



“Both a life saver and totally shameful”: young adult cancer survivors’ perceptions of medical crowdfunding

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Abstract

Purpose Young adults (YAs) diagnosed with cancer face high financial burden at a time in their lives when they are financially vulnerable. Some turn to medical crowdfunding, that is, using social media and other means to raise funds or resources to offset medical and usual life expenses. Major research gaps exist regarding the experiences of those who pursued crowdfunding. Thus, the study purpose was to describe the perceptions of, and experiences with, medical crowdfunding among a sample of YA cancer survivors.

Methods In February 2021, we distributed an online survey to YAs with a history of a cancer diagnosis, who had received grants from an organization that offers financial assistance. We calculated descriptive statistics on the crowdfunding sample and employed thematic analysis to analyze the open-ended questions.

Results In this sample ($N=113$), 46 YA cancer survivors had engaged in medical crowdfunding and shared their perceptions and experiences. Our central theme, “The Crowdfunding Compromise” captures the trade-offs participants faced, which included subthemes of “crowdfunding as useful/helpful,” “factors associated with crowdfunding success,” and “questioning the why?”.

Conclusions Among YA cancer survivors, medical crowdfunding brings shame and stigma in addition to financial support. YA cancer survivors demonstrate resilience in their attempts to find individual solutions to financial problems created by unchecked health care costs, the US health insurance infrastructure, and lack of legislation.

Implications for Cancer Survivors This study fills an important gap in understanding individual-level crowdfunding experiences. Implications include system-level approaches to addressing cancer-related financial burden and potential worsening of existing disparities through medical crowdfunding.

Keywords Cancer survivors · Crowdfunding · Cost of illness · Financial burden · Health disparities · Young adult

Introduction

For the nearly 80,000 young adults diagnosed each year in the United States (US) [1], cancer-related financial burden occurs at a time of great financial vulnerability

[2, 3]. Compared to 30 years ago, contemporary young adults (YAs) in general face greater job insecurity and greater financial vulnerability due to higher education-related expenses, higher costs of living, and lower minimum wages relative to cost of living [4, 5]. Among cancer survivors (defined as individuals diagnosed with cancer until end of life), YAs may be more negatively affected by cancer-related financial burden than those in other age-groups [6] as they struggle to pay medical debts while meeting existing financial obligations (student loans) and securing basics such as stable housing and reliable transportation [7]. Further, YAs with cancer face a myriad of troubling uncertainties that may affect their work goals and quality of life [8]. With generally limited savings and little to no experience navigating health care and health insurance, YAs can turn to the Internet to seek emotional,

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informational, and financial support [9, 10]. The need for financial support has led to the emergence of medical crowdfunding, that is, the use of social media platforms to campaign for donations of funds from the multitudes (“crowd”) to offset an individual’s daily living (e.g., housing, food, and utilities) and/or and illness-related (e.g., fertility preservation, co-pays, and transportation) expenses [11].

Medical crowdfunding has become common in the US; in 2019, one in five Americans reported that they, or someone in their household, contributed to a medical crowdfunding campaign [12]. Moreover, while some crowdfunding campaigns seek funds to support specific research projects or research in general (or development of technological innovations and other causes), one in three campaigns on GoFundMe (the most popular site for crowdfunding) [13] were created to help offset costs related to treatment for an acute or chronic medical problem [14]. Patients, or friends or family members on patients’ behalf, turn to crowdfunding when health insurance coverage proves inadequate and/or savings and income are insufficient to meet competing demands.

Medical crowdfunding can help offset cancer-related financial burden across the illness trajectory [15]. On the other hand, asking for money especially in public online spaces can be humbling, if not embarrassing, even among contemporary YAs who share aspects of their life online. However, alternatives, such as going without or cutting back on medically indicated care or essentials of daily living, can lead to decisional regret and poorer care and quality of life outcomes. Other problematic aspects of crowdfunding include worsening of existing health disparities and possibly reshaping of health care systems across the globe [16, 17]. For example, medical crowdfunding may favor recipients with socioeconomic privilege [18]. Individuals from disadvantaged groups are more likely than others to pursue crowdfunding, but are less successful in their campaigns, securing less funding [19]. Lee and Lehdonvirta [17] reviewed 1000 campaigns across illness types and found campaigns raised more money when the patient was located in counties where residents had higher incomes and better overall health. In the largest analysis of cancer-related crowdfunding campaigns to date ($N=144,061$ campaigns), Silver et al. [20] found similar results; campaigns in counties with higher numbers of affluent neighborhoods within its boundaries raised more than those in counties with higher numbers of deprived neighborhoods. Further, campaigns that described the fund recipient (the person with cancer) as “brave”, “worthy” (of donations), warm, or grateful received more donations than others [20]. Prior studies have not examined the role of recipient age group on funding outcomes.

Purpose

Despite its popularity, research of medical crowdfunding from recipients’ perspective is lacking. Prior research has typically entailed large-scale analysis of publicly available records of medical crowdfunding campaigns, such as GoFundMe pages [21, 22], with developing research of what motivates individuals to donate to crowdfunding campaigns—both medical and nonmedical [23]. The few studies that entailed direct contact with medical crowdfunding recipients focused on campaigns to benefit individuals who are transgender [24] or campaigns by adults with a variety of health issues [25]. A better understanding of medical crowdfunding can be gained with further exploration with fund recipients, especially those who face substantial financial burden that can negatively affect care and quality of life outcomes. Thus, the purpose of this study was to describe the perceptions of, and experiences with, medical crowdfunding among YA cancer survivors.

Materials and methods

Study population

The first author collaborated with leaders of a national young adult cancer organization, The Samfund (now a marquee program under Expect Miracles Foundation, a 501(c)(3) public charity) [26]. This foundation provides financial assistance in the form of grants to young adult cancer survivors in the US as they recover from the effects of cancer treatment on their finances. Since 2005, more than \$3,000,000 in grants have been awarded [26], with the average amount per award being roughly \$1,500. For each of the grant categories (e.g., rent/mortgage supplementation, medical expenses; car payments/repairs, grocery gift cards, continuing education, and utility assistance), there is a maximum distribution amount the applicant can request. Funds are raised through donations from networking events, peer-to-peer fundraising, and corporate sponsorships. To receive a grant, YAs with cancer must be between 21 and 39 years at the time of grant application, have completed active cancer therapy, and demonstrate clear connection between their cancer diagnosis and financial hardship. The application is submitted via an online form and requires documentation such as a physician-completed medical history, recent tax forms, and a personal statement detailing one’s current financial burden and need for financial assistance.

During February 2021, Samfund organization leaders used email to invite 933 past grant recipients from 2005 to 2020 funding cycles to participate in the study. Eligible YAs had received a grant in the past sixteen years (since

2005) and were informed through this invitation email that the survey would be open for two weeks. YAs provided electronic consent for their participation and did not receive any financial incentive for completing the survey. The local Institutional Review Board was deemed exempt from ongoing oversight—the study involved no direct contact with participants, and survey responses were not linked to potential personal identifiers.

Survey

We developed the survey about YA experiences with medical crowdfunding based on the literature and personal experiences as YA cancer survivors, clinicians, and leaders or members of organizations that offer support to YAs (see Supplementary information for a copy of the survey). To create a shared understanding of crowdfunding, we provided the following description at the start of the survey:

When you, or someone else, creates a ‘fund’ by raising money from other people. These people donate any amount to the fund, and the money can be used for anything—medical bills, living expenses, fertility preservation, or any other bills during or after cancer treatment. Keep in mind, crowdfunding is not always through a website like ‘GoFundMe.’ It can be put together through emails or in person. If you, or someone else, got your community to support you financially through cancer (especially if it was many small donations), you have done crowdfunding.

The survey consisted of a mix of short answer, fixed choice, and open-ended items related to the YA’s clinical characteristics (e.g., age at diagnosis) and experiences with crowdfunding. Additionally, we included questions about when during survivorship crowdfunding was utilized (e.g., before, during, or active treatment), how it was performed (e.g., through an online platform such as GoFundMe), and the amount of funds raised. We also asked YAs to tell us: what websites besides GoFundMe they used to raise funds, their perceptions regarding the necessity and efficacy of crowdfunding for YA cancer survivors, and what factors they perceived as being facilitators or barriers to crowdfunding.

Analysis

De-identified survey data were shared with the primary author via a double password-protected, accessed by invitation only, platform (Dropbox). We imported the data to Stata v.16 to calculate statistics that described the study sample and their medical crowdfunding outcomes. We used thematic analysis to analyze the open-ended questions [27, 28]. The reviewers included YA cancer survivors and PhD-trained nurse researchers with experience in qualitative methods.

One author (BG) compiled responses to each open-ended item into a master matrix and a second author (LG) verified accuracy. Then, we (LG, SW, and BG) read the responses to familiarize ourselves with the data. The study team met frequently to discuss coding and ideas regarding categories and themes that we were discovering in the data. We discussed and resolved all disagreements. In this iterative process, we continuously navigated between theme identification and writing [28].

Results

Participant characteristics

Of the 327 YA cancer survivors who engaged in the study (clicking the link distributed in the body of the email), 113 initiated the study survey (35% response rate; 12% completion rate). Of those, 46 (40.7%) had a history of medical crowdfunding (either initiated crowding and/or received funds raised via crowdfunding) and comprise the study sample (referred to hereafter as “crowdfunders”). Crowdfunder sociodemographics are displayed in Table 1. The other 67 YAs were thanked for their time, and the rest of the survey was not displayed to them. Thus, the analytic sample includes $n = 46$ YAs who reported having engaged in medical crowdfunding.

The average age of crowdfunders at the time of survey completion was 29 (± 5.17) years at time of crowdfunding and 34 (± 4.48) years at the time of survey completion. The crowdfunders were largely female (84.8%) and white (58.7%), with at least a bachelor’s degree (60.9% at time of survey completion).

Crowdfunding characteristics

Crowdfunders reported diverse experiences with crowdfunding (Table 1). The majority of crowdfunders (91.3%) engaged in crowdfunding during active treatment. Just 33% developed the campaign themselves; most campaigns were created by a friend (43.5%) or family member (41.3%). Stated crowdfunding goals ranged from \$500 to \$40,000 (mean goal = \$5,000); some campaigns ($n = 8$) did not explicate a goal. Actual amount raised ranged from \$0 to \$35,000 (mean amount raised = \$3,460); one crowdfunder did not provide the total amount raised. More than half of the crowdfunders did not reach their stated crowdfunding goal (52.2%), and 34.8% met the goal in a week to 6 months. Crowdfunders primarily pursued crowdfunding through social media platforms (78.3%), while others used individual “historic” means (e.g., benefits, fundraisers, and raffles) (13%). Nearly 70% of crowdfunders did not know if donations to them and/or their campaigns were

Table 1 Crowdfunder characteristics ($N=46$)

Variable	<i>M</i>	SD
Age at diagnosis	27.65	6.55
Current age	33.78	4.48
Age at time of crowdfunding	29.17	5.17
	<i>n</i>	%
Gender		
Female	39	84.8
Race		
White	27	58.7
African American/Black	5	10.9
Latin/Hispanic	5	10.9
Multi/biracial	4	8.7
Prefer not to respond	4	8.7
Area of residence during crowdfunding		
Rural	12	26.1
Suburban	20	43.5
Urban	14	30.4
Highest level of education (currently)		
Some high school, no diploma	5	10.9
High school diploma/GED	4	8.7
Some college credit, no degree	4	8.7
Trade/technical/vocational training	5	10.9
Associate degree	4	8.7
Bachelor's degree or higher	28	60.9
Highest level of education (at time of crowdfunding)		
Some high school, no diploma	1	2.2
High school diploma/GED	5	10.9
Some college credit, no degree	5	10.9
Trade/technical/vocational training	6	13.0
Associate degree	5	10.9
Bachelor's degree or higher	24	52.2
Timing of crowdfunding relative to active treatment		
Before	9	19.6
During	42	91.3
After	9	19.6
Developed crowdfunding campaign		
Friend	20	43.5
Family member	19	41.3
YA cancer survivor (themselves)	15	32.6
Co-workers	1	2.2
Representative of an organization	1	2.2
Source of Crowdfunding		
Website	36	78.3
GoFundMe	29	63.0
Private	2	4.4
Kickstarter	1	2.2
ChemoColdCaps.com	1	2.2
MealTrain	1	2.2
Facebook	2	4.3
Benefits/fundraisers/raffles	6	13.0
Other (fliers and word of mouth)	4	8.7
Tax-deductible donations		
Yes	5	10.9
No	9	19.6
Do not know	32	69.6

Table 1 (continued)

Variable	<i>M</i>	<i>SD</i>
Crowdfunding funds raised for		
Medical bills (during or after cancer treatment)	39	84.8
Living costs (rent, groceries, mortgage)	37	80.4
Follow-up care related to cancer treatment	15	32.6
Education/student loans	4	8.7
Mental health care	3	6.5
Service dog training	1	2.2
Wheelchair	1	2.2
Fertility preservation	1	2.2
Travel to appointments	1	2.2
Chemo cold caps	1	2.2
Met fundraising goal		
No	24	52.2
Yes, within 1 week	5	10.9
Yes, within 6 months	11	23.9
Do not remember	6	13.0
	Median	Range
Goal amount	\$5,000	\$500–\$40,000
Amount raised	\$3,400	\$0–\$35,000

Area of residence refers to the geographical area that the crowdfunder resided during the time they participated in crowdfunding. Some participants engaged in crowdfunding at multiple times in cancer trajectory and used crowdfunding funds for multiple expenses

tax-deductible. Lastly, crowdfunders used donated funds to pay assorted expenses, primarily medical bills (84.8%) and living expenses (80.4%).

Perceptions of crowdfunding

We labeled the overarching theme in crowdfunder's perceptions of, and experiences with, crowdfunding as "The Crowdfunding Compromise." Within this theme were the subthemes of "crowdfunding as useful/helpful," "factors associated with crowdfunding success," and "questioning the why?" Overall, crowdfunders emphasized benefits from crowdfunding and described individual and community level factors influencing their success. They also struggled to understand why medical crowdfunding was needed. Themes, descriptions, and exemplar quotes are in Table 2 and described below.

Crowdfunding as useful/helpful

All but two crowdfunders (96%) acknowledged medical crowdfunding as useful/helpful to address cancer-related financial burden. Perceptions of usefulness included recognition that campaigns were "a life saver" (P10) that they "wouldn't have been able to get treated without it..." (P22), and "it helped cover immediate expenses" (P42). Crowdfunders described explicit ways that campaigns offered financial and emotional support. For financial support, one participant said that the campaign helped them "afford treatment, be less stressed, and focus on [their] health rather

than bills" (P2). Another crowdfunder said their campaign "helped with the cost of drug coverage" and they "wouldn't have been able to afford [their] necessities without it" (P17).

Factors associated with crowdfunding success

We asked crowdfunders to use a list to select as many factors as applicable to indicate those they believed helped (facilitators to) or hurt (barriers to) their ability to raise funds through crowdfunding and to write in relevant factors not included on the list. Table 3 provides an overview of these factors. The majority of crowdfunders perceived that their age (59.5%) and socioeconomic status of their social network/community (57.1%) facilitated their crowdfunding efforts. One crowdfunder explained, "I have a very close-knit supportive community as well as a strong presence on social media, I was able to raise quite a bit in my times of need" (P12). A second crowdfunder remarked, "one's community has a lot of impact on how much a person can crowdfund... it only works when you're already connected to a wealthier community" (P17). Another crowdfunder added race and income as factors related to their success with crowdfunding, "I live and work in a wealthy, primarily white area. I truly believe this is why I raised so much money" (P22).

For these YA cancer survivors, using a crowdfunding platform facilitated campaign success in that it provided members of their established social networks with a tangible way to help even while physically distant. As one participant explained, "[Crowdfunding] gave people a way to support me and my family when they weren't sure what to do... and

Table 2 Perceptions and experiences of crowdfunding among crowdfunders

Theme	Sub-theme	Description	Exemplar quotes
The crowdfunding compromise	Crowdfunding as useful and/or helpful	Participants described crowdfunding as a solution to meet their immediate financial needs, and allowed them to focus on other aspects of cancer care and treatment	<p>“As the old saying goes, something is better than nothing and we needed all the help we could get.” (P32)</p> <p>“[Crowdfunding] helped cover costs I wouldn't have been able to cover on my own.” (P16)</p> <p>“I wouldn't have been able to survive financially without [crowdfunding].” (P40)</p> <p>“[Crowdfunding] allowed me to help provide for my family.” (P44)</p>
	Factors associated with crowdfunding success	Participants described both facilitators (factors that helped with raising money on crowdfunding); and barriers (factors that limited successful campaigns) to crowdfunding	<p>“Media attention gets the largest donations.” (P20)</p> <p>“I think if you have friends and connections with money you will make money crowdfunding anywhere.” (P19)</p> <p>“While people in our immediate circles—parents, grandparents, close friends, etc.—could help directly, crowdfunding allowed other people who cared to give in a convenient way.” (P14)</p>
	Questioning the “Why?”	Participants struggled with asking “Why is crowdfunding even necessary?” Participants saw crowdfunding to be humiliating and were frustrated they were required to leverage their vulnerability against financial support	<p>“I felt uneasy about asking for help paying for bills and living costs while I went through chemo.” (P5)</p> <p>“I've noticed crowdfunding gets the most support immediately after diagnosis. After treatment, the attitude seems to be ‘I already gave what I could. [Those without cancer] think the drama is over even if the patient is still financially struggling.’” (P31)</p>

Table 3 Perceptions of factors affecting crowdfunding

Factor	Facilitator (n = 42)		Barrier (n = 25)	
	n	%	n	%
Age	25	59.5	8	32.0
Level of education	4	9.5	4	16.0
Geographic location	11	26.2	0	0.0
Race	5	11.9	3	12.0
Socioeconomic status				
Socioeconomic status	17	40.5	7	28.0
Of crowdfunder	24	57.1	10	40.0
Of network/community				
Technological skills and access	12	28.6	5	20.0
Type of cancer	19	45.2	4	16.0

Factors crowdfunders perceived as helping (facilitators to) and hurting (barriers to) crowdfunding. Socioeconomic status of the crowdfunder refers to income, occupation, religion and where they lived when crowdfunding. Socioeconomic status of network/community refers to the income, occupation, religion, and living situation of the crowdfunder's community. Technical skills included how comfortable crowdfunders perceived they were with using and accessing the internet and internet fundraising platforms

it allowed for family and friends far away to show support" (P33).

On the other hand, sizeable proportions of crowdfunders perceived their age (32.0%) and lack of financial assets within their social network/community (40.0%) as barriers to their crowdfunding efforts. One crowdfunder described, "*Crowdfunding only works when you're already connected to a wealthier community*" (P20). Another crowdfunder further explained, "*Most of my relatives do not have disposable income.*" Many crowdfunders reflected on lack of financial assets within their age group, with one stating, "*Many of my friends [are] 25 or younger, and don't just have extra money to give away*" (P4). Additionally, barriers related to "*lack of popularity*" on social media platforms negatively affected campaign reach and ultimately the total funds raised. As one crowdfunder wrote, "*Crowdfunding only works when you get media attention*" (P21).

Questioning the "Why?"

The last subtheme under "The Crowdfunding Comprise" highlights expressed frustrations around the ethical considerations of crowdfunding. Some crowdfunders, especially those who set up campaigns for themselves, were not comfortable with the idea of crowdfunding, and felt "*uneasy*" and even "*humiliated*" asking for help. They questioned disclosing their diagnosis in a public forum and struggled with how much or little to share in the campaign. While crowdfunders were appreciative of the financial support they received, they struggled with why they had to crowdfund

in the first place, "*It paid the bills; however, I don't believe people should have to rely on other people to be able to afford living while undergoing cancer treatment*" (P4). One crowdfunder wrote about using a crowdfunding website that took a portion of funds raised, "*I didn't want to crowdfund when I was first diagnosed; I wasn't comfortable with the idea. My friend set it up for me, and it wound up being so very helpful. The percentage that the platform took was frustrating*" (P8). Another crowdfunder described this as, "*It was both a life saver and totally shameful of our country that this is necessary*" (P10).

While YA cancer survivors knew that the financial burden of cancer extended beyond active treatment, their social network and community members did not; one crowdfunder explained that they "*got the most support immediately after diagnosis and maybe a month or two into active treatment*" (P34). Crowdfunders in this study reflected that decreases in crowdfunding support later in the illness trajectory contributed to their financial vulnerability. As one participant stated, "*after treatment my circles were ready to move on... friends even advised me to 'stop asking people for money'*" (P14).

Discussion

This study represents an innovative, exploratory analysis on the crowdfunding experiences among YAs, an understudied subgroup of cancer survivors. To our knowledge, this study is the first to examine YA cancer survivors' experiences with crowdfunding. Asking beneficiaries of medical crowdfunding campaign allows us to better understand their motivators and reasons to inform interventions that improve cancer care delivery and its outcomes.

For the YA crowdfunders in this study, medical crowdfunding was a solution to meet immediate needs—that is, the financial burden due to their cancer diagnosis and treatment. And while the YAs found crowdfunding to be helpful in this regard, this behavior did not come without socioemotional costs. Crowdfunders questioned why they had to pursue crowdfunding as a partial solution to their cancer-related financial burdens. What arose from the qualitative data were tensions between the vulnerability inherent in disclosing their cancer diagnosis and resulting financial burden, the stigma associated with asking friends, family, and coworkers for donations and receiving much-needed funds. Medical crowdfunding necessitates exposing of physical and psychosocial vulnerabilities, which may be why family or friends launched the medical crowdfunding campaigns on the YA crowdfunder's behalf.

This study addresses the need for more education to be provided to persons with the diagnosis, their caregivers, their support networks, and American society overall

that the financial burden due to cancer does not end when treatment ends. Though many of our respondents noted that they crowdfunded during active treatment, they applied for a Samfund grant due to financial crisis after treatment completion. Furthermore, the social networks and communities in which they were crowdfunding were less receptive to fundraising campaigns during that phase in the cancer trajectory, possibly due to a lack of understanding around the financial costs associated with regular monitoring for disease recurrence and treatment-related complications, and with needed rehabilitation services. Though these YA survivors had crowdfunded during treatment, they faced new financial crises as medical bills and interest on missed loan payments and credit card debt accumulated, even when they did not “look sick” anymore, making it increasingly difficult to crowdfund and offset those expenses.

Despite the shame, fear, and vulnerability around asking one’s community and social networks for funds, it was felt that medical crowdfunding was necessary, even required at times. Similar to prior studies [22], YAs in this study used donated funds to pay medical and nonmedical bills. They also applied for funding through grant programs such as The Samfund to avoid financial crises. While it is not surprising that the majority of YA crowdfunders in this sample used social media platforms for crowdfunding, crowdfunding was not entirely limited to online efforts. Some used individual “historic” means, such as benefits, or fundraisers to raise funds. Future research can be directed toward what might explain the choice of online crowdfunding versus in-person “historic,” perhaps in relation to social support, technical literacy, and/or privacy over one’s cancer diagnosis.

This study extends prior work exploring how medical crowdfunding may affect identity, privacy, and social support [25, 29]. Specifically, around privacy, our unique results are grounded in qualitative work, directly asking individuals who had crowdfunded about their perceptions and experiences. We agree privacy is at stake with medical crowdfunding; YA crowdfunders in our study acknowledge fears related to publicly sharing personal health information [25]. They also take this concern further by questioning “Why” it must be this way. The subtheme of “Questioning the ‘why?’” is also captured by past work detailing this as the “privacy paradox” [29] and the “privacy-publicity tension,” where in order to receive funds via social media platforms, one must publicly disclose financial hardships and then some [25].

The present study also builds on the growing work around determinants of health disparities and how crowdfunding can worsen existing disparities. Our findings confirm past work arguing crowdfunding is less equitable in disbursing funds, and specific social determinants affect meeting fundraising goals, including large, affluent social networks, and one’s own socioeconomic status [11, 18, 20, 22]. Snyder

et al. [18] write in their call for ethics-focused social science research into the use of medical crowdfunding:

When medical crowdfunding is described as a solution to the problem of inadequate access to medical care through these websites and the feel-good stories they encourage in the media, they help to divert attention from the much harder and but necessary work of reforming health systems to ensure efficient and equitable access to medical care.

We agree and further argue that medical crowdfunding is the epitome of treating symptoms without attention to their root causes. In the context of potentially catastrophic cancer-related financial burden, medical crowdfunding by individuals is not the solution. More research is needed on the experiences of medical crowdfunders who did not reach their campaign goals, especially those with social determinants indicative of risk for poorer cancer outcomes. Moreover, research should focus on existing structures that contribute to cancer-related financial burden and on structural approaches to addressing its root causes.

Across the board, cancer is expensive to the health care system and these costs are passed onto patients and their families in the forms of cost-sharing and lost income due to responsibilities for clinical caregiving in the hospital and at home. YA cancer survivors demonstrate resilience in their attempts to find individual solutions to problems created by unchecked health care costs, the US health insurance infrastructure, and lack of legislation that would provide assistance, such as paid medical and family leave to people diagnosed with cancer and their caregivers. If financial vulnerability were unique to individual YA cancer survivors or even the YA population, perhaps crowdfunding and other forms of charity to individuals or foundations that offer financial support would be enough. However, cancer-related financial burden is a large-scale, structural problem that requires collective efforts to identify and enact structural solutions that move us towards cancer-related care not as a privilege for those who can afford to pay, but a right. That medical crowdfunding is necessary in the US is a moral outrage.

Limitations

This study had several limitations. First, YA crowdfunders were subject to recall bias regarding crowdfunding amounts; both goals and actual raised amounts were estimates. A future work might collect these data from YAs’ crowdfunding pages (if applicable). Second, only YAs who indicated that they had engaged in medical crowdfunding were asked to complete the full study survey. A greater perspective on crowdfunding in the adolescent and YA population can be gained by including survivors who chose not to crowdfund

to better understand their views on this means of seeking funds to offset medical and daily living expenses. And while we asked about knowledge of whether campaigns were tax-deductible, we did not ask if crowdfunders knew whether funds raised were taxable income, albeit not all funds raised are taxable. Lastly, we acknowledged potential biases inherent in our sampling frame; that is, the study sample was recruited from among YAs who received a grant from the Samfund to pay cancer-related expenses. Nevertheless, these findings are important because, while these YAs received grant support, they also acknowledged crowdfunding; that is, their financial burden and thus their financial needs were substantial enough to necessitate help from at least two resources.

Conclusion

In one of the first studies to qualitatively explore medical crowdfunding among YA cancer survivors, we found pursuit of financial assistance to be a compromise—between vulnerability, privacy, and financial support. The study findings call for more equitable, structural approaches to interventions to ameliorate cancer-related financial burden without potentially worsening existing health disparities.

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Data availability The data that support the findings of this study are available on request from the corresponding author. The data are not publicly available due to privacy or ethical restrictions.

Declarations

Ethics approval The local Institutional Review Board was deemed exempt from ongoing oversight; the study involved no direct contact with participants, and survey responses were not linked to potential personal identifier.

Consent to participate Participants provided electronic consent for their participation and did not receive any financial incentive for completing the survey.

Consent for publication Not applicable; confidentiality is assured for all participants regarding any personal responses and information provided, as all data collected were anonymized.

Conflict of interest All authors do not have any conflicts to disclose.

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