

Crowdfunding campaigns for the needs of people with rheumatic diseases living in Poland: a retrospective study

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Abstract

Introduction: Patients with rheumatic diseases may require costly treatment and continuous rehabilitation, which Internet collections may finance. We aimed to characterize medical crowdfunding campaigns for the needs of Polish people with rheumatic diseases.

Material and methods: We utilized data from the largest medical crowdfunding platform in Poland, Siepomaga.pl. All collections in the years 2009–2017 for the needs of people with rheumatic diseases were identified.

Results: Twenty-three of 2,656 collections were included (0.9%). Sixty-five and two percent of campaigns collected the financial target. The median amount of collected funds was 3,369 euros. Ten collections concerned conservative treatments (drug and/or rehabilitation), seven financed surgery, five supported the acquisition of medical equipment or its repair, and one aimed at facilitating a diagnostic consultation with a foreign specialist.

Conclusions: Polish patients with rheumatic diseases collect funds via medical crowdfunding, mostly for needs not covered by public healthcare or to obtain better health services in the private sector.

Key words: crowdfunding, rheumatic diseases, rehabilitation, charity.

Introduction

Crowdfunding is defined as financing predetermined aims through pooling of small contributions [1]. Collections for health needs via Internet donations are a novel phenomenon and have gained considerable public attention.

Thus, medical crowdfunding emerged, which is willingly used for financing therapies for children with rare diseases and patients with malignancies [2–4].

However, there are concerns that collections may be spent on unproven therapies [5], diverting funding to risky clinical trials [6].

Rheumatic diseases are one of the leading causes of disability [7] and are related to preterm mortality [8]. The advent of biological drugs impedes the development of irreversible consequences of many rheumatic diseases. However, novel therapies are costly and could be unavailable for many patients. Simultaneously, rheu-

matic diseases often require regular rehabilitation and orthopedic surgery, which some public healthcare systems may struggle to provide.

In such settings, medical crowdfunding might help cover unmet medical needs of people suffering from rheumatic illness. Yet, there is still a dearth of knowledge on crowdfunding for patients suffering from rheumatic diseases.

We aimed to characterize medical crowdfunding campaigns for the needs of patients with rheumatic diseases.

Material and methods

The study had a retrospective character and according to local regulations it did not require Ethical Board approval. We utilized data from the largest medical crowdfunding website in Poland, Siepomaga.pl, from

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the period 2009–2017. A description of the data collection process is presented elsewhere [2].

Initially, we selected all campaigns with at least one disease that was noted as affecting the musculoskeletal system and connective tissue according to the International Statistical Classification of Diseases and Related Health Problems, 10th Revision (ICD-10; Chapter M) [9].

Further, all collections for patients with at least one rheumatic disease (inflammatory arthropathy, connective tissue disease, vasculitis, bone and/or cartilage disease) were included. We carefully analyzed all included collections and excluded campaigns that raised funds for goals unrelated to rheumatic disease treatment.

For example, if a campaigner suffered from multiple comorbidities, including rheumatoid arthritis, but the aim of the collections was not mainly related to the treatment of rheumatoid arthritis, we excluded the campaign. We also excluded cases of injuries and/or post-traumatic complications. For data analysis descriptive statistics was used.

Results

Overall, 54 (2%) campaigners admitted suffering from at least one disease of the musculoskeletal system and connective tissue disease according to ICD-10 out of all 2,656 campaigns. Finally, we included 23 (0.9%) collections. The median age of campaigners was 25 (interquartile range: 8–43), and 13 of 23 (56.3%) were male. Fifteen of 23 (65.2%) campaigns collected an amount of funds at least equivalent to the financial target. The median amount of collected funds was 3,369 (1,214–9,593) euros. Table I contains the characteristics of the analyzed collections.

The number of collections was as follows: surgery ($n = 7$), conservative treatments ($n = 10$) (medications and/or rehabilitation), medical equipment or its repair ($n = 5$), and search for proper diagnosis by a foreign specialist ($n = 1$).

Discussion

Approximately one out of one hundred crowdfunding campaigns were dedicated to the needs of people suffering from rheumatic diseases. The previous research found that collections for adults with financial targets higher than 4,000 euros were less likely to be successful [2].

Rheumatic and musculoskeletal diseases were not statistically significantly associated with lower or higher odds of financial success [2]. In the analyzed subpopulation, the age of campaigners was mainly below 50 years. It may be related to limited Internet access and knowl-

edge about medical crowdfunding among the middle-aged and the elderly.

One-third of the collections were dedicated to patients who needed surgery. Generally, the described procedures were non-trivial and concerned reoperations to repair previous surgical complications or to enhance mobility. Patients in the Polish public healthcare system on average wait the longest for major orthopedic procedures among comparable countries [10]. Hence, it is to be expected that some people may seek solutions to their health problems in the private sector.

There were four collections for children suffering from TNF receptor associated periodic syndrome (TRAPS) to buy anakinra. Currently, the drug is refunded via a drug program for treating TRAPS [11], but in the years 2009–2017, anakinra for TRAPS could be financed only as an out-of-pocket purchase. Importantly, financial targets significantly differed between these four campaigns. A dose of anakinra in TRAPS is related to both body mass and the severity of the disease, which may explain the disproportions in financial targets.

Regular physical activity and rehabilitation are fundamental parts of long-term rheumatic disease management. However, the previous analysis found that campaigns collecting funds for rehabilitation were less likely to reach the financial target [2].

In contrast to surgery or novel drugs, rehabilitation could not be perceived as a “therapeutic miracle”; because of limited perceived efficaciousness, crowdfunding for rehabilitation may receive less social interest and donations [12].

The Polish public healthcare system does not fully finance the medical equipment mentioned in several campaigns. For example, the Polish National Health Fund (NFZ) provides a discount for electric wheelchairs up to 3,000 Polish zloty (~ 650 euro), but only for patients with at least bilateral limb paralysis and/or paresis. Therefore, medical crowdfunding may meet the needs of patients with rheumatic disease who suffer from immobility.

Strengths and practical implications

This is, to our best knowledge, the first study investigating medical crowdfunding for the needs of patients with rheumatic diseases. Our analysis pointed out several unmet needs of Polish citizens suffering from rheumatic diseases.

Moreover, our work may encourage clinicians to motivate their patients to initiate collections for treatments unavailable in the public healthcare system. Doctors should also be able to assist in selection of interventions on the grounds of current evidence and cost-efficiency, and also warn against unproven and risky therapies.

Table 1. Characteristics of crowdfunding campaigns for people suffering from rheumatic and musculoskeletal diseases

Gender	Age [years]	Rheumatic and/or musculoskeletal disease(s)	Aim of the collection	Collected sum [EUR]/financial target [EUR] (percentage)
Surgery				
M	5	Knee joint destruction after septic arthritis	Surgery in Aschau, Germany; rehabilitation	38,222/38,214 (100%)
M	18	Osteoarthritis secondary to Perthes disease	Femoral head arthroplasty in Germany	3,369/6,237 (54%)
F	31	Hip osteoarthritis secondary to offloading of the contralateral lower limb and rheumatoid arthritis	Left hip joint arthroplasty and rehabilitation	8,714/8,659 (100.6%)
M	34	Osteomyelitis, systemic lupus erythematosus with nephritis	Lower limb reoperation with implantation of antibacterial agent in the infected bone	12,643/12,643 (100%)
F	36	Lumbar spine discopathy	Lumbar spine surgery	2,146/2,123 (101.1%)
F	42	Complicated surgery of knee with osteoarthritis	Multi-stage knee reoperation	28,554/26,754 (106.7%)
F	43	Lumbar spine discopathy surgery complicated by anal sphincter paralysis	Surgery of implanting system stimulating anal sphincter in Germany	6,068/34,342 (17.7%)
Conservative treatment				
M	2	Congenital elastopathy, scoliosis, leg shortening	Rehabilitation holiday	318/1,233 (25.8%)
M	3	TRAPS	Anakinra	10,471/10,471 (100%)
M	5	TRAPS	Anakinra	8,180/8,180 (100%)
M	11	TRAPS	Anakinra	21,729/40,699 (53.4%)
F	12	TRAPS	Anakinra	63,332/80,936 (78.3%)
M	23	Systemic sclerosis	Diagnostics and treatment in Berlin, Germany	3,626/3,527 (102.8%)
M	44	Antiphospholipid syndrome, systemic lupus erythematosus	Drugs, rehabilitation	319/2,382 (13.4%)
F	45	Granulomatosis with polyangiitis	Drugs, hygiene products	2,427/2,415 (100.5%)
F	56	Osteoarthritis	Cost of drugs, food and hygiene products	1,295/1,271 (101.9%)
F	67	Rheumatoid arthritis, renal amyloidosis	Rehabilitation holiday	1,339/1,335 (100.4%)
Medical equipment				
F	2	Muscle disease of unknown etiology	Cough assist machine	6,464/6,429 (100.6%)
F	22	Sudeck syndrome	Active wheelchair	1,078/1,070 (100.7%)
F	25	Dermatomyositis	Panthera X wheelchair	1,282/2,844 (45.1%)
M	28	Rheumatoid arthritis	Elevator	383/12,567 (3.1%)
F	65	Rheumatoid arthritis	Electric wheelchair repair	1,146/1,146 (100%)
Diagnostics				
F	4	A joint disease of unknown etiology (suspected juvenile psoriatic arthritis)	Medical consultation in Marseille, France	668/666 (101.8%)

EUR – euro, F – female, M – male, TRAPS – TNF receptor associated periodic syndrome.

Furthermore, the elderly may require technical support from their communities to collect funds for their health needs through Internet websites.

Study limitations

The study has three major limitations. Firstly, the analyzed population consisted of Polish citizens, and the conclusions might not be applicable to other populations.

Secondly, rheumatic diseases mainly affect the adult population, while collections on Siepomaga.pl were run predominately for the needs of children (> 75%) [2]. For this reason, the final number of analyzed records was limited.

Finally, the dataset was created in 2018: thus, it does not include campaigns initiated during the COVID-9 pandemic or the Ukrainian refugee crisis. For this reason, the paper does not cover the unmet health needs of Polish people with rheumatic disease during the recent public health emergencies.

Conclusions

Polish people with rheumatic diseases collect funds via medical crowdfunding, mostly for needs not covered by public healthcare or to obtain better health services in the private sector.

Contribution: Mikołaj Kamiński and Aleksandra Borys performed preselection of records and they were further checked by Paweł Hrycaj. Finally all authors approved the final version of the paper.

The authors declare no conflict of interest.

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