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Crowdfunding to Compensate for Financial Burdens of Patients with Systemic Sclerosis

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Introduction

Systemic sclerosis (SSc) is a rare autoimmune disease that significantly impairs quality of life and has the highest mortality rate among rheumatologic conditions.[1] SSc is also associated with high financial burdens, as many treatments are not covered by health insurance due to a lack of FDA approved therapies for this disease state.[1-5] Previous studies have explored the use of crowdfunding as a means to financially support patients with dermatologic diseases such as juvenile dermatomyositis, epidermolysis bullosa, and alopecia, but no studies to date have investigated the use of crowdfunding for SSc.[6-8] In this study, we examined the use of the popular crowdfunding platform GoFundMe as a means to support SSc-related medical care.

Methods

On May 23, 2021, GoFundMe's publically available internal search engine was used to identify campaigns soliciting donations for SSc. Data were retrieved from GoFundMe via a Python script designed to target all campaigns containing the words "systemic sclerosis" and "scleroderma." Duplicate campaigns or campaigns unrelated to SSc were excluded. Campaign websites were reviewed to collect data on donation recipients, impact of SSc on quality of life, sources of financial burden, fundraising goals and outcomes, and allocation of donations. Stata SE 16.1 was utilized for data analysis.

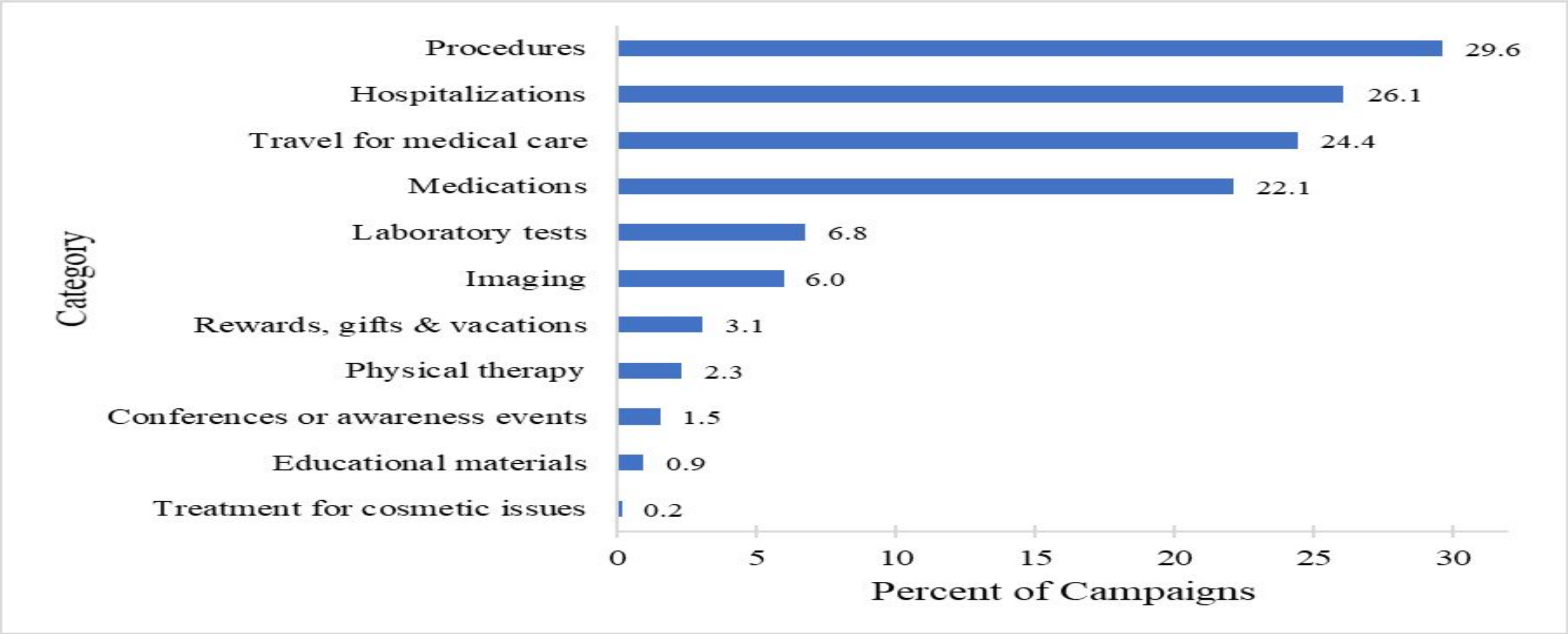
Results

Among 1,672 campaigns evaluated, 652 met inclusion criteria (Table 1). Of these campaigns, 78.2% (n=510) were created on behalf of someone with SSc and 31.1% (n=203) were created by someone with SSc. 71.8% (n=468) and 38.8% (n=253) of campaigns reported functional impairment and psychological distress associated with having SSc, respectively. 82.7% (n=539) of campaigns stated that the fundraising recipient had financial burdens related to SSc, including loss or expected loss of income (n=218, 33.4%), incomplete insurance coverage (n=166, 25.4%), lack of coverage for procedures (n=54, 8.3%), lack of coverage for medications (n=30, 4.6%), and lack of health insurance (n=13, 2%).

14.8% (n=96) of campaigns met their fundraising goal. The average fundraising goal was $21,627.83 (range $100 - $300,000); the average amount raised was $5,409.66 (range $0 - $44,780). 29.6% (n=193) of campaigns allocated donations to pay for procedures, 26.1% (n=170) for hospitalizations, 24.4% (n=159) for travel for medical care, and 22.1% (n=144) for medications (Figure 1). 88.8% (n=579) of campaigns stated that the donations would make life less burdensome or stressful for the recipient.

Figure and Table

Figure 1. Categories to which SSc crowdfunding campaigns allocated their donations



Abbreviation: SSc, systemic sclerosis

Table 1. Characteristics of SSc crowdfunding campaigns

Characteristic	N (%) N=652
Funding recipient	
Self (person with SSc)	203 (31.1)
Another person with SSc	510 (78.2)
SSc-related charitable organization	48 (7.4)
Impact of SSc described in campaign	
Financial burden	539 (82.7)
Functional impairment	468 (71.8)
Psychosocial distress	253 (38.8)
Unspecified impact on quality of life	102 (15.7)
Sources of financial burden	
Loss or expected loss of income	218 (33.4)
Lack of health insurance	13 (2)
Incomplete insurance coverage	166 (25.4)
Lack of insurance coverage for medications	30 (4.6)
Lack of insurance coverage for procedures	54 (8.3)
Fundraising goal (average, [range])	$21,627.83 [$100 - $300,000]
Amount raised (average, [range])	$5,409.66 [$0 - $44,780]
Campaigns meeting fundraising goal	96 (14.8)

Abbreviation: SSc, systemic sclerosis

Discussion

This study highlights both the financial hardships experienced by individuals with SSc, as well as the limited effectiveness of crowdfunding in providing substantial support. The majority of campaigns described quality-of-life-impairing financial strain, most commonly from a loss or expected loss of income. This likely reflects the campaigns' frequent reporting of SSc-associated functional impairment, a known risk factor for work disability among individuals with SSc.[9] Inadequate insurance coverage was the second biggest source of financial burden, with the top four areas of need relating to hospitalizations, travel for medical care, medications, and procedures. This result is in line with other dermatology crowdfunding studies that report incomplete insurance coverage for juvenile dermatomyositis, epidermolysis bullosa, and alopecia.[6-8] Given that most campaigns were created on behalf of individuals with SSc, our study also suggests that the financial burdens of SSc extend beyond patients themselves and are shared by their loved ones.

Unfortunately, despite the widespread financial need and dedicated efforts observed in our study, most campaigns were unsuccessful at meeting their fundraising goals. This finding is consistent with prior studies in which crowdfunding campaigns for other dermatologic diseases fell short of their targets.[6-8]
Well-intentioned as crowdfunding may be, this study and others suggest it may not be a reliable source of healthcare financing. Addressing root causes of these high out of pocket expenses for patients, including a dearth of FDA-approved treatments, is much more imperative.

Potential limitations of this study include the inability to evaluate specific factors that contribute to crowdfunding success, such as social network size.

Conclusion

Our study highlights the financial challenges confronting individuals with SSc, from disease-related loss of income to underinsurance. Moving forward, insurers and the government should make their policies and practices more equitable to mitigate these burdens.

References

1. Min MS, Kassamali B, Mazori DR, Vleugels RA, Merola JF, Cobos G, et al. The catch-22 of Limited Food and Drug Administration approval for connective tissue disease therapies. Journal of the American Academy of Dermatology. 2021;85(2):517–9. doi:10.1016/j.jaad.2021.03.103
2. Morrisroe K, Stevens W, Sahhar J, Ngian G-S, Ferdowsi N, Hansen D, et al. The clinical and economic burden of systemic sclerosis related interstitial lung disease. Rheumatology. 2019;59(8):1878–88. doi:10.1093/rheumatology/kez532
3. Fischer A, Zimovetz E, Ling C, Esser D, Schoof N. Humanistic and cost burden of systemic sclerosis: A review of the literature. Autoimmunity Reviews. 2017;16(11):1147–54. doi:10.1016/j.autrev.2017.09.010
4. Zhou Z, Fan Y, Tang W, Liu X, Thomason D, Zhou Z-Y, et al. Economic burden among commercially insured patients with systemic sclerosis in the United States. The Journal of Rheumatology. 2019;46(8):920–7. doi:10.3899/jrheum.180445
5. Denton CP, Khanna D. Systemic sclerosis. The Lancet. 2017;390(10103):1685–99. doi:10.1016/s0140-6736(17)30933-9
6. Goldman N, Kassamali B, Shahriari N, Lonowski S, Nwankwo C, Tran A, et al. Crowdsourcing as a means of fundraising for juvenile dermatomyositis. Pediatric Dermatology. 2022;39(3):379–81. doi:10.1111/pde.14943
7. Lim S, Encarnacion I, O'Connell KA, Smith RJ. Crowdfunding to alleviate financial burdens among patients with epidermolysis bullosa. Archives of Dermatological Research. 2023;316(1). doi:10.1007/s00403-023-02781-5
8. Desai S, Manjaly P, Lee KJ, Li SJ, Manjaly C, Huang KP, Mostaghimi A. Use of crowdfunding for expenses related to medical hair loss. J Am Acad Dermatol. 2022 May;86(5):1109-1110. doi: 10.1016/j.jaad.2020.09.008. Epub 2020 Sep 11. PMID: 32926974.
9. Lee JJY, Gignac MAM, Johnson SR. Employment outcomes in systemic sclerosis. Best Practice & Research Clinical Rheumatology. 2021 Sept;35(3):101667. doi:10.1016/j.berh.2021.101667

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