



CROWDSOURCING AS A MEANS OF FUNDRAISING FOR JUVENILE DERMATOMYOSITIS



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Background/Purpose

Juvenile Dermatomyositis (JDM) is a rare idiopathic inflammatory myopathy with an annual incidence ranging between 2-4 per million children. Previous research indicates significant financial and psychological hardship in patients and caregivers of orphan diseases. These added difficulties can complicate treatment goals and the full extent of these costs often go unnoticed by medical providers. This study uses the crowdsourcing platform GoFundMe as a means of characterizing the extent of these financial and psychological burdens in JDM. It also aims to assess the extent at which crowdsourcing may allow families to overcome the financial hardships associated with this illness.

Methods

On 8/27/21, forty-eight campaigns for JDM were identified using the GoFundMe internal search engine containing entries from 2013-2021. Of these 48, campaigns were organized into campaigns fundraising for either individual JDM-related care expenses (e.g. medical bills, travel expenses), JDM research, and unrelated expenses (e.g. college-funds). Campaigns were then coded on a variety of characteristics from both the general fundraising description and "Updates" section. Data was collected based on campaign type, demographics, fundraising goal/money raised, noted expenses and financial hardships.

Results

Figure 1: Specific expenses financial hardships documented by individual fundraising campaigns for JDM-related expenses

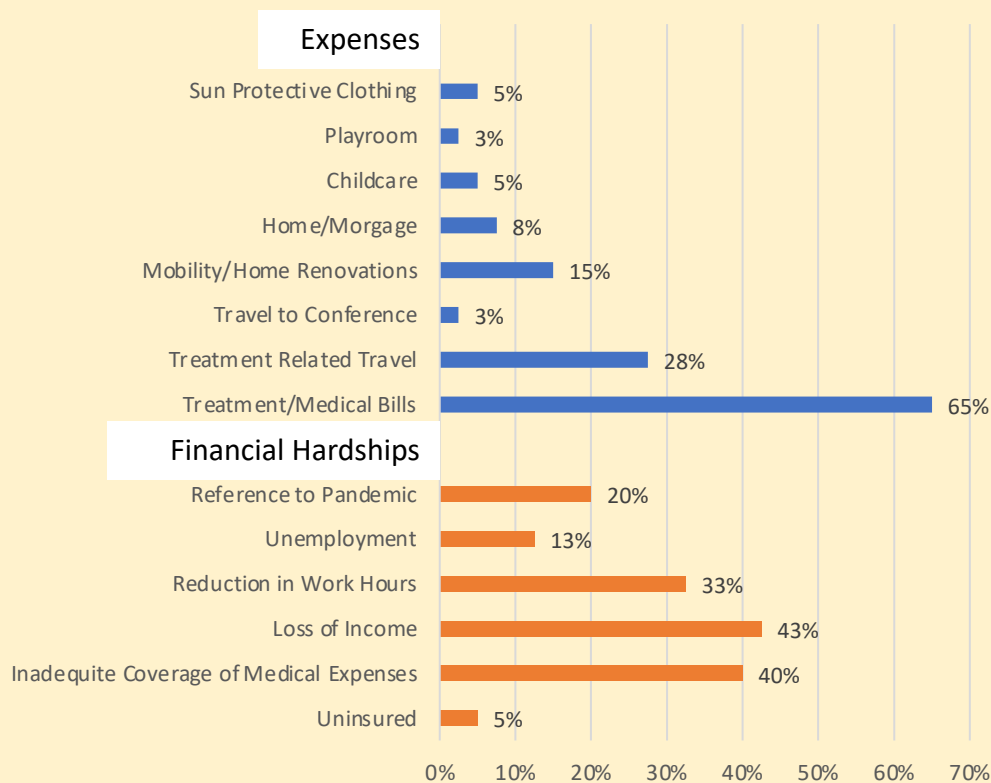


Table 1: Fundraising Campaign Characteristics and Notable Statements

Campaign Characteristics	n	%
Sociodemographic		
Gender of Patient		
Male	28	58.3
Female	18	37.5
Unspecified	2	4.2
Geographic Region		
USA	42	87.5
Europe	4	8.3
Australia	2	4.2
Campaign Organizer		
Fundraising for Own Immediate Family	16	33.3
Fundraising for Friend or Non-Immediate Family	32	66.7
Financial		
Total Donors	2393	
Total Funds Raised (USD)	\$237,219	
Campaigns Reaching 100% of Goal	8	16.7
Campaigns Reaching 50% of Goal	21	43.8
Notable Statements		
Financial Distress	"The doctor visits... have made it difficult for his mom to continue working regular hours and they are now struggling to pay bills."	
Travel Burden	"There are no wound specialists for children in her home town and it would take between 1-4 hours to see the nearest specialist."	
Insurance Issues	"[IVI]G is an 8 to 9 hour treatment and most insurance companies will not cover it."	

In total, 83.3% (n=40), 6.3% (n=3) and 10.4% (n=5) of campaigns were fundraising for individual JDM-related care expenses, JDM research, and unrelated expenses respectively. Ages of patients ranged from 2 to 23 years old with a median age of 8. While only 5.0% of campaigns were for uninsured patients, 40.0% cited inadequate insurance coverage of medical care. Loss of income was also common in caregivers (42.5%) with 32.5% reporting a significant reduction in work hours. The Covid-19 pandemic was referenced in 20% of campaigns created during the pandemic as a source of financial hardship. The median fundraising goal was \$10,000 with a mean of 57.9% of the fundraising goal being raised. The mean percentage of funds raised increased to 63.0% for campaigns active for >1 year

Conclusions

- Travel to academic hospitals was a significant expense with many families traveling across the country to access appropriate medical care. Frequent travel also proved to negatively impacted a family's ability to maintain regular employment with loss of income reported in close to half of caregivers. Alternative strategies for care, such as telehealth and home-treatments, may greatly reduce burden on families.
- Difficulties with insurance coverage was a frequent hardship described in this study. The observation that 40% of families with health insurance still reported inadequate coverage suggests that medical expenses are a problem beyond just for the uninsured.
- There appeared to be significant psychological burden associated with treatment of JDM. The added financial stress and lengthy treatment course seemed to constitute a substantial "hidden cost."
- Overall, crowdsourcing appeared to only partially ameliorate the full extent of this caregiver burden with significant gaps in out-of-pocket expenses remaining unaddressed.