

Patient crowdfunding for inflammatory skin disease



To the Editor: Inflammatory skin conditions are widely prevalent and affect patients physically, psychologically, and economically, from high treatment costs to functional damage, leading to decreased employment or the loss of work.^{1,2} To better understand the financial and psychosocial burdens of inflammatory skin disease, we sought to explore the use of fundraiser campaigns for these conditions on the publicly available crowdfunding website GoFundMe. Although previous research has characterized crowdfunding for individual dermatologic diseases,^{3,4} this study intended to compare data among common inflammatory skin conditions to determine the differences in psychologic distress, out-of-pocket costs, and social factors contributing to financial burden.

Fundraising campaigns were identified on the GoFundMe website using standard search functionality and included if the campaign was primarily raising funds for individual expenses for a person diagnosed with hidradenitis suppurativa (HS), atopic dermatitis (AD), psoriasis, or vitiligo (Supplementary Fig 1, available via Mendeley at <https://data.mendeley.com/datasets/tnxx8g64mj/1>). In total, 141, 173, 213, and 14 campaigns met the

inclusion criteria for HS, AD, psoriasis, and vitiligo, respectively. The collected campaign variables included demographics, financial data, reported expenses, financial hardships, and educational methods for describing their condition. The variables were tabulated, and statistical analyses were performed using independent sample *t* tests and logistic regression.

Besides “unspecified,” the most frequently reported expenses for each condition were related to medications (for psoriasis, vitiligo, and AD) and surgeries or procedures (for HS) (Fig 1). Campaigns for HS and vitiligo reported educational information about their disease more commonly than campaigns for psoriasis and AD (Table I). Psychologic distress was frequently reported across the inflammatory conditions, with the highest incidence among patients with vitiligo (71.4%). Reference to stigma caused by skin diseases (eg, bullying or embarrassment) was also highest among patients with vitiligo (57.1%) compared with patients with the other conditions (odds ratio, 10.4; CI, 3.5-30.9). For all the inflammatory diseases, 5.9% of patients reported being uninsured, with 20.9% stating that their health insurance failed to adequately cover medical expenses. For campaigns active for >6 months, the mean percentage of fundraising goals achieved was

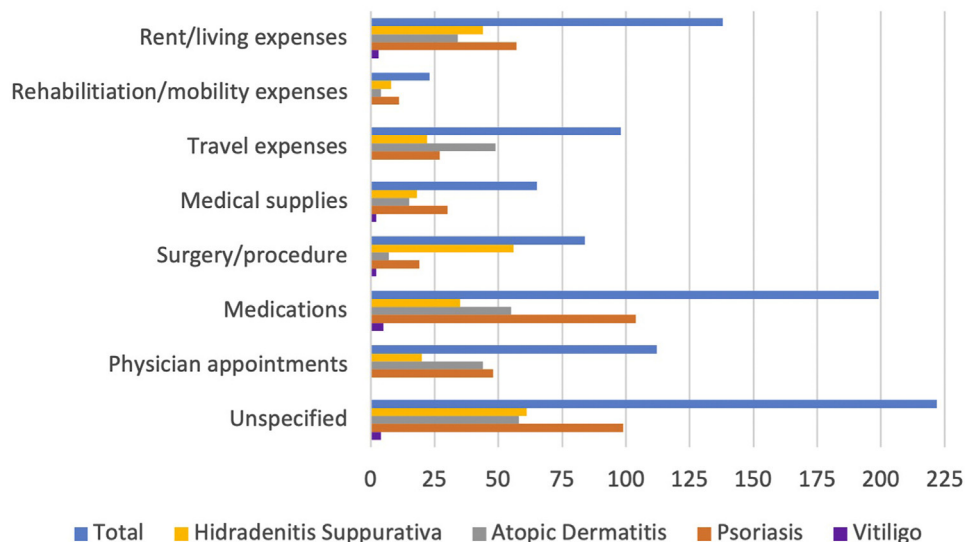


Fig 1. Number of fundraising campaigns for specified expenses by inflammatory skin disease type. Phototherapy was classified under “surgery/procedure” when administered by a clinician and under “medical device” while raising funds for an at-home phototherapy machine.

Table I. Demographics and characteristics of fundraisers for inflammatory skin diseases

Campaign demographics and characteristics	Hidradenitis suppurativa, n (%)	Atopic dermatitis, n (%)	Psoriasis, n (%)	Vitiligo, n (%)
Sex of patient				
Male	43 (30.5)	75 (43.4)	98 (46.0)	8 (57.1)
Female	97 (68.8)	97 (56.1)	108 (50.7)	4 (28.6)
Undisclosed	0 (0.0)	0 (0.0)	5 (2.3)	2 (14.2)
Geographic region				
United States	136 (96.5)	124 (71.6)	154 (72.3)	9 (57.6)
Canada	0 (0.0)	10 (5.8)	9 (4.2)	0 (0.0)
Europe	3 (2.1)	26 (15.0)	35 (16.4)	1 (7.1)
Australia	2 (1.4)	9 (5.2)	4 (1.9)	1 (7.1)
Educational tools				
Includes educational information about disease	91 (64.5)	27 (15.7)	34 (16.0)	5 (38.5)
Photographs of disease	33 (23.4)	120 (69.8)	96 (45.1)	12 (92.3)
Video of disease or treatment course	10 (7.1)	12 (7.0)	4 (1.9)	0 (0.0)
Provides updates on treatment	45 (32.1)	72 (41.9)	60 (28.2)	0 (0.0)
Psychologic distress				
Reference to psychologic distress	56 (39.7)	41 (23.8)	77 (36.2)	10 (71.4)
Reference to stigma caused by the disease	16 (11.3)	14 (8.1)	30 (14.1)	8 (57.1)
Financial hardships				
Loss of income	64 (45.4)	53 (30.8)	76 (35.7)	2 (15.4)
Unemployed	41 (29.3)	22 (12.8)	45 (21.1)	2 (15.4)
Need to cut back on work (if still employed)	32 (22.9)	24 (14.0)	34 (16.0)	0 (0.0)
Health insurance				
Specific mention of health insurance or health care system	46 (32.6)	48 (27.7)	59 (27.7)	0 (0.0)
Uninsured	6 (4.3)	13 (7.6)	13 (6.1)	0 (0.0)
Inadequate coverage of medical expenses if insured	39 (27.9)	30 (17.4)	44 (20.7)	0 (0.0)
Campaign financial success				
Total donors	2360	7492	4256	19
Campaigns reaching 100% of goals*	10 (8.3)	25 (17.0)	13 (7.8)	0 (0.0)
Campaigns reaching >75% of goals*	13 (10.8)	31 (21.1)	30 (18.1)	1 (12.5)
Campaigns reaching >50% of goals*	28 (23.3)	52 (35.3)	47 (28.3)	1 (12.5)

*Determined after 6 months of campaign activity.

highest for AD (45.3%; SD, 51.1%), followed by psoriasis (31.7%; SD, 41.9%), HS (26.0%; SD, 40.4%), and vitiligo (10.3%; SD, 29.1%). After 1 year, campaigns providing treatment updates were more likely to achieve a greater percentage of their goals ($P < .001$), as were fundraisers who included photographs of their disease ($P = .03$).

Taken together, these results suggest that underinsurance remains a significant burden for patients with inflammatory skin conditions. In particular, medication costs were the most frequently specified expense in this study. This finding is consistent with the rising out-of-pocket costs for therapeutics used for other inflammatory diseases.⁵ The fact that HS and vitiligo were more associated with direct, disease-oriented information speaks about the underrecognition of these conditions in the general public (at least compared with AD and psoriasis). Although providing updates or photographs was associated with greater fundraising success, this practice may pose ethical concerns if

patients feel pressure to disclose sensitive medical or personal information. The study limitations include self-reported data, incomplete demographic information, and bias toward patients with inadequate financial support. The generalizability of psychologic burden may also be limited by the small sample size. Overall, this study sought to highlight the complex financial and psychosocial burden associated with these conditions.

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Funding sources: None.

IRB approval status: Not applicable.

Key words: crowdsourcing; health policy; inflammatory skin disease; insurance; underinsurance.

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Conflicts of interest

Dr LaChance is the principal investigator for a research grant from Pfizer for a project exploring the role of the

Janus kinase/signal transducers and activators of transcription pathway in cutaneous connective tissue diseases.

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<https://doi.org/10.1016/j.jdin.2022.05.006>