

# Impact of feeling of stigmatization on the lives of adult patients with hidradenitis suppurativa

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## INTRODUCTION & OBJECTIVE

Hidradenitis suppurativa (HS) is a chronic inflammatory dermatosis with significant physical, social, and emotional burden. Studies have established the importance of feeling of stigmatization [ FS] in HS, but there is little information about the consequence of FS on daily life . The objective of this study was to investigate the impact of HS-associated FS on social, professional and family life and to explore the impact of stigma on treatment adherence.

## MATERIAL & METHODS

The ALL PROJECT involves 50,552 individuals, representative of the adult populations of 20 countries spread over 5 all five continents. In each of the 20 countries surveyed we conducted a population-based study on representative and extrapolable samples of the general population aged 16 years or more. Among the 50552 individuals, patients who reported HS, confirmed by a physician, were identified.

## RESULTS

A population of 586 HS respondents was identified, including 302 (51.5%) males. A total of 450 HS respondents reported FS (77.1%), of which 337 (57.5%) felt ostracized or rejected by others, 334(57.0%) felt looked at with disgust, 333 (56.8%) reported that people avoided touching them, and 314 (53.6%) reported that people avoided approaching them because of their HS. 134 HS respondents were considered to have no FS. The FS population was on average younger than the non-FS population (mean age 34.75± 10.2 years vs 40.45 ± 14.5 y; P <0.0001). Gender (Men 78.5% vs 75.7%, p 0.90) and BMI (24.65 vs 25.97, p 0.077), visible lesion location ( 72.7% vs 80.4%, p 0.45) were not predictive factors of FS. Signs/symptoms of HS such as burning sensations [45,40%vs 29,10%, p0,036371) and skin pain (43,80% vs 23.90% , p 0,003525) were all significantly more frequent in patients with reported FS. There were significant consequences for self-perception, relationships, daily life, sleep, and social and work life in subjects with reported FS. Patients with reported FS were more likely to avoid taking selfies (84.4% vs. 51.5%, P 7.93E-12) and tended to control their appearance whenever they passed in front of a mirror (71.7% vs. 34.3%, P 8.63E-12) due to HS. Poor adherence to therapy was associated with feelings of stigma (78.6% vs. 32.8%, P <0.0001)

## DISCUSSION

Our study established that FS was more frequent in young patients with signs/symptoms of HS . This can result in negative attitudes and behaviors towards people who are affected by HS, which can lead to social isolation and exclusion. FS is associated with poor adherence to therapy, which can lead to a vicious cycle of mutually reinforcing negative conditions. Efforts to reduce FS in patients who live with HS can include public education campaigns, increased access to healthcare and support services, and challenging stereotypes and prejudices through advocacy and activism. It is important to promote a message of empathy and understanding toward those affected by disease, rather than fear and rejection.



Table1 :Signs and symptoms of HS	Positive responses in FS n=452		Positive responses in non-FS n=134		P-value
	N	%	N	%	
Itching	262	58,0%	77	57,5%	0.91
Prickles	199	44,0%	47	35,1%	0.45
Burning sensation	205	45,4%	39	29,1%	0,03
Tingling	210	46,5%	43	32,1%	0.09
Skin pain	198	43,8%	32	23,9%	0,4%
None of these sensations	29	6,4%	15	11,2%	0.25

	TABLE 2. Psychosocial impact of HS n = 586		Positive responses in FS n = 452		Positive responses in non-FS n = 134		P-value
	N	%	N	%	N	%	
Impact on Professional life	<i>When you think about your skin problems, how much do you consider it to be inconvenient in your professional life?</i>						
	390	86,3%	70	52,2%	< 0.0001		
	<i>Have you had to take time off work or school?</i>						
	307	67,9%	30	22,4%	< 0.0001		
Impact on family life	<i>Have you felt less productive in your activity (work/study)?</i>						
	312	69,0%	34	25,4%	< 0.0001		
	<i>Have you had the feeling that you were absent from your activity while being there?</i>						
	327	72,3%	36	26,9%	< 0.0001		
Impact on interpersonal Relationship	<i>Have you had to give up participating in a family or professional event?</i>						
	323	71,5%	33	24,6%	< 0.0001		
	<i>Have you experienced difficulties in your relationship?</i>						
	337	74,6%	38	28,4%	< 0.0001		
Impact on interpersonal Relationship	<i>Did you lack time to take care of your family?</i>						
	306	67,7%	32	23,9%	< 0.0001		
	<i>Did you feel that you were absent from your family life?</i>						
	317	70,1%	25	18,7%	< 0.0001		
	<i>Have you noticed a change in your family, social or professional relationships?</i>						
	319	70,6%	32	23,9%	< 0.0001		
	<i>When you think about your skin problems, how embarrassing do you consider it in your personal life?</i>						
	403	89,2%	96	71,6%	< 0.0001		
	<i>Did you put off things that you thought were important to do?</i>						
	321	71,0%	42	31,3%	< 0.0001		
	<i>Do you feel that your sex life has been affected?</i>						
	332	73,5%	34	25,4%	< 0.0001		
<i>Have you given up vacations or hobbies?</i>							
297	65,7%	23	17,2%	< 0.0001			
<i>Have you had to change plans that were important to you?</i>							
309	68,4%	23	17,2%	< 0.0001			
<i>Have you felt discouraged?</i>							
325	71,9%	40	29,9%	< 0.0001			
<i>Have you had to be more careful with your spending, to dip into your savings?</i>							
334	73,9%	42	31,3%	< 0.0001			
<i>Do you have trouble sleeping?</i>							
335	74,1%	43	32,1%	< 0.0001			
<i>Did you lack time to take care of yourself?</i>							
302	66,8%	35	26,1%	< 0.0001			
<i>Have you felt tired?</i>							
319	70,6%	57	42,5%	< 0.0001			
<i>Do you take this into account when buying clothes?</i>							
312	69,0%	35	26,1%	< 0.0001			
<i>Have you given up beauty treatments or an appointment with a hairdresser, for example, because of your skin condition?</i>							
311	68,8%	21	15,7%	< 0.0001			