma is to what extent you should apply things you don't like versus the fact that they must experience having a good quality of life. (Mother 4, Daughter 15 years old)

I am really scared by the things they put into her body, but it's also fair to say that she has no life without treatment. (Mother 5, Daughter 16 years old)

Embedded in these considerations were worries about how their child might manage future studies, a job or establishing a family. It was not until the child confronted their parents by demanding a better quality of life or chose to receive a treatment that their parents had not dared accept that the participants realized the psychological and social impacts of psoriasis on their child's everyday life.

The problem is that what you must treat is not only what you see; it's the psychological burden as well. This was what we encountered when we received a mail from our son with three simple sentences about his quality of life. Then I realized that this was the signal. We had to try much more drastic medication. (Mother 3, Son 22 years old)

Another consideration about conflicting perspectives was how to balance the level of information about having psoriasis to other people. Some parents depicted having tried to tone down the impact of the disease to normalize the situation for their young people and themselves, as they felt an obligation to maintain a positive picture of life, the disease, and the future, and to focus on opportunities rather than limitations. On the other hand, they felt that it was their duty to prepare their young people for managing other people's reactions to their appearance. This could be experienced as a very emotional task, as it implied that as a parent you might feel repelled by the physical impression of the disease, and that you conveyed this perception to your child.

Somehow, you are actually telling your child that you think he is a bit unsavory when he leaves blood and scales on the toilet seat. Well, it sounds a bit harsh, but that is basically what you tell him. (Father 7, Son 15 years old)

## **Discussion**

In this study, we sought to understand parents' perspectives on living with their young people's psoriasis. Overall, we found that parents' understanding, acquisition of skills, and adaption in relation to management of their child's psoriasis depict an ongoing learning process toward acceptance of their child having a long-term condition, achieving acceptable treatment, and recognizing and gaining access to psychosocial help and support. This is in line with previous research on family adaptation to and coping with childhood chronic illness (20,32,33).

Our study highlights psoriasis as source of emotional stress to parents. Furthermore, it indicates that HCPs may fail to recognize parents' distress, causing parents to seek information elsewhere, independently decide to stop or adjust treatment, or engage in other interventions inside or outside the healthcare system. These findings are in accordance with the findings of other studies (20,34,35), suggesting that parents of children with atopic

dermatitis or eczema experience that their child's condition is not taken seriously by HCPs.

The parents in our study reported that they did not receive the needed information on treatment options, or they felt left alone to make treatment decisions on a trial and error basis, beyond what they felt capable of or comfortable with. This is problematic as parents mediate healthcare-related knowledge to their child (20) and poor communication between parents and HCPs may impair the development of self-management skills in adolescents (11).

Notably, our findings indicate that parents' decisions about treatment were not motivated by purely medical aspects, but should be understood as a complex bio-psychosocial process. Similarly, other authors have found that the extent of parents' involvement and active choices in treatment is based on several factors including their views on their information needs, relationship with HCPs, the opinions of others in their social networks, and their beliefs and feelings about medication (36,37). However, a narrative review from 2012 documents that the majority of parents prefer to actively take part in the decision-making, and argued that assessment of the parents' preferences, skills, and needs is crucial to support parents in their decision-making process (36).

We found that parents had experienced a contrast between their adolescent's focus on short-term quality of life and their own focus on long-term treatment-related risks. This is in line with a previous study (37) that investigated influences on treatment choices in young people with juvenile arthritis or inflammatory bowel disease. According to the Necessity–Concerns Framework (38), treatment perception is just as important as illness perception when determining patients' treatment-related decision-making. The framework comprises a necessity concerns dilemma when considering personal judgments about the need for treatment in relation to current and future health as opposed to concerns about potentially negative consequences (39). As our findings as well as others clearly illustrate, treatment cognition is important in this context. We found that parents focused on physical impact on the skin and their concerns about potential side effects of treatment, while to their adolescents, appearance, and stigmatization weighed more heavily. This is supported by a recent review of the literature across chronic skin conditions underlining that adolescents highlighted the negative social impact and stigmatization as 'the greatest difficulty,' while parents' concerns were primarily related to the physical burden and potential side effects of treatment (40). We also found that in childhood and early adolescence, parents had relied on their own preferences and goals regarding the child's treatment and care, as their child's preferences and decision-making capacities were limited in this developmental period, and that some parents had continued to do so during adolescence. However, collaborative decision-making between parents and young adolescents is shown to be beneficial (15) and a recent study has shown that adolescents do recognize the need not only for short-term but also for improved long-term perspectives (41). Significant differences have been documented in how adolescents (12–19 years) with a variety of chronic diseases and their parents perceive the adolescents' health-related quality of life (42). These differences are inclined to increase with ascending age of adolescents, as parents of older adolescents tend to overestimate the adolescents' quality of life. Thus, parents may find it difficult to make optimal decisions on when and how to involve their adolescents in treatment-related decisions and may tend to consider the necessity for treatment to be mainly skin-related and not an important factor in the prevention of emotional and social distress related to appearance.

Our findings did not uncover to what extent parents' decisions on treatment or other initiatives impacted their adolescent in the long term. However, it seems reasonable to assume that undertreatment of the skin during adolescence may add to the socio-emotional long-term burden of psoriasis (43). Thus, improved decision-making may only be accomplished when we understand how parents make medical and supportive decisions for their child or adolescent and when decision-making is shared between parents, adolescents, and HCPs.

### *Limitations and strengths*

Although steps were taken to ensure an open-minded approach to the parent perspective through the involvement of the co-moderator and coauthors, a limitation of this interpretive inquiry is that it included only seven mothers and one father. This was partly due to the recruitment principle that access to parents required permission from the young people in our previous study who were free to decide whether mothers and fathers could be accessed. With this gender distribution, our findings primarily reflect the perspectives of the mothers and do not fully take the different parent roles and family dynamics into consideration. Furthermore, it may be a limitation that participants generally had been seeing HCPs in a variety of clinical settings and locations. Although this variety may be helpful to understand the complexity of their experiences and perspectives, it may also complicate the process when trying to identify the participants' needs for supporting their young people from the hospital clinic.

The study provides a picture of the parents' perspectives at that specific time. The participants were asked to tell their stories back from the time when they first experienced their child's psoriasis. It can be discussed whether the parents' early experiences with the healthcare system may be transferable to present conditions. Although general knowledge about parents' needs of support has increased, it is still important to understand their individual needs especially during their child's transition into self-management (44,45). Although in our study some years had passed since the participants' first experiences, their stories are valuable. It may be both a strength and a limitation that participants have developed their point of view over time. A strength, because they may have developed a more reflected view of the special situations they had been living through, and a limitation, because they may have forgotten important information.

The strength of this study lies in its rigorous qualitative methodology, applied to explore an area of limited research in Denmark. In accordance with ID methodology (24), the combination of different data collection methods provided a well-suited approach to gain insight into the participants' perspectives on their young people's psoriasis. In particular, the discussions with the other participants in the focus group and the dyadic interview helped to reveal how the disease and the young people's challenges were articulated by the participants. The moderator, interviewer, and co-moderator were not known to the participants in advance, and this may have facilitated a more open and free dialog.

### *Clinical implications and future research*

Despite the small sample size, our study offers important knowledge for clinical practice. The findings may help HCPs to understand the stressful learning process experienced by parents. Parents' struggles with adapting to their child's psoriasis reflect the complexity of psoriasis management, as many individuals

with psoriasis may need several types of therapy over the course of their condition (46). Thus, parents could benefit from being offered interventions repeatedly and from an early stage to help them with anticipating the probable course of psoriasis and its possible impact on their child, and to develop decision-making skills for clarifying treatment goals and support needs. It is important that HCPs acquire an understanding of the benefits of supporting parents to become skilled and confident in caring for adolescents with psoriasis, as this influences self-management skills and long-term outcomes for young people. Training in communication skills and the involvement of parents and their young people in shared decision-making is fundamental for providing self-management care (47) and maintaining effective clinical relationships during this period (48). In Denmark, this need is amplified by the fact that healthcare for young people with psoriasis and their parents is provided in adult settings where HCPs are not necessarily prepared for or educated to supporting parents and young people's needs (48).

Our findings also highlight the conflicting perspectives attached to caring for a young person with psoriasis and the potential discrepancies between parents' and young people's focus. Parents may need support from HCPs to identify which difficulties are linked to the burden of psoriasis and which are typical of adolescence in general (18). We found that parents generally underestimated the biological and psychosocial impact of psoriasis on their children, suggesting that HCPs could actively seek to uncover parents' illness and treatment perception and facilitate discussion between parents and adolescents in order to ensure that optimal and shared treatment decisions are made for the young people (49). As recommended within appearance-related research (50), parents should be involved in active discussion of their ability and needs for help to support their young people during transition within routine care. This involvement of parents should be understood as an ongoing and individual process that continuously builds on parents' growing skills and experiences with the disease and its impact on their adolescent's life (51).

Since parents often experience lack of support from HCPs, future research could aim at clarifying more specifically which supporting interventions parents feel the want of, as well as identifying potential barriers for development of a positive parent-HCP relationship and ability of HCPs to provide useful interventions for supporting parents to improve adolescent self-management and well-being. Co-creation may be a useful approach to include the perspectives of parents, adolescents, and HCPs. Development of tools to assist HCPs in assessing parents' skills, needs, and preferences (36), as well as their illness and treatment perception, and to facilitate shared decision-making, is a further perspective.

## Conclusion

This study provides insight into some concerns and challenges of parents of young people with psoriasis. It reveals that parenting adolescents with psoriasis is a process involving experimental learning to understand and manage the complexity of psoriasis and its impact on adolescents' emotional and social life. It elucidates parents' self-management strategies and underlines that their beliefs about disease and treatment may greatly impact their child self-management and well-being. Their perception and feelings were seldom heard, and they often felt left alone with frustrations, worries and unsolved conflicts and concern. HCPs should be aware of the emotional stress that parents experience and actively seek to uncover the illness and treatment perceptions of parents as well as those of their young people to support shared

decision-making and the development of self-management skills. Future research should focus on how to integrate shared decision-making and self-management support interventions directed toward parents in routine clinical practice.

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