

The Use of Crowdfunding to Support Radiation Therapy Cancer Treatments

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Abstract. *Background/Aim:* The purpose of this study was to assess patients' use of a crowdfunding platform to raise funds for radiation treatment and to better understand the direct and indirect costs associated with treatments. *Materials and Methods:* The GoFundMe crowdfunding database was queried for four unique categories related to radiation treatment campaigns. Covariates identified included clinical and demographic variables, and associations between amount raised and these predictors were analyzed using a generalized linear model. *Results:* While 56% percent of campaigns cited direct costs associated with treatment, 73.4% of campaigns cited indirect costs related to treatment. Indirect expenses related to travel (31.7%) as well as living expenses (29.2%) were cited most often across all four treatment categories. *Conclusion:* This study enhances understanding regarding patients use of crowdfunding for radiation treatment. Increased focus should be placed on discussing the indirect costs of care with patients and their families.

The United States has observed a promising trend in increased cancer survival with improved screening protocols, advanced medical technologies, and the development of

targeted radiation and other treatments (1, 2). These advancements increased cancer survivorship on the world stage (3). However, the "financial toxicity", or exorbitant cost of cancer care in the United States, has increased at a substantial rate. (1) A study characterized the financial toxicity of cancer care for over 9.5 million newly diagnosed Americans over the age of 50 and found 42% of patients reported fully depleting their assets by the second year of their diagnosis (4). Patients, already dealing with the emotional and physical toll of a cancer diagnosis, may resort to radical lifestyle changes that include decreased food spending, selling their possessions and property, borrowing money from others, and declaring bankruptcy due to treatment expenses and the associated costs of treatment (5).

When compared with the cost of chemotherapy and pharmaceutical therapy in cancer care, radiation treatment is a relatively cost-effective modality that accounts for less than ten percent of the total costs of cancer care (6, 7). Yet, approximately half of all patients with cancer will receive radiation therapy as part of their treatment course (6), and the cost of radiation therapy in the United States may contribute to financial toxicity for patients and families (8). Furthermore, distinct forms of radiation therapy may have substantially different costs associated with treatment. Considering the financial toxicity of cancer therapy and the personal life changes that may occur as a result, patients and families have begun to use crowdfunding sources as an avenue to fund treatments and the expenses associated with cancer care. Despite its popular use, much is not known regarding patient and family use of crowdfunding platforms in order to fund cancer treatment. Few studies to date have performed an in-depth analysis of crowdfunding platforms to determine the primary causes of financial burden cited by patients and families during the length of cancer treatment (9), and no

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Table I. Radiation category search terms.

Proton therapy category search terms	External beam radiation therapy (EBRT) search terms	Brachytherapy search terms	Stereotactic radiotherapy (SRT) search terms
Proton therapy	External beam	Brachytherapy	Stereotactic radiosurgery
Protons	External beam radiation therapy	Internal radiation therapy	GammaKnife
Proton radiation therapy	EBRT	Interstitial brachytherapy	CyberKnife
Proton radiation	IMRT	Intracavitary brachytherapy	SRS
Proton beam	Intensity modulated radiation therapy	Radiation implant	SBRT
Proton beam therapy	Tomotherapy		SRT

IMRT: Intensity modulated radiation therapy; SRS: Stereotactic radiosurgery; SBRT: Stereotactic body radiation therapy.

studies to our knowledge have sought to discern whether significant differences exist for patients that receive distinct radiation therapy modalities during their treatment course.

The aim of this study was to search GoFundMe (10), the most popular worldwide crowdfunding platform, to determine patients' use of crowdfunding for radiation treatments. This may lead to an enhanced understanding of the direct and indirect costs that weigh the heaviest financial burden on patients, the association and magnitude of these costs related to distinct forms of radiation treatment, and the reasons behind the success of particular crowdfunding campaigns.

Materials and Methods

Data acquisition and categorization. Our group queried the GoFundMe crowdfunding database for four unique categories related to radiation treatment campaigns, which included those specific to proton therapy, external beam radiation therapy (EBRT), brachytherapy, or stereotactic radiotherapy (SRT). Utilizing multiple comprehensive search titles for each separate radiation treatment category, we systematically identified a total of 1,750 campaigns on September 22nd, 2019 related to one of these four categories. The search terms for each category are listed in Table I. Each campaign was studied in detail in order to record campaign metrics. Query results that did not apply to a given search term or to human subjects, query results that were in a language other than English, and repeat query results from overlapping search terms were excluded from the final analysis. As these data are publicly available on the worldwide web, no institutional review board approval was needed.

Data were recorded for each original campaign post and summarized in the final analysis for comparison between groups. Quantifiable measures included patient age, patient sex, patient diagnosis, country/state of origin, location of treatment, relation of campaign organizer to patient, total length of campaign, number of social media shares, number of individual donations, goal amount, and amount raised. All dollar amounts were converted to USD based on exchange rates on 9/22/2019. For data that were not quantifiable/quantitatively available, we employed manual text mining: direct and indirect medical costs cited by the organizer, previous treatments received, insurance status, whether there was any explanation of therapy in the original post, whether there was a link posted for further education about the therapy requested, and whether the risks, benefits or success rate of therapies were

discussed. Insurance status was determined from campaign organizer reporting, and under-insured patients were classified as those stating they were without insurance or lacking insurance coverage for the specific radiation therapy.

Statistical analysis. Dataset. The initial dataset included 555 patients (Brachytherapy: 74, EBRT: 49, Proton therapy: 263, and SRT: 169). The primary research objective was to identify clinical and demographic variables associated with the amount raised during the GoFundMe campaign. Based on literature review and investigators' clinical experience, the following covariates were identified as potential candidates: goal amount (USD), number of social media shares, campaign length (days), patient's age (years), direct and indirect cost citation, explanation of insurance coverage, treatment and patient location, and organizers' relation to the patient. After excluding the patients with missing data, no donations, and outliers, a dataset of 109 patients was used in the primary analysis (Figure 1).

Data analysis. The data were summarized using the mean (standard deviation) for continuous variables and frequency (percentage) for categorical variables (Table II). The summary measures were presented as overall and by treatment categories for the initial data set (Table III). For data involved in modeling, the summary measure was reported for overall patients due to data sparsity in treatment categories. The difference in distribution of continuous variables across the four treatment categories was compared using Kruskal-Wallis test. Similarly, the associations between categorical variables and treatment categories were assessed using either Pearson's Chi-Square test or Fisher's exact test.

The association between the amount raised during GoFundMe campaign and prior mentioned predictors was analyzed using a generalized linear model with a Gaussian probability distribution and identity link. The outcome was square root transformed to preserve normality assumption. An information-theoretic approach to multi-model inference was employed to obtain the parameter estimates, confidence interval, and relative importance of the 11 predictors. A total of 2,048 models (211) were fit. The corresponding point estimates, confidence limits, and Akaike-Information Criteria (AIC) measure were computed in each of the models. The weights for each model were calculated as the ratio of AIC of that model to the sum of AICs for all models. Frequentist model-average estimates, and confidence limits were obtained based on weighted average of the 2,048 models. The relative importance of predictors was estimated as the sum of weights for the models involving the predictor.

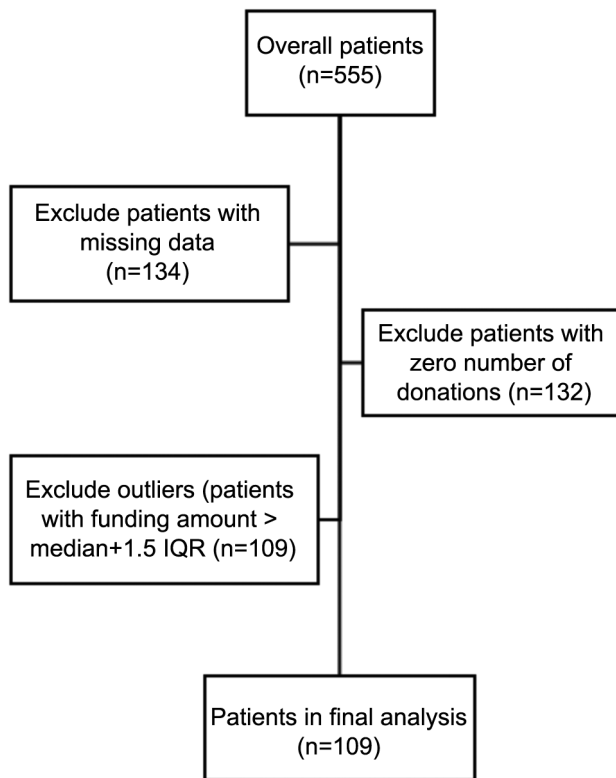


Figure 1. Flowchart for patients in final analysis. The *n* in each box represents the number of remaining patients after exclusion.

The precision around the estimates was reported using 95% confidence interval. A two-sided *p*-value of 0.05 was used to determine statistical significance. The analysis was performed using R 3.6.1. (R Development Core Team, Auckland, New Zealand).

Results

Of the 555 campaigns compiled, 109 were included in the primary analysis (Figure 1). Among the patients included in primary analysis, less than 1.8% of included campaigns related to brachytherapy, 4.6% of campaigns related to EBRT, 14.7% of campaigns related to SRT and associated terms (Methodology, Table I), and 78.9% consisted of posts raising money for proton therapy treatment (Table II). The mean amount raised by all campaigns was \$11,216 (SD 8,195), while the mean goal amount that campaigns sought to raise was \$34,554 (SD 50,647) (Table II). The average number of individual donations per campaign was \$135 (SD 102), and campaigns boasted an average of 1,060 social media shares (SD 1,201) (Table II). The median campaign length of all campaigns was 624 days, or approximately 1 year and 7 months (IQR=837 days) (Table II).

Regarding patient demographics, the average patient age was 18.6 years (SD 15.2); 62.4% of patients resided in the United States, and 84.4% of patients sought treatment in the

Table II. Overall crowdfunding campaign summary statistics.

	Overall N=109
Amount raised	11,216 (8195)
Goal amount	34,554 (50647)
Number of donations	135 (102)
Social media shares	1,060 (1201)
Campaign length days	751 (612)
Patient age	18.6 (15.2)
Patient gender:	
Female	53 (48.6%)
Male	56 (51.4%)
Direct cost citation:	
Yes	61 (56.0%)
No	48 (44.0%)
Indirect cost citation:	
Yes	80 (73.4%)
No	29 (26.6%)
Insurance coverage explained:	
Yes	9 (8.26%)
No	31 (28.4%)
Partial	9 (8.26%)
Unknown	60 (55.0%)
Explanation of therapy:	
Yes	29 (26.6%)
No	80 (73.4%)
Link to learn more:	
Yes	17 (15.6%)
No	92 (84.4%)
Explanation of risk/benefit:	
Yes	41 (37.6%)
No	68 (62.4%)
Previous treatment:	
Yes	86 (78.9%)
No	8 (7.34%)
Unknown	15 (13.8%)
Treatment category:	
Brachytherapy	2 (1.83%)
EBRT	5 (4.59%)
Proton	86 (78.9%)
SBRT	16 (14.7%)
Patient location:	
USA	68 (62.4%)
Outside USA	41 (37.6%)
Treatment location:	
USA	92 (84.4%)
Outside USA	17 (15.6%)
Organizer's relation to patient:	
Self	4 (3.67%)
Immediate family	51 (46.8%)
Extended family	16 (14.7%)
Others	38 (34.9%)

United States (Table II). Conversely, 37.6% of campaigns involved patients that lived outside of the United States, and only 15.6% of campaigns sought treatment outside the United States (Table II). The majority of campaign organizers were

Table III. Summary statistics by treatment category.

	Overall N=555	Brachytherapy N=74	EBRT N=49	Proton N=263	SBRT N=169	p-Value	N
Amount raised	15,079 (26,363)	8,644 (17,711)	5,757 (6,456)	20,850 (33,332)	10,856 (16,029)	<0.01	535
Goal amount	34,055 (48,373)	21,421 (24,761)	19,083 (22,189)	40,724 (55,683)	30,680 (43,609)	<0.01	517
Number of donations	155 (280)	94.9 (243)	52.7 (46.6)	225 (361)	94.9 (106)	<0.01	532
Social media shares	879 (1147)	457 (603)	398 (401)	1207 (1414)	616 (659)	<0.01	450
Campaign length days	708 (559)	531 (475)	856 (711)	737 (564)	697 (520)	0.02	555
Patient age	21.0 (16.4)	36.5 (17.9)	19.6 (21.5)	14.6 (12.3)	32.5 (13.4)	<0.01	223
Patient gender						<0.01	555
Female	305 (55.0%)	59 (79.7%)	24 (49.0%)	116 (44.1%)	106 (62.7%)		
Male	250 (45.0%)	15 (20.3%)	25 (51.0%)	147 (55.9%)	63 (37.3%)		
Direct cost citation						<0.01	555
Yes	341 (61.4%)	32 (43.2%)	40 (81.6%)	117 (44.5%)	152 (89.9%)		
No	214 (38.6%)	42 (56.8%)	9 (18.4%)	146 (55.5%)	17 (10.1%)		
Indirect cost citation						<0.01	555
Yes	310 (55.9%)	20 (27.0%)	25 (51.0%)	175 (66.5%)	90 (53.3%)		
No	245 (44.1%)	54 (73.0%)	24 (49.0%)	88 (33.5%)	79 (46.7%)		
Ins coverage procedure Explained						<0.01	555
Yes	67 (12.1%)	6 (8.11%)	5 (10.2%)	35 (13.3%)	21 (12.4%)		
No	224 (40.4%)	11 (14.9%)	12 (24.5%)	56 (21.3%)	145 (85.8%)		
Partial	27 (4.86%)	5 (6.76%)	3 (6.12%)	16 (6.08%)	3 (1.78%)		
Unknown	237 (42.7%)	52 (70.3%)	29 (59.2%)	156 (59.3%)	0 (0.00%)		
Explanation of therapy						<0.01	555
No	413 (74.4%)	51 (68.9%)	43 (87.8%)	178 (67.7%)	141 (83.4%)		
Yes	142 (25.6%)	23 (31.1%)	6 (12.2%)	85 (32.3%)	28 (16.6%)		
Link to learn more						0.01	555
No	501 (90.3%)	70 (94.6%)	45 (91.8%)	226 (85.9%)	160 (94.7%)		
Yes	54 (9.73%)	4 (5.41%)	4 (8.16%)	37 (14.1%)	9 (5.33%)		
Explanation of risk/benefit						<0.01	555
No	413 (74.4%)	70 (94.6%)	36 (73.5%)	162 (61.6%)	145 (85.8%)		
Yes	142 (25.6%)	4 (5.41%)	13 (26.5%)	101 (38.4%)	24 (14.2%)		
Previous treatment						<0.01	555
Yes	415 (74.8%)	50 (67.6%)	30 (61.2%)	201 (76.4%)	134 (79.3%)		
No	79 (14.2%)	24 (32.4%)	19 (38.8%)	1 (0.38%)	35 (20.7%)		
Unknown	61 (11.0%)	0 (0.00%)	0 (0.00%)	61 (23.2%)	0 (0.00%)		
Patient location						0.86	466
USA	318 (68.2%)	48 (68.6%)	32 (72.7%)	171 (66.8%)	67 (69.8%)		
Outside USA	148 (31.8%)	22 (31.4%)	12 (27.3%)	85 (33.2%)	29 (30.2%)		
Treatment location						<0.01	369
USA	308 (83.5%)	13 (59.1%)	33 (75.0%)	200 (90.1%)	62 (76.5%)		
Outside USA	61 (16.5%)	9 (40.9%)	11 (25.0%)	22 (9.91%)	19 (23.5%)		
Organizer's relation to patient						0.02	555
Self	64 (11.5%)	12 (16.2%)	8 (16.3%)	21 (7.98%)	23 (13.6%)		
Immediate family	212 (38.2%)	30 (40.5%)	20 (40.8%)	111 (42.2%)	51 (30.2%)		
Extended family	52 (9.37%)	5 (6.76%)	5 (10.2%)	32 (12.2%)	10 (5.92%)		
Others	227 (40.9%)	27 (36.5%)	16 (32.7%)	99 (37.6%)	85 (50.3%)		
Indirect cost: Medical bill						<0.01	555
No	450 (81.1%)	74 (100%)	41 (83.7%)	193 (73.4%)	142 (84.0%)		
Yes	105 (18.9%)	0 (0.00%)	8 (16.3%)	70 (26.6%)	27 (16.0%)		
Indirect cost: Time off work						<0.01	555
No	466 (84.0%)	74 (100%)	48 (98.0%)	202 (76.8%)	142 (84.0%)		
Yes	89 (16.0%)	0 (0.00%)	1 (2.04%)	61 (23.2%)	27 (16.0%)		
Indirect cost: Travel						<0.01	555
No	379 (68.3%)	61 (82.4%)	33 (67.3%)	152 (57.8%)	133 (78.7%)		
Yes	176 (31.7%)	13 (17.6%)	16 (32.7%)	111 (42.2%)	36 (21.3%)		
Indirect cost: Living expense						<0.01	555
No	393 (70.8%)	62 (83.8%)	35 (71.4%)	146 (55.5%)	150 (88.8%)		
Yes	162 (29.2%)	12 (16.2%)	14 (28.6%)	117 (44.5%)	19 (11.2%)		

Table III. Continued

Table III. *Continued*

	Overall N=555	Brachytherapy N=74	EBRT N=49	Proton N=263	SBRT N=169	<i>p</i> -Value	N
Indirect cost: Family support						0.01	555
No	538 (96.9%)	74 (100%)	47 (95.9%)	259 (98.5%)	158 (93.5%)		
Yes	17 (3.06%)	0 (0.00%)	2 (4.08%)	4 (1.52%)	11 (6.51%)		
Goal amount: Raised						<0.01	510
No	413 (81.0%)	28 (90.3%)	43 (91.5%)	197 (74.9%)	145 (85.8%)		
Yes	97 (19.0%)	3 (9.68%)	4 (8.51%)	66 (25.1%)	24 (14.2%)		

The summary statistics presented above are mean (standard deviation) for continuous variables and frequency (percentage) for categorical variables. The “Yes” category for indirect cost citation includes “medical bill/time off work/cost of travel/living expense/family support”. The categories for “Organizer’s Relation to Patient” include Self; Immediate Family (Children/Sibling/Spouse/Parents); Extended Family; Others (Church/Friend/Unknown). The “Yes” category for “Previous Treatment” includes “chemotherapy/surgery/ immunotherapy/radiation/other”.

immediate family members (46.8%), extended family (14.7%), or the patients themselves (3.7%). Meanwhile, 34.9% of campaigns were organized by friends, pastors, and community members other than family or self (Table II).

Only 56% percent of campaigns cited the specific direct costs associated with treatment for which funding was requested, while 73.4% of campaigns cited the indirect costs related to treatment such as travel-associated costs and time away from work (Table II). The majority of campaigns did not explain insurance status (55%). About 28% of campaigns stated there was no insurance coverage for the requested treatments, and 8.3% of campaigns endorsed that there was insurance coverage of the requested treatment (Table II). A majority of campaigns noted that patients had received previous treatment such as surgery, chemotherapy, or immunotherapy (78.9%), yet few cited an explanation of the therapy for which funding was being requested (26.6%) (Table II). Only 37.6% of campaigns provided an explanation of the risks or benefits that were associated with the requested therapy, and still fewer provided a link for donators to learn more about the therapy in question (15.6%) (Table II).

When assessing the relative importance of the above factors that led to successful campaigns, the only statistically significant variable associated with campaign success was the number of social media shares that a campaign was able to generate ($p=0.01$) (Table IV). The slope estimates in Table IV represent average change in amount raised (square root transformed) when the continuous covariates increase by 1 unit when all other covariates are held fixed. For categorical covariates, the slope estimates for each level represented the average difference between the level and reference level when all other covariates were held fixed. The relative importance of covariates that determined which campaigns achieved success in reaching their goal amount in descending order were the number of social media shares that the campaign achieved ($p=0.01$), goal amount of the campaign ($p=0.11$), and the citation of direct costs ($p=0.13$) (Table IV, Figure 2).

Table IV. *Parameter estimates regarding factors associated with campaign success.*

	Estimate (95%CI)	<i>p</i> -Value
Social media shares	0.01 (0.00, 0.01)	0.01
Goal amount	0.07 (−0.02, 0.16)	0.11
Campaign length (Days)	0.00 (−0.01, 0.00)	0.76
Patient age	−0.20 (−0.71, 0.32)	0.46
Direct cost citation		
No	13.84 (−4.10, 31.79)	0.13
Yes (Ref)	-	-
Patient gender		
Male	8.07 (−7.73, 23.87)	0.32
Female (Ref)	-	-
Insurance coverage		
No	−13.64 (−46.08, 18.80)	0.41
Partial	4.38 (−19.98, 28.74)	0.72
Unknown	−7.48 (−30.27, 15.31)	0.52
Yes (Ref)	-	-
Treatment location		
Outside USA	−8.16 (−29.15, 12.83)	0.45
USA (Ref)	-	-
Patient location		
Outside USA	1.32 (−6.46, 9.10)	0.74
USA (Ref)	-	-
Indirect cost citation		
No	0.83 (−5.79, 7.45)	0.81
Yes	-	-
Organizer’s relation to patient		
Immediate family	5.16 (−13.93, 24.25)	0.6
Extended family	3.98 (−12.27, 20.22)	0.63
Others	3.87 (−11.72, 19.46)	0.63
Self	-	-

In all campaigns (555 campaigns) where data were collected, campaigns raising funds for proton therapy were the most successful in meeting their goal amount (25.1%), followed by SRT (14.2%), brachytherapy (9.7%), and lastly campaigns raising funds for EBRT (8.5%) (Table III).

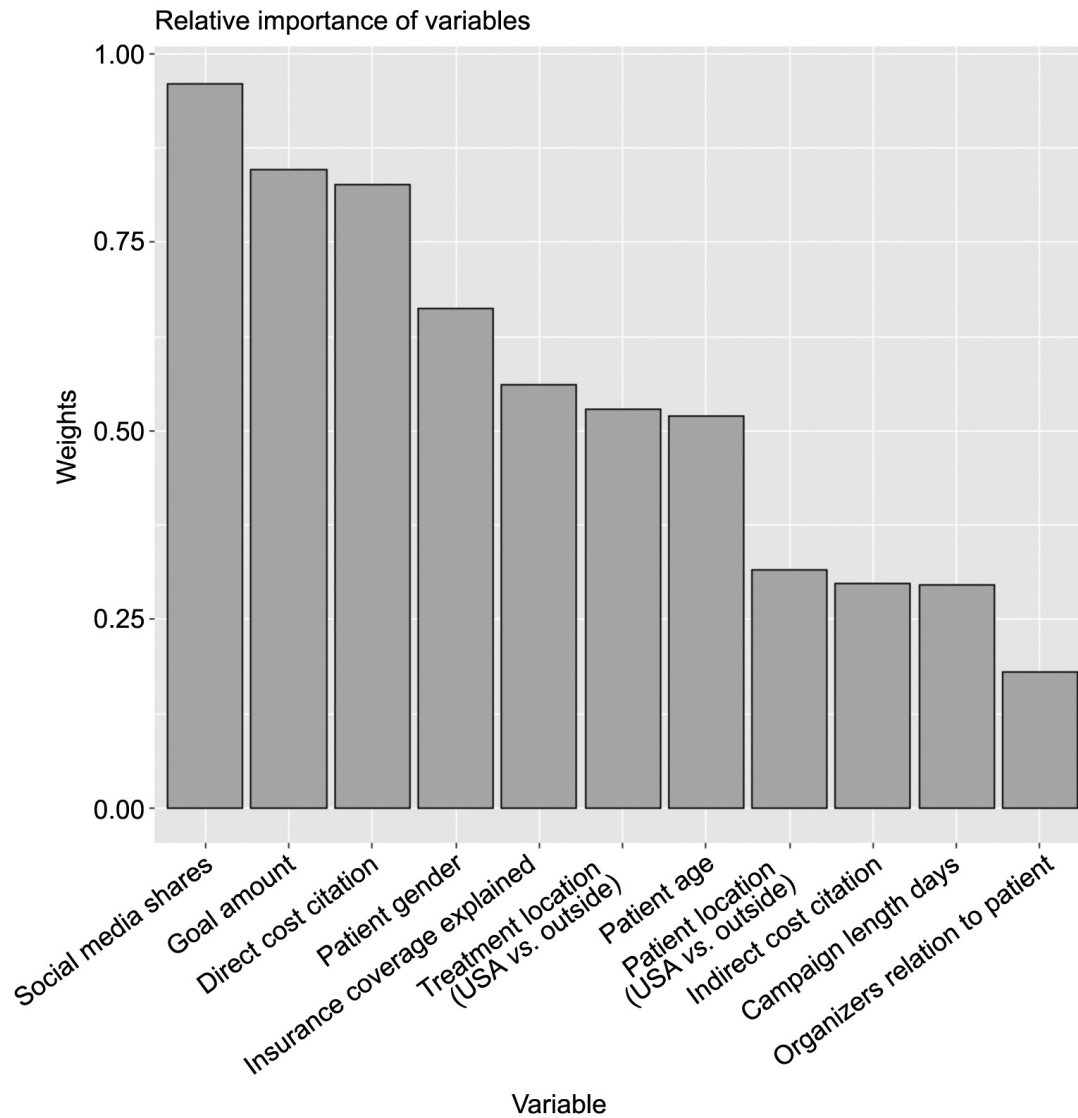


Figure 2. Plot of relative importance of covariates.

Campaigns that raised money for proton therapy requested the largest number of funds on average (\$40,724) and raised the most money on average (\$20,850) ($p < 0.01$) (Table III). Regarding indirect costs cited by campaigns, the need to cover medical bills was cited most often by proton therapy campaigns (26.6%), as was time off work (23.2%), travel costs (42.2%), and additional living expenses (44.5%) (Table III). Costs associated with supporting family were cited most often by campaigns raising funds for SRT treatment (6.5%). Across all treatment categories, travel expenses (31.7%) and funds needed to continue paying living expenses (29.2%) were the most commonly cited indirect costs discussed by campaign organizers (Table III).

Discussion

Success in crowdfunding for different forms of radiation therapy was mostly based on the number of social media interactions that a campaign was able to generate, with no significant differences in fundraising success existing between age, gender, insurance status, campaign length, or original goal amount. Other studies have similarly found no difference in donation totals between patient age, sex, and insurance status (9). While one might suspect that a lengthier campaign could generate greater funding due to a longer period of accepted donations, this was not found to be a significant factor in campaign fundraising goal realization. Few studies to date have assessed

the impact of social media sharing with GoFundMe campaign success (11). Yet in a crowdfunding platform that is based on raising and spreading awareness for an individual cause, it stands to reason that the ability of a campaign to extend beyond immediate family and into multiple degrees of separation from a social circle would allow a campaign to generate more funding. Almost half of all campaign organizers were immediate family members (Table II), yet efficacious campaigns often had hundreds or thousands of donations. Indeed, improving fundraising outcomes for campaigns centered on enhanced sharing and spread of campaign information, particularly to members outside of immediate family.

The mean amount raised by all campaigns was less than 33% of the goal amount stated by campaign organizers, with previous studies showing even lower rates of success for cancer crowdfunding campaigns (9, 11). A majority of campaigns cited indirect costs related to treatment as opposed to the direct costs associated with cancer care, indicating that concerns such as travel costs, time away from work, and family support were of concern to patients and families organizing campaign posts. Campaigns rarely delved into extensive detail on the radiation therapy being requested, with approximately a quarter of campaigns listing thorough explanations of the treatment, and less than one in five campaigns providing a link for donators to learn more regarding the therapy being requested by organizers.

While radiation therapy accounts for a fraction of the cost of overall cancer care (6) and is a relatively cost-effective modality compared to pharmaceutical agents (12), notable variation in radiation costs can exist depending on patient geographic region and the type of radiation therapy being sought (8). Not all modalities of radiation therapy are equally cost-effective, with a 2012 study in the *Journal of the National Cancer Institute* finding that the median Medicare reimbursement for prostate cancer proton therapy treatment averaged \$32,428, while the cost of intensity-modulated radiation therapy (IMRT) for comparable treatment amounted to \$18,575 (13). Due to relatively high facility and equipment expenses, and lack of randomized phase three trials for clinical superiority over other radiation modalities in the treatment of many cancer types, proton therapy has come under scrutiny regarding cost-effectiveness (14). Several studies have further noted that insurance coverage for proton therapy represents a significant barrier to patient care, with only thirty percent of private insurers approving initial requests for treatment in some instances (15). Given the limited access to proton centers across the country, and the impact of insurance delays or denials of treatment, many patients and families have resorted to alternative means of funding their treatment expenses with crowdfunding platforms such as GoFundMe (9, 11, 16).

We observed the highest mean goal amount set by campaigns across all groups in the Proton therapy category

(\$40,724), yet campaigns raising money to fund proton therapy also raised the largest amount on average (\$20,850) and had the largest percentage of successful campaigns (25.1%) compared to other therapy categories (Table III). Higher requested amounts may be due to a combination of factors, which include higher direct costs of care and difficulty with insurance coverage, and may also be compounded by increased indirect costs such as travel expenses due to the limited number of proton centers and regionality of treatment. We also observed that campaigns requesting donations for proton therapy cited travel expenses and time lost from work as additional cost burdens, more than any other treatment category (Table III). Previous studies have demonstrated that patients receiving proton therapy are more likely to travel over 200 miles compared to those seeking treatment with traditional photon-based approaches, lending support to the idea that this is truly an increased financial need and consideration in this cohort of patients (17). The proton radiotherapy treatment category demonstrated the youngest average age among groups in the study (14.6), consistent with increased proton treatment use among pediatric populations relative to the general population (18). Availability of these centers is increasing, but there is still substantially more limited access compared to access to photon treatment centers, which can further contribute to increased indirect costs of treatment such as travel and time lost from work (18).

Notably, indirect costs related to supporting family were most often cited by campaigns that sought treatment for SRT (6.5%, $p < 0.01$), where the average patient age was more than double that of the proton therapy group (Table III). This indicates that in this population, patients may be more likely to be caregivers or financial providers for their household. With an increased understanding of these social factors, healthcare professionals may be able to better tailor therapy according to patient schedules in order to reduce the burden of these additional costs. Overall, indirect expenses related to travel for therapy (31.7%) as well as living expenses (29.2%) were cited most often across all four treatment categories (Table III).

Based on these results, we recommend that practices implement tools for financial toxicity screening for patients and families when planning for treatment and develop strategies that may assist families with these additional burdens to reduce the financial toxicity of cancer treatment. Such strategies have already been implemented by some practices across the country and include education regarding resources and foundations that assist with additional costs of treatment, vouchers for travel and gas expenses, and funds that address stay and boarding in a treatment location that is different from the home location of the patient (19-21). Even a brief discussion of costs between providers and patients may reduce expenses (22, 23). Increased

transparency regarding direct costs of care and intentional discussions regarding differences in costs between radiation therapy modalities for a specific indication would also enhance patient education and understanding of financial obligations being undertaken. Our analysis of crowdfunding campaigns seeking assistance for cancer treatment reveals that the burdens of direct and indirect costs are substantial for families. A combined approach that explains direct costs of care with transparency, implements screening tools for financial toxicity, and provides substantive resources for mitigation of indirect costs of care is needed to address these issues.

Study limitations. Limitations to this study include that the designation of insurance status was determined by organizer self-reporting within the crowdfunding platform. There may be limited applicability of these results to patients requesting treatment funds for cancer care outside of the GoFundMe crowdfunding platform, as user demographics and campaign characteristics may differ across crowdfunding platforms.

Clinical implications. Future work in this area of research includes the exploration of strategies that may address patient concerns regarding direct and indirect costs of care. Clinical practices could use screening tools in their workflow and collaborate with social workers to identify areas of significant cost burden for patients and their families. Clinical practices can enhance transparency of costs associated with different radiation therapy modalities and can implement funding programs that are designed to address distinct costs associated with care such as travel expenses, boarding, and assistance with mitigation of time lost from work. Further work is needed on the effect of enhanced transparency in mitigating expenditures, the impact of financial toxicity risk screening tools for identifying indirect cost needs, and the efficacy of resources for addressing such needs.

Conclusion

This study enhances understanding about the reasons that patients crowdfund for radiation treatment and the factors most associated with campaign success in raising funding. Based on our analysis, indirect costs, such as travel expenses and time away from work, make up a large component of crowdfunding requests and represent an important burden for patients. These findings suggest the importance of discussing the indirect costs of care with patients and their families.

Conflicts of Interest

The Authors have no other personal or institutional interest with regards to the authorship and/or publication of this manuscript.

Authors' Contributions

AVP, MB, MM, DAC, HDS, and GL were involved in the design and conception of this study. MM, HK, LS, XZ, KM, and DS were involved with data collection. AVP, MB, and GDL were involved with data analysis. AVP, MM, and MB verified the data. MB and AVP compiled tables and figures. AVP, MB, and MM drafted the manuscript. All Authors critically revised the manuscript. AVP and GDL supervised the study.

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References

- Mariotto AB, Yabroff KR, Shao Y, Feuer EJ and Brown ML: Projections of the cost of cancer care in the United States: 2010-2020. *J Natl Cancer Inst* 103(2): 117-128, 2011. PMID: 21228314. DOI: 10.1093/jnci/djq495
- Miller KD, Nogueira L, Mariotto AB, Rowland JH, Yabroff KR, Alfano CM, Jemal A, Kramer JL and Siegel RL: Cancer treatment and survivorship statistics, 2019. *CA Cancer J Clin* 69(5): 363-385, 2019. PMID: 31184787. DOI: 10.3322/caac.21565
- Arnold M, Rutherford MJ, Bardot A, Ferlay J, Andersson TM, Myklebust TÅ, Tervonen H, Thursfield V, Ransom D, Shack L, Woods RR, Turner D, Leonfellner S, Ryan S, Saint-Jacques N, De P, McClure C, Ramanakumar AV, Stuart-Panko H, Engholm G, Walsh PM, Jackson C, Vernon S, Morgan E, Gavin A, Morrison DS, Huws DW, Porter G, Butler J, Bryant H, Currow DC, Hiom S, Parkin DM, Sasieni P, Lambert PC, Møller B, Soerjomataram I and Bray F: Progress in cancer survival, mortality, and incidence in seven high-income countries 1995-2014 (ICBP SURVMARK-2): a population-based study. *Lancet Oncol* 20(11): 1493-1505, 2019. PMID: 31521509. DOI: 10.1016/S1470-2045(19)30456-5
- Gilligan AM, Alberts DS, Roe DJ and Skrepnek GH: Death or debt? National estimates of financial toxicity in persons with newly-diagnosed cancer. *Am J Med* 131(10): 1187-1199.e5, 2018. PMID: 29906429. DOI: 10.1016/j.amjmed.2018.05.020
- Collado L and Brownell I: The crippling financial toxicity of cancer in the United States. *Cancer Biol Ther* 20(10): 1301-1303, 2019. PMID: 31291813. DOI: 10.1080/15384047.2019.1632132
- Baskar R, Lee KA, Yeo R and Yeoh KW: Cancer and radiation therapy: current advances and future directions. *Int J Med Sci* 9(3): 193-199, 2012. PMID: 22408567. DOI: 10.7150/ijms.3635
- Storme G, Dhaese S, Corens D and De Ridder M: The cost of cancer care is not related to its outcomes. *Ecancermedicalscience* 10: 687, 2016. PMID: 27994643. DOI: 10.3332/ecancer.2016.687
- Paravati AJ, Boero IJ, Triplett DP, Hwang L, Matsuno RK, Xu B, Mell LK and Murphy JD: Variation in the cost of radiation therapy among medicare patients with cancer. *J Oncol Pract* 11(5): 403-409, 2015. PMID: 26265172. DOI: 10.1200/JOP.2015.005694
- Cohen AJ, Brody H, Patino G, Ndoye M, Liaw A, Butler C and Breyer BN: Use of an online crowdfunding platform for unmet financial obligations in cancer care. *JAMA Intern Med* 179(12):

- 1717-1720, 2019. PMID: 31498408. DOI: 10.1001/jamainternmed.2019.3330
- 10 Vox F, Folkers KM, Turi A and Caplan AL: Medical crowdfunding for scientifically unsupported or potentially dangerous treatments. *JAMA* 320(16): 1705-1706, 2018. PMID: 30357284. DOI: 10.1001/jama.2018.10264
 - 11 Loeb S, Taneja S, Walter D, Zweifach S and Byrne N: Crowdfunding for prostate cancer and breast cancer. *BJU Int* 122(5): 723-725, 2018. PMID: 29786946. DOI: 10.1111/bju.14408
 - 12 Verma V, Shah C, Rwigema JC, Solberg T, Zhu X and Simone CB 2nd: Cost-comparativeness of proton *versus* photon therapy. *Chin Clin Oncol* 5(4): 56, 2016. PMID: 27506804. DOI: 10.21037/cco.2016.06.03
 - 13 Yu JB, Soulos PR, Herrin J, Cramer LD, Potosky AL, Roberts KB and Gross CP: Proton *versus* intensity-modulated radiotherapy for prostate cancer: patterns of care and early toxicity. *J Natl Cancer Inst* 105(1): 25-32, 2013. PMID: 23243199. DOI: 10.1093/jnci/djs463
 - 14 Wang D: A critical appraisal of the clinical utility of proton therapy in oncology. *Med Devices (Auckl)* 8: 439-446, 2015. PMID: 26604838. DOI: 10.2147/MDER.S65594
 - 15 Mendenhall WM, Smith S, Morris CG, Bradley JA, Mailhot Vega RB, McIntyre K, Klein SL and Mendenhall NP: Insurance coverage for adjuvant proton therapy in the definitive treatment of breast cancer. *Int J Part Ther* 6(2): 26-30, 2019. PMID: 31998818. DOI: 10.14338/IJPT-19-00070.1
 - 16 Song S, Cohen AJ, Lui H, Mmonu NA, Brody H, Patino G, Liaw A, Butler C, Fergus KB, Mena J, Lee A, Weiser J, Johnson K and Breyer BN: Use of GoFundMe® to crowdfund complementary and alternative medicine treatments for cancer. *J Cancer Res Clin Oncol* 146(7): 1857-1865, 2020. PMID: 32219517. DOI: 10.1007/s00432-020-03191-0
 - 17 Shen CJ, Hu C, Ladra MM, Narang AK, Pollack CE and Terezakis SA: Socioeconomic factors affect the selection of proton radiation therapy for children. *Cancer* 123(20): 4048-4056, 2017. PMID: 28654202. DOI: 10.1002/cncr.30849
 - 18 Journy N, Indelicato DJ, Withrow DR, Akimoto T, Alapetite C, Araya M, Chang A, Chang JH, Chon B, Confer ME, Demizu Y, Dendale R, Doyen J, Ermoian R, Gurtner K, Hill-Kayser C, Iwata H, Kim JY, Kwok Y, Laack NN, Lee C, Lim DH, Loreda L, Mangona VS, Mansur DB, Murakami M, Murayama S, Ogino T, Ondrová B, Parikh RR, Paulino AC, Perkins S, Ramakrishna NR, Richter R, Rombi B, Shibata S, Shimizu S, Timmermann B, Vern-Gross T, Wang CJ, Weber DC, Wilkinson JB, Witt Nyström P, Yock TI, Kleinerman RA and Berrington de Gonzalez A: Patterns of proton therapy use in pediatric cancer management in 2016: An international survey. *Radiother Oncol* 132: 155-161, 2019. PMID: 30414759. DOI: 10.1016/j.radonc.2018.10.022
 - 19 Fitch MI, Gray RE, McGowan T, Brunskill I, Steggles S, Sellick S, Bezjak A and McLeese D: Travelling for radiation cancer treatment: patient perspectives. *Psychooncology* 12(7): 664-674, 2003. PMID: 14502591. DOI: 10.1002/pon.682
 - 20 Cheng AC and Levy MA: Determining burden of commuting for treatment using online mapping services – a study of breast cancer patients. *AMIA Annu Symp Proc 2017*: 555-564, 2018. PMID: 29854120.
 - 21 Smith SK, Nicolla J and Zafar SY: Bridging the gap between financial distress and available resources for patients with cancer: a qualitative study. *J Oncol Pract* 10(5): e368-e372, 2014. PMID: 24865219. DOI: 10.1200/JOP.2013.001342
 - 22 Hunter WG, Zafar SY, Hesson A, Davis JK, Kirby C, Barnett JA and Ubel PA: Discussing health care expenses in the oncology clinic: Analysis of cost conversations in outpatient encounters. *J Oncol Pract* 13(11): e944-e956, 2017. PMID: 28834684. DOI: 10.1200/JOP.2017.022855
 - 23 Zafar SY, Chino F, Ubel PA, Rushing C, Samsa G, Altomare I, Nicolla J, Schrag D, Tulskey JA, Abernethy AP and Peppercorn JM: The utility of cost discussions between patients with cancer and oncologists. *Am J Manag Care* 21(9): 607-615, 2015. PMID: 26618364.

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