

Introduction

Hidradenitis suppurativa(HS) is a major therapeutic challenge for clinicians and the one inflammatory dermatosis responsible for the heaviest burden on our patients. The diversity of the disease and the fact that it progresses in flare-ups make it difficult to draw up recommendations. With the arrival of new biotherapies in sight, we wanted to assess the current state of patient management in 2022.

Materials and methods

For this declarative survey of patients' perception and experience, an anonymous 12-minute online questionnaire was disseminated via Reso between 22/11/22 and 04/01/23. The survey included questions on the patient's care pathway, impact on quality of life, patient needs and expectations, satisfaction with treatment and current management of pain.

Discussion

Although the burden of HS has already been the subject of many published papers, we lack recent data on management in France, as the latest SFD recommendations were published in 2019. The results of this patient survey highlight the lack of pain management in day to day life and during relapses, leading us to question the prescriptions given to patients in advance. In addition to the emergency use of antibiotics in the case of abscesses, we need to think about a more in-depth assessment of pain during our HS consultations, with a treatment proposal adapted to the VAS, probably involving the use of Tier 2 or even Tier 3 painkillers. It is also interesting to note the needs and expectations of our patients in terms of information about the disease and the current and upcoming disease-modifying treatments.

Results

419 patients with HS were included (80% female, with an average age of 37). The first HS lesions appeared at the age of 20.7 years in 60% of patients. The average time to diagnosis was 9 years. 51% of the patients surveyed were stage II, 22% stage I and 27% stage III. At the time of diagnosis, the area's most frequently affected were the pelvic region (groin, buttocks, intergluteal fold 91%) and the armpits (61%). Over the past year, patients reported having had 12 outbreaks, and 3 sites currently affected.

Only 7% of patients were in complete clinical remission at the time of the survey. On average, patients reported having had 6.2 incisions and 3.6 surgical drainage procedures. The intensity of pain associated with Verneuil lesions over the past year was assessed at 7.4/10 (VAS) on average and 8.9/10 during flare-ups. Pain was managed with moist dressings or antibiotic ointments (61%) and standard analgesics (52%) or combined analgesics (33%), 9% used morphine and 49% practiced self-incision/drainage. For more than 20% of patients, nothing relieved the pain. 19% had no substantive treatment because for 54% of them, no treatment was effective. Among the 419 respondents, 13% were being managed with biotherapy. Only 51% of patients had ever heard of biotherapies, and 82% would like information on the subject. 96% would like to see improvements in treatment, and 72% would like better pain management.

Conclusion

Pain management in HS currently seems inadequate.

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