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Ximenes, Bárbara Álvares Salum; Fleury Junior, Luiz Fernando Froes; Terra, Taiane Medeiros; Ribeiro, Ana Maria Quinteiro; Junqueira, Rafael Ferreira; Freire, Alexandra Sousa; Miranda, Flávia Tandaya Grandi; Peres, Marina Dumont Palmerston

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Original Article

Authors:

Bárbara Álvares Salum Ximenes¹
 Luiz Fernando Froes Fleury Junior¹
 Taiane Medeiros Terra¹
 Ana Maria Quinteiro Ribeiro¹
 Rafael Ferreira Junqueira¹
 Alexandra Sousa Freire¹
 Flávia Tandaya Grandi Miranda¹
 Marina Dumont Palmerston Peres¹

¹ Dermatology Service, Department of Tropical Medicine and Dermatology, Clinical Hospital, Universidade Federal de Goiás - Goiânia (GO), Brazil.

Correspondence:

Bárbara Álvares Salum Ximenes
 Rua B, 16 - Quadra 10 - Lote 10
 Jardins Paris
 74885-636 Goiânia (GO), Brazil
 Email: barbara_ximenes@hotmail.com

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Quality of life assessment of patients with hidradenitis suppurativa using adalimumab: a pilot study

Avaliação da qualidade de vida de pacientes com hidradenite supurativa em uso de adalimumabe: estudo-piloto

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ABSTRACT

Introduction: Hidradenitis suppurativa (HS) is a chronic skin disease whose mechanism is not yet fully understood. It has a direct impact on the quality of life of affected patients, but there is no well-established therapy for its treatment.

Objective: To assess the quality of life of patients diagnosed with HS on adalimumab using the Dermatology Life Quality Index (DLQI) questionnaire.

Methods: Information was collected from patients with HS on adalimumab and standard DLQI questionnaires were applied before the beginning of treatment and at least 12 weeks after.

Results: Of the three patients included, two presented decreased DLQI. Of these two, one showed significant improvement after treatment with adalimumab. The third patient showed worsening of this index.

Conclusions: The impact of hidradenitis suppurativa on the quality of life of affected patients is significant and is related to factors other than adequate therapy. Life habits such as smoking and alcoholism, as well as the presence of other comorbidities, probably impact these indices. Affected patients should be assessed globally to determine the actual impact on the quality of life related to the disease in question. Thus, we suggest further studies with a larger number of patients.

Keywords: Hidradenitis suppurativa; Quality of life; Indicators of quality of life

RESUMO

Introdução: A hidradenite supurativa (HS) é uma doença de pele crônica, cujo mecanismo ainda não está totalmente esclarecido. Exerce impacto direto na qualidade de vida dos pacientes acometidos, mas não há uma terapia bem estabelecida para seu tratamento.

Objetivo: Avaliar a qualidade de vida dos pacientes com diagnóstico de HS em uso de adalimumabe por meio do questionário Dermatology Life Quality Index (DLQI).

Métodos: Foram coletadas informações de pacientes portadores de HS em uso de adalimumabe, e utilizados questionários- padrão do DLQI, aplicados antes do início do tratamento e no mínimo 12 semanas após.

Resultados: Dos três pacientes incluídos, dois apresentaram diminuição do DLQI. Dos dois, um apresentou melhora importante após o tratamento com o adalimumabe. O terceiro paciente demonstrou piora desse índice.

Conclusões: O impacto da hidradenite supurativa na qualidade de vida dos pacientes acometidos é importante e está relacionado a outros fatores além da terapêutica adequada. Hábitos de vida, como tabagismo e etilismo, além da presença de outras comorbidades, provavelmente exercem impacto nesses índices. Os pacientes acometidos devem ser avaliados de forma global, a fim de se determinar o real impacto na qualidade de vida relacionado à doença em questão. Para isso, sugerimos novos estudos com um número maior de pacientes.

Palavras-Chave: Hidradenite supurativa; Qualidade de vida; Indicadores de qualidade de vida

INTRODUCTION

Hidradenitis suppurativa (HS), or “acne inversa”, is a chronic, inflammatory, recurrent and debilitating skin disease that affects the hair follicle. Most of the time, the disease presents after puberty, with painful, deep, and inflamed lesions in areas with the representativeness of apocrine glands, mainly armpits, inguinal and anogenital region.^{1,2}

The precise inflammatory mechanism that leads to HS lesions is not yet fully known. The central pathogenic event is considered to be the occlusion of the upper parts of the hair follicle, leading to a perifollicular lymphohistiocytic inflammation. Stimulation of inflammatory cells by microbial products that activate TLR2 may be an essential triggering factor in the chronic inflammatory process. The pro-inflammatory role of cytokines IL-12, IL-23, and IL-17 are also reported.^{1,2}

Primary criteria for the diagnosis of HS include recurrent, painful, or suppurative lesions more than twice in six months. They are characterized by nodules, sinus tracts, underarm abscesses, or scars in the armpits, genitofemoral area, perineum, buttocks, and inframammary region. Secondary criteria include positive family history and healthy skin microbiota in affected areas.^{1,2}

There is no well-established and universally accepted therapy for the treatment of HS. Current therapeutic options include antibiotics, retinoids, immunosuppressive treatment, surgery, and, more recently, biological agents such as adalimumab and infliximab.²

Determining treatment response can be challenging due to the limitations of currently available methods for assessing disease activity.³ Several criteria have already been proposed for classifying and assessing the severity of HS. Hurley's classification separates patients into three groups with different severity levels, but only makes a qualitative classification of lesions, and it is not suitable for evaluating the efficacy of clinical trial interventions. The Sartorius score, in turn, assesses the severity of HS in a more detailed and dynamic way but may fail in severe cases where initially separated lesions become confluent. Also, it includes lesions that may not be sensitive to clinical treatment, and it is not ideal for analyzing therapeutic efficacy. The Physician Global Assessment (PGA) divides the disease into six different stages and has been the most frequently used criterion for assessing improvement in clinical trials. The Hidradenitis Suppurativa Clinical Response (HiSCR) was developed to address the problems mentioned above, considering improvements in disease activity, simplifying the scoring process, and increasing the sensitivity to identify specific HS lesions.³

Furthermore, a parameter widely used in various skin conditions can evaluate the influence of HS on the quality of life of affected patients thoroughly: the Dermatology Life Quality Index (DLQI). This questionnaire aims to measure how much skin involvement influenced daily activities and interpersonal relationships in the last week. Combined with the questionnaires mentioned above, it can be a useful tool for patient follow-up in clinical practice as well as but also in assessing patients in clinical trials.^{4,5}

METHODS

Information was collected from patients with HS on adalimumab followed at the Dermatology Outpatient Clinic of a referral hospital, aged 18 to 60 years, of both sexes, classified as Hurley II or III, or with lesions refractory to three months of antibiotic therapy or isotretinoin target dose therapy. Patients using isotretinoin had not been released or had contraindications to the use of acitretin. Standard DLQI questionnaires were applied before the start of adalimumab treatment and at least 12 weeks after the start of the treatment. Weight, body mass index (BMI), presence of comorbidities, and lifestyle habits were also assessed (smoking, alcoholism, physical inactivity).

Individuals younger than 18 years old and older than 60 years, pregnant women or women planning to get pregnant in the next four months, and patients using adalimumab in different regimens than that described in the package insert for HS treatment (160mg on D1; or two 40mg injections per day for two consecutive days - D1 and D2, followed by 80mg on D15 and D29, followed by a 40mg dose per week), were excluded from this pilot study. We also excluded patients who did not agree to participate in the study or did not sign the informed consent form (ICF).

RESULTS

Of the 14 patients diagnosed with HS under regular follow-up at the Dermatology Outpatient Clinic of a referral hospital, four were selected for adalimumab use. One of these patients was excluded from the study because he did not take the induction dose as proposed.

After exclusion, three patients using adalimumab for HS treatment were evaluated. Two patients were staged as Hurley 3 and one as Hurley 2. One patient had inguinal and perineal lesions, one had inguinal and axillary lesions, and the last one had lesions in the inguinal, axillary, and retroauricular regions. Two patients were female and one male, all aged 37 to 38 years. One patient had adequate weight for height, one was overweight, and another presented grade I obesity. Two patients were smokers and none had a history of alcoholism. Only one patient had other comorbidities (osteoarthritis). All had DLQI greater than 10 before the beginning of the treatment: one patient presented a decrease of 16 points after 20 weeks of treatment, one, a reduction of one point after 32 weeks of treatment, and another a decrease of seven points after 48 weeks of treatment (Table 1).

DISCUSSION

In the assessed patients, HS had a significant impact on all DLQI subdomains. Still, it is noteworthy the value attributed to symptoms and feelings and the intervention in daily activities.^{5,6} This impact seems to be more critical than that present in patients with other skin diseases commonly related to poor quality of life, such as chronic urticaria, psoriasis, atopic dermatitis, and neurofibromatosis.⁶ This is because all patients presented DLQI greater than 10, which means a great effect of the skin condition on quality of life. Still compared to other skin diseases in which the use of immunobiologicals may lead to complete remission, thus raising the level of quality of life to zero DLQI, patients

TABLE 1: REPRESENTATION OF DEMOGRAPHIC DATA AND DERMATOLOGY LIFE QUALITY INDEX (DLQI) INDEXES BEFORE AND AFTER ADALIMUMAB USE

	DLQI before	DLQI after	Types of lesion	Site	Hurley	Age	Sex	BMI	Comorbidities	Alcoholism	Smoking
Patient 1	28	12	Nodules, fistulas and scars	Armpits and groin	3	38	F	31.83	None	No	No
Patient 2	24	23	Fistulas, beams and scars	Vulva and perineum	3	37	F	29.29	None	No	Yes
Patient 3	18	25	Nodules, fistulas and scars	Groin	2	38	M	24.22	Osteoarthritis	No	Yes

with HS on adalimumab didn't present this level of intervention, maintaining rates higher than 10 throughout the treatment, even with some improvement in quality of life.

Although not objectively assessed, we observed the feeling of frustration in those patients who did not show a significant improvement in the quality of life. The same was observed in those patients whose response to treatment did not match the expectation initially created.

Another matter observed was the difficulty of understanding the applied questionnaire. In the case that the patient did not understand very well what was questioned, using the DLQI as a response parameter may not have been adequate, thus to consider that this index worsened in one of the evaluated subjects can be a bias.

As expected, the impact of HS on quality of life correlated with the severity of skin involvement,^{7,8} worsening the DLQI of the patient with lesions in more exposed regions, and with a history of smoking, being the only non-smoking patient who presented the most significant response after the adalimumab use.

CONCLUSIONS

The skin plays a crucial role in interpersonal relationships, self-esteem, and perception of self-image and public image, as it is the most significant and most visible part of the human body.^{5,9} Therefore, due to the character of the disease, many patients with HS have to deal with depression and embarrassment. Also, pain (commonly reported), fever, and fatigue may prevent individuals from performing everyday tasks.¹

Collecting baseline data regarding the personal impact of hidradenitis suppurativa is a necessary first step in determining the extent to which adopted interventions improve the quality of life of patients with the disease.⁴ Patient expectations regarding the treatment should be managed.

The choice of using adalimumab to treat severe or refractory lesions should consider the risks and cautions involved in using an immunobiological. Also, this line is often viewed by patients as the last opportunity for treatment, which can increase frustration and worsen the quality of life in cases that do not respond as expected or considerably improve the quality of life of those who present a good response.

Thus, the information obtained in this research can undoubtedly contribute to broadening the knowledge about the subject, allowing a better structuring of the approach, considering better care for patients with this disease, with an impact mainly on social inclusion and improved quality of life of these patients. We expect further studies, including more patients, to be conducted in the future to determine the real influence of adalimumab use on the quality of life of patients with HS.

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DECLARATION OF PARTICIPATION:

Bárbara Álvares Salum Ximenes |  ORCID 0000-0001-5111-1809

Study design and planning; preparation and writing of the manuscript; data collection, analysis, and interpretation; critical literature review.

Luiz Fernando Froes Fleury Junior |  ORCID 0000-0002-1202-6211

Study design and planning; intellectual participation in propaedeutic and/or therapeutic conduct of studied cases.

Taiane Medeiros Terra |  ORCID 0000-0002-6479-8686

Study design and planning; data collection, analysis, and interpretation.

Ana Maria Quinteiro Ribeiro |  ORCID 0000-0001-9872-0476

Approval of the final version of the manuscript; study design and planning; preparation and writing of the manuscript; data collection, analysis, and interpretation; active participation in research orientation; intellectual participation in propaedeutic and/or therapeutic conduct of the studied cases.

Rafael Ferreira Junqueira |  ORCID 0000-0003-2693-0938

Approval of the final version of the manuscript; study design and planning.

Alexandra Sousa Freire |  ORCID 0000-0001-5092-7128

Study design and planning; preparation and writing of the manuscript; critical literature review.

Flávia Tandaya Grandi Miranda |  ORCID 0000-0002-4323-2499

Study design and planning; preparation and writing of the manuscript; critical literature review.

Marina Dumont Palmerston Peres |  ORCID 0000-0001-9961-5184

Study design and planning; preparation and writing of the manuscript; critical literature review.