Crowdfunding to Compensate for Financial Burdens of Patients with Systemic Sclerosis

Bina Kassamali, MD BA; Theodore Okoli, BA; Subin Lim, BA; Raza H. Mir; Katherine Young, BS, M.Eng.; Sarah B. Haseeb; Kevin Yang, MD; Jacqueline Maher, BA; Daniel R. Mazori, MD; Avery H. LaChance, MD, MPH

Systemic Sclerosis

Crowdfunding to Compensate for Financial Burdens of Patients with Systemic Sclerosis: A Narrative Review

_systemic sclerosis (SSc) is a rare autoimmune disease that significantly impairs quality of life and has the highest mortality rate among rheumatologic conditions. 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. Previous studies have explored the use of crowdfunding as a means to financially support patients with dermatologic disorders, such as juvenile dermatomyositis, epidermolysis bullosa, and alopecia, but no studies to date have investigated the use of crowdfunding for SSc. 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 publicly 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. Data collection was finalized on May 28, 2021.

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, 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=64, 9.3%), lack of coverage for medications (n=30, 4.6%), and lack of health insurance (n=13, 2%). 14.8% (n=56) of campaigns stated that the donations would make life less burdensome or stressful for the recipient.

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 impacting 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. Inadequate insurance coverage was the second biggest source of financial burden, with the top four areas of need relating to hospitalization, travel for medical care, medications, and procedures. This result is in line with other dermatology crowdfunding studies that report inadequate insurance coverage for juvenile dermatomyositis, epidermolysis bullosa, and alopecia. 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. 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 undermining. Moving forward, insurers and the government should make their policies and practices more equitable to mitigate these burdens.