Title

Longitudinal remote monitoring of hidradenitis suppurativa: a pilot study.

Journal

British Journal of Dermatology, 190(2)

Authors

Fonjungo, Fonette
Barnes, Leandra
Cai, Zhuo
et al.

Publication Date

2024-01-23

DOI

10.1093/bjd/ljad385

Peer reviewed

Longitudinal remote monitoring of hidradenitis suppurativa: a pilot study

https://doi.org/10.1093/bjd/ljad385

Dear Editor, Longitudinal home-based monitoring of disease progression is commonly used to support management of chronic diseases such as hypertension. The role of remote monitoring in hidradenitis suppurativa (HS) has not been well defined. Several factors complicate the remote evaluation of HS, including patients' hesitancy to expose intimate body areas.[1] We sought to investigate the feasibility of longitudinal home monitoring of people with HS.

Eligible participants were aged $\geq$ 18 years, diagnosed with HS at Stanford Dermatology and had access to a smartphone. We recruited 75 patients by telephone and during in-person visits. Twenty-seven patients consented to participate and were enrolled in the study; 22 of the 27 were women (9 Hispanic, 7 Black, 5 Asian, 4 non-Hispanic White and 2 American Indian/Native Hawaiian). Six, 13 and 8 participants had Hurley stage I, II, and III disease, respectively. We developed a digital tool, utilizing Twilio and REDCap, that sent automated weekly text reminders (October 2022–March 2023) to collect photographs of HS-affected skin and symptom reports from participants. After photographs were uploaded, participants reported average weekly pain using a modified pain visual analogue scale.[2] The Skindex-Mini was used as a quality of life (QoL) measure to assess the frequency with which participants were bothered by their symptoms, emotionally and physically.[3] Participants who did not complete their survey after the initial request received reminders 24 and 48 h later. Two dermatologists evaluated the photographs for appropriate lighting, focus and distance.[4] Feedback was provided and reuploads were requested for inadequate photographs. We performed a Welch *t*-test to compare upload rates, pain and QoL scores. We collected feedback on our tool from 37% of participants.

Over 26 weeks, we collected 421 photos. Four participants withdrew owing to external stressors. On average, the number of uploads per participant was 8.6. The weekly

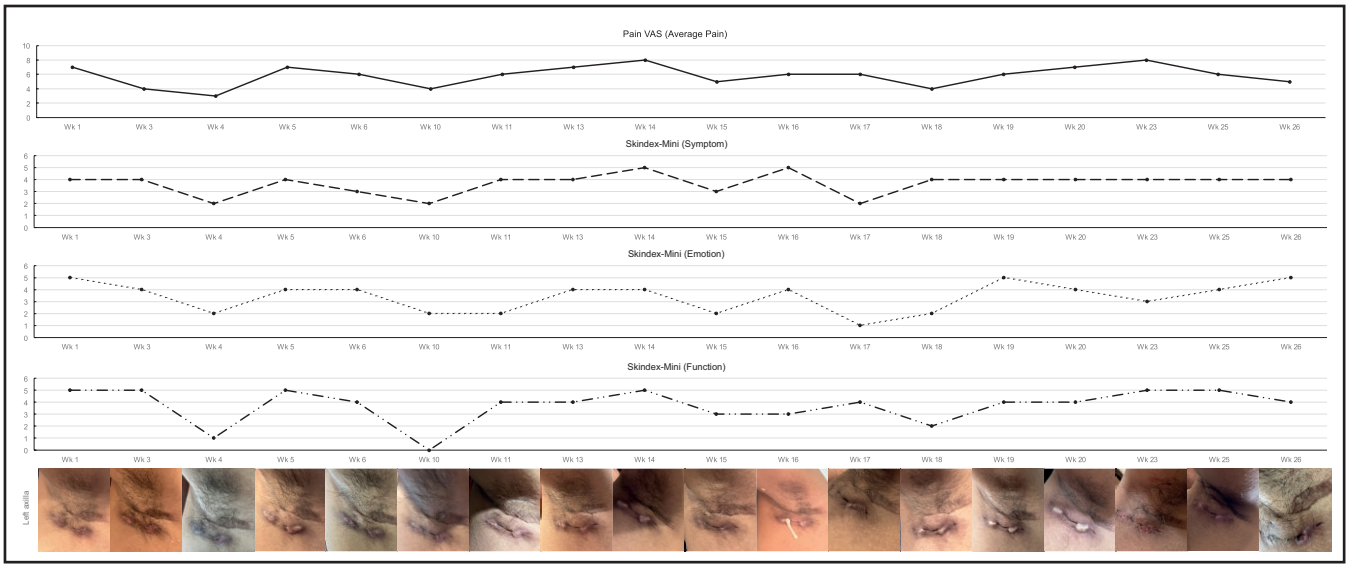

Figure 1 To determine the feasibility of longitudinal remote monitoring of disease activity in people with hidradenitis suppurativa our digital tool sent automated weekly text reminders for 26 weeks to collect the data sampled. With each photo upload, the participant reported their average pain for the week using a modified pain visual analogue scale (VAS; 0–10). Using the Skindex-Mini (0–6), the participant reported the frequency at which they were bothered by their skin symptoms (Symptom), frequency at which skin symptoms impacted their emotions (Emotion) and frequency at which skin symptoms affected their function (Function) that week.

proportion of participants who completed uploads ranged from 14% to 77%. The overall text-response rate was 39%: 42% after the initial request, 31% after the first reminder, 24% after the second reminder and 3% after additional reminders. The average response time was 1.8 days. Participants following inguinal lesions had the highest participation (mean uploads 8), while those following genital lesions had the lowest (mean uploads 3.5). Participants with Hurley stage I disease were 3.6 times more likely to complete uploads than participants with Hurley stage III (mean uploads for those with stage I HS 12.3 vs. 3.5 for those with stage III HS; $P=0.04$). Two dermatologists determined that 97% of photographs had adequate distance, lighting and focus to identify new nodules and/or overt drainage. Ninety-eight per cent of photo uploads had complete QoL and pain scores. Participants with more severe disease had higher pain scores and worse QoL over time ($P<0.001$). Figure 1 shows an example of data collected from one participant, including photos, pain and QoL scores measured over 26 weeks.

Our findings show that it is possible to remotely collect images of HS affected skin and patient-reported outcomes over time. This is in line with conclusions made by Patel *et al.*,[1] who remotely assessed disease activity in people with HS via telephone consultations. Participants reported decreased interest in completing uploads during flares due to pain hindering their physical function. This may provide context to our finding that the more severe the Hurley stage, the less likely participants were to complete uploads. Interestingly, we learned that some participants valued taking snapshots of their disease activity over time and observing treatment response. One participant stated: 'Monitoring my skin has made me more aware. I reflect each week and when I don't flare, I ask myself what I did differently. It makes me feel good to be consciously caring for my skin.' In a study that analysed self-destructiveness in 100 people with HS, Głowaczewska *et al.* found that people with HS were more prone to passive self-destructive behaviours that led to health negligence and curbed clinical improvement.[5] This highlights the possible patient-centred benefits of remote HS monitoring. Increased upload rates from participants with mild disease is encouraging as it would be advantageous to initiate monitoring early in the disease course. A single-centre retrospective study suggests that progression from Hurley stage I to Hurley stage II over a 3-year period may be predictive of progression to Hurley stage III HS and therefore may be a potential clinical biomarker of poor prognosis.[6] Close prospective monitoring of disease progression in larger cohorts is warranted to confirm these findings. This pilot study provides proof of concept that will support future studies. Our findings suggest that longitudinal monitoring may be feasible in people with HS, especially in individuals with mild disease.

Fonette E. Fonjungo[1,2,3] Leandra A. Barnes[1] Zhuo Ran Cai[1] Haley B. Naik[4] Edward S. Eid[1] Maria A. Aleshin[1] Vanessa Nava[1] Tiffani Johnson[1] Mary-Margaret Chren[3] and Eleni Linos[1]

[1]Department of Dermatology, Stanford Medicine, Palo Alto, CA; [2]Meharry Medical College, Nashville, TN; [3]Vanderbilt University School of Medicine, Nashville, TN and [4]Department of Dermatology, University of California San Francisco, San Francisco, CA, USA

Correspondence: Fonette Fonjungo. Email: fonjungo.f@gmail.com

Funding sources: Funding for this article was provided by the National Institutes of Health Mid-career Investigator Award in Patient-Oriented Research (K24AR075060), Research Project Grant (R01AR082109) and supported by the Vanderbilt Medical Scholars Program.

Conflicts of interest: The authors declare no conflicts of interest.

Data availability: Owing to the sensitive nature of this research and to maintain patient privacy, the data underlying this article cannot be shared publicly.

Ethics statement: This study was approved by Stanford's Institutional Review Board (IRB #60677).

References

1 Patel NP. Remote consultations for patients with hidradenitis suppurativa during the COVID-19 pandemic: a single-centre experience. *Clin Exp Dermatol* 2021; **46**:1079–81.
2 van Straalen KR, Ingram JR, Augustin M *et al.* New treatments and new assessment instruments for hidradenitis suppurativa. *Exp Dermatol* 2022; **31**(Suppl. 1):33–39.
3 Orenstein LAV, Amah A, Shaw FM *et al.* Validation of the three-item Skindex-Mini among hidradenitis suppurativa patients with diverse racial backgrounds. *J Cutan Med Surg* 2020; **24**:457–60.
4 Jiang SW, Flynn MS, Kwock JT *et al.* Quality and perceived usefulness of patient-submitted store-and-forward teledermatology images. *JAMA Dermatol* 2022; **158**:1183–6.
5 Głowaczewska A, Reszke R, Szepietowski JC *et al.* Indirect self-destructiveness in hidradenitis suppurativa patients. *J Clin Med* 2021; **10**:4194.
6 Vanlaerhoven AMJD, Ardon CB, van Straalen KR *et al.* Hurley III hidradenitis suppurativa has an aggressive disease course. *Dermatology* 2018; **234**:232–3.