



ORIGINAL ARTICLE

Improving the disease awareness: how a communication campaign brings hidradenitis suppurativa to the light

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Abstract

Background Hidradenitis suppurativa is an inflammatory skin disease that presents a recurrence of painful and suppurating lesions in the apocrine gland-bearing regions, with a strong impact on the patients' life quality. Despite its peculiar presentation, early forms are often underestimated by patients and this would inevitably result in late diagnosis and delayed therapy.

Objectives Improved communication around the disease could facilitate self-diagnosis and a quicker response from healthcare practitioners, especially in this moment when we dispose of effective treatment against this disease.

Methods A HS awareness campaign was conducted for 2 years with the help of a media agency and a patients' association.

Results Results confirm that a better communication has a strong impact on the disease awareness.

Conclusions This paper demonstrates that the more this disease awareness is carried on, the more quick, effective and efficient the patient's management could be.

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Conflict of interest

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Introduction

Hidradenitis suppurativa (HS) is an inflammatory skin disease with a characteristic clinical presentation of recurrent or chronic painful or suppurating lesions in the apocrine gland-bearing regions.¹ The prevalence of HS is unknown and varies from 0.03% to 4%.²

Because of sparse epidemiologic data, disease burden of HS has not yet been established, and its actual prevalence worldwide is probably underestimated.

Surveys show that the mean delay in establishing a diagnosis of HS from the time of its initial presentation is 7.2 years.³ This may be due to insufficient awareness of HS and lower knowledge throughout the general population about this disease or to the fact that patients may accept recurrent symptoms that follow standard treatments and not seek further care.

The importance of effective communication has already been recognized by the medical literature during the last decades⁴⁻⁷;

the high value of the communication between the healthcare practitioner and the patient has been highlighted,⁸ together with the effectiveness of specific training courses to enhance healthcare practitioners' communication skills. Besides, a new value has been given to the so-called *disease awareness*,⁶⁻⁹ since the increase of screenings is of course fundamental, but it is also important to handle a communication which can lead to new diagnosis.⁶⁻⁸ This takes us to the aim of the present paper, which presents a new way to communicate with people through a comprehensive and integrated communication⁷⁻¹⁰ which takes advantage from the use of a more 'democratic' word, like 'cyst', also affecting the genital area, spread through social and mass media.¹⁰ This impacts on the HS awareness, which positively levers both on diagnosis skills and a more effective and efficient patient's management.

Methods/the Italian HS awareness campaign

The HS awareness campaign was conducted during a period of 2 years (2017 and 2018) by a media agency (Personal Media) with

[†]HS Awareness Working Group members are listed in Appendix.



Figure 1 Flyer of the HS campaign ‘Che nome dai alle tue cisti?’ (‘How do you name your cysts?’).

the patronage of the patients’ association Inversa Onlus. This campaign was intended to give the chance to exploit a free dermatologic screening reserved for people suffering from HS – or who think they may be suffering from this disease – and it took place on the whole Italian territory in hospitals and medical centres which joined this initiative. The communication around it was carried by using the more understandable term ‘cyst’, instead of the HS one (Fig. 1), and it was developed by integrating mass media (television, radio and local newspapers), social media (Facebook) and by continuously carrying out digital PR and institutional relations (with hospitals and medical diagnostic centres), whilst people could book, via telephone, a free screening during special and dedicated open days (34 in 2017 and 31 in 2018).

Results and discussion

As shown in Table 1, the target of the campaign was heterogenous, since during the open days the youngest person checked was 10 years old and the oldest was 78, and the M:F ratio was 38 : 62, confirming the existing literature.¹¹ Regarding communication effectiveness, the 936 communication actions (546 in 2017 and 390 in 2018) were able to identify 555 new cases of HS (out of a potential 60 000 derived from the 20 million Facebook users, considering a minimal prevalence of 0.03%). Furthermore, the campaign was also useful to spread knowledge about HS: through the dedicated Facebook page and the information material (both printed and web-based) in which HS was described and explained, the selected users were able to consider whether they could be affected by HS. This approach resulted in a strong impact on visit requests by patients potentially suffering from HS and this is demonstrated by the 2017 and 2018 results: the first year 688 screening reservations led to 299 (43.45% of the requests) new HS diagnoses, whilst the 463 screening reservations during the second year led to 256 (55.3% of the requests) new diagnoses.

Conclusion

Results definitively confirm the literature^{6–9} and give an answer to the demand coming from previous studies⁸: a better managed

Table 1 ‘Che nome dai alle tue cisti?’ (‘How do you name your cysts?’) HS campaign: inputs and final results overview

Organizing committee			
Members	Activities' description		
Inversa Onlus	As one of the major patients' association, it supported the initiative and spread the communication about it		
Hospitals	They both run the free screenings and did the new diagnosis		
Diagnostic centres			
Personal Media agency	Run and organized the open days and all the contacts with both the audience and the doctors. It planned all the disease awareness campaign and it made HS knowledge more 'democratic', by using the common word 'cyst'		
'Che nome dai alle tue cisti?' Campaign inputs			
2017		2018	
Communication actions	Number	Communication actions	Number
Campaign web page	385	Campaign web page	268
TV and radio	30	TV and radio	6
Online news	33	Online news	28
Newspaper	57	Newspaper	48
Agency web page	21	Agency web page	19
Agency	20	Agency	21
Total	546	Total	390
2017 – 34 stages report		2018 – 31 stages report	
Total contacts	2050	Total contacts	2383
Info requested via email	91	Info requested via email	90
Phone calls	1959	Phone calls	2293
Reservations	688	Reservations	463
Screenings done	629	Screenings done	417
HS new diagnosis	299	HS new diagnosis	256

communication has a strong impact on disease awareness and improved disease awareness allows the healthcare structures to better manage patients, with, for instance, the presence of specialized nurses and dedicated management teams.⁸ Furthermore, the integrated communication campaign, developed by using more understandable terminology, has improved the general awareness around HS, which is often misdiagnosed, and its daily care practices. As a result, the number of patients who take action could potentially increase substantially. One factor in whether or not patients seek help is the shame of the condition during intimacy. Privacy issues should be taken in account, as privacy policies on social media such as Facebook are very strict, and could potentially impact campaigns.

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Appendix

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