ORIGINAL REPORT

MJS PUBLISHING

ActaDV Acta Dermato-Venereologica ActaDV Advances in dermatology and venereology

Hidradenitis Suppurativa Changes Major Life Decisions of Affected Patients: A Cross-sectional Study

Marta SZEPIETOWSKA[1,2*], Piotr K KRAJEWSKI[3,4,5], Przemyslaw PACAN[6], Anna WOJAS-PELC[1], Lukasz MATUSIAK[3,4] and Andrzej K JAWOREK[1*]

[1]Department of Dermatology, Jagiellonian University Medical College, Cracow, Poland, [2]Doctoral School of Medical and Health Sciences, Jagiellonian University Medical College, Cracow, Poland, [3]Division of Dermatology, Venereology and Clinical Immunology, Faculty of Medicine, Wroclaw University of Science and Technology, Wroclaw, Poland, [4]Department of Dermato-Venereology, 4th Military Hospital, Wroclaw, Poland, [5]Lübeck Institute of Experimental Dermatology, University of Lübeck, Lübeck, Germany, and [6]Department of Psychiatry, Institute of Medical Sciences, Rzeszow University, Rzeszow, Poland

Hidradenitis suppurativa (HS) is a chronic inflammatory disease associated with substantial physical and psychosocial burden. Its long-term impact on major life-changing decisions (MLCD) remains poorly investigated. This cross-sectional study included 123 adult HS patients assessed using the validated Major Life-Changing Decision Profile (MLCDP). Disease severity was evaluated with Hurley staging and IHS4. Quality of life (DLQI, HiSQOL), disease acceptance (AIS) and psychiatric symptoms (PHQ-9, GAD-7) were also assessed. Overall, 87.8% of patients reported at least one affected MLCD, with a mean of 6.2±5.2 decisions per patient. The mean MLCDP total score was 20.1±17.9 points without sex differences. The most frequently affected areas concerned lifestyle habits, physical activity and intimate relationships. Patients with Hurley stage III demonstrated significantly higher MLCDP scores compared with stages I and II. MLCDP correlated with IHS4 (r=0.218), pain intensity (r=0.256), DLQI (r=0.401), HiSQOL (r=0.507), PHQ-9 (r=0.354) and GAD-7 (r=0.315) (all p<0.05). A strong inverse correlation was observed with illness acceptance (r=−0.584, p<0.001). HS substantially influences key life decisions, particularly in patients with advanced disease and reduced psychological adaptation.

Key words: Hidradenitis suppurativa; psychosocial burden; major life-changing decisions.

Submitted Feb 17, 2026. Accepted after revision May 12, 2026

Published May 27, 2026.
DOI: 10.2340/actadv.v106.adv-2026-0427

Acta Derm Venereol 2026; 106: adv-2026-0427.

Corr: Marta Szepietowska, Department of Dermatology, Jagiellonian University Medical College, Botaniczna 3, 31-503 Cracow, Poland and Andrzej K Jaworek. Emails: marta.szepietowska@doctoral.uj.edu.pl; andrzej.jaworek@uj.edu.pl

SIGNIFICANCE

Hidradenitis suppurativa (HS) often begins in early adulthood, a critical period for education, career development and family planning. This study demonstrates that nearly 90% of patients report that HS affects major life-changing decisions, particularly in social, physical and intimate domains. Clinically advanced disease, higher pain intensity, poorer quality of life, lower illness acceptance and depressive and anxiety symptoms were all associated with greater life-decisions impact. These findings highlight that HS burden extends beyond current signs and symptoms and underscore the importance of early, comprehensive management aimed not only at disease control but also at preventing long-term cumulative life impairment.

Hidradenitis suppurativa (HS) is a chronic, inflammatory and recurrent disease of the pilosebaceous unit, predominantly affecting intertriginous areas such as the axillae, groin and anogenital region. The condition is characterized by painful nodules, abscesses, sinus tracts and progressive scarring, leading to substantial physical discomfort and functional impairment (1, 2). HS typically begins in early adulthood and follows a long-lasting, relapsing course, frequently accompanied by diagnostic delay and significant disease burden (2–4). Beyond cutaneous manifestations, HS is associated with numerous systemic comorbidities, including metabolic syndrome, cardiovascular disease, inflammatory bowel disease and spondyloarthropathies (2, 5). Importantly, the disease has been shown to exert a profound negative impact on patients' quality of life (QoL), psychosocial functioning, employment status and interpersonal relationships, often exceeding that observed in other chronic dermatological conditions (6–11).

The long-term burden of chronic diseases extends beyond current symptoms and QoL impairment, potentially influencing key choices that shape an individual's life trajectory. These decisions, referred to as major life-changing decisions (MLCD), include areas such as education, career development, family planning, social relationships, lifestyle habits and physical activity (12, 13). The concept of MLCD is closely related to cumulative life course impairment, describing the irreversible consequences of chronic illness on personal, social and professional development (14). To systematically assess this phenomenon, Bhatti et al. (15) developed the Major Life-Changing Decision Profile (MLCDP), a validated instrument designed to evaluate

the extent to which chronic diseases affect critical life decisions. Subsequent studies have demonstrated that dermatological conditions such as psoriasis, atopic dermatitis and acne significantly influence MLCD, with strong associations observed between MLCDP scores and disease severity (16–19).

In contrast, data on MLCD in HS remain extremely limited. To date, only a single study has examined life-changing decisions in HS. However, this analysis relied on an author-developed tool (20). Given the severe physical symptoms, high psychosocial burden and early onset of HS during crucial life stages, it is plausible that the disease substantially affects major life-changing decisions. The aim of the present study was to evaluate the influence of HS on MLCD using the validated MLCPD. This cross-sectional study seeks to provide a comprehensive and methodologically robust assessment of MLCD in HS patients, thereby addressing an important gap in the current literature.

MATERIAL AND METHODS

Study design and participants

This cross-sectional observational study was conducted among 132 adult patients diagnosed with HS. Participants were consecutively recruited during routine dermatological consultations at tertiary referral centres in Wroclaw and Cracow, Poland. 123 of them (response rate of 93.2%) agreed to participate (only one patient decided not to participate), fulfilled all study questionnaires (8 patients provided not fully filled questionnaires) and were considered for final analysis. The diagnosis of HS was put by experienced dermatologists based on established clinical criteria (2). All participants were aged 18 or older, with the mean age of 36.35±12.41 years, and provided written informed consent prior to inclusion. The details of the study group, including demographics and clinical characteristics, were included in **Table I**. The study was performed in accordance with the principles of the Declaration of Helsinki and was approved by the local ethics committee (Ethics Committee of Lower Silesian Medical Chamber, Wroclaw, Poland - decision number 12/BNBP/2025).

Clinical severity assessment

Disease severity was assessed using two complementary physician-rated instruments. The Hurley staging system was applied to classify patients into 3 stages based on the presence and extent of inflammatory lesions, sinus tracts and scarring (21). In addition, the International Hidradenitis Suppurativa Severity Score System (IHS4) was used as a dynamic measure of disease activity, calculated based on the number of inflammatory nodules, abscesses and draining tunnels. According to IHS4 total score, HS severity is categorized as mild (up to 3 points), moderate (4–10 points) or severe (greater than 10 points) (22). Subjective symptom intensity was evaluated by patients using the Numeric Rating Scale (NRS) (23). Participants rated the highest intensity of pain and itch on a scale from 0 (no symptoms) to 10 (the most severe imaginable symptoms), reflecting their overall disease experience.

Assessment of major life-changing decisions

The impact of HS on MLCD was evaluated using the Major Life-Changing Decision Profile (MLCDP), a validated self-administered questionnaire designed to assess how chronic diseases influence key decisions across the lifespan (15, 24). The MLCDP consists of 32 items grouped into five domains: education, employment/career, family and intimate relationships, social life and physical aspects of life. Each item is rated on a 5-point Likert scale ranging from 0 (no impact or not applicable) to 4 (very strong impact). The questionnaire allows for calculation of the total number of affected decisions as well as a cumulative score reflecting the overall magnitude of disease-related influence on life decisions. Higher scores indicate a greater impact of the disease on major life choices (15).

Quality of life assessment

Health-related QoL was assessed using two validated instruments. The Dermatology Life Quality Index (DLQI) was employed to measure the impact of HS on daily functioning over the preceding week. The DLQI consists of 10 items covering symptoms, daily activities, leisure, work or school, personal relationships and treatment-related burden, with higher scores indicating greater impairment (25, 26). In addition, disease-specific QoL was evaluated using the Hidradenitis Suppurativa Quality of Life (HiSQOL) questionnaire, which provides a more targeted assessment of the physical, emotional and social consequences of HS (27, 28).

Assessment of disease acceptance

Acceptance of the disease was measured using the Acceptance of Illness Scale (AIS) (29, 30). This instrument evaluates patients' psychological adaptation to chronic illness by assessing perceived limitations, feelings of dependency and emotional responses to health-related restrictions. The AIS consists of 8 statements rated on a 5-point scale, with total scores ranging from low to high acceptance of the disease (29, 30).

Assessment of psychiatric symptoms

Symptoms of depression and anxiety were assessed using standardized self-report screening tools.

Table I. Demographics and clinical characteristics of studied hidradenitis suppurativa group

Characteristics	Whole group (*N=123*)	Females (*n=62*)	Males (*n=61*)	*p*
Age [years], mean±SD	36.35±12.37	36.27±12.95	36.43±11.87	0.941
Marital status, *N (%)*				0.926
Single	56 (45.5)	29 (46.8)	27 (44.3)	
Married	42 (34.1)	20 (32.3)	22 (36.1)	
Informal relationship	24 (19.5)	13 (21.0)	11 (18.0)	
Widow/widower	1 (0.8)	0 (0.0)	1 (1.6)	
Education, *n (%)*				0.120
Primary	5 (4.1)	2 (3.2)	3 (4.9)	
Secondary	62 (50.4)	26 (41.9)	36 (59.0)	
Higher	56 (45.5)	34 (54.8)	22 (36.1)	
Professional status, *n (%)*				**0.046**
Working	103 (83.7)	56 (90.3)	47 (77.0)	
Not working	13 (10.6)	5 (8.1)	8 (13.1)	
Retired/pensioner	7 (5.7)	1 (1.6)	6 (9.8)	
Time from HS diagnosis [years], *mean±SD*	5.98±5.27	5.33±4.55	6.62±5.86	0.202
Time from the first symptoms [years], *mean±SD*	9.86±6.45	10.01±7.22	9.71±5.63	0.804
Hurley, *n (%)*				**0.003**
Stage I	20 (16,2)	11 (17.7)	8 (13.1)	
Stage II	86 (69.9)	49 (79.0)	37 (60.7)	
Stage III	17 (13,8)	2 (3.2)	16 (26.2)	
IHS4, *mean±SD*	8.51±6.99	7.49±6.55	9.62±7.36	0.097

ihs4:international hidradenitis suppurativa severity score system; n:numer; sd:standard deviation.

Depressive symptoms were evaluated with the Patient Health Questionnaire-9 (PHQ-9), which measures the frequency of depressive symptoms experienced over the previous 2 weeks (31, 32). Anxiety symptoms were assessed using the Generalized Anxiety Disorder-7 (GAD-7) scale, designed to screen for and quantify the severity of generalized anxiety symptoms (33, 34). Higher scores on both instruments indicate greater psychological symptom burden (31–34).

Statistical analysis

Statistical analyses were performed using IBM SPSS Statistics version 26 (SPSS Inc., Chicago, IL, USA). The distribution of continuous variables was assessed for normality using the Shapiro–Wilk test. Depending on data distribution, continuous variables were presented as means with standard deviations. Categorical variables were summarized as absolute numbers and percentages. Comparisons between groups were conducted using appropriate parametric or nonparametric tests. For continuous variables with normal distribution, the Student *t*-test was applied for comparisons between 2 groups, whereas the Mann–Whitney *U* test was used for non-normally distributed data. When comparisons involved more than 2 groups, one-way analysis of variance (ANOVA) or the Kruskal–Wallis test was employed, followed by post hoc analyses with Bonferroni corrections when applicable. Categorical variables were compared using the χ^2 test or Fisher exact test, depending on expected cell counts. Associations between MLCDP scores and clinical severity measures, QoL indices, disease acceptance, and psychological variables were evaluated using correlation analyses. Pearson correlation coefficient was used for normally distributed variables, while Spearman rank correlation coefficient was applied for non-parametric data. All statistical tests were two-tailed, and a *p*-value of less than 0.05 was considered statistically significant.

RESULTS

Overall, 87.8% of HS patients (*n*=108) declared the presence of at least one affected MLCD by the disease, with no significant differences between women (87.1%) and men (88.5%). The mean number of affected MLCDs in the whole group was 6.2±5.2, and this value was comparable between females (5.5±4.7) and males (6.8±5.9), without statistically significant gender differences (**Table II**).

The most frequently reported MLCDs concerned social, physical, and family-related aspects of life (**Table III**). Changes in lifestyle habits were particularly common, with 75.6% of HS patients reporting modifications in eating habits and 56.1%, indicating changes in smoking or alcohol consumption. Over half of the respondents (56.9%) reported changing the type or colour of clothing, and 29.3% declared limiting social interactions. Physical activity was also substantially affected by HS. Avoidance of swimming was reported by 64.2% of participants, while 48.8% decided not to engage in sports activities and 43.1% changed the type of sport practised. Nearly half of the patients (48.8%) reported becoming more physically active, indicating heterogeneous behavioural adaptations. In the domain

Table II. Number of major life-changing decisions affected in any way by hidradenitis suppurativa

Life decisions	Whole group (*n=123*)	Females (*n=62*)	Males (*n=61*)	*p*
MLCDP≥1 *n* (%)	108 (87.8)	54 (87.1)	54 (88.5)	NS
Mean±SD	6.2±5.2	5.5±4.7	6.8±5.9	NS

MLCPD: Major Life-Changing Decision Profile; NS: non-significant; SD: standard deviation.

Table III. Major life-changing decisions in hidradenitis suppurativa across gender groups

Measures	Whole group *n (%)*	Females *n (%)*	Males *n (%)*	*p*
Education				
I decided to leave education early	16 (13.0)	3 (4.8)	13 (21.3)	**0.014**
I decided to change my study subject	4 (3.3)	1 (1.6)	3 (4.9)	NS
I decided to study near home	8 (6.5)	0 (0.0)	8 (13.1)	**0.0003**
Job/career				
I decided to change my job/career	22 (17.9)	7 (11.3)	15 (24.6)	NS
I decided to give up my job/career after starting	19 (15.4)	8 (12.9)	11 (18.0)	NS
I decided to take early retirement	8 (6.5)	2 (3.2)	6 (9.8)	NS
I decided to work flexible working hours	34 (27.6)	16 (25.8)	18 (29.5)	NS
I decided to select a job/career suitable for my health	35 (28.4)	16 (25.8)	19 (31.2)	NS
I decided not to take promotion	10 (8.1)	3 (4.8)	7 (11.5)	NS
I decided to work shorter hours	21 (17.0)	11 (17.7)	10 (16.4)	NS
I decided to become self-employed	16 (13.0)	6 (9.7)	10 (16.4)	NS
I decided to remain unemployed	12 (9.8)	6 (9.7)	6 (9.8)	NS
Family/relationship				
I decided to change my plans for when to have children	35 (28.5)	15 (24.2)	20 (32.8)	NS
I decided not to have children	20 (16.2)	10 (16.1)	10 (16.4)	NS
I decided not to have a sexual relationship	69 (56.1)	33 (53.2)	36 (59.0)	NS
I decided not to marry or have a long-term partner	34 (27.6)	13 (21.0)	21 (34.4)	NS
I decided to get divorced or separate from my partner	6 (4.9)	2 (3.2)	4 (6.6)	NS
Social				
I decided to change my eating habits	93 (75.6)	49 (79.0)	44 (72.1)	NS
I decided to change my smoking/drinking alcohol habits	69 (56.1)	33 (53.2)	36 (59.0)	NS
I decided not to travel or go for holidays abroad	35 (28.5)	15 (24.2)	20 (32.8)	NS
I decided to move	10 (8.1)	3 (4.9)	7 (11.5)	NS
I decided not to move	18 (14.6)	6 (9.7)	12 (19.7)	NS
I decided not to move abroad	12 (9.8)	4 (6.5)	8 (13.1)	NS
I decided to wear different types/colours of clothes/shoes	70 (56.9)	40 (64.5)	30 (49.2)	NS
I decided not to be involved in community activities	19 (15.4)	9 (14.5)	10 (16.4)	NS
I decided not to socialize	36 (29.3)	14 (22.6)	22 (36.1)	NS
I decided not to wear makeup	15 (12.2)	13 (21.0)	2 (3.3)	**0.006**
Physical				
I decided not to go swimming	79 (64.2)	44 (71.0)	35 (57.4)	NS
I decided not to take part in any sports activities	60 (48.8)	28 (45.2)	32 (52.5)	NS
I decided to change to different sporting activities	53 (43.1)	22 (35.5)	31 (50.8)	NS
I decided to be more physically active	60 (48.8)	27 (43.6)	33 (54.1)	NS
I decided to give up driving	18 (14.6)	8 (12.9)	10 (16.4)	NS

of family and relationships, more than half of the respondents (56.1%) decided not to engage in sexual relationships. Changes in reproductive plans were also common: 28.5% of patients altered their plans regarding having children, while 16.2% decided not to have children at all. No significant sex-related differences were found in these areas. HS also influenced decisions related to education and professional life with gender differences. Leaving education early was reported by 13.0% of respondents, with this decision being significantly more frequent among men than women (21.3% vs 4.8%, p=0.014). Choosing to study close to home was reported exclusively by men (13.1% vs 0.0%, p=0.0003). In the professional domain, 28.4% of patients selected a job suitable for their health condition, 27.6% opted for flexible working hours, and 17.9% decided to change their job or career. No statistically significant gender differences were observed in most work-related decisions. A notable gender difference was observed in appearance-related decisions. Women significantly more often decided not to wear makeup compared with men (21.0% vs 3.3%, p=0.006) (Table III).

The mean total MLCDP score in the whole group was 20.1±17.91 points, with no significant difference between females (18.2±16.5 points) and males (21.8±19.7 points) (**Table IV**). Among individual domains, the highest mean scores were observed in the social (7.5±6.6 points) and physical (5.5±4.9 points) domains. A statistically significant sex difference was found again in the education domain, with higher scores in men compared with women (1.0±1.9 points vs 0.1±0.3 points, p=0.002). No significant gender differences were observed in the job/career, family/relationships, social or physical domains (Table IV).

A statistically significant difference in MLCDP total scores was observed between Hurley stages (p=0.018). Post hoc analysis revealed that patients with Hurley stage III disease had significantly higher MLCDP scores (37.1 ± 25.1 points) compared to both Hurley stage I (13.9 ± 11.8 points**,** p=0.028) and Hurley stage II (16.4 ± 11.6 points, p=0.031) (**Fig. 1**). When MLCDP total scores were analysed according to IHS4 severity categories, a gradual increase in scores was observed with increasing disease severity (mild: 15.6 ± 18.2 points, moderate: 18.9 ± 13.6 points and severe: 20.9 ± 17.1 points**)**; however, these differences did not reach statistical significance. This finding is consistent with the relatively modest but statistically significant correlation observed between MLCDP total score and IHS4 scores (r = 0.218, p=0.035). Moreover,

Table IV. Major life-changing decision profile scores – total score and domains scores

Measure points; mean±SD	Whole group (*n=123*)	Females (*N*=62)	Males (*N*=61)	*p*
MLCDP total score	20.1±17.9	18.2±16.5	21.8±19.7	NS
Education	0.5±1.4	0.1±0.3	1.0±1.9	**0.002**
Job/career	3.8±7.0	2.9±6.4	4.4±7.6	NS
Family/ relationships	2.9±3.8	2.3±3.2	3.3±4.2	NS
Social	7.5±6.6	7.8±7.2	7.7±6.2	NS
Physical	5.5±4.9	5.2±4.6	5.5±5.2	NS

MLCPD: Major Life-Changing Decision Profile; NS: non-significant.

Table V. Correlations between major life-changing decision profile score and clinical and psychosocial measures

Measures	*r*	*p*
International Hidradenitis Suppurativa Severity Score System	0.218	0.035
Numeral Rating Scale - pain	0.256	0.006
Numeral Rating Scale - itch	NS	NS
Dermatology Life Quality Index	0.401	<0.001
Hidradenitis Suppurativa Quality of Life	0.507	<0.001
Patient Health Questionnaire-9	0.354	<0.001
GAD-7: Generalized Anxiety Disorder-7	0.315	<0.001
Acceptance of Illness Scale	−0.584	<0.001

NS: non-significant.

a significant positive correlation was observed between MLCDP and pain intensity measured by NRS (r=0.256, p=0.006). No such relationship was found between MLCDP total score and itch intensity (**Table V**).

A moderate positive correlation was demonstrated between MLCDP scores and dermatology-specific QoL impairment measured by DLQI (r=0.401, p<0.001). An even stronger association was found with HiSQOL (r=0.507, p<0.001). Importantly, a strong negative correlation was noted between MLCDP and illness acceptance measured by AIS (r=−0.584, p < 0.001). Significant positive correlations were also observed between MLCDP total score and symptoms of depression and anxiety. MLCDP scores correlated with PHQ-9 (r=0.354, p<0.001) and GAD-7 (r=0.315, p<0.001) (Table V).

DISCUSSION

The present study demonstrates that HS substantially influences MLCDs, with nearly 90% of patients reporting that the disease affected at least one important life choice. These findings confirm that the burden of HS extends beyond current symptoms and QoL impairment, affecting long-term personal, social and professional trajectories.

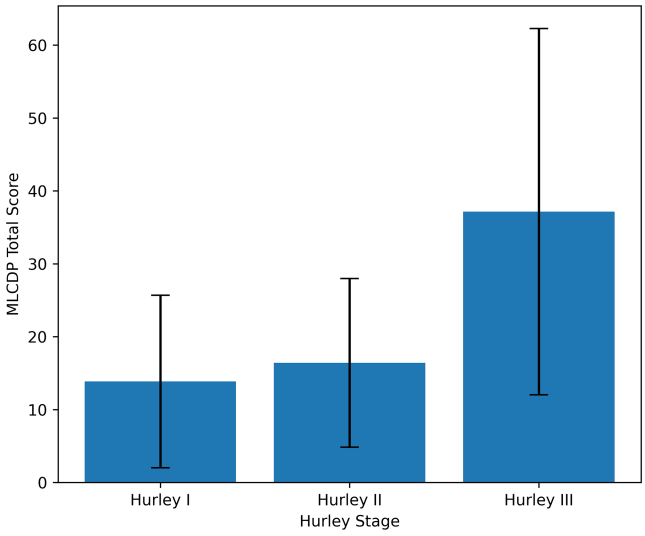

Fig. 1. Major life-changing decision profile (MLCDP) scores across different Hurley stages. The differences are statistically significant (p=0.018) across Hurley stages. Post hoc analysis shows that patients with Hurley stage III disease had significantly higher MLCDP scores compared to both Hurley stage I and Hurley stage II (p=0.028 and p=0.031, respectively).

The concept of MLCD is closely linked to cumulative life course impairment (CLCI), which describes the irreversible consequences of chronic illness on life opportunities and development (14). Chronic diseases may shape the decision-making process by narrowing perceived options, modifying risk assessment and altering self-perception. As suggested previously, the presence of visible, stigmatizing or painful symptoms may lead patients to avoid certain educational paths, career opportunities or intimate relationships (12–14). In this context, MLCD represent not merely subjective perceptions but potential turning points in a patient's life course (12).

HS typically begins in early adulthood, a critical developmental period characterized by decisions regarding education, career establishment, partner selection and family planning. Unlike many chronic conditions with later onset, HS emerges at a time when identity formation and long-term planning are particularly dynamic (35). Therefore, even moderate disease activity during these formative years may have disproportionate and lasting consequences. Our results support this perspective, as domains related to social functioning, physical activity, lifestyle habits and intimate relationships were among the most frequently affected. Importantly, patients with advanced structural disease (Hurley stage III) exhibited significantly higher MLCDP scores, indicating that cumulative inflammatory proces with the consequent development of skin-damaged lesions translates into broader life-course consequences.

Research on MLCD in dermatology remains scarce. To date, the concept has been systematically explored primarily in psoriasis, acne and, more recently, atopic dermatitis (16–19). In psoriasis, Bien et al. (16) reported that over 90% of patients experienced at least one affected MLCD, with strong correlations between MLCDP scores, disease severity, QoL impairment, itch intensity and reduced illness acceptance. Similarly, Spanish investigators demonstrated that psoriasis influenced career choice, job performance, social

relationships and clothing decisions, particularly in women and in patients with early disease onset or psoriatic arthritis (19). In acne, which also predominantly affects young individuals, MLCD were observed in over 70% of participants and were closely linked to QoL, stigmatization and also illness acceptance (17). More recently, the study on atopic dermatitis confirmed that MLCD are significantly impaired, especially in patients with severe disease (18).

Compared with these dermatoses, HS is characterized by intense pain, malodour, drainage, scarring and involvement of intimate body areas, which may uniquely amplify psychosocial consequences (1, 2). In our study, MLCDP total score correlated not only with objective disease activity (IHS4) but also with pain intensity, dermatology-specific and disease-specific QoL impairment, depressive and anxiety symptoms and, most strongly, with illness acceptance. The inverse correlation with acceptance of illness was particularly pronounced, suggesting that psychological adaptation may play a central role in mitigating or exacerbating life-course impact. This observation aligns with findings in psoriasis and acne, where reduced acceptance was consistently associated with higher MLCDP scores (16, 17).

Only one previous study has specifically examined MLCD in HS. The Spanish cross-sectional analysis by Ureña-Paniego et al. (20) included 50 patients and reported that HS significantly affected job performance, lifestyle habits, clothing choices and sports participation, with female sex and higher disease severity associated with greater impact. While their results are directionally consistent with ours, important methodological differences should be emphasized. The Spanish study relied on a Likert-scale assessment of selected life domains (20), whereas our investigation employed the validated MLCDP, enabling standardized and comparable quantification of affected decisions across five domains. Our findings extend previous data by demonstrating significant associations between MLCDP and both clinical and psychosocial parameters in a relatively large HS cohort. The observed correlation between MLCDP and pain underscores the central role of symptom burden in shaping life decisions. Furthermore, the association with depressive and anxiety symptoms suggests bidirectional interactions: psychological distress may both result from and contribute to altered life trajectories.

An additional noteworthy finding of the present study is that a substantial proportion of patients reported modifying lifestyle-related decisions, including eating habits, alcohol consumption and smoking. This observation is particularly relevant in the context of HS, as tobacco smoking has been consistently associated with increased disease severity and a more refractory course, while obesity is recognized as a major aggravating factor, with weight reduction contributing to clinical improvement (36–39). Although the MLCDP instrument does not specify the direction of these changes, it is reasonable to assume that at least part of these modifications may reflect patients' attempts to influence disease activity through behavioural adjustments. Such decisions may therefore represent not only a consequence of disease burden, but also an element of the therapeutic process, potentially mediated by medical counselling and patient education. Equally important is the high proportion of patients reporting avoidance of sexual relationships. This finding is understandable given the typical localization of HS lesions in anogenital areas, as well as the presence of pain, drainage, scarring and malodour. These factors may substantially limit sexual activity and intimacy, which was previously demonsrated in numerous studies (8, 40).

Limitations

Several limitations should be acknowledged. First, this was a cross-sectional study conducted in referral centres in a single country, which may limit generalizability. Cultural, socioeconomic and healthcare system differences may influence both disease perception and life decision-making processes. Second, although the sample size was relatively substantial for HS research, longitudinal data would be required to determine causality and to assess the temporal dynamics between disease severity and life decisions. Third, self-reported measures are inherently subject to recall bias, especially when evaluating decisions made over extended periods. Nevertheless, the study also has important strengths. It is, to our knowledge, the first investigation in HS to use the validated MLCDP instrument, enabling standardized evaluation of important aspect of cumulative life impact. The comprehensive assessment of clinical severity, symptom intensity, QoL, psychological distress and illness acceptance allowed multidimensional analysis.

Conclusion

HS significantly affects MLCDs, particularly in patients with advanced disease and impaired psychological adaptation. Given the early onset of HS and its chronic, relapsing course, early and comprehensive management strategies are essential. Beyond controlling signs and symptoms of the disease, clinicians should consider the potential long-term life-course impact of HS and incorporate psychological support and patient education into routine care. Addressing MLCD may help to mitigate cumulative life course impairment and improve overall patient outcomes.

ACKNOWLEDGEMENTS

Data Availability: The data that support the findings of this study are available from the corresponding author upon reasonable request.

Ethics committee: The study was approved by the local ethics committee - Ethics Committee of Lower Silesian Medical Chamber, Wroclaw, Poland – decision number 12/BNBP/2025.

The authors have no conflicts of interest to declare.

REFERENCES

1. Jemec GBE. Clinical practice. Hidradenitis suppurativa. N Engl J Med 2012; 366: 158–164. https://doi.org/10.1056/NEJMcp1014163
2. Sabat R, Alavi A, Wolk K, Wortsman X, McGrath B, Garg A, et al. Hidradenitis suppurativa. Lancet 2025; 405: 420–438. https://doi.org/10.1016/S0140-6736(24)02475-9
3. Di Cesare A, Nikolakis G, Kanni T, Giamarellos-Bourboulis EJ, Matusiak L, Szepietowski JC, et al. Identification of clinical features affecting diagnostic delay in paediatric hidradenitis suppurativa: results from a multicentre observational study. Br J Dermatol 2022; 187: 428–430. https://doi.org/10.1111/bjd.21247
4. Saunte DM, Boer J, Stratigos A, Szepietowski JC, Hamzavi I, Kim KH, et al. Diagnostic delay in hidradenitis suppurativa is a global problem. Br J Dermatol 2015; 173: 1546–1549. https://doi.org/10.1111/bjd.14038
5. Krajewski PK, Matusiak Ł, Ständer S, Thaçi D, Szepietowski JC, Zirpel H. Risk of cardiovascular disorders in hidradenitis suppurativa patients: a large-scale, propensity-matched global retrospective cohort study. Int J Dermatol 2024; 63: 799–805. https://doi.org/10.1111/ijd.17186
6. Chernyshov PV, Finlay AY, Tomas-Aragones L, Poot F, Sampogna F, Marron SE, et al. Quality of life in hidradenitis suppurativa: an update. Int J Environ Res Public Health 2021; 18: 18. https://doi.org/10.3390/ijerph18116131
7. Krajewski PK, Matusiak Ł, von Stebut E, Schultheis M, Kirschner U, Nikolakis G, et al. Quality-of-life impairment among patients with hidradenitis suppurativa: a cross-sectional study of 1795 patients. Life 2021; 11: 11. https://doi.org/10.3390/life11010034
8. Krajewski PK, Strobel A, Schultheis M, Staubach P, Grabbe S, Hennig K, et al. Profound sexual dysfunction among patients with hidradenitis suppurativa: a cross-sectional study. Dermatol Ther 2024; 14: 1823–1838. https://doi.org/10.1007/s13555-024-01196-y
9. Gupta AK, Liddy A, Economopoulos V, Magalhaes R. Global patterns of comorbidities among patients with hidradenitis suppurativa: a systematic review and meta-analysis. Int J Dermatol 2026; 65: 991–998. https://doi.org/10.1111/ijd.70131
10. Szepietowska M, Krajewski PK, Pacan P, Wojas-Pelc A, Matusiak L, Jaworek AK. A cross-sectional study on relationships between depression and anxiety in hidradenitis suppurativa patients and disease severity, subjective symptoms, and quality of life. J Clin Med 2026; 15: 15. https://doi.org/10.3390/jcm15020700
11. Dalgard FJ, Gieler U, Tomas-Aragones L, Lien L, Poot F, Jemec GBE, et al. The psychological burden of skin diseases: a cross-sectional multicenter study among dermatological out-patients in 13 European countries. J Invest Dermatol 2015; 135: 984–991. https://doi.org/10.1038/jid.2014.530
12. Bhatti ZU, Salek S, Finlay AY. Concept of major life-changing decisions in life course research. Curr Probl Dermatol 2013; 44: 52–66. https://doi.org/10.1159/000350389
13. Bhatti ZU, Finlay AY, Bolton CE, George L, Halcox JP, Jones SM, et al. Chronic disease influences over 40 major life-changing decisions (MLCDs): a qualitative study in dermatology and general medicine. J Eur Acad Dermatol Venereol 2014; 28: 1344–1355. https://doi.org/10.1111/jdv.12289
14. Sampogna F. Life course impairment and quality of life over time. In: Kimball AB, Linder MD, editors. Dermatological Diseases and Cumulative Life Course Impairment: S.Karger AG. 2013: p. 0. doi: 10.1159/000350781.
15. Bhatti ZU, Salek SS, Bolton CE, George L, Halcox JP, Jones SM, et al. The development and validation of the major life changing decision profile (MLCDP). Health Qual Life Outcomes 2013; 11: 78. https://doi.org/10.1186/1477-7525-11-78
16. Bień B, Krajewski PK, Szepietowski JC. Life-changing decisions in patients suffering from psoriasis: a cross-sectional study. Dermatol Ther 2025; 15: 841–855. https://doi.org/10.1007/s13555-025-01370-w
17. Bień B, Krajewski PK, Szepietowski JC. Acne influences life-changing decisions among young adults. Ital J Dermatol Venerol 2024; 159: 174–181. https://doi.org/10.23736/S2784-8671.24.07754-5
18. Fuentes-Barragán L, García-Moronta C, Sanabria-de la Torre R, León-Pérez FJ, Molina-Leyva A, Arias-Santiago S, et al. Impact on major life-changing decisions in patients with atopic dermatitis. Acta Derm Venereol 2025; 105: adv42241. https://doi.org/10.2340/actadv.v105.42241
19. Sanchez-Diaz M, Díaz-Calvillo P, Soto-Moreno A, Molina-Leyva A, Arias-Santiago S. Factors influencing major life-changing decisions in patients with psoriasis: a cross-sectional study. Acta Derm Venereol 2023; 103: adv11640. https://doi.org/10.2340/actadv.v103.11640
20. Ureña-Paniego C, Soto-Moreno A, Díaz-Calvillo P, Cuenca-Barrales C, Molina-Leyva A, Arias-Santiago S. Impact of hidradenitis suppurativa on major life-changing decisions: a cross-sectional study. Indian J Dermatol 2025; 70: 283–286. https://doi.org/10.4103/ijd.ijd_926_23
21. Hurley H. Axillary hyperhidrosis, apocrine bromhidrosis, hidradenitis suppurativa, and familial benign pemphigus: surgical approachRoenigk R, Roenigk H, editors. Dermatologic surgery: Marcel Dekker; 1989: 729–739 pp.
22. Zouboulis CC, Tzellos T, Kyrgidis A, Jemec GBE, Bechara FG, Giamarellos-Bourboulis EJ, et al. Development and validation of the International Hidradenitis Suppurativa Severity Score System (IHS4), a novel dynamic scoring system to assess HS severity. Br J Dermatol 2017; 177: 1401–1409. https://doi.org/10.1111/bjd.15748
23. Phan NQ, Blome C, Fritz F, Gerss J, Reich A, Ebata T, et al. Assessment of pruritus intensity: prospective study on validity and reliability of the visual analogue scale, numerical rating scale and verbal rating scale in 471 patients with chronic pruritus. Acta Derm Venereol 2012; 92: 502–507. https://doi.org/10.2340/00015555-1246
24. Wójcik E, Reszke R, Krajewski PK, Matusiak Ł, Madziarska K, Ali FM, et al. Major life changing decision profile: creation of the Polish language version. Dermatol Ther 2021; 34: e14568. https://doi.org/10.1111/dth.14568
25. Finlay AY, Khan GK. Dermatology Life Quality Index (DLQI)--a simple practical measure for routine clinical use. Clin Exp Dermatol 1994; 19: 210–216. https://doi.org/10.1111/j.1365-2230.1994.tb01167.x
26. Szepietowski J, Salomon J, Finlay AY. Dermatology life quality index (DLQI): Polish version. Clin Dermatol 2004.
27. Thorlacius L, Esmann S, Miller I, Vinding G, Jemec GBE. Development of HiSQOL: a hidradenitis suppurativa-specific quality of life instrument. Skin Appendage Disord 2019; 5: 221–229. https://doi.org/10.1159/000496234
28. Krajewski PK, Matusiak Ł, Szepietowska M, Rymaszewska JE, Jemec GBE, Kirby JS, et al. Hidradenitis Suppurativa Quality of Life (HiSQOL): creation and validation of the Polish language version. Postepy Dermatol Alergol 2021; 38: 967–972. https://doi.org/10.5114/ada.2020.97064
29. Felton BJ, Revenson TA, Hinrichsen GA. Stress and coping in the explanation of psychological adjustment among chronically ill adults. Soc Sci Med 1984; 18: 889–898. https://doi.org/10.1016/0277-9536(84)90158-8
30. Juczynski Z. Skala akceptacji choroby AIS. In: Narzędzia pomiaru w promocji i psychoonkologii zdrowia: Pracownia Testów Psychologicznych. 2009: p. 162–166.

31. Kroenke K, Spitzer RL, Williams JB. The PHQ-9: validity of a brief depression severity measure. J Gen Intern Med 2001; 16: 606–613. https://doi.org/10.1046/j.1525-1497.2001.016009606.x
32. Dajpratham P, Pukrittayakamee P, Atsariyasing W, Wannarit K, Boonhong J, Pongpirul K. The validity and reliability of the PHQ-9 in screening for post-stroke depression. BMC Psychiatry 2020; 20: 291. https://doi.org/10.1186/s12888-020-02699-6
33. Spitzer RL, Kroenke K, Williams JBW, Löwe B. A brief measure for assessing generalized anxiety disorder: the GAD-7. Arch Intern Med 2006; 166: 1092–1097. https://doi.org/10.1001/archinte.166.10.1092
34. Plummer F, Manea L, Trepel D, McMillan D. Screening for anxiety disorders with the GAD-7 and GAD-2: a systematic review and diagnostic metaanalysis. Gen Hosp Psychiatry 2016; 39: 24–31. https://doi.org/10.1016/j.genhosppsych.2015.11.005
35. Arnett JJ. Emerging adulthood. A theory of development from the late teens through the twenties. Am Psychol 2000; 55: 469–480.
36. Poulsen AH, Zhang DG, Nielsen VW, Maul JT, Ring HC, Thyssen JP, et al. Impact of smoking on disease severity and treatment outcomes in hidradenitis suppurativa. J Eur Acad Dermatol Venereol 2026. https://doi.org/10.1111/jdv.70344
37. Mallela T, Sayed C. Smoking tobacco is associated with specific phenotypes of hidradenitis suppurativa. Int J Dermatol 2026; 65: 193–197. https://doi.org/10.1111/ijd.70074
38. Theut Riis P, Saunte DM, Benhadou F, Del Marmol V, Guillem P, El-Domyati M, et al. Low and high body mass index in hidradenitis suppurativa patients-different subtypes? J Eur Acad Dermatol Venereol 2018; 32: 307–312. https://doi.org/10.1111/jdv.14599
39. Krajewski PK, Złotowska A, Szepietowski JC. The therapeutic potential of GLP-1 receptor agonists in the management of hidradenitis suppurativa: a systematic review of anti-inflammatory and metabolic effects. J Clin Med 2024; 13: 13. https://doi.org/10.3390/jcm13216292
40. Cuenca-Barrales C, Montero-Vílchez T, Szepietowski JC, Matusiak L, Molina-Leyva A. Sexual impairment in patients with hidradenitis suppurativa: a systematic review. J Eur Acad Dermatol Venereol 2021; 35: 345–352. https://doi.org/10.1111/jdv.16726