International Journal of Chemical and Biochemical Sciences
(ISSN 2226-9614)

Journal Home page: www.iscientific.org/Journal.html

Satisfaction with Life in Family Caregivers of Children with Psoriasis

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Abstract

Psoriasis is a chronic skin disease that affects approximately 2% of the world's population, with almost one-third of patients developing psoriasis within the first 20 years of life. Psoriasis is a complex disease with various manifestations that can have a significant impact on patients' and caregivers' daily functioning. The current study aimed to assess life satisfaction in family caregivers of children with psoriasis and its associated factors. It included 165 caregiver-child dyads with children aged from 9 months to 12 years, diagnosed with different types of psoriasis for at least 6 months, and after the exclusion of any other chronic disease in the children and their caregivers. The severity of psoriasis was assessed using the PASI score and caregivers' satisfaction with life was assessed using the Satisfaction with Life Scale (SWLS). The prevalence of satisfaction with life among the caregivers was estimated to be 52.1% with a mean SWLS score (20.9 ± 5.8). Semiprofessional/ professional caregivers with a university education and middle/ high socioeconomic level reported higher satisfaction with life. On the other hand, caregivers of children with previous hospitalization for psoriasis, pustular psoriasis subtype, and self-reported stressful events as a precipitating factor reported lower life satisfaction.

Keywords: Caregiver, Childhood Psoriasis, Satisfaction with life, Satisfaction with life scale (SWLS), PASI score.

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1 Introduction

Psoriasis is a chronic, relapsing, multisystem inflammatory disease that primarily affects the skin and joints [1]. It is a multifactorial disease caused by a combination of immunological imbalances, genetic associations, and environmental factors [2]. Compared to adult-onset psoriasis, juvenile psoriasis has more often reported precipitating triggers, with infection being found more frequently including bacterial (especially streptococcal) and viral infections [3]. Psoriasis affects approximately 2% of the world's population with approximately one-third of psoriasis cases present during childhood. The prevalence of childhood psoriasis increases linearly from 0.1% at 1 year of age to 1.2% at 18 years of age [4]. This makes psoriasis a significant dermatological problem for the pediatric population [5, 6]. Childhood-onset psoriasis can occur at any age, even in infancy. The median age of onset is believed to be between 7 and 10 years [7-9]. Approximately 30% of children with psoriasis have an affected first-degree relative [10], and a positive family history can predict early onset of the disease [11]. Girls are more likely to develop psoriasis earlier than boys [12], and some research also suggests a slight female predominance [13].

Psoriasis has a variety of symptoms and severities. The general clinical presentation of psoriasis in children is similar to those of adults. However, some clinical features of pediatric psoriasis are noteworthy, including a tendency to affect the facial and anogenital areas, a higher prevalence of diaper rash in neonates and guttate psoriasis, and smaller and softer plaques than in adults [14]. Patients with psoriasis experience a decrease in life satisfaction and feelings of loneliness, as well as an increase in internalized stigma. As the severity of the disease increases, satisfaction with life decreases and feelings of loneliness and internalized stigma increase. This highlights the need to treat psoriasis not just as a skin condition, but as a complex disease [15]. Families with chronically ill children suffer more detrimental psychological effects than those with average, typical, or normal children. Families face increased financial strain, fewer opportunities for social interaction, and higher levels of parental stress. [16]. The satisfaction of caregivers with their lives is another crucial factor. Life satisfaction is "an overall evaluation of one's feelings and attitudes about life at a particular point in time, ranging from negative to positive [17]. Strong associations were observed between life satisfaction, burnout, and caregiver burden [18].

Therefore, it seems necessary to develop a comprehensive approach to skin diseases that considers not only the medical aspects but also the emotions and quality of life of the patients and the caregivers.

2 Rationale and objectives

In recent years, there has been a growing interest in the health of caregivers. Understanding how providing care affects life satisfaction is crucial. It is also important to identify those factors that affect caregivers' life satisfaction since it may help identify those who are more vulnerable to impaired satisfaction. Additionally, knowledge is needed to develop support and care for caregivers. Therefore, this study was conducted to measure the life satisfaction of caregivers of psoriatic children and its associated factors.

3 Subjects and methods

A Cross-sectional descriptive study with an analytical component was carried out on 165 caregivers and their children from August 2021 to March 2023 at the dermatology outpatient clinic of Mansoura University Hospital in Egypt. The caregivers' satisfaction with life was evaluated using the Satisfaction with Life Scale (SWLS). Prior to their participation in the study, informed consent was obtained from all caregivers. All precautions were taken to maintain the privacy of the data. All data were used for scientific purposes only.

3.1 Sample size:

A convenience sample of 165 caregiver-child dyads were included in the study due to limited availability of cases fulfilling legibility criteria. These are all patients who attended the clinic during years of data collection.

3.2 Inclusion criteria:

Cooperative caregivers of infants from 9 months of age up to 12-year-old children with at least six months of history of psoriasis.

3.3 Exclusion criteria:

Children and caregivers with mental illness, chronic systemic, or dermatological conditions other than psoriasis that affect caregivers' satisfaction with life.

3.4 Children Data:

- **Detailed history including:**
  - **Personal history**: name, age, sex, and education.
  - **Present history**: onset, course, duration of disease, and precipitating factors.
  - **Past history** of previous hospitalization for psoriasis.
  - **Family history** of psoriasis or other autoimmune diseases.

- **Detailed general examination** to exclude any other chronic systemic disease.
- **Dermatologic examination:** assessment of the extent and severity of psoriasis by PASI score with a score of ≥ 10 is considered moderate to severe psoriasis [19].

3.5 Caregivers' data:

Assessment of satisfaction with life: using the Satisfaction with Life Scale (SWLS) which is a 5-point scale for measuring one's overall cognitive judgment of own life satisfaction. Participants indicated the extent to which they agreed or disagreed with each of the five items using a 7-point scale ranging from 7 "strongly agree" to 1 "strongly disagree" [20].

Scoring and interpretation: Though scoring should be kept continuous (sum up scores on each item): 31 – 35 Extremely satisfied, 26 - 30 Satisfied, 21 - 25 Slightly satisfied, 20 Neutral, 15 - 19 Slightly dissatisfied, 10 - 14 Dissatisfied, and 5 - 9 Extremely dissatisfied [21]. In data analysis, we compared satisfied caregivers including (slightly satisfied, satisfied, and extremely satisfied) with other levels combined.

3.6 Statistical analysis and data interpretation:

IBM SPSS Statistics for Windows, Version 25.0 (IBM Corp, 2017) was used for the statistical analysis. Normally distributed continuous data were shown as mean ± standard deviation, whereas Median (minimum-maximum) was used to express non normally distributed continuous data. Categorical data were shown as number and percentage. The Chi-square test was used to compare categorical data between two groups. The Fisher exact test was used when the expected count in any cell was less than 5. Mann-Whitney and Kruskal-Wallis tests were used to compare non-normally distributed data. The Epi Info software was used to calculate the Crude Odds Ratio (COR) and its 95% confidence interval. Significant univariate characteristics associated with satisfaction were included into a forward Wald binary logistic regression analysis to identify significant independent predictors.

4. Results

More than half of the caregivers were satisfied (52.1%) and categorized as slightly satisfied (26.7%), satisfied (21.8%), and extremely satisfied (3.6%), 7.3% were neutral, and two-thirds (40.6%) were dissatisfied and categorized as slightly dissatisfied (27.3%), dissatisfied (9.7%), and extremely dissatisfied (3.6%) **(Figure 1).** The prevalence of satisfaction with life among caregivers of psoriatic children was estimated to be 52.1% with a mean SWLS score (20.9 ± 5.8). There was a statistically significant association between caregivers with university education, semiprofessional/professional caregivers, and middle/high socioeconomic level and greater satisfaction with life ($p = 0.001$, 0.04, and <0.001; respectively) **(Table 1).** There was no significant association between caregivers' satisfaction with life and child sociodemographic characteristics including age sex, and education **(Table 2).** The children without stressful events as a precipitating factor for psoriasis were associated with a significantly higher satisfaction with life among their caregivers than those with stressful events reported as a precipitating factor ($p = 0.02$). There was a significant increase in satisfaction with life among caregivers of psoriatic children without a history of previous hospitalization for psoriasis or pustular psoriasis at time of recruitment (p value =0.04 and 0.01; respectively) **(Table 3).**

Multivariate logistic regression analysis of independent predictors of satisfaction with life among caregivers of psoriatic children revealed that middle/high socioeconomic level with AOR=3.7 and CI= (1.9-7.6), absence of stress with AOR=5.1 and CI= (1.2-21.02), and absence of previous hospitalization for psoriasis with AOR=3.9 and CI= (1.1-14.1) were the independent predictors of caregivers' satisfaction with life **(Table 4).**

Table 1: Satisfaction with life according to caregivers' sociodemographic and care-related characteristics.

Variables	Total N (%)	Satisfied N (%)	P value	COR (95 % CI)
Overall	165(100)	86(52.1)		
Age				
<30	51	27(52.9)	0.9	1.05(0.5-2.03)
≥30	114	59(51.8)		1r
Sex				
Male	7	4(57.1)	0.8	1.2(0.3-5.7)
Female	158	82(51.9)		1r
Current marital status				
Married	155	82(52.9)	0.5	1.7(0.5-6.2)
Not married*	10	4(40)		1r
Education				
< High school	44	16(36.4)		1r
High school	87	45(51.7)	0.1	1.9(0.9-3.9)
>High school	34	25(73.5)	0.001	4.9(1.8-12.9)
Occupation				
Housewife	111	55(49.5)		1r
Manual worker	34	16(47.1)	0.8	0.9(0.4-2)
Semiprofessional/professional	20	15(75)	0.04	3.1(1.04-8.9)
Residence				
Rural	123	68(55.3)	0.2	1.6(0.8-3.3)
Urban slum/Urban	42	18(42.9)		1r
Socioeconomic level				
Very low /low	87	31(35.6)	<0.001	1r
Middle/High	78	55(70.5)		4.3(2.2-8.3)
Relationship with the patient				
Mother	150	80(53.3)	0.3	1.7(0.6-5.1)
Others**	15	6(40)		1r
Main caregiver				
Yes	160	83(51.9)	0.9	1r
No	5	3(60)		1.4(0.2-8.6)
Living with patient				
Yes	162	84(51.9)	0.6	1r
No	3	2(66.7)		1.9(0.2-20.9)

Mean SWLS score (20.9± 5.8); median 21(5-33).
COR=crude odds ratio, CI: confidence interval.
*: includes single, widow, and divorced.
**: includes father, grandmother, and sister.

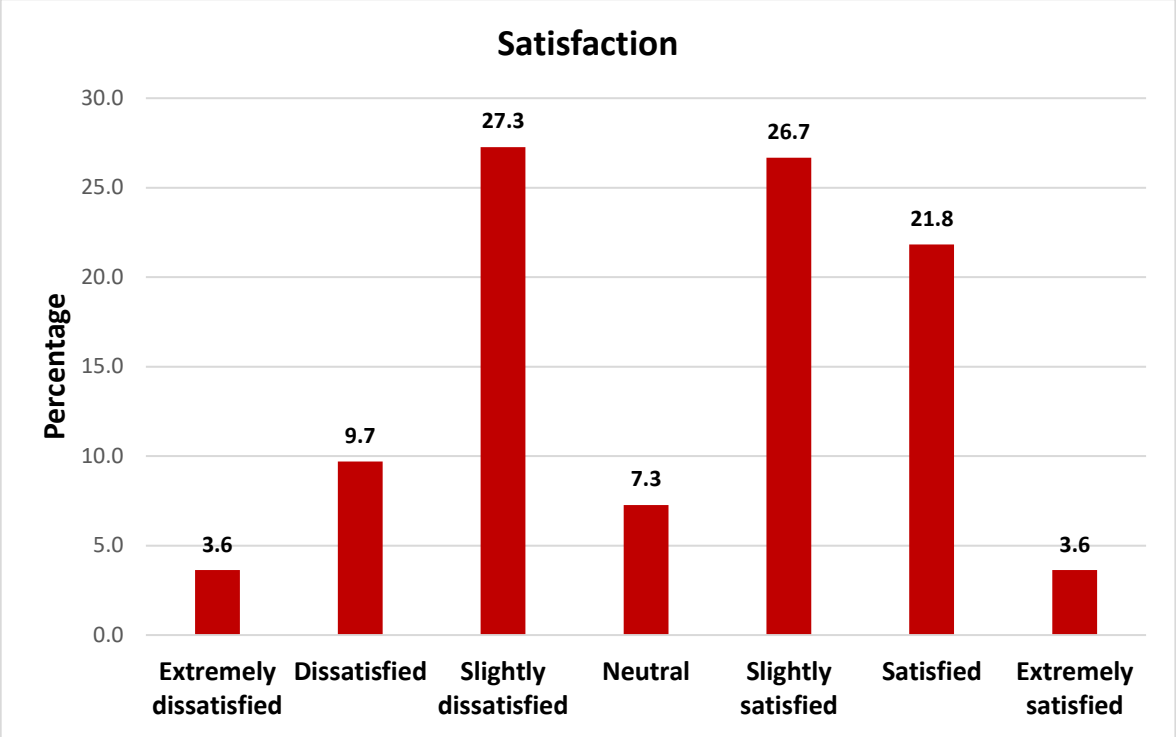

Figure 1. Satisfaction with life among studied caregivers of psoriatic patients.

Table 2: Satisfaction with life according to child sociodemographic characteristics.

	Total N (%)	Satisfied N (%)	P value	COR (95 % CI)
Overall	165(100)	86(52.1)	-	-
Age (years) (mean ± SD)	8.4 ±3			
<6	44	22(50)	0.7	1r
6-12	121	64(52.9)		1.1(0.6-2.2)
Sex				
Male	75	41(54.7)	0.6	1.2(0.7-2.2)
Female	90	45(50)		1r
Education				
Preschool	38	20(52.6)		1r
Primary	99	51(51.5)	0.9	0.9(0.5-2.02)
Preparatory	28	15(53.6)	0.9	1.04(0.4-2.8)
Family history				
Negative	119	66(55.5)	0.2	1.6(0.8-3.2)
Positive	46	20(43.5)		1r
Parental consanguinity				
Negative	123	67(54.5)	0.3	1.4(0.7-2.9)
Positive	42	19(45.2)		1r

Table 3: Satisfaction with life according to child clinical characteristics

Variables	Total N (%)	Satisfied N (%)	P value	COR (95 % CI)
Overall	165	86(52.1)	-	-
Duration of disease				
≤12 months	88	46(52.3)	0.9	1.01(0.5-1.9)
>12 months	77	40(51.9)		1r
Previous hospitalization for psoriasis				
No	150	82(54.7)	0.04	3.3(1.01-10.9)
Yes	15	4(26.7)		1r
Precipitating factors:				
1. Obesity				
No	161	84(52.2)	0.9	1.1(0.2-7.9)
Yes	4	2(50)		1r
2. Streptococcal infection				
No	138	72(52.2)	0.9	1.01(0.4-2.3)
Yes	27	14(51.9)		1r
3. Stress				
No	151	83(55)	0.02	4.5(1.2-16.7)
Yes	14	3(21.4)		1r
4. Systemic drugs				
No	162	85(52.5)	0.6	2.2(0.2-24.8)
Yes	3	1(33.3)		1r
Psoriasis subtype*:				
Psoriasis vulgaris				
No	1	1(100)	0.9	Undefined
Yes	164	85(51.8)		1r
Pustular psoriasis				
No	159	86(54.1)	0.01	Undefined
Yes	6	0		1r
Erythrodermic psoriasis				
No	163	84(51.5)	0.5	1r
Yes	2	2(100)		Undefined
Psoriatic arthritis				
No	164	85(51.8)	0.9	1r
Yes	1	1(100)		Undefined
Total PASI				
Mild	116	60(51.7)	0.9	1r
Moderate or sever	49	26(53.1)		1.05(0.5-2.1)

*: Categories are not mutually exclusive.

Table 4: Independent predictors of satisfaction with life among studied caregivers.

Variable	B	P value	AOR (95%CI)
Socioeconomic level			
Very low /low	-		1r
Middle/High	1.3	<0.001	3.7(1.9-7.6)
Stress			
No	1.6	0.02	5.1(1.2-21.02)
Yes	-		1r
Previous hospitalization for illness			
No	1.4	0.04	3.9(1.1-14.1)
Yes	-		1r
Constant	-3.7		
% Correctly predicted	69.7		
Model $\chi 2$, p value	36.9, <0.001		

β: regression coefficient, AOR: Adjusted Odds Ratio, CI: Confidence Interval. P value ≤ 0.05 is considered statistically significant.

5. Discussion

Satisfaction with life is defined as the "desire to change one's life; satisfaction with past, and satisfaction with future [22]. It is a universal concept that indicates a positive attitude towards life in general. Healthier, happier people pay less attention to the adversities that life throws at them [23]. The present study aimed to measure satisfaction with life in caregivers of children with psoriasis hoping to shed light on the factors that influence caregiving satisfaction. Knowing the characteristics of caregivers is important for identifying groups at risk of having difficulties, establishing support groups based on those characteristics, and developing home care. Assessment of satisfaction with life in caregivers of children with chronic dermatoses is sparse. In the literature, few studies assessed the satisfaction with life in caregivers of children with atopic dermatitis [24, 25]. Jang et al. [24] studied the dynamics of various factors associated with the quality of life in children and their families, especially the disease severity and psychosocial aspects of parents such as satisfaction with life and parental stress. They used a Korean translation of SWLS to assess the Satisfaction with life among the parents and found that life satisfaction of the parents was correlated with generic and dermatology-specific QoL of children. Gieler et al. [25] examined the degree of satisfaction with life experienced by single mothers of children with atopic eczema in Germany using the satisfaction with life questionnaire and proved that single mothers were significantly less satisfied than mothers living with partners, regardless of their child's health. Although we didn't find any previous research that assessed satisfaction with life in caregivers of children with psoriasis, some studies assessed the satisfaction with life in psoriasis patients and were all conducted in Poland [26-28]. Jankowiak et al. [27] used the Polish version of SWLS to investigate the satisfaction with life in psoriatic patients. Patients had moderate levels of satisfaction. A higher frequency of depressive symptoms and a lower quality of life were associated with a lower level of patient satisfaction. Another study was conducted by Kowalewska et al. [28] who assessed satisfaction with life among patients with psoriasis and found that more than half of the patients had low satisfaction with life. Also, Miniszewska et al. [26] surveyed psoriatic patients to determine life satisfaction and QoL in psoriatic patients and found that they had low life satisfaction as well as poor QoL in all domains. A Turkish study by Duran and Yürekli [29] studied satisfaction with life in patients with different skin diseases including dermatitis, psoriasis, acne, scabies, and urticaria, and found that patients with psoriasis had a lower satisfaction with life than patients with dermatitis and acne. In this study, the prevalence of satisfaction with life from mild to extreme satisfaction among caregivers of studied psoriatic children was 52.1% with a mean satisfaction with life score of (20.9 ± 5.8). No statistically significant correlation was found between caregivers' age and SWLS score in our study. Our results agreed with Jang et al. [24] study on families of children with atopic dermatitis, and Sezek et al. [30] who evaluated life satisfaction in caregivers who are providing home health care to patients in Turkey. In contrast to our finding, a Swedish study by Sandstedt et al. [31] found that life satisfaction was higher in older caregivers who looked after patients with amyotrophic lateral sclerosis. On the other hand, Vignola et al. [32] conducted a study in Italy that evaluated the quality of life among caregivers and patients with amyotrophic lateral sclerosis. They used the SWLS and found that caregivers with lower ages had higher SWLS scores. These controversial results can result from variations in societies, diseases being studied, and other caregiver and patient-related characteristics. On the other hand, our study agreed with the mentioned previous studies in that no significant association was found between the gender of the caregivers and overall caregivers' satisfaction with life. Satisfaction with life was statistically higher in semiprofessional/ professional caregivers and in those with university education compared to housewives / non-employed caregivers and caregivers with low educational levels in the current study. Our results agreed with a Turkish study conducted by Danacı and Koç [33] who evaluated life satisfaction among caregivers of cancer patients admitted to the emergency department, and Sezek et al. [30]. The researchers found that caregivers with higher levels of education and actively employed caregivers had significantly higher scores on SWLS than caregivers with low levels of education and non-employed ones. In this study, caregivers with middle/high socioeconomic levels had a statistically significant higher satisfaction with life when compared to caregivers with low socioeconomic levels. Our results agreed with Danacı and Koç [33]. They found that caregivers with a higher income had greater satisfaction with life. Higher income and socioeconomic level would relieve the financial burden of the disease resulting in higher satisfaction.

In the current study, the age and gender of the children didn't have a significant effect on the satisfaction of caregivers. Jang et al. [24] also found that the satisfaction of caregivers of children with atopic dermatitis was not significantly affected by the age or the gender of the children. Caregivers of patients without a history of previous hospitalization for psoriasis were associated with a statistically significant higher satisfaction with life than caregivers of previously hospitalized patients in the current study. Hospitalization obliges the caregivers to leave their work and stay away from their other family members and home leading to more caregiving stress and less satisfaction. Caregivers of children with pustular psoriasis reported statistically significant reduced life satisfaction due to the frequency of flares and the relatively prevalent hospitalization during flares. Kharawala et al. [34] German study of the clinical, humanistic, and financial costs associated with generalized pustular psoriasis discovered that the disease has a high burden both during acute flares, serious events that carry a significant risk of morbidity and mortality, and in afterward of flares.

Self-reported stressful events as a precipitating factor for psoriasis in children was associated with a statistically significant lower caregiver satisfaction in our study. This may be attributed to the viscous circle between psoriasis and stress. While psoriasis leads to stress in both patients and caregivers, stress also precipitates and exacerbates psoriasis and so on. Multivariate logistic regression analysis of independent predictors of satisfaction with life among caregivers of psoriatic children in the current study revealed that middle/high socioeconomic level,

absence of stress, and absence of previous hospitalization for psoriasis were the independent predictors of caregivers' satisfaction with life. Multivariate logistic regression in a previous study by Sandstedt et al. [31] indicated that satisfaction with life was associated with older age and not living with the patient.

6. Conclusions

Satisfaction with life may be negatively affected in caregivers of psoriatic children by different caregiver and child-related characteristics. So, it is crucial to identify those factors to develop support and care for caregivers who are more vulnerable to impaired satisfaction. Socioeconomic level, stress, and hospitalization history are the most important predictors to consider when assessing caregiver satisfaction with life.

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