REVIEW

The Burden of Atopic Dermatitis: Summary of a Report for the National Eczema Association

Aaron M. Drucker[1], Annie R. Wang[1], Wen-Qing Li[1,2], Erika Sevetson[3], Julie K. Block[4] and Abrar A. Qureshi[1,2]

To assess the patient-level and societal burden of atopic dermatitis, we comprehensively reviewed the literature related to quality of life, social, economic, academic, and occupational impacts. Atopic dermatitis has profound impacts on patient and family quality of life. A conservative estimate of the annual costs of atopic dermatitis in the United States is $5.297 billion (in 2015 USD). People with atopic dermatitis may change their occupation because of their skin disease. Research gaps include quality of life assessments outside of tertiary care centers, impacts on partners and families of adult patients, and updated comprehensive cost estimates.

Journal of Investigative Dermatology (2016) ■, ■–■; doi:10.1016/j.jid.2016.07.012

INTRODUCTION

Atopic dermatitis (AD), also called eczema, is a chronically relapsing skin disease. It is prevalent in approximately 10.7% and 7.2% of US children and adults, respectively (Shaw et al., 2011; Silverberg et al., 2015). The onset of AD is usually in early childhood, and it can have an impact on the entire family unit. Additionally, AD is increasingly recognized as a disease that often persists into or begins in adulthood (Margolis et al., 2014). Thus, AD can have a detrimental effect on the lives of patients and their families throughout the lifespan. This includes impacts on quality of life (QoL) and social, academic, and occupational impacts. AD places a tremendous financial burden on patients, their families, and society as a whole through direct medical costs and decreased productivity. All of these aspects together—QoL, social, academic, and occupational impacts, along with direct and indirect costs—encompass the burden of disease of AD.

Recently, the National Eczema Association, a US patient advocacy group, funded a comprehensive review of the literature to document the evidence to date on the burden of AD. This review article summarizes the findings of the report to the National Eczema Association.

RESULTS AND DISCUSSION

QoL

QoL in children with AD. Chamlin et al. (2004) interviewed the parents of 26 children with AD to determine how AD affects QoL for these young patients. That article lists the impacts of AD mentioned by at least 20% of participating families. Impacts on physical health included itching and scratching, sleep, pain, bleeding, and dietary limitations. Emotional impacts included behavioral problems, irritability, crying, and problems with treatments. Physical functioning was impaired via clothing restrictions; interference with activities such as bathing, playing (especially outdoors) and swimming; and having to hold children's hands to prevent scratching. Social functioning was impaired: parents noted that both adults and children avoided interacting with children with AD. Although this qualitative study provides important information on the nature of AD's impacts on children, its generalizability is limited by its conduct in a tertiary care setting. Although AD severity was not measured among children in this study, the population of AD patients was likely skewed toward the more severe end of the AD spectrum.

In other studies, consequences of AD found to most affect QoL in childhood are itching and scratching, impacts on sleep, treatment, sports, and embarrassment related to the condition (Ballardini et al., 2014; Ben-Gashir et al., 2004; Ganemo et al., 2007; Ho et al., 2010; Ricci et al., 2007). Many studies have observed that as AD severity increases, QoL decreases (Alzolibani, 2014; Ben-Gashir et al., 2004; Brenninkmeijer et al., 2009; Ho et al., 2010; Hon et al., 2015; Maksimovic et al., 2012; Monti et al., 2011; Torrelo et al., 2013).

A study using the Children's Life Quality Index (CLQI), a generic QoL instrument, compared QoL among children aged 5–16 years with various chronic diseases, including 106 patients with generalized eczema (Beattie and Lewis-Jones, 2006). Generalized eczema had the second-largest impact on QoL, following only cerebral palsy, among all chronic diseases studied. One strength of this study was its use of both generic (CLQI) and skin-specific (Children's Dermatology Life Quality Index) tools for participants with skin disease. Among participants with skin disease, the CLQI and Children's Dermatology Life Quality Index were highly

---

[1] *Department of Dermatology, Alpert Medical School of Brown University, Providence, Rhode Island, USA;* [2] *Department of Epidemiology, Brown University School of Public Health, Providence, Rhode Island, USA;* [3] *Health and Information Services, Brown University Library, Providence, Rhode Island, USA; and* [4] *National Eczema Association, San Rafael, California, USA*

Correspondence: Aaron M. Drucker, Department of Dermatology, Brown University, Box G-D, Providence, Rhode Island 02912, USA. E-mail: aaron_drucker@brown.edu

Abbreviations: AD, atopic dermatitis; CLQI, Children's Life Quality Index; QoL, quality of life; SF-36, Short Form (36) Health Survey

Received 5 May 2016; revised 23 June 2016; accepted 12 July 2016; corrected proof published online XXX

correlated ($r = 0.72$, $P < 0.001$), indicating that the CLQI was able to capture the impact of skin disease on QoL in general. However, it did not include any other validated generic QoL measures, and so the ability of the CLQI to measure QoL in noncutaneous conditions is unclear.

QoL in adults with AD. Aspects of QoL reported to be most affected by AD in adults are symptoms and emotional impact, with less of an impact on social functioning (Holm et al., 2006b). However, social functioning can be affected as well: in a survey of college students (n = 336), 25.5% of participants with self-reported eczema believed that it impaired their social life (Roosta et al., 2010). AD can also limit simple every day activities; in a community-based survey of 559 AD patients, 35% believed that AD affected their choice of clothing, and 32% believed it limited shaving or wearing makeup (Anderson and Rajagopalan, 2001).

Impaired QoL in AD is correlated with disease severity and increased itch and sleep disturbance (Beikert et al., 2014; Chrostowska-Plak et al., 2013; Holm et al., 2006b; Maksimovic et al., 2012; Misery et al., 2007; Sanchez-Perez et al., 2013; Wittkowski et al., 2004). However, the correlation of QoL with objective disease severity is often only moderate (Chrostowska-Plak et al., 2013; Haeck et al., 2012; Maksimovic et al., 2012; Wittkowski et al., 2004), and in one article, which used baseline data from a small (n = 55) randomized controlled trial for AD, baseline QoL, measured by the Dermatology Life Quality Index, and disease severity measured by the Objective Scoring Atopic Dermatitis scale were not significantly correlated ($r = 0.17$, $P = 0.23$) (Haeck et al., 2012). Changes in the Objective Scoring Atopic Dermatitis scale and Dermatology Life Quality Index over the course of the 6-week trial were also not correlated ($r = 0.19$, $P = 0.20$). In other studies, involvement of readily visible areas of the body, such as the face, and genital involvement are other predictors of impaired QoL in AD (Beikert et al., 2014; Holm et al., 2004; Misery et al., 2007). These findings suggest that for adults, factors outside of objective AD severity have a significant impact on QoL.

Kiebert et al. (2002) used the Short Form (SF)-36 Health Survey, a generic health status measure, to assess QoL among 107 AD patients and compared their results with previously published SF-36 scores for the general population and other medical conditions (Kiebert et al., 2002). Although physical component scores of the SF-36 were higher (indicating better QoL) for AD compared with patients with depression, type 2 diabetes, and hypertension, mental component scores were lower (indicating worse QoL) for AD patients compared with type 2 diabetes and hypertension. Only clinical depression had worse mental component scores than AD. There were no statistically significant differences between AD and psoriasis in Dermatology Life Quality Index and SF-36 physical component scores, but SF-36 mental component scores were significantly lower (indicating worse QoL) in AD. Although these are important data that help contextualize the impact of AD on QoL, the Kiebert et al. study has limitations. First, as with other studies in this review, recruitment was limited to tertiary care. Further, the study did not take into account basic demographics, such as age and sex, when comparing the SF-36 scores of the participant population (mean age = 36 years, 85% female) with those of the general population or those of people with other diseases. Comparing SF-36 scores with controls matched by basic demographic characteristics would be more valid.

Based on a large sample (n = 3,308) recruited from the general high school population in Oslo, Norway, eczema with itch was associated with suicidal ideation (odds ratio = 3.57, 95% confidence interval = 2.46–5.67) and mental health problems as measured by the Strength and Difficulties Questionnaire (odds ratio = 2.57, 95% confidence interval 1.59–4.15) (Halvorsen et al., 2014). A large US population-based survey found that adults with eczema and fatigue were significantly more likely to rate their overall health as only poor or fair compared with participants without eczema or fatigue (odds ratio = 8.63, 95% confidence interval = 7.15–10.43) (Silverberg et al., 2015). These two studies (Halvorsen et al., 2014; Silverberg et al., 2015) provide important, high-quality evidence about the impacts of itch and sleep, respectively, on the lives of AD patients outside of tertiary care, with large sample sizes and, in the case of Silverberg et al. (2015), a population-based design.

QoL in families of AD patients. The impact of AD on QoL is not limited to patients themselves. The International Study on Life with Atopic Eczema found that 30% of patients and caregivers believe that AD affects other members of their household (Zuberbier et al., 2006). That study's large sample (n = 2,002) of patients with moderate to severe AD, multinational design (US, France, Germany, Spain, UK, The Netherlands, Mexico, and Poland), and use of validated outcome measures make it a unique source for data on the burden of AD at the more severe end of the spectrum.

Parents of young children with AD can be particularly burdened by a lack of sleep and by the emotional weight of seeing their children suffer. In a study of 270 AD patients and their parents in Chicago and San Francisco, 61% of parents said that their own sleep was disturbed because of their children's AD (Chamlin et al., 2005). However, that study was limited to tertiary care, did not use a validated measure of sleep disturbance, and did not compare sleep disturbance with a non-AD reference group. A UK study of 26 families with a child with AD and 29 families with a child with asthma aimed to compare the two diseases in terms of their impacts on parental sleep (Moore et al., 2006). Although the small sample size limits the interpretation of this study, the results were striking: mothers spent 78 minutes and fathers spent 90 minutes per night attending to children with AD, compared with no time for parents of children with asthma.

In a German study of parents of children with AD, maternal mental health scores on the SF-12 Health Survey, a generic measure of overall health, were significantly impaired on average compared with normative standards, indicating that AD may have a significant impact on the mental health of parents (Warschburger et al., 2004). This study was conducted in a unique setting (pediatric inpatient AD program), limiting generalizability; there was no association between disease severity and parental SF-12 scores; and reference standards were used as a comparison for SF-12 scores instead of a matched control group.

The time required to care for a child with AD is burdensome for families (Chamlin et al., 2004). One study in a