



Digital Oncology

Patients' crowdfunding campaigns for alternative cancer treatments

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The authors declare no
competing interests

For more on **how many cancer
patients use CAM** see
Integr Cancer Ther 2012;
11: 187–203

For more on **why cancer
patients use CAM** see
<https://www.cancerresearchuk.org/about-cancer/cancer-in-general/treatment/complementary-alternative-therapies/about/why-used>

For more on the **impact of CAM
on patients' survival** see
J Natl Cancer Inst 2018; 1: 110

For more on the **evidence on the
effectiveness of homeopathy
for treating health conditions**
see https://www.nhmrc.gov.au/_files_nhmrc/publications/attachments/cam02a_information_paper.pdf

For more the **role of
crowdfunding to fund CAM in
cancer** see *Lancet Oncol* 2017;
18: 269

For more on **GoFundMe market
share** see <https://www.fastcompany.com/40554199/gofundme-keeps-gobbling-up-competitors-says-its-very-good-for-the-market>

For more on **Unproven Stem
Cell-Based Interventions** see
JAMA 2018; 8; 319: 1935–6

For more on **palliative care at
the end of life** see
Health (London) 2015;
19: 263–79

It is estimated that approximately half of all patients with cancer use complementary and alternative medicine (CAM), and its popularity is on the rise. Patients with cancer seek these alternative therapies for a variety of reasons including providing a sense of control, helping with pain, and coping with treatment. But there are clear risks associated with this trend, including concerns that desperate patients can be exploited or that the CAM treatment could be harmful, or result in an adverse interaction with conventional therapy. Indeed, a 2018 study found that use of CAM by patients with cancer was associated with a reduced chance of survival.

Although the activity of various CAM therapies continues to be debated in the academic literature, there is a broad consensus in the scientific community that therapies such as homeopathy are ineffective. Research has consistently shown that CAM therapies perform no better than placebo.

For patients who are unable to pay for alternative cancer treatments out of pocket, medical crowdfunding enables campaigners to harness social networks to pool resources for health-related care. This rapidly growing practice is dominated by the online platform GoFundMe, which hosts more than 80% of the global market for personal crowdfunding and has raised more than US\$5 billion from more than 50 million donors. There is evidence that crowdfunding is used to fund unproven stem-cell treatments, but the funding of alternative treatments, including those for cancer, has not been examined. As a result, we sought to understand how and why crowdfunding is used to fund unproven CAM cancer treatments.

On June 8, 2018, we searched the crowdfunding platform GoFundMe for medical crowdfunding campaigns that included the words “cancer” and “homeopathic”, “homeopath”, or “homeopathy” using the platform’s search engine. We used variations of “homeopathy” to identify campaigns for clearly unproven cancer treatments. This process identified 220 unique campaigns.

For each campaign, we recorded information about the amount of money requested and pledged, number of donors, number of Facebook shares, location of the campaign host, date the campaign was initiated, recipient’s underlying medical condition, rationale for seeking CAM cancer treatment, alternative treatments (including those other than homeopathy) sought, activity claims made, and information about whether the

recipient had died. For campaigns that had not recorded the recipient’s death, we searched obituary records and recorded when there was adequate personal information for the recipient.

We found three categories of rationales for seeking CAM cancer treatments: individuals who want to try every available treatment and who are using it to complement traditional treatment; individuals who chose to forgo traditional treatment because of fear of its effects or skepticism about its activity; and individuals who cannot pursue traditional treatment for financial or medical reasons but do not wish to forgo treatment.

186 (85%) of 220 campaigners were located in the USA, 23 (10%) in Canada, eight (4%) in the UK, and one each in Germany, Ireland, and Spain. They requested US\$5 795 602, and were pledged \$1 413 482 (24% of the total requested) by 13 621 donors. These campaigns were shared on Facebook 112 353 times. Campaign recipients were a very ill group, as evidenced by the fact that at least 62 (28%) had died following the start of their campaigns.

In addition to self-described homeopathic treatments, campaigners sought a range of other unproven cancer treatments, including dietary changes such as juicing and organic foods (n=85), supplements, vitamins, and herbal remedies (n=68), vitamin C infusions (n=30), oxygen, ozone, and hyperbaric treatments (n=24), acupuncture (n=20), cannabis-based treatments including cannabidiol (n=18), naturopathy (n=18), immunotherapy for unapproved settings (n=17), cleanses and detoxification (n=16), energy healing (n=13), hyperthermic treatments (n=10), traditional Chinese medicine (n=9), pH balancing and alkaline water treatments (n=9), mistletoe (n=8), Ayurveda, yoga, and meditation (n=8), light, ultraviolet, and infrared treatments (n=8), chiropractic treatments (n=6), lymphatic massage and drainage (n=6), massage (n=6), magnets (n=5), chelation therapy (n=5), essential oils (n=4), autohemotherapy (n=3), indigenous medicines (n=3), low-dose chemotherapy (n=3), osteopathy (n=3), and hypothermic treatments (n=2).

83 (38%) individuals used alternative treatments as complementary to traditional treatment. They wanted to try “every treatment method available”, often seeing homeopathic treatments as something that would “enhance” traditional treatments. 63 (29%) of 220 campaigns were for individuals who chose to forgo traditional treatment because of a fear of its effects or skepticism about activity. They often felt alternative treatments were a more natural alternative to “synthetic

medicines". Individuals who could not pursue traditional treatment for financial or medical reasons comprised 69 (31%) of the campaigns. A characteristic example of one of these campaigns included one recipient who saw alternative treatment as their "last and only hope". Four (2%) of campaigns included two rationales and nine (4%) gave no rationale.

63 (29%) campaigns made unsubstantiated, positive claims about the activity of these treatments. These included personal anecdotes ("Thus far, he's been immersed in cancer-fighting foods, supplements, herbs, etc... we believe this is why the tumour growth has slowed, and not spread") and sweeping activity statements ("Homeopathic/naturopathic medicine has been proven to have outstanding healing results and a lot of patients are still able to live their lives because of it."). Only two (1%) campaigns acknowledged the uncertain activity of these treatments.

These findings show that crowdfunding campaigners seek funding for alternative cancer treatments to complement proven treatments, as an alternative to proven treatments, and because proven treatments are not available. Campaigns driven by any of these rationales have the potential to exacerbate problems associated with the use of alternative cancer treatments, including wasting resources and raising false hopes for better health. Importantly, through crowdfunding and the power of social networks, these problems are spread to larger communities. This funding source also gives patients who have been told that continued care with traditional methods is futile the opportunity to preserve the hopes of themselves and their social networks that some unproven method of treatment will reverse their cancer. As such, crowdfunding might make it more difficult to acknowledge a terminal diagnosis and accept palliative care options insofar as palliative care is viewed by many patients as giving up on treatment.

Crowdfunding for alternative cancer treatments raises distinct ethical concerns as well. The second rationale for seeking alternative treatments raises the specific concern that crowdfunding is enabling individuals to forgo proven cancer treatments by financing unproven alternatives. Whereas individuals might prefer alternatives to proven treatments even without the availability of crowdfunding, limits on insurance coverage have made seeking alternative treatments prohibitively expensive for some; by crowdfunding these treatments, abandoning traditional treatments becomes more feasible. As noted, this can have a substantial negative effect on survival rates.

Crowdfunding can also enable the spread of misinformation about the activity of CAM cancer treatments. Although only 63 (29%) of campaigns made positive statements about the activity of alternative cancer



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treatments, these statements might be particularly compelling because they come in the form of personal narratives and often from trusted, familiar sources. This is a concern that has been seen in crowdfunding for unproven stem-cell treatments, for which the need to convince potential donors that their money will be well spent might encourage exaggerated claims of activity. Even if activity is not explicitly addressed, the fact that patients are seeking funds might be interpreted as an implicit endorsement of the value and desirability of these treatments, and these campaigns serve to normalise CAM treatment of cancer in the public.

Because our search was limited to crowdfunding campaigns for self-described homeopathic treatment of cancer, these results only reveal a sample of the full range of campaigns for unproven, alternative cancer treatments. In light of these findings, there should be concern that crowdfunding has the potential to exacerbate existing and create new problems within the market for alternative cancer treatments. Oncologists and other medical practitioners should be prepared to discuss these concerns with their patients. Cancer research agencies and patient support groups could raise the profile of these issues with public statements of concern around the role of crowdfunding in encouraging the use of unproven cancer treatments. Partnerships with crowdfunding platforms should also be sought to combat the worst forms of harm and misinformation transmitted via these campaigns.

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