Caregiver illness beliefs, self-efficacy and severity of atopic dermatitis in the child predict caregiver quality of life

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Abstract

Background: Atopic Dermatitis (AD) affects up to 20% of children and significantly negatively impacts their and their caregiver's quality of life (QoL). Research shows that caregivers with lower QoL may struggle to manage their child's AD effectively, and modifiable factors that affect their ability include illness perceptions and self-efficacy (SE). The study aimed to investigate the relationship between AD severity, caregiver illness perceptions, QoL and SE in the management of a child's AD. *Methods:* 103 caregivers of children with atopic dermatitis completed an online survey consisting of the Patient Oriented Eczema Measure, Dermatitis Family Impact Questionnaire, Parental Self-Efficacy with Eczema Care Index, and Illness Perception Questionnaire - Revised. *Results:* Correlation analyses showed significant relationships between a child's AD severity and caregiver illness perceptions, SE and QoL. Certain illness perceptions (consequences and emotional representations) had a greater impact on QoL than AD severity. Hierarchical regression analysis showed that AD severity, illness perceptions and SE predicted 72% of the variance in caregiver QoL. SE mediated the relationship between consequences, illness coherence, personal control, treatment control, timeline acute/chronic, identity and QoL. *Conclusion:* The findings support the role of illness perceptions and SE in explaining QoL in caregivers of children with AD. Interventions aimed at caregivers to treat AD in children should target both SE and illness perceptions, particularly emotional representations.

i. Conflict of interests

ii. Financial support

iii. Abstract and keywords

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Methods: 103 caregivers of children with atopic dermatitis completed an online survey consisting of the Patient Oriented Eczema Measure, Dermatitis Family Impact Questionnaire, Parental Self-Efficacy with Eczema Care Index, and Illness Perception Questionnaire - Revised.

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Conclusion: The findings support the role of illness perceptions and SE in explaining QoL in caregivers of children with AD. Interventions aimed at caregivers to treat AD in children should target both SE and illness perceptions, particularly emotional representations.

Keywords: Atopic Dermatitis; Caregiver; Self Efficacy; Illness Beliefs; Quality of Life; Mediating; Children

iv. Main text

Introduction

Atopic Dermatitis (AD) is the most common form of eczema.[1] It is a chronic, inflammatory and relapsing disease that causes intense itching and dry, cracked and lichenified skin.[2] Estimated to affect up to 20% of children in high-income countries,[3] it usually appears within the first five years of life and in 50-70% of cases it clears after ten years.[4] The negative impact of AD on a child's quality of life (QoL) extends to parents and caregivers[5,6] and affects almost every aspect of the caregiver's life, from physical wellness and the mental burden to work, family and social life.[8] Caring for a child with AD can be a source of stress,[9] and frequently disturbed sleep can cause chronic fatigue with more severe AD having a greater impact,[7] which may affect the caregiver's ability to administer treatments and help their child cope.[10]Therefore it is important to consider what may impact the caregiver's coping strategies and ability to manage their child's condition, such as caregiver self-efficacy (SE).

SE refers to an individual's belief in their ability to perform certain behaviours to obtain favourable outcomes.[11] Research shows that higher parent/caregiver SE is associated with more adaptive coping methods, which are then linked to better child health outcomes.[12] In the case of parents, caregiver SE can predict QoL in those they look after and in themselves.[13] How a caregiver views their child's illness may also affect their QoL. Leventhal's Common-Sense Model of Self-Regulation (CSM) provides a framework to understand how an individual responds to an illness and its characteristics. Illness perceptions are both cognitive and emotional and determine which cognitive and behavioural coping strategies are employed. Thereby they affect physical and psychological outcomes.[14] The Illness Perception Questionnaire-Revised (IPQ-R) provides a quantitative measure of these concepts (see supplement table a). Negative illness perceptions have been linked to lower caregiver and patient QoL.[15] To date, one study has looked at the impact of caregiver illness perceptions on family QoL where a child suffers from AD.[16] Using a brief IPQ scale (B-IPQ) they found that identity, consequences, illness concerns and emotional representations significantly correlated with decreased QoL. However, the B-IPQ does not measure beliefs about how recurrent the illness is which may be useful when considering eczema flare ups.

Research shows that illness perceptions can also predict SE in diverse populations,[17–19] and SE is a recommended target in interventions to treat AD in children,[20] rather than illness perceptions. However, different illness perceptions may correlate with psychological outcomes for different conditions.[21,22] Furthermore, SE

is behaviour specific and different chronic illnesses require different management behaviours. Once a child has been diagnosed with AD, the caregiver is likely following instructions to complete several health-related tasks to manage the symptoms. Potentially modifiable factors that can influence caregiver ability are illness perceptions and SE. Therefore, this study combines the Common Sense Model of Self-Regulation (CSM) and self-efficacy theory and aims to investigate the relationships between AD severity illness perceptions, self-efficacy and QoL in a population of caregivers of children with AD.

Methods

2.1 Study design and population.

This was a cross-sectional, questionnaire-based study. To meet the eligibility criteria caregivers had to be over 18 years of age and be caring for a child aged 0-16 who had received a diagnosis of AD from a doctor and was currently experiencing AD symptoms. An *a priori*power analysis indicated that a sample of 84 was required to obtain statistical power at 80% with alpha set at 0.05 (two-tailed) and a medium effect size (r=0.3).

2.2 Data collection

Participants were recruited between March 28th and May 1[st,] 2023, via targeted social media posts to eczema support groups. Participants completed an eligibility screening questionnaire, read the participant information sheet and provided informed consent before beginning the online survey.

2.3 Measures

Demographics

Data was collected on the caregiver (gender, ethnicity, continent of residence), how many children they had and how many had received a diagnosis of AD. If they had more than one child with AD, they were asked to complete the survey thinking about the child that had more severe AD. They provided information about the affected child (age, gender, years since AD diagnosis).

AD severity

The Patient Oriented Eczema Measure (POEM) for proxy completion measures AD severity from the carer's perspective.[23] Higher scores indicate greater severity. The POEM has good construct validity and high internal consistency and this was reflected in the current study's data (Cronbach α=0.83).

Caregiver Self-Efficacy

The Parental Self-Efficacy with Eczema Care Index (PASECI)[24] measures parental self-efficacy in managing childhood eczema in four domains: managing medication, managing eczema and symptoms, communicating with health care professionals, and managing personal challenges when caring for your child with eczema. Higher scores indicate greater self-efficacy. There was high internal consistency in all four domains in the current study (Cronbach's α=0.86 to 0.93).

Caregiver Illness Perceptions

The Illness Perception Questionnaire - Revised (IPQ-R)[25] measures the components of illness beliefs detailed in Leventhal's CSM. It includes 9 subscales: Identity, timeline acute/chronic, timeline cyclical, consequences, personal control, treatment control, emotional representations, illness coherence, and causes (see supplement table a). In line with author guidelines, the IPQ-R was adapted for the parent's perception of eczema therefore, 'my illness' was replaced with 'my child's illness' and/or 'their eczema'. In the current study, internal consistency ranged from acceptable to excellent (Cronbach's α=0.70 to 0.94). Subscales in the acceptable range were timeline cyclical (α=0.70) and treatment control (α=0.77).

Quality of Life

3

The Dermatitis Family Impact Questionnaire[26] measures how having a child with AD impacts adult family members. Higher scores indicate a greater impact and therefore lower QoL. There was high internal consistency in the current study (Cronbach's α=0.94).

2.4 Data analysis

Data was analysed using SPSS version 28. The relationship between IPQ-R subscales, AD severity, caregiver SE and QoL were examined using Spearman Rho (where data did not meet assumptions for parametric tests) and Pearson correlations. Multiple regression models explored predictors of caregiver QoL. All tests were two-tailed and alpha was set at 0.05. Mediation analysis using the PROCESS macro was conducted to see if SE mediated between IPQ-R domains and QoL scores. The direct and indirect effect and the 95% CI were estimated based on 5000 bootstrapped samples.

Results

3.1 Participant characteristics

Of the 279 who responded to the advert, 240 were eligible. After reading the participant information sheet 142 continued. Of these, 37 were lost to attrition. Based on demographics, there were no significant differences between completers and non-completers. Of the remaining, 2 were excluded for providing the ages of multiple children leaving 103 participants.

The majority of participants were female (n=93, 90.3%), white (n=88, 85.4%) and living in Europe (n=69, 67%) or North America (n=30, 29.1%). On average participants had two children, with one diagnosed with AD. See Table 1. Children were aged 3 months to 16 years and had lived with AD from 1 month to 16 years. The majority of the children had moderate (n=49, 47.6%) or severe (n=28, 27.2%) AD. See Table 1.

3.2 Causal attributions of atopic dermatitis

The most frequently endorsed cause was hereditary factors (68%), followed by altered immunity (44.7%), bad luck (42.7%), and diet (39.8%).

3.3 The relationship between atopic dermatitis severity, caregiver illness perceptions, self-efficacy and quality of life

As total DFIQ scores, and IPQ-R scores for treatment control and illness coherence, were non-normally distributed, Spearman's rho correlations were used for those variables and Pearson's correlations for the remaining. Bivariate correlations revealed significant associations between variables as shown in Table 2.

Illness perceptions and atopic dermatitis severity

Positive correlations between AD severity and illness perceptions indicated that when AD was more severe, caregivers were more likely to believe that their child's AD was chronic, had greater consequences on the child and their family, had a greater emotional impact and more symptoms were experienced and attributed to the AD. Negative correlations between AD severity and some illness perceptions indicated that when AD was less severe, caregivers had a better understanding of their child's condition and were confident in their ability to control the AD. Timeline cyclical (whether the AD re-occurs) did not correlate significantly with any other variable.

Illness perceptions and caregiver quality of life

Higher impact on the family and thereby a lower caregiver QoL was positively associated with chronic AD, greater consequences, greater emotional impact, and more symptoms were experienced and attributed to the AD. Significant negative associations existed between QoL and personal control, treatment control, and illness coherence indicating that when the caregiver believed they had a good understanding of their child's AD, and felt that treatment was effective and they were able to control the condition, there was less effect on the family and therefore higher QoL.

Illness perceptions and caregiver self-efficacy

Higher caregiver SE was associated with caregivers reporting less chronic AD, fewer consequences, less emotional impact, and fewer symptoms experienced and attributed. Higher caregiver SE was also significantly associated with higher personal and treatment control and a better understanding of their child's AD.

3.4 Predictors of caregiver quality of life

As shown in Table 3, a three-step hierarchical linear regression model was conducted to assess the ability of AD severity, illness perceptions and caregiver SE to predict caregiver QoL. Only IPQ-R subscales that significantly correlated with DFIQ scores were included in the model. No demographic variables significantly correlated with QoL so were excluded.

Model 1, which included AD severity as the sole predictor, explained 34.6% of the variance in caregiver QoL. Model 2 explained 71.4% of the variance in caregiver QoL and included AD severity which accounted for 34.6% of the variance, and illness perceptions which accounted for 36.8%. Significant illness perception predictors were emotional representations, consequences, and identity. Model 3 explained 72.2% of variance of caregiver QoL. Adding caregiver SE to model 3 contributed 0.9% to the variance explained and did not result in a significant difference. Additionally, caregiver SE was not a significant predictor. The strongest predictors were consequences (β=0.62) emotional representations (β=0.49), identity (β=0.31) and AD severity (β=0.29) meaning that for every 1-unit increase in consequences, emotional representations, identity and AD severity scores there were 0.62, 0.49, 0.31 and 0.29 increases in family impact scores respectively.

3.5 The mediating role of caregiver self-efficacy between illness perceptions and quality of life

To examine whether caregiver SE mediates the relationship between illness perceptions and caregiver QoL, 7 separate models using different illness perceptions as a predictor in each model were produced. For each model, simple linear regressions were run for pathways a, b and c (see supplement table d). Path a is the direct effect of the predictor (illness perception) on the mediator (caregiver SE). Path b is the direct effect of the mediator (caregiver SE) on the outcome (caregiver QoL). Path c is the direct effect of the predictor (illness perception) on the outcome (caregiver QoL). Path c' is the direct effect between the illness perception and caregiver QoL when the mediator is taken into account. This pathway and the indirect/mediating effect were produced in the PROCESS macro in SPSS.

Mediation analysis confirmed the direction of the regression paths and found that caregiver SE had a statistically significant mediating effect between all illness perceptions and QoL, except emotional representations (see Table 4). The relationships between timeline acute/chronic, illness coherence and identity and QoL were no longer significant when the indirect effect via SE was accounted for, indicating a full mediation effect. This implies that the effect of these illness perceptions on QoL within those models was transmitted entirely through SE. SE partially mediated between consequences, personal control and treatment control and QoL. SE did not mediate between emotional representations and QoL.

Discussion

There were significant correlations between AD severity, caregiver illness perceptions, QoL and SE. Timeline cyclical (whether the AD was believed to be re-occurring) did not significantly correlate with any other variable. This was unexpected as AD can be chronic and episodic.[2] This non-significance could be explained by varying item agreement within the timeline cyclical subscale. For example, in an AD adult population, agreement with an IPQ-R item which refers to symptoms changing daily, was significantly lower than other items that are explicitly cyclical.[27] Building on existing evidence,[16,27] this study found stronger correlations between QoL, emotional representations and consequences than between AD severity and QoL. This suggests that caregiver QoL may be impacted more by a caregiver's emotional response to their child's AD and their perceptions of its consequences on the child's life than severity of the AD.

When asked about causal beliefs 68% of participants in this study believed their child's AD was hereditary. There is a direct link between cause and control factors[28] and 'hidden causes' under which genetic/biologic factors are classified are considered the least controllable compared to environmental or behavioural causes.[29]

This implies that parents who believe their child's AD is hereditary may feel they have less control over it, thereby lowering their SE.

The hierarchical regression model found that caregiver illness perceptions (consequences, emotional representations and identity), AD severity, and SE predicted 72% of the variance in caregiver QoL. Adding SE at the third step did not explain additional variance. These results might suggest that SE is not a significant predictor of QoL which contrasts with existing research.[12,13] A probable explanation is that the lack of additional variance explained by SE is due to multicollinearity, as SE is correlated with, and mediates, illness perceptions. In order to explore this a separate simple linear regression was run with just SE as the predictor, where it was able to explain 25% variance in QoL.

The importance of SE is further shown in the results of the mediation analysis, where SE mediated between all illness perceptions and QoL, except emotional representations. SE was found to fully mediate the relationship between caregiver views on chronicity, illness coherence and identity and QoL. This implies that the effect of these illness perceptions on QoL within those models was transmitted entirely through SE and so SE rather than these illness beliefs may be better targeted in interventions aimed at improving QoL. SE did not mediate between emotional representations and QoL, and therefore interventions should also focus on negative emotions such as fear anger and depression. Not only were negative emotions linked to reduced QoL but can also cause individuals to underestimate their ability thereby reducing SE.[30]

This study has a number of limitations. The mediation and hierarchical regression models leave a proportion of variance unexplained. Unexplored predictors could include coping strategies, and anxiety and depression, which are common in caregivers of children with AD.[9,31] Whilst the current study's mediation models are rudimentary and oversimplify the mechanisms between illness perceptions and self-efficacy, the results offer preliminary support to the integration of the CSM and SE models. More variables included and controlled for in future longitudinal research would allow for a more thorough examination of the causal mechanisms.

Overall, the study's results imply that SE, emotional representations and perceptions of consequences are the most important variables to target to improve caregiver QoL. The findings emphasise the need for psychological assessment and treatment of caregivers to be embedded in the dermatological treatment pathway and have several implications. Clinicians need to be aware that caregivers can be less capable of managing their child's condition if they perceive the consequences more negatively and struggle emotionally. By assisting caregivers to gain a realistic understanding of the consequences and causes of their child's AD, clinicians may be able to reduce the negative emotional impact. The findings provide a foundation for future interventions targeting these modifiable variables to support better QoL in caregivers who, in turn, can provide optimum care to their children living with AD.

v. Acknowledgements

N/A

vi. Impact statement

Reduced caregiver QoL may negatively impact their ability to care for a child with atopic dermatitis. This is the first study to examine the role of illness beliefs and self-efficacy in the QoL of a population of caregivers of children with atopic dermatitis. Our results suggest that a caregiver's view of the consequences of their child's atopic dermatitis and their emotional response has a greater effect on their QoL than the objective severity of the child's condition. Whilst self-efficacy mediates between most illness perceptions and QoL, it does not between emotional representations and QoL. Therefore, clinicians and intervention designers should consider taking into account and/or addressing caregiver illness beliefs and self-efficacy in order to support parents.

vii. References

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viii. Tables

Table 1. Participant and Child Characteristics

Participant Characteristics	
Gender (N,%)	
Female	93 (90.3%)
Male	8 (7.8%)
Prefer not to say	2 (1.9%)
Ethnicity (N,%)	
White	88 (85.4%)
Hispanic, Latino or Spanish origin	3 (2.9%)
Black	1 (1%)
Asian	7 (6.8%)

Participant Characteristics	
Other ethnicity or origin	3 (2.9%)
Prefer not to say	1 (1%)
Continent of Residence (N,%)	
North America	30 (29.1%)
Europe	69 (67%)
Asia	3 (2.9%)
Australia	1 (1%)
Number of Children (N,%)	
1	38 (36.9%)
2	48 (46.6%)
3	12 (11.7%)
4	4 (3.9%)
5	1 (1%)
Number of Children with AD (N,%)	
1	87 (84.5%)
2	14 (13.96%)
3	2 (1.96%)
Characteristics of children	
Age	
Mean (± SD)	4.6 years (± 4.1)
Median (range)	3.6 years (3 months to 16 years)
Time living with AD	
Mean (± SD)	3.8 years (± 3.8)
Median (range)	2 years (1 month to 16 years)
AD Severity (N,%)	
Clear or almost clear (0-2)	3 (2.9%)
Mild (3-7)	15 (14.6%)
Moderate (8-16)	49 (47.6%)
Severe (17-24)	28 (27.2%)
Very severe (25-28)	8 (7.8%)

Table 2. Pearson and Spearman correlations between AD severity, QoL, caregiver SE and IPQ-R subscales

	AD Severity	QoL ρ
AD Severity	-	
QoL ρ	0.62***	-
Caregiver SE	-0.43***	-0.49***
IPQ-R Subscales		
Timeline acute/chronic	0.28**	0.28**
Timeline cyclical	NS	NS
Consequences	0.5***	0.77***
Personal control	-0.36***	-0.31***
Treatment control ρ	-0.36**	-0.38***
Illness coherence ρ	-0.27**	-0.33***
Emotional representations	0.35***	0.72***
Identity	0.36***	0.45***
ρ denotes Spearman correlations	***p<0.001 **p<0.01 *p<0.05 (two-tailed)	***p<0.001 **p<0.01 *p<0.05 (two-tailed)

Table 3. Hierarchical linear regression to predict QoL

	Model 1	Model 2	Model 3
	β (95% ˆI)	β (95% ˆI)	β (95% ˆI)
AD severity	0.73 (0.53 to 0.93) ***	0.33 (0.17 to 0.5)***	0.29 (0.12 to 0.46) ***
Timeline acute/chronic		-0.16 (-0.42 to 0.10)	-0.17 (-0.42 to 0.09)
Consequences		0.55 (0.25 to 0.85)***	0.62 (0.31 to 0.92)***
Personal control		-0.03 (-0.3 to 0.24)	-0.04 (-0.30 to 0.23)
Treatment control		0.03 (-0.32 to 0.38)	0.10 (-0.26 to 0.46)
Illness coherence		0.07 (-0.13 to 0.27)	0.12 (-0.09 to 0.33)
Emotional representations		0.58 (0.32 to 0.84)***	0.49 (0.21 to 0.77)***
Identity		0.31 (0.08 to 0.54)**	0.31 (0.08 to 0.54)**
Caregiver SE			-0.02 (-0.04 to 0.00)
R^2	0.346	0.714	0.722
R^2 Change	0.346	0.368	0.009
F ratio	53.41 (p<0.001)	29.31 (p<0.001)	26.89 (p<0.001)
	***p<0.001 **p<0.01 *p<0.05	***p<0.001 **p<0.01 *p<0.05	***p<0.001 **p<0.01 *p<0

Model	Predictor	β υνστανδαρδισεδ α-πατη (95% ˆI)	β υνστανδαρδισεδ β-πατη (95% ˆ
1	Timeline acute/chronic	-3.25* (5.78 to -0.73)	-0.08*** (-0.1 to -0.5)
2	Consequences	-3.92*** (-5.99 to -1.85)	-0.08*** (-0.1 to -0.5)
3	Personal control	5.03*** (2.82 to 7.23)	-0.08*** (-0.1 to -0.5)
4	Treatment control	7.26*** (4.62 to 9.90)	-0.08*** (-0.1 to -0.5)
5	Illness coherence	5.22*** (3.55 to 6.90)	-0.08*** (-0.1 to -0.5)
6	Emotional representations	-5.74*** (-7.43 to -4.05)	-0.08*** (-0.1 to -0.5)
7	Identity	-2.78* (-5.08 to -0.48)	-0.08*** (-0.1 to -0.5)

Table 4. Summary of mediation models

***p<0.001 **p<0.01 *p<0.05