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Prince sultan military medical city Riyadh, Saudi Arabia quality of life for parents having children with atopic dermatitis in Riyadh 2020 cross-sectional survey

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Abstract

Background: Atopic dermatitis is the most common chronic inflammatory skin disease in children. Therefore, it has an impact on patients' quality of life (QoL). Families with children having AD are vulnerable to have diversity of physical as well as psychological difficulties, including experiencing extreme fatigue, stress, frustration, and low QoL, particularly when there is slow or no improvement in the condition.

Aims/Objectives: We aimed to assess the quality of life (QOL) of parents having children with AD and to determine its predictors.

Methods: This was an observational, cross-sectional survey study among families with children suffering from AD. Data was collected by the validated Arabic version of the dermatitis family impact (DFI) questionnaire [19]. The study has been conducted after taking the institutional review board approval at PSMMC. Due to the COVID-19 pandemic, data was collected online by sending an invitation to the parents explaining the aims and objectives of the research through WhatsApp, SMS messages, and social media.

Results: A total of 93 parents having a child with atopic dermatitis (only one parent per family) participated in the current study, with a mean (\pm SD) age of 29.49 (\pm 5.02). The vast majority (97.8%) of the respondents reported that mothers are the ones who take care of the AD child. The mean age of the children was 4.85 (\pm 2.71). The overall mean (\pm SD) score of the DFI was 16.97 (\pm 7.55). The highest impact of having a child with atopic dermatitis was on the expenditures with a mean (\pm SD) score of 1.91 (\pm 0.84) out of 3. On the other hand, the lowest effect was on the family leisure activities, with a mean score of 1.55 (\pm 0.83). The level of effect of atopic dermatitis on the quality of life of parents having children with atopic dermatitis is severe in 23.66%, moderate in 43.01% of the respondents, and low in 27.96%. The DFI total score differed significantly only by participants' age and marital status.

Conclusion: Atopic dermatitis (AD) had a moderate impact on the QOL of parents whose children had AD. Marital status and both parents and child age were the factors that significantly correlated with the parents' QoL.

Keywords: Atopic dermatitis, quality of life and parents

Introduction

Atopic dermatitis (AD), also known as atopic eczema or simply eczema, is the most common chronic inflammatory skin disease in children [1]. It is characterized by the presence of dry and scaly patches on the skin of the scalp, forehead, and face. AD has a significant impact on patients' quality of life (QoL) due to its chronic nature and the inconvenience of treatment methods. Since AD mostly affects children [1], it has also an impact on the QoL of parents [2, 3]. Families with children having AD are vulnerable to have diversity of physical as well as psychological difficulties, including experiencing extreme fatigue, stress, frustration, and low QoL, particularly when there is slow or no improvement in the condition [4]. The worldwide prevalence of AD among children was estimated to be 5–20% [5]. The AD prevalence seems to be increasing, particularly in developed countries and mainly in urban areas [6]. Genetic factors and a sanitary environment are among the predisposing factors of AD [7]. Additionally, other factors including reduction in antimicrobial peptides, skin barrier defects, dysfunctional innate immune response, and systemic inflammation are involved in AD pathogenesis [5].

In Saudi Arabia a study was conducted in Jeddah 2015 result showed 21.6% of children suffer from AD [8]. The main symptom of AD is itching, and it can lead to frequent scratching, painful skin, loss of sleep, and skin infections [9]. A recent study in Greece 2020 concluded that quality of life had moderate effect on parents quality of life especially in parent psychological status can lead to anxiety, low mood, frustration and overprotection for child thus lead to unpleasant result in management care [10].

A global review study included United States, Italy and Brazil 2018 showed that although atopic dermatitis is not a fatal disease it can severely affect quality of life in many domains [11]. Moreover, A study was done in Poland 2017 to determine quality of life for parents caring for children having atopic dermatitis revealed that mother affected them negatively more than fathers due to their emotional liability and affection toward their children [12]. Also in Sao Paulo – Brazil 2017 impact of Atopic Dermatitis on the quality of life of pediatric patients and their guardians concluded that Atopic dermatitis affects the quality of life of both children and their guardians, thus should be consider in the clinical evaluation because can make huge change in the management plan [13]. Currently, there is an increased interest in patients' QOL, including that of dermatological patients [14-16]. Previous studies showed a significant positive association between AD and decreased quality of life [17, 18]. Though, the influence of a child's disease on other family members was not studied enough, particularly in Saudi Arabia. The limited number of studies published regarding the QoL of families of patients with AD showed that it has a negative impact on the well-being of parents [19-21].

In the current study, we aimed to assess the quality of life

(QOL) of parents of children with AD and to determine its predictors.

Methods

This was an observational, cross-sectional survey study. The population for this study was ninety-three families with children suffering from AD, and participants were from parents of children with AD where distributed online due to COVID crisis the clinic was shut down, Riyadh, Saudi Arabia, The inclusion criteria for the current study were parents having children aged from 0-15 years and confirmed diagnosis of atopic dermatitis from a dermatologist, while the exclusion criteria were children having other dermatological diseases and parents having psychological diseases.

The data collection tool for the current study was the validated Arabic version of the dermatitis family impact (DFI) questionnaire [20]. This is a 10 items questionnaire, with questions regarding the influence of the child's AD on his/her family regarding housework, food preparation, sleep, family activities and entertainment, shopping time, expenditure, tiredness, emotional distress, relationship between family members, and treatment. Each item is to be answered on a 4-Likert scale (0 not at all, 1 a little, 2 a lot, and 3 very much). A score of zero indicates no effect of AD on the family and 3 indicates high impairment. The interpretation of the total score is as follows: 0-5 normal, 6-10 low, 11-20 moderate, and >20-30 severe impacts on family quality of life.

The Cronbach's alpha value of the questionnaires was 0.978 which reflects the excellent reliability of the questionnaire (supplementary table 1).

Supplementary Table 1: Reliability for the items of the questionnaire

	Scale mean if item deleted	Scale variance if item deleted	Corrected item-Total correlation	Cronbach's alpha if item deleted
Over the last week, how much effect has your child having eczema had on housework, e.g. washing, cleaning	15.25	46.54	0.90	0.98
Over the last week, how much effect has your child having eczema had on food preparation and feeding.	15.26	46.50	0.92	0.97
Over the last week, how much effect has your child having eczema had on the sleep of others in family.	15.26	46.11	0.94	0.97
Over the last week, how much effect has your child having eczema had on family leisure activities, e.g. swimming.	15.42	46.59	0.86	0.98
Over the last week, how much effect has your child having eczema had on time spent on shopping for the family.	15.41	46.29	0.89	0.98
Over the last week, how much effect has your child having eczema had on your expenditure, e.g. costs related to treatment, clothes, etc.	15.05	46.92	0.81	0.98
Over the last week, how much effect has your child having eczema had on causing tiredness or exhaustion in your child's parents/carers.	15.22	45.91	0.93	0.97
Over the last week, how much effect has your child having eczema had on causing emotional distress such as depression, frustration or guilt in your child's parents/carers.	15.25	45.86	0.92	0.97
Over the last week, how much effect has your child having eczema had on relationships between the main carer and partner or between the main carer and other children in the family.	15.41	46.81	0.81	0.98
Over the last week, how much effect has helping with your child's treatment had on the main carer's life.	15.19	45.55	0.94	0.97

The study has been conducted after taking the institutional review board (IRB) approval, at PSMCMC. Due to the COVID-19 pandemic, data was collected online through sending an invitation to the parents explaining the aims and objectives of the research through whatsapp, SMS messages and social media. It was clearly written in the invitation that participation in the study is completely voluntary and that their data will be kept confidential and will be used for research purposes only. Parents who accepted to

participate in the study were asked to sign a consent form, and they were directed automatically to the survey link to fill it up. The survey was filled anonymously and electronically via online survey software (Google Forms), limited to one response only.

Statistical analysis

Questionnaire data was filled in excel sheet manually then transferred to SPSS.

Data were analyzed by using Statistical Package for Social Studies (SPSS 22; IBM Corp., New York, NY, USA). Continuous variables were expressed as mean \pm standard deviation and categorical variables were expressed as percentages. The t-test and one way ANOVA were used for continuous variables. Cronbach's alpha was used to assess the reliability and internal consistency of the items in the questionnaire. A p -value <0.05 was considered statistically significant.

Results

A total of 93 parents having a child with atopic dermatitis (only one parent per family) participated in the current

study, with a mean (\pm SD) age of 29.49 (\pm 5.02), and the mean number of children in their families was 2.67 (\pm 1.64). The highest percentage of the participants was from primary healthcare centres at 16.1%. The vast majority (97.8%) of the respondents reported that mothers are the ones who take care of the atopic dermatitis child.

Among those who take care of the child, more than half were married at 58.1%, while 37.6% were divorced, and their educational level was mostly (72%) bachelor degree. All (100%) of the participants were from the central region, and the highest percentage (48.4%) have a monthly income of 20000-25000 SAR. For the atopic dermatitis children, the mean age was 4.85 (\pm 2.71). Data is shown in table (1).

Table 1: Demographic characteristic of study participants

		Number (n = 93)	%
Who is taking care of the child	Father	2	2.2
	Mother	91	97.8
Social status for who is taking care of child	Married	54	58.1
	Divorced	35	37.6
	Widow	4	4.3
Educational status for who is taking care of child	High school	13	14.0
	Bachelor degree	67	72.0
	Post grad	13	14.0
Income of the family	<5000	2	2.2
	5000-10000	5	5.4
	10000-15000	5	5.4
	15000-20000	17	18.3
	20000-25000	45	48.4
	>25000	19	20.4
Residency place	Central region	93	100.0
Age for who is taking care of child (Mean \pm SD)		29.49	5.02
Age of child (Mean \pm SD)		4.85	2.71
How many children in the family (Mean \pm SD)		2.67	1.64

The overall mean (\pm SD) score of the DFI was 16.97 (\pm 7.55), out of 30, indicating that children with atopic dermatitis have a moderate effect on the quality of life of their parents. The current study results revealed that the highest impact of having a child with atopic dermatitis was on the point of expenditures (costs related to treatment, clothes, etc.), where the mean (\pm SD) score was 1.91 (\pm 0.84) out of 3, and 35.48%, and 29.03% reported its DFI effect as "a lot", and "very much", respectively. On the other hand, the lowest effect was on the family leisure activities, with a mean score of 1.55 (\pm 0.83), and the highest percentage (40.86%) reported that its effect is "little". Similarly, the impact of atopic dermatitis on the relationships between the main

caregiver and partner or between the main caregiver and other children in the family was among the lowest scores, with a mean score of 1.56 (\pm 0.85). The highest percentage (41.94%) of the respondents reported that having a child with atopic dermatitis affecting a lot on their housework, with a mean (\pm SD) score of 1.72 (\pm 0.80). Similar results were obtained for the effect on food preparation and the sleep of other family members, as 43.01% and 40.86% of the participants reported "a lot", with a mean score of 1.71 (\pm 0.79), and 1.71 (\pm 0.80), respectively. These data with the remaining questions scores and percentages are shown in tables (2 and 3).

Table 2: Frequency and percentages for answers of the questionnaire of quality of life for parents having children with atopic dermatitis

		Number	%
Over the last week, how much effect has your child having eczema had on housework, e.g. washing, cleaning	not at all	4	4.30
	little	34	36.56
	a lot	39	41.94
	very much	16	17.20
Over the last week, how much effect has your child having eczema had on food preparation and feeding.	not at all	4	4.30
	little	34	36.56
	a lot	40	43.01
	very much	15	16.13
Over the last week, how much effect has your child having eczema had on the sleep of others in family.	not at all	4	4.30
	little	35	37.63
	a lot	38	40.86
	very much	16	17.20
Over the last week, how much effect has your child having eczema had on family leisure activities, e.g. swimming.	not at all	8	8.60
	little	38	40.86

	a lot	35	37.63
	very much	12	12.90
Over the last week, how much effect has your child having eczema had on time spent on shopping for the family.	not at all	7	7.53
	little	40	43.01
	a lot	33	35.48
Over the last week, how much effect has your child having eczema had on your expenditure, e.g. costs related to treatment, clothes, etc.	very much	13	13.98
	not at all	2	2.15
	little	31	33.33
Over the last week, how much effect has your child having eczema had on causing tiredness or exhaustion in your child's parents/carers.	a lot	33	35.48
	very much	27	29.03
	not at all	4	4.30
Over the last week, how much effect has your child having eczema had on causing emotional distress such as depression, frustration or guilt in your child's parents/carers.	little	34	36.56
	a lot	36	38.71
	very much	19	20.43
Over the last week, how much effect has your child having eczema had on relationships between the main carer and partner or between the main carer and other children in the family.	not at all	4	4.30
	little	37	39.78
	a lot	33	35.48
Over the last week, how much effect has helping with your child's treatment had on the main carer's life.	very much	19	20.43
	not at all	6	6.45
	little	45	48.39
	a lot	26	27.96
	very much	16	17.20
	not at all	4	4.30
	little	34	36.56
	a lot	34	36.56
	very much	21	22.58

Table 3: Quality of life score in parents having children with atopic dermatitis

	Mean	SD
Over the last week, how much effect has your child having eczema had on housework, e.g. washing, cleaning	1.72	0.80
Over the last week, how much effect has your child having eczema had on food preparation and feeding.	1.71	0.79
Over the last week, how much effect has your child having eczema had on the sleep of others in family.	1.71	0.80
Over the last week, how much effect has your child having eczema had on family leisure activities, e.g. swimming.	1.55	0.83
Over the last week, how much effect has your child having eczema had on time spent on shopping for the family.	1.56	0.83
Over the last week, how much effect has your child having eczema had on your expenditure, e.g. costs related to treatment, clothes, etc.	1.91	0.84
Over the last week, how much effect has your child having eczema had on causing tiredness or exhaustion in your child's parents/carers.	1.75	0.83
Over the last week, how much effect has your child having eczema had on causing emotional distress such as depression, frustration or guilt in your child's parents/carers.	1.72	0.84
Over the last week, how much effect has your child having eczema had on relationships between the main carer and partner or between the main carer and other children in the family.	1.56	0.85
Over the last week, how much effect has helping with your child's treatment had on the main carer's life.	1.77	0.85
Overall (out of 30)	16.97	7.55

The results showed that the level of effect of atopic dermatitis on quality of life for parents having children with atopic dermatitis is severe in 23.66%, moderate in 43.01% of the respondents, and low in 27.96%, as shown in table (4).

Table 4: Level of effect of atopic dermatitis in quality of life for parents having children with atopic dermatitis

Level of effect	Number	%
Normal	5	5.38
Low	26	27.96
Moderate	40	43.01
Severe	22	23.66

Table (5) shows the quality of life score in parents having

Table 5: Quality of life score in parents having children with atopic dermatitis by their demographic characteristic

		Mean	SD	P value
who is taking care of the child	Father	9.00	1.41	0.132
	Mother	17.14	7.54	
Social status for who is taking care of child	Married	17.56	7.50	0.029*

children with atopic dermatitis by their demographic characteristics. The DFI total score differed significantly ($P = 0.029$) by participants' marital status, where it was the highest among married participants at 17.56 (± 7.50), and the lowest among the widowed one at 7.25 (± 4.27). Also, the score was higher among young aged participants (< 30 years) and young children (aged < 6 years) at 18.75 (± 7.21) and 19.82 (± 7.00), compared to 15.37 (± 7.57), and 11.53 (± 5.28) for parents aged ≥ 30 years old and children aged < 6 years, with a P -value of 0.030, and < 0.001 , respectively. In contrast, there was no significant difference between who takes care of the child, their educational level, income, or number of children in the family, with the DFI score, since all the P values were > 0.05 .

	Divorced	17.17	7.31	
	Widow	7.25	4.27	
Educational status for who is taking care of child	High school	17.92	9.82	0.736
	Bachelor degree	16.58	6.72	
	Post grad	18.00	9.46	
Income of the family	<5000	21.00	1.41	0.539
	5000-10000	15.20	10.23	
	10000-15000	13.80	11.92	
	15000-20000	16.12	7.65	
	20000-25000	16.60	6.11	
	>25000	19.47	8.96	
Age for who is taking care of child	<30y	18.75	7.21	0.030*
	>=30y	15.37	7.57	
Age of child	<6y	19.82	7.00	<0.001*
	>=6y	11.53	5.28	
How many children in the family	<=2	18.05	6.88	0.088
	>2	15.32	8.30	
* Significant <i>p</i> value				

Discussion

The current study evaluated the impact of children's AD on parent's QoL using the DFI. The total mean score of the DFI in the current study is considered higher compared to a recently published study from Serbia at 16.97 (± 7.55) vs. 12.6 (± 6.9), indicating that AD has a more impact on parents QoL in our case [22]. The mean score of all the assessed domains were lower than ours except for the expenditure domain at 2.1 (0.8) compared to 1.91 (± 0.84).

Children's AD influenced parents' QoL most by increasing expenditure. Such finding is similar to what has been reported in a similar study [22], and in a study conducted in Poland in which the authors evaluated the impact of children's AD on parent's QoL using the Family Dermatology Life Quality Index (FDLQI) [22]. AD has a high economic burden; this is basically due to the direct cost including both prescription medications and over-the-counter moisturizing options, which are necessary for AD treatment and flares prevention, particularly when patients' symptoms are not well controlled [24]. In addition, there are indirect costs of AD including home environment changes, homeopathic or alternative treatments, and work productivity losses [25]. Different results were obtained from a survey study of parents of 203 AD infants, where, caregivers reported that the greatest impact that AD had on their own lives is sleep loss and tiredness [26].

In accordance with a previously published study, the current study revealed that children affected by AD can cause some parents to feel depressed, exhausted, and emotionally distressed [27, 28]. Sleep disruption is well known to occur in patients with AD [29], so, unsurprisingly, their parents' sleep is also diminished [30]. The highest percentage of the parents reported that AD child affects a lot on the sleep of others in the family. Sleep loss is of critical importance to parents since impaired sleep can be associated with anxiety, and depression [31]. Besides, children's sleep deprivation may have a resultant negative impact on the parents' work performance as well as coping skills [32].

Overall, caregivers' quality of life is affected by several factors and could be directly affected by their children's QoL instead of disease severity. Therefore, treatment strategies targeting specific atopic dermatitis symptoms should improve patient and caregiver quality of life.

Much effort and constant attention from the parents or caregivers might be needed in a trial to distract the child to prevent scratching and rubbing the skin, which may put

strain on the relationship [33]. In our case, the family relationship was among the lowest affected domains by AD. In line with previous studies [34, 35], we found that mothers are usually the primary caregivers and carry the major burden of caring for children with chronic conditions.

Moreover, the current study was consistent with a previous similar one in that family QoL is no significantly correlated with the educational level or the number of children the family [35]. In contrast, the two studies differ in the correlation with marital status, since it was significant in our case, but not in the previous one [35]. Maksimovic N *et al.* in their recently published study (2020), found that parental higher education level was associated with greater improvement in parental life quality in a one-year prospective cohort study [22].

The current study has some limitations, and its results must be interpreted with caution. The sample size was rather small, and the inclusion of more parents in the cohort could have increased statistical power. Therefore, larger study populations are needed to confirm these observations. The study was performed in Saudi Arabia; therefore the results cannot be generalized to other countries, or even to the whole kingdom, since this research was performed in Riyadh, the capital of Saudi Arabia, therefore, these results do not necessarily reflect the circumstances in other areas, especially the rural ones. Future research should also take into account culture and traditional family models. Additionally, we have not analyzed the number of medications or type of therapy, and the severity of the disease. Finally, the mothers in the current study were mostly the primary caregivers, which may have further influenced the results. However, the impact of AD, on the QoL of family members appears to be meaningful, and therefore more care needs to be taken to treat AD as well as in further research on this matter.

Conclusion

This study provides an in-depth view of the atopic dermatitis-related quality of life among caregivers in Saudi Arabia. Atopic dermatitis (AD) had a moderate impact on the QoL of parents whose children had AD. The study highlights the relationship between caregivers' sociodemographic factors and quality of life in atopic dermatitis patients, and marital status and both parents and child age were the factors that significantly correlated with the parents' QoL. Future studies should investigate

interventions to address factors influencing both the quality of life and the disease severity of children and their caregivers.

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