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ORIGINAL ARTICLE

Care for children with severe chronic skin diseases

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Abstract

In this study, the care for children with a severe chronic skin disease in our national expert center of pediatric dermatology was evaluated. Patients and their parents were questioned by using existing questionnaires: 50 pediatric patients completed the modified "my positive health" questionnaire of Huber and 51 parents completed Pelentsov parental needs scale. Nineteen involved professionals answered a questionnaire with open boxes. Parents of children with a variety of chronic skin diseases and young adult patients were interviewed to find out what an optimal approach would look like according to them. Children with a severe chronic and/or congenital skin disorder score high on the "my positive health" questionnaire, indicating they are able to adapt and self-manage. Their highest median score was measured for the dimension "quality of life." Their parents expect improvement of "working with health care professionals," more specifically they want them to adopt a more holistic approach throughout the patient's life. Structured interviews showed they expect that a multidisciplinary team of care providers determine together with the patient and its family—in advance—which care is needed, at what time and by whom. The interviewed professionals indicated adoption of a holistic multidisciplinary approach as the single largest improvement to achieve better care.

Conclusion: Although these children with a severe chronic and/or congenital skin disease were able to adapt and self-manage, they need a more personalized integrative multidisciplinary and systematic transmural approach covering all aspects of life during their lifetime.

What is Known:
- *Severe skin disorders affect the child and its family in several ways. In our expert center, we try to optimize the care for these children through a multidisciplinary approach.*

What is New:
- *To our knowledge, no English publication describes the requirements for good care for pediatric patients with severe chronic skin disorders and how to optimize this care. We evaluated the health status of children with severe chronic skin disorders and the strengths and weaknesses of past and current care by questioning these children, their parents, adult patients, and involved professionals.*

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Keywords Pediatric dermatology · Severe congenital skin disorders · Multidisciplinary approach · Evaluation of care · Quality of life

Abbreviations

CDLE	Chronic discoid lupus erythematosus
CLOVES	Congenital, lipomatous, overgrowth, vascular malformations, epidermal nevi, and spinal/skeletal anomalies and/or scoliosis
CMN	Congenital melanocytic naevus
DIM	Dimension
ED	Ectodermal dysplasia
e.g.	For example
Erasmus MC	Erasmus University Medical Center
etc.	Etcetera
F	Female
IFAP	Ichthyosis follicularis, alopecia, and photophobia
IPEX	Immune dysregulation, polyendrocrinopathy, enteropathy, X-linked
LUMBAR	Lower body hemangioma, urogenital anomalies, myelopathy, bone deformities, anorectal malformations, renal anomalies
M	Male
N/A	Not applicable
Pt	Patient
SWS	Sturge-Weber syndrome

Introduction

Severe skin disorders affect the child and its family in several ways: in addition to the medical aspect, there are psychosocial and financial aspects as well.

A literature search concerning the health status of pediatric patients with severe chronic and/or congenital skin disorders resulted in studies describing the quality of life of frequently occurring skin conditions. The majority of existing research has focused on acne, atopic dermatitis, hemangiomas, ichthyosis, psoriasis, and vitiligo [4]. In their meta-ethnography and review article, Ablett and Thompson describe parental, child, and adolescent experience of chronic skin conditions [1].

Concerning patient care, most of the current literature on quality improvement in dermatology focuses on the adult population. Only one recent study evaluated patient satisfaction in pediatric dermatology and concluded that the patient-physician relationship significantly contributes to the patient experience in pediatric dermatology, as does the cheerfulness of the practice and its sensitivity to patient needs [2]. The study did not make a distinction as for the severity of the skin disorder.

The literature search furthermore resulted in guidelines for management of different skin disorders as atopic dermatitis, psoriasis, epidermolysis bullosa, urticaria, mastocytosis, and systemic lupus erythematosus [5, 6, 9–11]. The vast majority of these guidelines focuses on the treatment of the chronic skin condition in its active phase. One case report described the multidisciplinary approach to a child with incontinentia pigmenti in a 5-year follow-up program [13].

To our knowledge, no English publication describes the requirements of good care for pediatric patients with severe chronic skin disorders and how to optimize this care. We approach these patients and their family in a multidisciplinary way. In this project, the health status of the pediatric patients with severe chronic and/or congenital skin disorders was evaluated. In addition, the strengths and weaknesses of the past and current care were measured, both from the point of view of the patients and their parents, as well as from the point of view of the involved professionals.

Materials and methods

Questionnaires/interviews

To evaluate the health status of the pediatric patients, the model of positive health developed by Machteld Huber was used. It describes health as “the ability to adapt and self-manage.” The model of positive health questions the patient’s physical condition, his sense of self-esteem, resilience, and self-management by displaying 6 dimensions: physical functioning, daily routine, mental health, social participation, meaning, and quality of life. Each dimension is made up of several questions (39 in total) [8]. The existing questionnaire was modified after permission of Huber by adding the domain “skin,” which included 17 additional questions (Table 1) that were developed by our steering group (consisting of 2 pediatric dermatologists, 2 pediatricians, 1 rehabilitation doctor, 1 psychologist, 2 dermatology nurse specialists, and 1 adult patient with a severe congenital skin disorder). The questionnaire was used for all the pediatric age categories. Since a few questions are irrelevant for young children, a column “not applicable” (N/A) was added. The parents were asked to complete the list for their child if the patient was < 4 years old and to complete the list together with their child if the child was between 4 and 8 years. Children ≥ 8 years were advised to try to complete the questionnaire themselves. At the end of the questionnaire, 3 open questions were asked (“what do you think is good in health care?”, “what do you think can be better in health care?”, and “suggestions for solutions?”) and an open box for comments was included (electronic supplementary material). The individual score for each patient for each dimension was calculated, as well as a total score on the “my

Table 1 Domain “My skin” from the “my positive health questionnaire”

My skin	Not true		Completely correct			Not applicable
	1	2	3	4	5	N/A
1. I am happy with myself and my skin	O	O	O	O	O	O
2. I have no itching	O	O	O	O	O	O
3. My skin does not burn/does not hurt	O	O	O	O	O	O
4. I sleep well with my skin (disorder)	O	O	O	O	O	O
5. With my skin (disorder) I can exercise like my peers	O	O	O	O	O	O
6. With my skin (disorder) I can play like my peers	O	O	O	O	O	O
7. With my skin (disorder) I can participate in social activities like my peers	O	O	O	O	O	O
8. With my skin (disorder) I can study well	O	O	O	O	O	O
9. With my skin (disorder) I can wear the clothes/shoes that I want	O	O	O	O	O	O
10. I like to treat my skin	O	O	O	O	O	O
11. I treat my skin as advised by the doctor	O	O	O	O	O	O
12. I have no pain while treating my skin	O	O	O	O	O	O
13. I do not argue about the treatment of my skin	O	O	O	O	O	O
14. I am not afraid of side effects of the treatment of my skin because I know how to perform the treatment	O	O	O	O	O	O
15. I can deal with the fact that the treatment of my skin takes a lot of time	O	O	O	O	O	O
16. I can deal well with comments from others about my skin	O	O	O	O	O	O
17. I like to be cuddled/touched	O	O	O	O	O	O

positive health” questionnaire. In addition, the average and the median scores for all patients for each dimension were calculated. If more than half of the questions for a dimension were answered as “N/A,” this dimension was not included in the calculations (overall average score of the patient, average and median results of the patients per dimension).

Pelentsov et al. developed a “parental needs scale for rare diseases” to measure the supportive care needs of parents caring for a child with a rare disease. In this scale, 4 sections are covered: understanding the disease, working with health care professionals, emotional issues, and financial needs [12]. Pelentsov confirmed “the parental needs scale for rare diseases” could also be used to question the parents of pediatric patients with a chronic (mostly congenital) severe skin disorder. With his permission, the scale was translated to Dutch. An open box was added at the end of the questionnaire (electronic supplementary material). The individual score for each parent per section was calculated and an overall needs scale was calculated for each parent. The average and median of all parents were calculated per section, as well as for the overall needs scale.

Based on open questions, the experience of involved health care professionals was questioned, as well as their ideas for improvement of health care, both in the past and present. In addition, suggestions for solutions were asked (electronic supplementary material).

The questionnaires for patients and parents were sent by post and those for professionals by email. Patients, parents, and professionals who had not answered the questionnaire after 2 weeks received a reminder by email.

In addition, parents and adult patients were invited to participate in structured interviews that were led by an experienced professional of our steering group. Four structured interviews took place in the Erasmus MC – Sophia Children’s Hospital. Through open questions, a conversation was initiated to find out what an optimal approach would look like.

Respondents

We included pediatric patients (age < 18 years) with a chronic (mostly congenital) severe skin disorder, known within the center of pediatric dermatology of the Erasmus MC University Medical Hospital Rotterdam – Sophia Children’s Hospital. A total of 77 patients and their parents were included. We also contacted 17 adult patients (age ≥ 18 years) with a severe chronic skin disorder as “experts.” A total of 33 professionals involved in the care of children with severe chronic skin disorders were contacted: pediatric dermatologists, pediatricians, rehabilitation medical specialists, psychologists, and dermatology nurse specialists.

Four structured interviews took place: two with parents (4 respectively 5) of children with congenital melanocytic naevi (CMN), one with adult patients (4 patients with Netherton syndrome), and one with a composite group of an adult patient (with Netherton syndrome, who was president of the patient network) and the father of a pediatric patient with ichthyosis.

Results

Fifty out of the 77 "my positive health" questionnaires for pediatric patients were returned (50/77, 65%): 22 children were male and 28 were female, all aged between 7 months and 17 years. For these 50 respondents, 16 different diagnoses were made (Table 2(a)).

The median scores of all the patients on the different dimensions ranged from 7.5/10 to 9.9/10. These results are displayed in the spider web in Fig. 1a. The lowest median score was measured for the first dimension "my skin." The highest median score was measured for the fifth dimension "quality of life." The overall median of the average scores of all patients on all dimensions was 9/10. The individual overall average score fluctuated between 6.4/10 and 10/10. Three patients achieved a maximum overall score: a 9-month-old boy with SWS and a boy and girl (of 2 and 3 years old) with a CMN. As these 3 patients were young, their questionnaires were completed by their parents. The lowest overall mean score (6.4/10) belonged to a 7-year-old patient with a severe form of ichthyosis.

We elicited opinion from 17 adult patients. Nine of them completed the "my positive health" questionnaire (9/17, 53%): 5 were male and 4 were female, all aged between 18 and 68 years. For this group of 9 adult patients, 3 diagnoses were made (Table 2(b)).

The median score of their responses on the different dimensions ranged from 5.5/10 to 8.5/10. These scores are displayed in the spider web in Fig. 1b. The lowest median score was measured for the second dimension "bodily functions." The highest median score was measured for the fifth dimension "quality of life." The median result for the dimension "my skin" was 6/10. The overall median of the average scores of all patients on all dimensions was 7.3/10. The individual overall average score fluctuated between 5.1/10 (a 42-year-old woman with ichthyosis) and 8.5/10 (a 23-year-old man with Netherton syndrome).

For the individual scores of the pediatric and adult patients on each dimension, as well as the average score on the "my positive health" questionnaire, we refer to the electronic supplementary material.

Out of the 79 sent questionnaires for parents (parental needs scale for severe chronic skin diseases), 51 were returned (51/79, 65%) (Table 2(c)). Most respondents were mothers ($n = 39/51$, 76%); 3 questionnaires were completed by both parents ($n = 3/51$, 6%).

The median overall needs score was 21.9/100. The needs score for the section "understanding the disease" was the lowest: median 1.6/25. The median needs score for the section "working with health care professionals" was the highest: 9.4/25. The median needs score was 4.2/25 for the section "emotional issues" and 6.2/25 for the section "financial needs." In addition, parents indicated the need for the following services: financial advisor, neighborhood team, psychological counselor, patient network, genetic counsel, or family planning. The individual scores of parents are shown in the electronic supplementary material.

Nineteen of the 33 (19/33, 58%) professionals who were contacted answered the questions about care for children with severe skin conditions (Table 2(d)). They suggested the following for improvement of care: regular and low-threshold interdisciplinary advice, further improvement of multidisciplinary approach, a case manager, more time per patient (= more attention for psychosocial factors), proactive offer of a psychosocial treatment context that focuses on (neuro) psychological development, enforcement of the resilience of families on how to deal with a visible condition in the family situation, more consultations, more secretarial support, further development of care pathways and nursing at home.

The answers given by pediatric and adult patients, by parents, and by professionals to the open questions are shown in Table 3.

Table 4 shows the results of what an optimal approach would look like according to the participants in the structured interviews.

Discussion

In this study, we evaluated the health status of children with severe chronic and/or congenital skin disorders and measured the strengths and weaknesses of the past and current care, both from the point of view of the patients and their parents, as well as from the point of view of the involved professionals. The modified "my positive health" questionnaire of Huber was used to evaluate the health status of these children. The 50 pediatric patients who completed the questionnaire achieved an overall median score of 9/10. This means that they experience their own health—in the broad sense—as good and that they are able to adapt and self-manage. Their highest median was scored on the dimension "quality of life." The parents were questioned by using Pelentsov parental needs scale. Based on the 51 returned questionnaires, the median overall general needs score was 21.9/100. This overall needs score is obtained by summing the four subscales together: "understanding the disease," "working with health care professionals," "emotional issues," and "financial needs." An overall needs score of 0/100 means there is no need for supportive care; an overall needs score of 100/100 indicates an immense need for supportive care. The highest median needs score was achieved for the section "working with health care professionals." This implies that parents are dissatisfied about working with health care professionals. The median needs score for the section "understanding the disease" was the lowest, which means that parents can confidently explain their child's disease and respond to questions about it. Although the symptoms and needs of the affected children are heterogenous, their parents' supportive care needs are likely to be homogenous.

Table 2 Description and number of responders who completed the questionnaires: (a) pediatric patients; (b) adult patients; (c) parents; (d) professionals

(a) Pediatric patients who completed the modified "my positive health" questionnaire

Diagnosis	Number of patients
Ichthyosis	12
Congenital melanocytic naevus	10: 8 large and 2 medium sized
Sturge-Weber syndrome	4
Vascular malformation	4
Ectodermal dysplasia	4
Cutaneous mastocytosis	3
IFAP syndrome	2
Netherton syndrome	2
Severe eczema (treated with ciclosporine)	2
LUMBAR syndrome	1
CLOVES syndrome	1
IPEX syndrome	1
Chronic discoid lupus erythematosus	1
Hereditary fibrosing poikiloderma	1
Severe scleroderma	1
Erythroderma (casus pro diagnosi)	1
TOTAL	50

(b) Adult patients who completed the modified "my positive health" questionnaire

Diagnosis	Number of patients
Netherton syndrome	5
Ichthyosis	3
Klippel-Trenaunay syndrome	1
TOTAL	9

(c) Parents who completed the modified parental needs scale for severe chronic skin diseases

Age category of the child	Diagnosis of their child	Number of completed questionnaires
< 4 years	Ichthyosis	5
	Sturge-Weber syndrome	3
	Cutaneous mastocytosis	2
	Congenital melanocytic naevus	4
	IFAP syndrome	1
	LUMBAR syndrome	1
	CLOVES syndrome	1
	ED	1
	Erythroderma	1
	Subtotal	19
4–8 years	Ichthyosis	6
	Sturge-Weber syndrome	1
	Cutaneous mastocytosis	1
	Congenital melanocytic naevus	1
	Hereditary fibrosing poikiloderma	1
	Netherton syndrome	1
	Vascular malformation	1
	Subtotal	12
8–18 years	Ichthyosis	1
	Congenital melanocytic naevus	4
	IFAP syndrome	1
	Severe scleroderma	1
	Severe eczema	2
	Netherton syndrome	1
	Vascular malformation	3
	ED	3
	CDLE	1
	IPEX syndrome	1
	Subtotal	18
> 18 years	Netherton syndrome	1
	Ichthyosis	1
	Subtotal	2
	Total	51

(d) Professionals who completed our questionnaire

Profession	Number of responders
(Pediatric) dermatologists	5
Pediatricians	7
Dermatology nurse specialists	3

Table 2 (continued)

Psychologists	3
Rehabilitations doctor	1
TOTAL	19

Structured interviews were conducted with parents of children with a variety of chronic skin diseases and with young adult patients in order to explore their view on an optimal approach. The suggestions in the open boxes in the questionnaires were also used. The following needs were mentioned for an optimal approach: more structured information about the disease, a multi-year plan instead of incidental control, more contact between parents and children who have the same disease (important role for the patient network), and attention for psychosocial aspects in patient and its family. Parents expect that a team of care providers determine together with the patient and its family in advance which care is needed, at what time and by whom. The 19 interviewed professionals mentioned the importance of e-health and social media and they indicated adoption of a holistic multidisciplinary approach as the single largest improvement point (both in the open boxes and in the structured interviews) to achieve better care. We conclude that a child with a severe chronic and/or congenital skin disease requires a more personalized integrative multidisciplinary and systematic transmural approach covering all aspects of life during their lifetime [7].

High quality of life against all odds

Although this may seem counterintuitive, the results of the "my positive health" questionnaire show an excellent score in terms of quality of life. The general population, physicians, and other health care workers may perceive that people with disabilities have a poorer quality of life. However, when people can develop successful strategies for coping, impaired functioning does not strongly change the perceived quality of life. This phenomenon is known as the "disability paradox." This term was first used by Albrecht and Devlieger in 1999. Their analysis revealed that quality of life is dependent upon finding a balance between body, mind, and spirit in the self and on establishing and maintaining a harmonious set of relationships within the person's social context and external environment [3]. We believe the disability paradox explains the gap between the perception of the quality of life, which—in contrast to the general perception—is deemed very high by our population of kids.

Who has the problem?

The question could be raised whether the care for children should be improved, given that the scores on the "my positive health" questionnaire are quite good. Is the health care professional the only person involved who believes care for children with a severe chronic skin disease should be improved? This hypothesis can be refuted by the results of the questionnaire for parents of children with severe chronic skin conditions. The median overall needs score was 21.9/100, with the highest median sub-score for the section "working with health care professionals." In addition, from the structured interviews

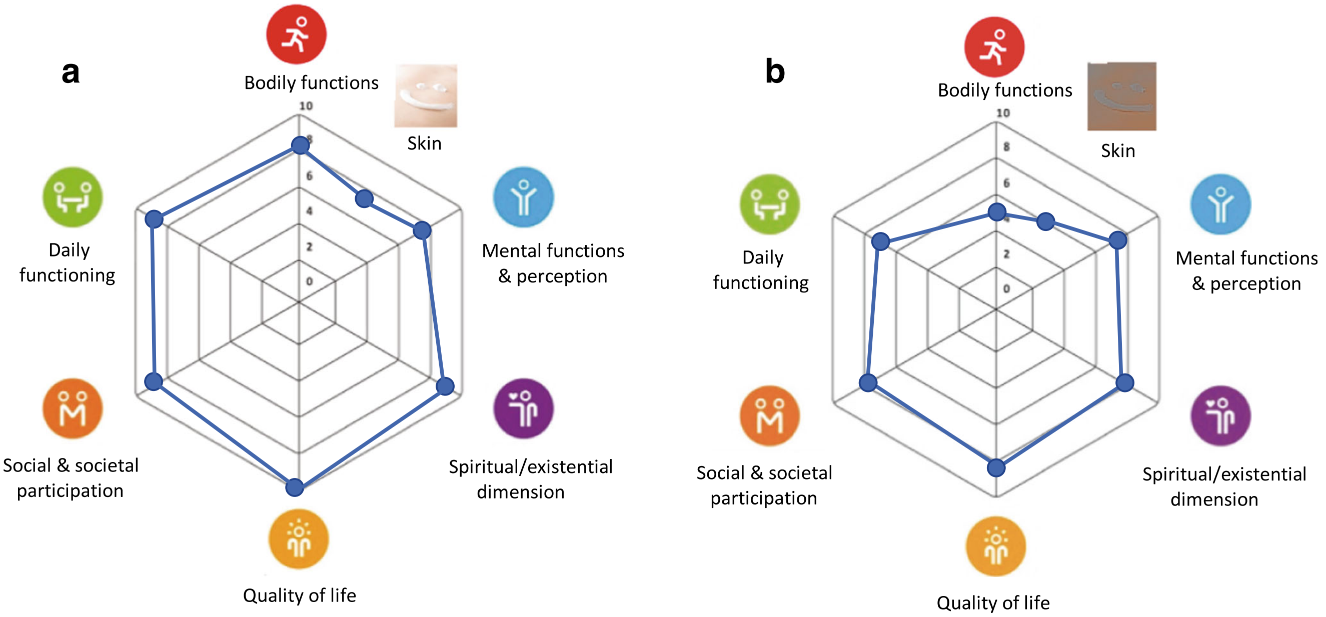

Fig. 1 Spider web with median scores on the dimensions of the "my positive health" questionnaire. **a** Pediatric patients. **b** Adult patients

Table 3 Opinions of the pediatric patients, adult patients, parents, and professionals

	What goes well in health care	What can be better in health care
Pediatric patients		
Present	- More technical possibilities	- Communication
		- More customization to avoid waste
Adult patients		
Past	- Parents were well informed	- Doctor did not listen to patient
	- Reachability of doctor	- Less knowledge about the condition
	- Attention for symptomatic treatment	- Psychological treatment of patient/parents/family
Present	- More research	- Knowledge about rare skin diseases
	- Multiple treatment options	- Psychological treatment of patient/parents/family
	- Doctors listen to patient - Shared decision-making	- Financial help
	- Health care professionals work together	
	- Accessibility of doctor	
	- Digital patient file: easy to reach professional, easy for professionals to discuss	
Parents		
Past	- Complete examination of our child (anamnesis, clinical examination)	- Communication (with parents, between professionals)
	- Less organizational pressure - Less costs	- Knowledge of professionals about rare skin diseases (referral to colleague if not familiar with the condition)
Present	- Good explanation	- Communication (with parents, between professionals)
	- Shared decision-making	- Specific treatments/rules for the condition of our child
	- A lot of consultations, extra mail contact if necessary	- Information/updates about possible studies that may lead to improvement/healing in the future
	- Doctor's involvement	- Different appointments are not clustered
	- Patient day (organized by pediatric dermatology department): child meets other children suffering from the same skin disease, health care professionals are easily accessible for questions	- High organizational pressure
Professionals		
Past	- More doctors/nurses per patient	- No multidisciplinary approach in diagnostic/ therapeutic phase
	- More time for the patient	- No shared decision-making
	- Warmer contacts thanks to less administration	- No/less attention for the patient and his family and for psychosocial aspects in patients and their parents
	- Better acceptance of serious diseases (by parents/the society/professionals)	- No attention for neglect (e.g., for under-treated eczema)
Present	- More guidelines	- Unanimous approach (regardless of which specialist the child consults)
	- Better communication, shared decision-making	- More holistic approach
	- Attention for psychosocial aspects, whole family is involved	- More intense cooperation
	- Empathy and acceptance for severe skin diseases	- Better relation between doctor and patient (which will lead to a better compliance, more continuity)
	- Multidisciplinary approach	- More attention for psychosocial aspects and relation between parents and children
	- e-health and social media	- More help at home (e.g., from nurses)
		- Financing of therapy

and suggestions in the open boxes, it is clear that parents of a child with a severe chronic and/or congenital skin disease want a personalized integrative multidisciplinary approach covering all aspects of life.

Medical, psychosocial, and financial aspects affect the child and its family in different ways. Similar findings were reported in the review by Ablett and Thompson about "parental, child, and adolescent experience of chronic skin conditions." In this review, the experience of childhood skin conditions as eczema, psoriasis, and acne were investigated. Their findings highlight that parents experience social, psychological, and practical burdens as a result of caring for their child

Table 4 Optimal approach according to the participants (adult patients, parents, and professionals) in the structured interviews

An optimal approach:

- starts at birth and evolves with the patient during the whole life
- must aim to ensure that every child with a severe skin disorder should receive essentially the same care
- adjusts specific needs adapted to the specific skin disorder/to preferences of the child and his parents
- provides following of the patient in an expert center
- provides a fixed evaluation moment (instead of incident control) with a central health care provider every 2–3 months (more frequently if needed) to evaluate how the patient and his family are doing, what problems are the most important at that moment, which support can help
- provides a "central person": the pediatrician or the dermatologist. He/she assesses which expertise is needed at what time (physical therapy, psychologist, dietician, social worker, financial advisor…).

There must be at least one conversation with the psychologist and with the social worker in the approach of each patient. Attention must be paid to the needs of parents and siblings of the child with the severe skin disorder.

- provides information (e.g., on the risk and benefit of treatment) to support/justify decision-making
- provides unanimous advice
- provides multidiscipline patient visit at the clinic
- questions the network (this is the responsibility of the general practitioner, "central person" or social worker)
- involves the patient network (moral support by sharing knowledge and experience, provision of information on the natural history of the skin disorder and the possible treatments and outcomes)
- includes the annual completion of questionnaires to screen the health of the child and the needs of the parents

and that the child's skin condition may impact the parent-child relationship [1]. This is also our experience in daily practice. The answers on the questions at the end of the parental needs scale confirmed this. For example, 30% of the parents indicated the need for a psychological counselor and 25% indicated the need for a social worker.

Based on our data, not only professionals, but also children with severe chronic skin conditions and their parents think that care needs to be improved.

Strengths and limitations of current study

As far as we know, our study is the first to evaluate the care of children with severe skin diseases from the perspective of the patients, their parents, and the involved professionals. We adapted the questionnaire of Huber to include skin disease-specific issues. The questionnaires for patients and parents are easy to use. Moreover, they are dynamic tools, which is extremely important since the impact of the skin condition and the parental needs are likely to vary according to the child's developmental stage. The percentage of responders among patients and parents and the professionals were 65% and 58% respectively, which is high.

Despite these strengths, the study has limitations that should be taken into consideration. Recruitment challenges and sufficiently large sample sizes are a frequent problem for researchers in the area of rare diseases such as severe chronic and/or congenital skin disorders, with the current study confirming these findings. The survey was conducted in Dutch, which implies there might have been parents and/or patients with another native language who were unable to complete the questionnaires. This might have resulted in a response bias. Furthermore, (parents of) children with a severe disease and time-consuming care may not have enough time left to respond to this survey. In addition, it is possible that parents of young children, who completed the questionnaires for or with them, assessed their quality of life higher than it actually was.

Most respondents on the questionnaire for parents were mothers. The majority of them (62%) were married, 15% lived with a partner, 10% were divorced, and another 10% were single. One mother was a widow. As fathers accounted for a smaller number of survey responses, their perspectives on parental supportive care needs are underrepresented. Although Huber recommends using the "my positive health" tool for children aged ≥ 8 years, we used the questionnaire for all the pediatric age categories and let the parents of younger children complete the questionnaires for or with them. Since several questions were irrelevant for young children, we added a column "N/A." This might have influenced the results. In addition, anyone completing a survey self-selects to do so, and there is always the possibility of selection bias. Finally, this study did not consider the variability in severity and within each skin disorder. This might be a limitation. We think it is a strength as the similarities were more present in the questionnaires, interviews, and remarks. Due to the above limitations, it is unlikely that the results are generalizable to all patients and parents of a child with a severe, chronic skin disease. More research is needed to evaluate innovations in the care of pediatric patients with a severe chronic and/or congenital skin disease.

We conclude that children with a severe chronic and/or congenital skin disease require a more personalized integrative multidisciplinary and systematic transmural approach covering all aspects of life during their lifetime.

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Authors' contributions Hannelore De Maeseneer designed the study, performed data collection and analysis, and drafted the manuscript.

Dirk Van Gysel and Sofie De Schepper critically reviewed the manuscript.

Carsten R. Lincke, Barbara J. Sibbles, Josette J.W.M. Versteegh, Welling Oei, and Robert F. Pangalila were involved in the design of the study and in data interpretation and they critically reviewed the manuscript.

Suzanne G.M.A. Pasmans conceived the study, coordinated all study phases, and has supervised and extensively revised the manuscript.

All authors read and approved the final manuscript including the authorship list.

Compliance with ethical standards

Conflict of interest The first author (Hannelore De Maeseneer) has received an unrestricted grant of Laboratoires Expanscience. The other authors declare that they have no conflict of interest.

Ethical approval This article does not contain any studies with human participants or animals performed by any of the authors.

Informed consent Informed consent was obtained from all individual participants included in the study.

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