

Crowdfunding in urology: Canadian perspective

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Abstract

Introduction: Crowdfunding is becoming an increasingly used resource for patients to cover costs related to medical care. These costs can be related directly to treatments or indirectly to loss of income or travel-related costs. Little is known as to the extent of which crowdfunding is used for urological disease here in Canada. This study offers a first look at the prevalence of crowdfunding for urological disease and the factors surrounding its use.

Methods: In January 2020, we queried the GoFundMe internal search engine for fundraising campaigns regarding urological ailments. Results were categorized according to the major organs of urological disease.

Results: Crowdfunding campaigns are very prevalent within several areas of urology. Prostate cancer and chronic kidney disease represent the most frequent reason for campaigns. Fundraising goals and actual funds raised for malignant disease were significantly more than for benign disease. Interestingly, there was a significant portion of crowdfunding campaigns to cover costs for non-conventional treatments and transplant tourism.

Conclusion: Crowdfunding use to help cover direct and indirect costs of medical care is becoming increasingly apparent through several facets of medicine. This study shows that this statement holds true when looking at patients with urological disease in Canada. As urologists, we need to be aware of this trend, as it highlights the often-unforeseen financial burdens experienced by our patients.

Introduction

Crowdfunding has become a common entity in today's society. It refers to online platforms that allow for funding of projects or ventures by a large number of people.¹ Originally designed to help start-up companies get off the ground, crowdfunding has also begun to play a prevalent role in the field of medicine.² This has become increasingly apparent in a number of recent publications looking at its utilization for various aspects of health care.³⁻⁶

With the cost of health care on the rise, the number of medications and treatments that are not covered by conventional insurance plans is increasing.⁷⁻⁸ This is especially apparent in the United States where public health insurance is limited and hence patients are often faced with the ominous task of finding funds to cover basic medical needs.⁹⁻¹⁰ In a public system such as Canada the financial strain is less apparent although patient out-of-pocket expense may be evolving with an increasing number of off-label medications and procedures coming onto market.¹¹

It is for this reason that many patients are turning to crowdfunding platforms to help bridge this gap in funding. However, there are also many non-medical costs that patients and families incur when dealing with illness. These include loss of income, cost of travel for care, and equipment such as wheelchairs and medical devices needed for rehabilitation.⁵

Patients with urologic disease and illness are not exempt from these financial burdens. The number of 'off label' treatments in the realm of prostate and kidney cancer has grown immensely over the years.¹²⁻¹⁴ Also, with centralization of certain procedures, including robotics, many patients have to travel and stay close to academic centres from their surgery or treatment.¹⁵ These unforeseen financial burdens are often daunting for patients and their families and can magnify the stress of dealing with illness.

Little is known as to the extent of which crowdfunding is utilized for urologic disease here in Canada. This study offers a first look at the prevalence of crowdfunding for urologic disease and the factors surrounding its utilization. We also look to better define which disease processes and patient populations turn to crowdfunding and also identify variables that might help predict a successful campaign. In doing so, the study may help identify areas of financial strain for patients and potentially elucidate reimbursement gaps in our health care system.

Methods

In January 2020 we queried the GoFundMe internal search engine for fundraising campaigns regarding urologic ailments. Results were categorized according to the major organs of urologic disease: prostate, bladder, kidney and testicle. Search terms for campaigns used a key organ followed by the word "Canada." The first 150 campaigns for

each organ that resulted from the search were analyzed. Search results were further subcategorized into malignant and benign diagnosis and predefined variables of each campaign were recorded.

Search results were cross-examined and all duplicate and non-urologic campaigns were eliminated. Approval by research ethics board was deemed unnecessary seeing as all information gathered was available to the general public.

Results

Fundraising goals and outreach

The average fundraising goals of all the urological campaigns analyzed was \$24,476 and the average amount raised in total was \$8, 892. Testicular campaigns possessed the highest average fundraising goal of all conditions (testis: \$46,719; prostate: \$16,516; bladder \$12,067; kidney: \$22,964). Additionally, testicular campaigns raised the greatest amount of money on average (testis: \$17,637; prostate: \$3,548; bladder: \$5,598; kidney: \$8,786). There were more donors on average for testicular campaigns (testis: 116; prostate: 31; bladder: 50; kidney: 58). In addition, testicular campaigns also had a higher average number of shares (testis: 544; prostate: 155; bladder: 238; kidney: 361).

When looking at disease process cancer campaigns had higher averages for their fundraising goal in comparison to benign campaigns (cancer: \$34,862; benign: \$6,109). Cancer campaigns were also able to raise more money on average (cancer: \$19,797; benign: \$2,045). Cancer campaigns also had more donors compared to benign campaigns (cancer: 99; benign: 17) as well as more shares (cancer: 548; benign: 92).

Campaign recipients and organizers

The most common type of recipient overall was human (71%) followed by charitable organization (29%). Prostate disease had the highest proportion of charitable organizations as recipients (60%), which were mainly ‘Movember’ campaigns.

The majority of campaigns were organized by a friend or family member (prostate: 31%; testis: 78%; bladder: 87%; kidney: 72%). Prostate campaigns had the largest proportion of self-initiated campaigns (prostate: 60%; testis: 22%; bladder: 13%; kidney: 28%).

Campaign descriptors and content

Testis campaigns had the highest word count on average compared to the other campaigns (testis: 679; prostate: 306; bladder: 489, kidney: 431). Cancer campaigns used more words in comparison to benign (cancer: 509; benign: 306).

In regards to key words, many campaigns commented on the recipient’s role within their family including identifying the recipient as a parent (prostate: 29%; testis: 22%; bladder: 27%, kidney: 43%) or other family member (ex. brother, daughter,

grandfather) (prostate: 21%; testis: 56%; bladder: 20%; kidney: 26%). Another common key phrase identified was the description of the recipient as a “good person” (prostate: 14%; testis: 44%; bladder: 40%; kidney: 25%).

The profile photo was most often a non-medical photo of the recipient (prostate: 52%, testis: 44%, bladder: 67%, kidney: 40%) and rarely was the photo of the recipient medical in nature (prostate: 0%; testis: 11%; bladder: 7%; kidney: 11%). Photos of the recipient with family were also used (prostate: 14%; testis: 33%; bladder: 20%; kidney: 32%). Profile pictures also consisted of other images, such as advertisements for organizations or cartoons (prostate: 33%; testis: 11%; bladder: 7%; kidney: 17%).

Purpose of campaign

Explanations for the expenditure and breakdown of expenses was provided in some campaigns (prostate: 24%; testis: 22%; bladder: 27%; kidney: 32%).

The primary purposes for bladder and kidney campaigns were to raise funds for treatment, whereas the primary purpose for prostate campaigns was often to raise money on behalf of a charity/fundraiser. A smaller proportion of financial requests were for loss of income, travel/accommodations, food and hospital parking (table 1).

Some campaigns requested funding to help cover non-conventional treatments; this was especially apparent for prostate, testicular and bladder (prostate: 23%; testis: 50%; bladder: 19%; kidney: 16%). Kidney campaigns often sought funds to support obtaining an organ via transplant tourism (19%).

Discussion

This is among the first studies to look at utilization of crowdfunding within the field of Urology. Similar to the trend in other fields of medicine this study shows that crowdfunding has become a common support for patients dealing with urologic disease. This trend will likely continue to increase in the future as constricted health care budgets may continue to place more direct and indirect costs into the hands of patients.

Many of the campaigns in our study were performed in support of charitable organizations; this was especially apparent in prostate and testicular campaigns where Movember and Prostate Cancer Canada were the charities of choice. The main charity advocated for in kidney campaigns was the Kidney Foundation of Canada, and bladder campaigns only mentioned one charity initiative. This finding is not surprising given the extent of social media use and the fact that most crowdfunding sites are built around sharing campaigns via social media platforms. For charitable organizations this allows maximal exposure to individuals to raise funds.

Given that Canada has a universal health care system that covers most essential treatments for Canadian citizens, the authors originally hypothesized that most crowdfunding campaigns would be to cover non-medical costs such as LOI and travel for

treatment. We were surprised to see that the majority of campaigns were to cover costs for obtaining treatment, of which a large proportion of these were for nonconventional and alternative medicine.

Geographically, nine out of ten provinces were represented in our study, with the only outlier being Prince Edward Island. The majority of campaigns originated in Ontario, British Columbia and Alberta (37%, 18%, 18%, respectively). Quebec, which is the second most populous province in Canada, only represented 4% of campaigns, which is likely a result of most crowdfunding sites being offered solely in the English language. These findings are very similar to the geographic distribution found in a recent publication looking at use of crowdfunding for Chronic Kidney Disease (CKD) in Canada.⁴

When broken down by malignant vs. benign disease there is a fairly even split overall between the two, 56% and 42% respectively. However when broken down further by disease site, Prostate and Kidney make up the majority of the campaigns, with prostate campaigns being driven mainly by cancer, where as kidney campaigns are driven by benign disease (ESRD, and transplant). This finding is not surprising given the high incidence of these disease processes in Canada and the significant costs associated with each.¹⁶⁻¹⁷

Similar to other studies, the most common requested contribution by most campaigns was financial to help pay for treatments, travel or loss of income. The funding goals and amounts raised in our study seem consistent when compared to findings or other recent studies. Loeb et al. found that the average goal and actual amounts raised for prostate cancer in the US were \$16,274 and \$1449 respectively, compared to our findings of \$15,920 and \$3548 here in Canada. Similarly, Pol et al. found that the average amount raised for kidney campaigns to be \$3724, compared to our finding of \$4878.

Our study does have limitations. This study is a descriptive look at the utilization of crowdfunding by patients with urological disease within the Canadian system. Despite our interesting findings we did not look at predictors of successful campaigns or funds raised, although this would be a plausible goal for future studies. Furthermore, we did not look into the discernible ethical concerns that arise regarding why patients need to raise funds for treatment within a universal health care system, why certain diagnoses are worthy of more support than others, and how the collected funds are actually expended. Although touched upon by other recent studies we have not delved into these disquiets.

Conclusions

Crowdfunding utilization to help cover direct and indirect costs of medical care is becoming increasingly apparent through several facets of medicine. This study shows that this statement holds true when looking at patients with urologic disease here in Canada.

As urologists we need to be aware of this trend as it highlights the often-unforeseen financial burdens experienced by our patients. Furthermore our findings may help outline some funding deficiencies for urologic disease within the Canadian healthcare system and potential opportunities for improvement.

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Figures and Tables

Table 1. Comparison of crowdfunding campaigns in urology				
Variable	Prostate	Testis	Bladder	Kidney
Recipient, n (%)				
Human patient	17 (40%)	7 (78%)	15 (100%)	46 (87%)
Organization	25 (60%)	2 (22%)	0 (0%)	7 (13%)
Who started campaign, n (%)				
Self	25 (60%)	2 (22%)	2 (13%)	15 (28%)
Family/friend	13 (31%)	7 (78%)	13 (87%)	38 (72%)
Charity	4 (10%)	0 (0%)	0 (0%)	0 (0%)
Location, n (%)				
ON	17 (40%)	3 (33%)	3 (20%)	21 (40%)
AB	5 (12%)	2 (22%)	3 (20%)	12 (23%)
QC	2 (5%)	1 (11%)	0 (0%)	2 (4%)
BC	9 (21%)	0 (0%)	4 (27%)	9 (17%)
MB	3 (7%)	1 (11%)	1 (7%)	1 (2%)
SK	0 (0%)	0 (0%)	0 (0%)	2 (4%)
NS	3 (7%)	0 (0%)	1 (7%)	1 (2%)
NB	1 (2%)	0 (0%)	0 (0%)	1 (2%)
NT	0 (0%)	0 (0%)	1 (7%)	0 (0%)
Not specified	2 (5%)	2 (22%)	2 (13%)	4 (8%)
Disease process, n (%)				
Benign	42 (100%)	9 (100%)	10 (67%)	6 (11%)

Cancer	0 (0%)	0 (0%)	5 (33%)	47 (89%)
Primary purpose, n (%)				
Treatment	2 (5%)	1 (11%)	6 (40%)	21 (40%)
Travel	0 (0%)	1 (11%)	1 (7%)	2 (4%)
Loss of income	3 (7%)	0 (0%)	6 (40%)	4 (8%)
Non-conventional	12 (29%)	5 (56%)	2 (13%)	15 (28%)
Charity/fundraiser	22 (52%)	2 (22%)	0 (0%)	7 (13%)
Other	3 (7%)	0 (0%)	0 (0%)	4 (8%)
Profile photo features, n (%)				
Recipient	22 (52%)	4 (44%)	10 (67%)	21 (40%)
Medical	0 (0%)	1 (11%)	1 (7%)	6 (11%)
Family	6 (14%)	3 (33%)	3 (20%)	17 (32%)
Other	14 (33%)	1 (11%)	1 (7%)	9 (17%)
Description: Words (mean)				
Benign	0	0	813	412
Cancer	306	679	328	722
Total	306	679	489	431
Key words, %				
Parent	12 (29%)	2 (22%)	4 (27%)	23 (43%)
Other family	9 (21%)	5 (56%)	3 (20%)	14 (26%)
Family caregiver	0 (0%)	0 (0%)	2 (13%)	10 (19%)
Children	4 (10%)	0 (0%)	3 (20%)	22 (42%)
Good person	6 (14%)	4 (44%)	6 (40%)	13 (25%)
Stats	10 (24%)	1 (11%)	0 (0%)	1 (2%)

Expenditure	10 (24%)	2 (22%)	4 (27%)	17 (32%)
Movember/ moustache	16 (38%)	1 (11%)	0 (0%)	0 (0%)
Number of shares, mean				
Benign	0	0	87	281
Cancer	155	544	313	1180
Total	155	544	238	361
Number of followers, mean				
Benign	0	0	24	45
Cancer	31	125	65	186
Total	31	125	51	59
Number of updates, mean				
Benign	0	0	4	20
Cancer	3	4	3	8
Total	3	4	3	19
Number of donors, mean				
Benign	0	0	23	43
Cancer	31	116	64	183
Total	31	116	50	58
Funds: Goal, \$, mean				
Benign	–	–	\$6300	\$18 137
Cancer	\$16 156	\$46 719	\$14 950	\$61 625
Total	\$16 156	\$46 719	\$12 067	\$22 964
Funds: Raised, \$, mean				
Benign	–	–	\$3292	\$4888

Cancer	\$3548	\$17 637	\$6752	\$51 253
Total	\$3548	\$17 637	\$5598	\$8786

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Table 2. Non-conventional treatments and alternative therapies
Non-conventional treatments
RIFE (USA)
Phenolic compound from olive oil
HIFU
Unspecified treatment (Germany)
Sheep Sorrel roots
Electro cancer therapy with BET-7 device (Germany)
Immunotherapy (Canada)
DMSO, B17, hyperbaric chamber, chemo at CIPGO clinic (Mexico)
CHIPSA therapy (Mexico)
Naturopathic medicine (Canada)
Holistic treatment (Germany)
Immune system management (Canada)
Immunity therapy (Mexico)
Immunotherapy (opdivo, Yervoy) (U.S.)
Foundation one genome screening
Unspecified alternative treatment (Mexico)
Unspecified treatment (Israel)
Oxygen therapy chamber
Naturopathic medicine and hyperbaric chambers (Canada)
Unspecified treatment (U.S.)
Transplant (Philippines)
Transplant outside of Canada
Transplant (Israel)
Transplant (India)
Transplant (Afghanistan)
Transplant (Turkey)
Regional chemotherapy (Germany)
Holistic treatment (U.S.)
Unspecified treatment (Mexico)
Transplant (Mexico)