

RESEARCH ARTICLE

Impact on Quality of Life of Chronic Paediatric Dermatoses on their Family Members – A Study from Tertiary Care Hospital in North India

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ABSTRACT

Background: Skin conditions can be very chronic, recalcitrant, and difficult to treat. They have a huge impact on patient's quality of life. But when it comes to skin problems in children, the impact is on children and their primary caregivers. Although many studies are trying to quantify the impact on quality of life of patients, very less is done for impact on the family members and primary caregivers of the children.

Aim: To evaluate the impact on the quality of life of the family members of the affected children and compare the two scales used.

Material and Methods: A Performa-based cross-sectional study was conducted in 100 family members presenting to dermatology OPD to consult for their children. Using family dermatology quality of life questionnaire (FDQLI), a 10 item easy-to-use handy questionnaire and impact on family scale (IOF), a 24 item questionnaire, we evaluated the impact on the quality of life of family members of the affected children.

Results: Hundred family members of hundred children were included in the study. 48 males and 52 females. Mean age of children was 6.93 years. Chronic Skin diseases which we encountered in children were atopic dermatitis (30%) followed by vitiligo (15%), alopecia areata (13%), psoriasis (8%), chronic urticaria (6%), haemangioma (4%) and others (24%). Most of the children were accompanied by their fathers. Family history of similar disease was positive in 16% of children. Mean FDQLI score of hundred children in the study was 12.71 ± 3.76 . Mean IOF score in the study 59.93 ± 4.75 . There was a significant positive correlation between IOF and FDQLI scale ($p = 0.000$).

Conclusion: Chronic pediatric skin dermatoses cause a significant effect on the quality of life of their respective family members/primary caregivers. The impact depends on various financial, social, and personal factors and each of them should be given enough importance. Enough questionnaires/scales should be developed to ascertain the impact on these parents and counselling of these parents should become an important part of overall management.

Keywords: Chronic skin conditions, Family members, Primary caregivers, Quality of life.

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INTRODUCTION

Conditions that are persistent or long-lasting in its effects are termed chronic. The more chronic the disease, the more it affects patients' quality of life. WHO defines quality of life as 'individuals' perceptions of their position in life in context of the culture and value systems in which they live and about their goals, expectations and standards. Chronic skin conditions harm quality of life of patients as well as parents due to its cosmetic disability leading to embarrassment, rejection and social withdrawal in patients. Quality of life impacts a person himself and those around him like spouses, family members, guardians, and caretakers.¹ When it comes to a child's health,

the parents can do whatever is in their hands to comfort their child and get them treated as soon as possible. However, if the disease is chronic or incurable, it affects the patient and traumatizes the parents.

For children, their home is a safe place to be themselves and forget about the outside world. So, when a child is affected by a disease, it causes significant distress to the parents and siblings. The disease can affect patients' mental and physical health, such as anxiety, depression, embarrassment, and social awkwardness. While we tend to focus on the physical effects of the skin disease, emotional repercussions are important. So emotional and social aspects are as much an issue as

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physical appearance, sometimes even more debilitating. So psych dermatology is gaining awareness now wherein not only skin condition is treated, focus on psychological impact is also made. Many studies have been done and are still being done to throw some light on these very important facts. But the one thing got overlooked is the effect of these problems on the family members of the patients.

Anything which affects children, directly or indirectly, affects parents too. Children who can't earn themselves are not a burden, but the responsibility of the parents and parents do everything in their power and limits to protect their children. In India, 70 percent of the population can't afford medical bills and charges thrown on them each time they come to the hospital. They have to leave their job between work times to come with their child to the hospital, affecting daily wage workers. Parents suffer much strain for these multiple hospital visits. All these factors should be considered while treating children with OPD. These factors are being focused on in this study to observe and evaluate the amount of distress and burden parents suffer when children have chronic skin diseases.

AIMS AND OBJECTIVES

To evaluate the quality of life in family members of the children with chronic skin diseases using FDLQI questionnaire and IOF scale and to compare of FDQLI and IOF scores among various diseases in children.

MATERIAL AND METHOD

This study included family members of hundred children between 3 months to 14 years of age, attending the Dermatology OPD with chronic dermatoses of more than six weeks, at Maharishi Markandeshwar Institute of Medical Sciences and Research, Mullana.

Information was shared and proper consent was taken from all subjects and their family members for participation. Followed by which a thorough history of each patient was recorded in the proforma specifically designed for this study. The proforma included their chief complaints, name, age and sex of patient, duration of illness, diagnosis, relationship of the family member accompanying, occupation and education of the family member etc. (attached as annexure)

A complete and detailed dermatological examination was done and findings were noted in the proforma to confirm the diagnosis.

Family dermatology quality of life index (FDQLI) and IOF scale was administered in primary caregiver/family members to assess the quality of life in family members of the patients. Family members were questioned accordingly and scoring was done for each question. Sum of all the scores was calculated and assigned to each subject.

RESULTS

As seen in Table 1, Out of 100 children, forty-eight were male and fifty-two were female children. The mean age of children presenting to dermatology OPD was 6.93 years \pm 4.3 years. According to the age, children were divided into less than 5 years,

Table 1: Demographic study of the cases

<i>Socio demographic data</i>		<i>Frequency</i>
Age	<5 Years	37
	5–10 Years	37
	>10 Years	26
Sex	Male	48
	Female	52
Primary caregiver	Father	76
	Mother	23
Region	Ambala	36
	Yamuna Nagar	26
	Saharanpur	23
	Others	15
Family history	Negative	84
	Positive	16

between 5 to 10 years and more than 10 years. The overall quality of life was also significantly more impaired in family members of children with an age group of more than 10 years (p value=0.004) compared to younger children. The primary caregivers who accompanied the children were mostly fathers (76%), whereas mothers were only present with 23% of the children. In our study, only 16% of people gave a history of similar lesions in family, the majority of whom were suffering from atopic dermatitis. No significant association was seen between the quality of life of primary caregivers with a history of similar disease in the family compared to those who did not have any family history.

In our study, the most common chronic skin diseases which we encountered in children were Atopic dermatitis (30%) followed by vitiligo (15%), alopecia areata (13%), psoriasis (8%), chronic urticaria (6%), haemangioma (4%) and others (24%). The group 'others' included chronic conditions like- dermatophytosis, seborrheic dermatitis, scabies, plantar keratoderma, pachyonychia congenita, warts etc.

Mean FDQLI score of hundred children in the study was 12.71 ± 3.76 . Highest scored question was 'time spent on looking after child's skin disease in terms of applying creams and giving other medications' (mean score-1.85), and the least scored question was 'effect on personal relationship with child' (mean score-0.7).

The mean IOF score in our study was 59.93 ± 4.75 , with the range of 46 to 73. The highest-scoring question was 'travelling to hospital is a strain on me' (mean score-3.44). And the least scored question was 'nobody understands the burden I carry' (mean score-1.09). Mean scores of each of the four factors were calculated; financial (12.8), social (22.15), personal strain (14.2), mastery (10.25).

The quality of life was affected in all diseases and there was no significant difference between the mean scores of each disease. Mean FDQLI score was maximum in alopecia areata (14.38 ± 2.84), followed by vitiligo (13.73 ± 3.71). The mean IOF score was maximum in vitiligo (61.13 ± 4.19), followed by alopecia areata (60.62 ± 3.73) (Table-2).

Table 2: Comparison of impact on quality of life among various diseases

Diseases	<i>Alopecia Areata</i>	<i>Atopic Dermatitis</i>	<i>Vitiligo</i>	<i>Psoriasis</i>	<i>Haemangioma</i>	<i>Urticaria</i>	<i>Others</i>
No of Cases	13	30	15	8	4	6	24
Mean age	9.38	4.91	9.23	10	2.6	4.17	7.05
Mean fdqli	14.38	13.0	13.73	11.75	8.75	11	12.17
Mean iof	60.62	60.07	61.13	58.88	57	58.5	59.83

Table 3: Comparison of impact on quality of life according to duration of the disease and treatment

Disease duration				Treatment duration			p value
No. of years	<1	1-3	>3	<1	1-2	>2	
No of cases	52	33	15	68	20	12	
Mean FDQLI	11.1	12.94	17.8	11.54	13.6	17.83	0.000
MEAN IOF	58.73	59.48	65.07	59.01	59.9	65.17	0.000

Table 4: Comparison between IOF and FDQLI scale

	<i>Spearman's rho</i>	<i>Financial IOF</i>	<i>Social IOF</i>	<i>Personal IOF</i>	<i>Mastery IOF</i>	<i>Total IOF</i>
Total FDQLI	Correlation Coefficient	0.483	0.555	0.430	0.512	0.719
	p-value	0.000	0.000	0.000	0.000	0.000
Financial FDQLI	Correlation Coefficient	0.443	0.437	0.356	0.498	0.621
	p-value	0.000	0.000	0.000	0.000	0.000
Personal FDQLI	Correlation Coefficient	0.293	0.480	0.303	0.322	0.503
	p-value	0.003	0.000	0.002	0.001	0.000
Social FDQLI	Correlation Coefficient	0.389	0.314	0.362	0.359	0.502
	p-value	0.000	0.001	0.000	0.000	0.000

Financial aspect was most affected by Atopic dermatitis (12.93 ± 1.97). Social impact was maximum in Alopecia areata (22.70 ± 2.42), followed by vitiligo (22.67 ± 1.35). Vitiligo affected Personal strain with a maximum score (14.80 ± 1.66) whereas coping techniques/Mastery were maximum in alopecia areata (11.54 ± 1.51) followed by psoriasis.

The mean duration of the disease onset amongst children presenting to our OPD was 1.96 ± 2.09 years. In FDQLI, it was seen that as the duration of disease increases the quality of life is impaired more. The mean FDQLI score of family members of children with duration of disease more than 3 years was 17.8 ± 2.68 . It was significantly more as compared to the group with less than 1-year disease duration 11.10 ± 2.8 . (p value=0.000).

In IOF also, the mean IOF score of family members of children with longer duration of disease was (65.17 ± 2.25) as compared to family members of children with lesser disease duration (58.73 ± 4.04) (p value=0.000). (Table 3)

The score of quality of life of family members increased significantly (p value=0.000) with increasing duration of treatment as well. The mean FDQLI score was maximum for more than 2 years i.e. 17.83 ± 3.01 . Whereas mean score for group of the duration of treatment less than 1 years was $11.55 \pm$

2.94 . Similarly, the mean IOF score was 65.17 ± 2.25 for the group with a disease duration of more than 2 years compared to the group with a treatment duration of less than a year, which had a mean IOF score of 59.01 ± 3.95 . (Table 3).

Our study showed that the overall quality of mothers' life as primary caregivers was affected more than fathers. Mean IOF score of mothers (61.52) was more than mean score of fathers (59.45), although the difference was not significant (p value = 0.067).

For the ease of comparison between the two scales, we divided questions of FDQLI into similar impact factors as IOF i.e. Financial, Social and Personal. The corresponding sectors of each scale were compared. It was observed that there was a highly significant positive correlation between the two family QOL instruments. (p value=0.000) (Table 4.)

The individual scores of financial, personal and social factors and total QOL scores are positively and significantly correlating with each other (p value=0.000).

DISCUSSION

Chronic skin conditions affect patients and also their family members or primary caregivers in many ways. What we take

care of as doctors or dermatologists is just one aspect of it, other aspects need to be unfolded and explored for better compliance and management of chronic skin conditions.

As we know, counseling of primary caregivers is equally important as counseling of patients, especially when patients are small children who cannot understand the implications of everything.

This study gives an overview of the negative impact of common skin conditions, such as alopecia areata, psoriasis vulgaris, vitiligo, chronic urticaria, acne vulgaris etc. All these diseases share a common feature that is their chronicity.

In our study, female children were more as compared to males, unlike the study done by Ezzedine K, where in males presenting with chronic skin condition were significantly more than females.²

The mean age of children presenting to our skin OPD was 6.93 years \pm 4.3 years ranging from 3 months to 14 years which was in accordance to study done by Pratik Gahalaut where mean age of children was around 8 years.³

Most of the common chronic conditions that we encountered in our setting were atopic dermatitis (30%) followed by vitiligo (15%), alopecia areata (13%), psoriasis (8%), chronic urticaria (6%) and haemangioma (4%). A study published by Del Pozo Magana BR, also showed atopic dermatitis as the most common dermatoses presenting in children, followed by viral warts and acne.⁴

Majority of the children were having a disease duration of less than 1 year. This finding can be attributed to parents being more scared and concerned when children are younger. Similar findings in accordance to our study were also seen in a study published by Kassaab.⁵

FDQLI questionnaire is designed to evaluate the effect of chronic skin conditions in children on their parents and primary caregivers. As we calculated the final score after scoring each of the 10 questions, the Mean FDQLI score of 100 patients and their family members in our study came out to be 12.71 \pm 3.76 with the range of 3 to 30 in FDQLI questionnaire, which was lower than what other studies reported earlier.⁶ This score is classified as the moderate impact on family, implicating that dermatological diseases significantly affect family members' quality of life.

In our study, questions like time spent on looking for their child, emotional distress, financial difficulties in terms of household expenditure were most highly scored among the family members. On the other hand, personal relationships with kids and leisure activities were not as affected. A study done by F Sampogna showed similar results in which the time spent by parents on applying creams was the most commonly answered question.⁷

Impact on family scale (IOF) questionnaire which consists of 24 questions was also calculated. Mean IOF score in our study was 59.93 \pm 4.75. The highest scored question was 'Travelling to the hospital is a strain on me' (mean score-3.44), whereas the least scored question was 'Nobody understands the burden I carry' (mean score-1.09). This finding can be attributed to the fact that people in our area usually do not have a facility of personal/private transport. They have to use

public transport which requires planning and earlier booking. Coming to the hospital also means a loss of wage for that day for the laborers.

We divided the subjects into three age groups, to ascertain the effect of age of the children on the quality of life of family members. As children grow, their awareness of themselves, their disease, and their cosmetic appearance increases. Older children can express their distress and communicate better to parents. Their curiosity makes them question their parents about their health. Therefore, parents of older children are affected more than parents of younger children. It was seen that social embarrassment in family members with children of older age group (>10 years) (mean score-2.42) was significantly more as compared to parents of children less than 5 years of age (mean score-1.35) with a p value of 0.000. This finding was similar to what was seen by Milena Ražnatović in his study.⁸

We observed that the overall quality of life of the mothers as primary caregivers was affected more than fathers. Mean IOF score of mothers (61.52) was more than mean score of fathers (59.45), although the difference was not significant (p value=0.067). Areas like cutting hours from their work and stress about the financial problems for the family were more among fathers, whereas feelings like emotional anguish, disappointment, thinking of not having more children were more among mothers.

These findings were in accordance with Marciniak J's study, which included 50 children of atopic dermatitis with their parents. It was found that atopic dermatitis in children influences both parents' quality of life; however, it had a more significant influence on quality of life of mothers than that of fathers (mean FDLQI: 17.1 \pm 5.3 vs. 14.7 \pm 5.8 points; p < 0.001). Due to the children's disease, mothers spent more time caring for them and carried out more household duties.⁹

FDQLI is a 10 item questionnaire that is easy to use and apply in busy OPD. Compared to IOF, scale is not very detailed and there is no factor division. Both the quality of life scales were compared in terms of financial, personal, social, and mastery factors. It was observed that both the scales were having a significant positive correlation with each other, both overall and individually in each factor. (p-value-0.000)

Today, there are many national guidelines for children with different skin conditions that recommend measuring health-related Quality of life as part of the usual assessment process. Health related quality of life measurement also plays an important role in educational programs for children with chronic skin conditions and their parents.¹⁰

CONCLUSION

Quality of life in family members and parents is not given that much importance in our society although increasing studies are now done to evaluate at least the patients' quality of life, more studies are needed for family's quality of life. Most of the studies on the quality of life focus mainly on assessing the quality of life of patients, but very little is known about the impact of disease on families of patients, which can be very significant in the case of children.

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