ORIGINAL RESEARCH

Exploring the Psychosocial Impact on Parents of Adolescents Diagnosed With Hidradenitis Suppurativa: A Retrospective Claims-Based Analysis

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ABSTRACT

Background: Chronic conditions, such as hidradenitis suppurativa (HS), can have an immense impact on patient quality of life; however, less is known about the influence that these diseases may have on the parents of adolescent patients with HS. This study aims to investigate the significance of an HS diagnosis on an adolescent's parents, including depression, anxiety, and changes in employment status. An understanding of this relationship can assist in both the prevention, screening, and treatment of mental health conditions in parents.

Methods: This retrospective cross-sectional analysis was conducted using data from the MarketScan Claims database. Data were collected for adolescents and their parents using a 3-year study period between 1/1/2015-12/31/2017; families with adolescents aged 11-17 years with HS and randomly selected age-/sex-matched adolescents without HS and their families (1:5 ratio) were used as controls, and a total of 20,568 families were included in this study. Claims of depression, anxiety, and employment status change in parents of adolescents with HS were compared against parents of adolescents without HS using regression analysis.

Results: The study population involved 20,568 families, including 3,428 families with HS (mean [SD] age of adolescent: 14.54 [1.70]) and 17,140 control families (mean [SD] age of adolescent: 14.35 [1.92]). The majority of adolescents in the study were female (81.7%). Parents of adolescents with HS experienced significantly higher rates of depression (21.53% vs. 19.57%, p = 0.009) than unaffected parents, as well as significantly higher rates of employment status change (6.30% vs 5.21%, p = 0.01).

Conclusions: Parents of adolescents with HS are more likely to experience depression and changes in employment status than unaffected parents. These results highlight the significant consequences that an HS diagnosis has on a family and underscore the need for further attention and resources for the mental health of these susceptible caregivers.

INTRODUCTION

Hidradenitis suppurativa (HS) is a chronic skin condition that causes painful lumps and nodules to form on the body, mainly affecting folds of the body such as the groin and axilla[1]. The exact prevalence remains unclear but seems to be anywhere between 0.05 – 4% depending on the source, with significant variations in prevalence reported in different countries, populations, and study designs[1-3]. HS is often diagnosed in the 3rd or 4th decade of life, but there is often a 3- to 12-year diagnostic delay, with a mean delay of 7.2 years[4]. HS is a chronic inflammatory condition that can be exacerbated by various familial and environmental factors

including smoking, obesity, and genetic mutations[1-3]. The resultant effect is a heavy disease burden on both the patient and potentially also on the patient's providers and caregivers.

HS has a negative impact on patient qualify of life. Studies have shown that patients with HS experience both severe physical and psychological symptoms[5,6]. These detrimental consequences of HS are often due to active lesions, but can also be attributed to chronic damage from past inflammation, leading to continued distress[5]. Additionally, quality of life surveys of HS patients consistently show that HS patients suffer from impaired quality of life compared to non-HS patients, and score worse in domains such as pain, embarrassment, psychological distress, intimate relationships, etc.[6]. HS patients also consistently endure higher rates of depression, anxiety, and suicidality than non-HS patients, highlighting the adverse mental-health implications of HS[7]. While the detrimental impacts of an HS diagnosis on the patients themselves have been well-documented, less is known about how an HS diagnosis affects the patient's family members. In a cross-sectional study exploring the impact of psoriasis in adolescents on their families, psoriasis was found to affect the quality of life of families even in cases of mild disease[8]. In another study involving parents of children with psoriasis, psoriasis was shown to negatively impact all parents interviewed, with the greatest effect on emotional well-being, among other domains[9]. In addition to the mental-health influence of psoriasis on caregivers, the severity of psoriasis was also found to be negatively correlated with the financial status of psoriasis patients and their families, contributing to reduced quality of life as well[10]. Together, these studies suggest a significant burden associated with

an adolescent's psoriasis on multiple domains of the parent's life. A systematic review that analyzed the disease loads of both atopic dermatitis and psoriasis on their families substantiated these results, finding that childhood atopic dermatitis also appeared to negatively impact maternal physical and mental well-being, while furthermore inducing feelings of exhaustion, frustration, helplessness, etc.[11]. Psoriasis had similar effects, with emotional wellness being an area of substantial impact. Despite these findings regarding other dermatologic conditions in adolescents, we are not aware of any studies on the impact of HS in an adolescent on a parent. A better understanding of this relationship may help to guide future interventions targeted at this population while contributing to the growing knowledge base surrounding this complex disease. Thus, this novel study examines the impact of an HS diagnosis on an adolescent's parents, including mental health issues and work-related disruptions.

METHODS

This is a retrospective cross-sectional analysis of de-identified claims data obtained from the IBM MarketScan Commercial Claims database. The database contains a wide array of medical claims data for over 265 million patients. These data include health insurance claims across the continuum of care (e.g. inpatient, outpatient, outpatient pharmacy, carve-out behavioral healthcare) from large employers and health plans across the United States.

Selection Criteria

A 3-year study period was used (January 1, 2015 – December 31, 2017; these were the most recent complete years of data available at the time). Families with

adolescents aged 11-17 years with HS were identified using ICD-9/10 codes for HS (705.83 and L73.2, respectively), and randomly selected age-/sex-matched adolescents without HS and their families (1:5 ratio) were used as controls. Parents were linked to their children using a unique family ID in the MarketScan database, and if a family had multiple children, only the oldest child was included. Only those with continuous enrollment during this time were included. Additionally, parents who were younger than the adolescent's age + 18 years were also excluded from the study; this was due to the nature of the de-identified data possibly coding for these family members as "parents" when they may just be siblings. Demographic information, prevalence of depression or anxiety (new or existing), employment status, and changes in employment status were collected. Depression was defined as ICD-9 codes 296.2, 296.3, 300.4, 301.1, or 311, and ICD-10 codes F320, F321, F322, F323, F324, F325, F329, F330, F331, F332, F333, F3341, F3342, F339, F340, F341, F6089. Anxiety was defined as ICD-9 codes 300.0X, and ICD-10 codes F410, F411, F418, F419. Employment status change was defined as a change from active full-time to active part-time/seasonal, retirement, or disability. Depression/anxiety diagnoses before or after the HS diagnosis were combined since HS was likely present in the patient prior to the actual date of HS diagnosis (as outlined previously) and had already begun affecting both the patient and the patient's family.

Statistical Analysis

Descriptive statistics and regression analysis were conducted using SAS Version 9.4. Differences between the HS and control group outcome variables were analyzed using the χ^2 test, and p-values were calculated. When the univariate analysis was significant for HS, a multivariate logistic regression model was then created for each of the desired outcome variables (depression, anxiety, employment status). The independent variables included in the logistic regression models were parental HS status, adolescent sex, parental sex, parental age, parental obesity, and child's HS status. This study was approved by the Penn State College of Medicine Institutional Review Board.

RESULTS

Cohort statistics

This study included 20,568 families; 3,428 in the HS group and 17,140 in the control group (Table 1). The majority of adolescents in both the HS group and control group were female (81.71% and 81.74%, respectively). Approximately half of the parents were female in both the HS group and control group (53.93% and 52.16%, respectively). Notably, 3.2% of parents in the HS cohort also had a diagnosis of HS compared to 0.3% in the control group. In the HS group, 76.2% of parents were employed full-time, compared to 79.71% of parents in the control group. Finally, in the HS group, 47.49% of the parents were obese, while only 31.46% of the parents in the control group were obese. This disparity will be addressed later in the discussion section.

Depression

Table 2 shows a comparison of the frequency of parental depression for the HS and control groups, as well as a logistic regression analysis using the variables in Table 1 as predictors of depression. The rate of parental depression was significantly higher in the HS group than in the control group (21.53% vs. 19.57%, p = 0.009).

Roughly equal proportions of female adolescents were seen in both the overall cohort and the depression cohort (~82%); however, there was a much higher proportion of female parents with depression than there were female parents in the overall cohort (69% vs. 52%, p < 0.0001). After adjusting for parental sex, parental age, parental HS status, parental obesity, and change in employment status, the presence of HS in the adolescent was not a significant predictor (OR: 1.06 (95% CI: 0.98, 1.16), p = 0.15) of depression in the parent(s). Of these variables, parental sex and parental obesity were found to be significant predictors of HS status.

Anxiety

Table 3 presents a comparison of the HS and control groups for families related to anxiety. Overall, there were no significant differences between the HS and control families.

Employment Status

Table 4 displays a comparison between the HS and control groups for families who experienced a change in employment status. The rate of employment status change was significantly greater for HS families than for control families (6.30% vs 5.21%, p = 0.01). Notably, this difference primarily impacted a single parent rather than both parents. Regression analysis shows that after adjusting for parental sex, parental age, parental HS status, parental obesity, depression, anxiety, and adolescent sex, the presence of HS in the adolescent contributed to a higher odds (OR: 1.17 (95% CI: 1.02, 1.34), p = 0.021) of employment change in the parent(s). Parental obesity, depression, anxiety, and parental age were all significant predictors of HS status.

In this large retrospective claims-based study, parents of adolescents affected by HS were found to be at higher risk for enduring both depression and changes in employment status. While overall anxiety rates were slightly higher in parents of adolescents with HS than parents of adolescents without HS, these differences were not significant.

Parents of adolescents with HS experienced significantly higher rates of depression in the univariate analysis than parents of adolescents without HS. Most of the disparity between the HS and control groups for depression came from one parent being affected. It should also be noted that these results held even when factoring in the higher proportion of *parents with* HS in the HS group than the control group, and parental HS status was not a significant predictor in the logistic regression model. In the multivariate analysis controlling for parental sex, parental age, parental HS status, parental obesity, and change in employment status, adolescent HS status was no longer found to be a significant predictor of parental depression. Of the above variables, parental obesity was the most significant predictor of parental depression, with obese parents having much higher odds of being depressed than nonobese parents. Parental obesity may serve as a mediating variable, where the stress of an adolescent having HS leads to a parent becoming obese and depressed. Additionally, depression seems to more heavily affect mothers than fathers, as evidenced by the higher percentage of female parents represented in the depression cohort as compared with the percentage of female parents in the overall cohort (69% vs. 52%, p < 0.0001). This

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conclusion is supported by the logistic regression analysis showing that parental sex was a significant predictor for depression, with fathers having substantially lower odds of developing depression (OR: 0.45 (95% CI: 0.42, 0.48), p < 0.001). These

Table 1. Descriptive statistics for families with or without an adolescent affected by HS

	HS in Adolescent Group	Control Group
Total number of families	3,428	17,140
One parent enrolled	1,191	4,787
Two parents enrolled	2,237	12,353
Number of parents with HS	110	52
Adolescent age, mean (SD)	14.54 (1.70)	14.35 (1.92)
Adolescent sex, n (%)		
Male	627 (18.29%)	3,130 (18.26%)
Female	2,801 (81.71%)	14,010 (81.74%)
Parent age, mean (SD)	45.48 (6.26)	45.58 (6.26)
Parent sex, n (%)		
Male	2,610 (46.07%)	14,109 (47.84%)
Female	3,055 (53.93%)	15,384 (52.16%)
Parent is obese	1,628 (47.49%)	5,393 (31.46%)

Table 2. Odds of parental depression for families with or without an adolescent affected by HS

	HS in Adolescent Group (N = 3,428)	Control Group (N = 17,140)	p-value	OR (CI), p-value*
Number of affected families, n (% of total cohort)	738 (21.53%)	3,355 (19.57%)	0.009	HS present in adolescent: 1.06 [0.98, 1.16], 0.15
One affected parent	661 (19.28%)	3,008 (17.55%)	0.02	-
Two affected parents	77 (2.25%)	347 (2.02%)	0.40	-
Adolescent sex, n (%)				
Male	123 (16.69%)	587 (17.50%)	0.60	0.94 [0.86, 1.02], 0.16
Female	614 (83.31%)	2,768 (82.50%)	-	1.0 [ref]
Parent sex, n (%)				
Male	239 (29.33%)	1,144 (30.90%)	0.38	0.45 [0.42, 0.49], <0.0001
Female	576 (70.67%)	2,558 (69.10%)	-	1.0 [ref]
Age of parent, mean (SD)	46.26 (6.26)	45.71 (6.47)		
25-40, n (%)	147 (18.04%)	801 (21.63%)	0.02	1.00 [0.86, 1.17], 0.97
41-55, n (%)	611 (74.97%)	2,642 (71.35%)	0.04	0.86 [0.75, 0.99], 0.038
>55, n (%)	57 (6.99%)	260 (7.02%)	0.98	1.0 [ref]
Parent is obese	-	-	-	1.81 [1.69, 1.95], <0.0001

*Multivariate logistic regression included parental HS status, child's HS status, parental age, parental sex, adolescent sex, and employment status change.
CI: 95% Confidence interval

Table 3. Odds of parental anxiety for families with or without an adolescent affected by HS

	HS in Adolescent Group (N = 3,428)	Control Group (N = 17,140)	p-value
Number of affected families, n (% of total cohort)	906 (26.43%)	4,434 (25.87%)	0.49
One affected parent	787 (22.96%)	3,921 (22.87%)	0.92
Two affected parents	119 (3.47%)	513 (2.99%)	0.14
Adolescent sex, n (%)			
Male	161 (17.79%)	837 (18.88%)	0.44
Female	744 (82.21%)	3,597 (81.12%)	
Parent sex, n (%)			
Male	309 (30.15%)	1,632 (32.99%)	0.08
Female	716 (69.85%)	3,315 (67.01%)	
Age of parent, mean (SD)	45.68 (6.09)	45.55 (6.31)	
25-40, n (%)	219 (21.37%)	1,088 (21.99%)	0.66
41-55, n (%)	739 (72.10%)	3,562 (71.99%)	0.94
>55, n (%)	67 (6.64%)	298 (6.02%)	0.53

Table 4. Odds of parental change in employment for families with or without an adolescent affected by HS

	HS in Adolescent Group (N = 3,428)	Control Group (N = 17,140)	p-value	OR (CI), p-value*
Number of affected families, n (% of total cohort)	216 (6.30%)	893 (5.21%)	0.01	HS present in adolescent: 1.17 [1.02, 1.34], 0.021
One affected parent	139 (4.05%)	508 (2.96%)	<0.001	-
Two affected parents	77 (2.25%)	385 (2.25%)	1	-
Adolescent sex, n (%)				
Male	39 (18.06%)	168 (18.81%)	0.80	1.01 [0.89, 1.15], 0.87
Female	177 (81.94%)	725 (81.19%)		1.0 [ref]
Parent sex, n (%)				
Male	130 (44.37%)	580 (45.38%)	0.75	0.95 [0.86, 1.06], 0.36
Female	163 (55.63%)	698 (54.62%)		1.0 [ref]
Age of parent, mean (SD)	46.32 (6.79)	46.77 (6.76)		
25-40, n (%)	69 (23.55%)	247 (19.33%)	0.10	0.51 [0.42, 0.63], <0.0001
41-55, n (%)	199 (67.92%)	903 (70.66%)	0.36	0.52 [0.44, 0.63], <0.0001
>55, n (%)	25 (8.53%)	128 (10.02%)	0.44	1.0 [ref]
Parent is obese	-	-	-	1.32 [1.18, 1.49], <0.0001
Number of parents with concurrent depression, n (%)	58 (26.85%)	259 (29.00%)	0.53	1.46 [1.27, 1.68], <0.0001
Number of parents with concurrent anxiety, n (%)	69 (31.94%)	330 (36.95%)	0.17	1.44 [1.27, 1.65], <0.0001

*Multivariate logistic regression included parental HS status, child's HS status, parental age, parental sex, adolescent sex, parental depression, parental anxiety, and employment status change. CI: 95% Confidence interval

findings are generally consistent with the global trend of the incidence of depression being 1.7-fold greater in women than men[12]. This is meaningful from a clinical perspective as it helps clinicians recognize that mothers of adolescents with HS may be at increased risk for depression; thus, mental health screenings and counseling should be emphasized in this group. This is also consistent with past studies reporting that other dermatologic conditions such as atopic dermatitis and psoriasis harm maternal physical and mental well-being, and induce feelings of exhaustion, frustration, helplessness, etc.[11]. A similar study using the MarketScan database found that parents of children with autism spectrum disorder (ASD) were significantly more likely to carry a diagnosis of depression than parents of children without ASD, with mothers being at higher risk[13]. Therefore, more focus should be placed on interventions aimed at addressing the mental health of these parents. In addressing mental-health needs in parents of adolescents with ASD, recommended practice guidelines include dialoguing with other parents in similar situations, engaging in self-reflection, improving problem-solving abilities, and finding purpose in one's life, all under the guidance and support of a physician[14]. Similar guidelines could be beneficial in supporting parents of adolescents with HS.

In addition to the mental health effects, parents of adolescents with HS also faced higher rates of employment status change than parents of adolescents without HS, and our logistic regression model, following adjustment, showed that adolescent HS status was associated with a significant increase in change from active full-time employment to active part-time/seasonal, retirement, or disability even when accounting for obesity, depression, and

anxiety, as shown by the results in Table 4. Again, parental HS status was not a significant predictor for employment status, despite the higher proportion of parents with HS in the HS group than the control group. Similar to the regression model for depression, parental obesity was the most significant predictor of employment status change; obese parents were much more likely to experience employment status changes than their non-obese counterparts. Moreover, the entirety of the difference between the HS and control groups for employment status change could be seen from one parent being affected (4.05% vs. 2.96%, p < 0.001), suggesting that HS primarily impacts the employment of a single parent rather than both parents in a household. Previous studies have reported a similar impact of chronic inflammatory conditions in children on parents' work status. A MarketScan study done by Rasu et. al. found that parents of children with juvenile idiopathic arthritis (JIA) missed 2.78 times more hours of work compared to the parents of children without JIA[15]. While there were no significant differences observed in the univariate analysis of parental age groups for employment status change, this was still a significant variable in the logistic regression model. Younger parents were less likely to experience a change in employment, as shown by the odds ratios for both parents aged 25-40 (OR = 0.51, p < 0.0001) and 41-55 (OR = 0.52, p < 0.0001) compared to 55+. Thus, the importance of addressing the mental health of these parents cannot be understated.

There are certain limitations to the results of this study. While some confounders such as age and sex were accounted for, other factors such as race/ethnicity and economic status were not adjusted for, as these variables were not available in the MarketScan database. While obesity was

included in the regression analysis, there was a large disparity in the percentage of parents with obesity in the HS cohort compared to the control cohort, so future studies aim for more similar obesity rates between the two groups. Additionally, given the nature of the study and the IBM MarketScan database, diagnoses of neither HS nor depression/anxiety could be clinically confirmed. Another drawback of the MarketScan database is that it is limited to those with private insurance, thus excluding those without health insurance as well as those who may have lost health insurance through unemployment. Another limitation of the MarketScan database was the inability to confirm the role of the person in the family (i.e. mother, father), and thus does not account for the psychosocial impact on mothers vs. fathers in single-parent families. To prevent siblings from being accidentally coded as parents, "parents" who were younger than their adolescent's age + 18 years were removed from the study, but this may have unintentionally included/excluded some patients. Additionally, diagnoses of depression and anxiety were limited to those cases that were reported on a claim, so overall depression and anxiety may be underestimated due to cases being unreported. Finally, in this study, cases of incident and prevalent depression/anxiety were combined into one group; however, as previously stated, due to the frequency of delay in diagnosing HS, this appeared plausible to do.

CONCLUSION

Our study indicates that parents of adolescents with HS are significantly more likely to either have or be diagnosed with depression than unaffected parents. This disparity is mainly seen in parents under the age of 55. While parents of adolescents with HS experience higher rates of depression, only parental sex and parental obesity are significant predictors for odds of depression. Furthermore, parents of adolescents afflicted by HS are significantly more likely to experience a change in employment status than unaffected parents, with parental obesity and HS status being significant predictors. Taken altogether, this study shows that HS is a disease that affects not only the quality of life of the patient but also the patient's caregivers; thus, more attention and resources, for both prevention and intervention, should be given to the mental health of these parents. The disease burden of HS extends beyond just the patients themselves, so it is important to have communication and discussions with family members around the difficulties of an HS diagnosis in their loved ones and identify those who are struggling early on.

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