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The Experience of Financial Stress among Emerging Adult Cancer Survivors

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Abstract

Objective: The experience of cancer-related financial stress was examined within the developmental context of emerging adulthood.

Methodological Approach: This study is a secondary analysis of data drawn from two samples of testicular or hematologic cancer survivors. In-depth interviews from 52 emerging adult cancer survivors, ages 18–29, were coded by combining thematic analysis with an abductive approach.

Findings: Emergent themes included some common to most age groups, including worries about medical costs and availability of health insurance, as well as specific age-related concerns, such as fertility preservation. Financial stress appeared to interrupt developmental tasks of emerging adulthood, including completing an education, establishing independence, and managing relationships. Surprisingly, financial stress was experienced as a benefit for some participants.

Conclusion: Financial stress affects emerging adult cancer survivors in unique ways. To provide support, health professionals should consider survivors' developmental life stage to understand their financial stress, and ultimately, to improve quality of life.

Keywords

Cancer Survivors; Cost of Illness; Financial Hardship; Stress; Young Adult; Quality of Life

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Compliance with Ethical Standards:

Ethical Approval: All procedures performed involving human participants were in accordance with the ethical standards of the institutional research committee.

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Introduction

Cancer survivors incur substantial medical costs, including “out of pocket” costs, lost days of work, need for specialized assistance, and medical debt, potentially leading to bankruptcy [1–3]. Compared to those without a history of cancer, cancer survivors are more likely to report financial hardships across material, behavioral, and psychological domains [4]. These financial hardships have been referred to by many terms including *financial toxicity*, *financial burden*, *financial strain*, and *financial sacrifice* [2–3; 5], and often result in reports of decreased health-related quality of life [6]. In this study, *financial stress* is used to encompass these multiple terms and to describe the psychological burden related to illness-related expenditures.

The study focuses on financial stress experienced by an understudied population of cancer survivors: emerging adults (EA). *Emerging adulthood* is a life stage embedded within young adulthood, usually defined as between 18 to 29 years of age [7]. In emerging adulthood, one is neither an adolescent nor fully an adult. Normative developmental tasks during this life stage include gaining independence from family, developing a sense of identity, making and maintaining relationships, and pursuing education and employment goals [7–9].

As expressed by Landwehr and colleagues, “the financial burden of cancer is uniquely challenging for young adult cancer survivors, who lack not only the life experience and financial security of older adults but also the parental support that may benefit children” (p. 863) [10]. Financial burden encompasses objective stressors, e.g., out-of-pocket costs, and subjective strain [5; 11]. Compared to older adults, younger adult cancer survivors spend almost twice as much out-of-pocket [12]. Over half (58%) of younger adult cancer patients report distress about finances [12] and difficulty paying medical bills [11]. Young adult cancer survivors also struggle to meet burgeoning employment and education goals [13], which may have lasting consequences when coupled with cancer-related disability or withdrawal from work [14]. This financial stress often leads to declines in well-being [15].

Most studies of financial stress among cancer survivors have defined “young” with an arbitrary age cut off of participants under 65 [e.g., 5; 11; 16]. A recent study that examined cancer-related financial stress across the lifespan [17] found a consistent process of stress proliferation at all life stages but noted that the nature of the stressors varied. This suggests financial stress can be better understood if one considers the developmental context in which it is experienced.

The developmental tasks of emerging adulthood may be interrupted by the “off-time” nature of a cancer diagnosis at this life stage [18]. A cancer diagnosis in emerging adulthood is particularly unexpected and fewer age peers are facing the same issues, leading to an overall lack of support [19]. Thus, how cancer-related financial stress affects EA cancer survivors may be distinct to this (as to any) developmental life stage and affect quality of life in unique ways. The current study adopts this psychological lens of developmental context to understand how EA cancer survivors experience cancer-related financial stress. This premise is explored with data from survivors of two commonly diagnosed cancers among young adults: testicular cancer and hematologic (blood) cancers. These two cancers have

comparable and relatively high survival rates among adults younger than 45, ranging from 60.4% (acute myeloid leukemia) to 95.6% (testicular cancer) [20].

Methods

The study is a secondary analysis of data from two interview studies of young adults with cancer: a study of health-related quality of life in testicular cancer [21] and a study of the psychosocial adaptation among young adults with hematologic cancer [22].

Recruitment

Testicular cancer participants were recruited through the California Cancer Registry with an invitation to participate in a study on “health-related quality of life.” Participants had to have a histologically-confirmed cancer diagnosis and physician authorization; those with severe psychiatric disorder or cognitive impairment were excluded. Of those eligible and invited (n = 660), 334 individuals were unreachable. Purposive sampling was used to achieve thematic saturation [23] of themes relevant to understanding health-related quality of life. This was achieved by consecutively inviting those interested to participate. Thirty-six individuals were invited; of these, 15 did not participate because of scheduling difficulties and 5 were ultimately not eligible (in instances when Registry data were inaccurate). Of those interviewed (n = 21), 20 were aged 18–29. It should be noted that the data for the testicular cancer study were collected prior to the passing of the Affordable Care Act.

Hematologic cancer participants were recruited from a university-based cancer center or from *Stupid Cancer*, an Internet-based young adult cancer survivor organization. Eligibility criteria included having a diagnosis of hematologic cancer made no less than three months and no longer than five years ago, no prior cancer diagnosis (excluding non-melanoma skin cancer) and being aged 18–49. Participants recruited at the cancer center were referred to the study by a physician or nurse practitioner, instructed to refer all eligible patients. Six eligible patients were aged 18–29 and consented to participate; one was excluded because of limited cognitive capacity. Participants recruited from *Stupid Cancer* were invited through social media or while attending a *Stupid Cancer* conference. Of those recruited, 27 were aged 18–29.

Procedures

Both studies involved semi-structured interviews with topics including challenges of having cancer, medical decisions, social relationships, life goals, and identity as a young cancer survivor (e.g., “What challenges do you think you faced experiencing cancer as a young person that might be different for someone much older?”). Neither study asked directly about financial stress. One-on-one interviews with the participant were conducted by the Principal Investigators and advanced doctoral students. After providing consent, testicular cancer survivors were interviewed in person or by telephone, and hematologic cancer survivors were interviewed in person or by video call. Interviews ranged 45 to 90 minutes. No repeat interviews were carried out. Participants were compensated \$100 in the testicular cancer study and \$50 in the hematologic cancer study.

Data Coding and Analysis

Data were coded and analyzed using thematic analysis [24], combined with an abductive approach [25]. Audio recorded interviews were transcribed verbatim and coded using an online software package, Dedoose (Version 4.5) [26]. One coder (SG) used line-by-line coding to identify and label segments of text related to expressions of financial stress, i.e., any mention of the financial costs and consequences related to cancer diagnosis and treatment. In a second iteration of coding, text was examined for how participants expressed their reactions to and emotions surrounding these financial costs and consequences. Subsequent iterations involved developing codes and revising them in consultation with the other authors. Discrepancies were resolved by discussion. Similar codes were organized into themes informed by the developmental context of emerging adulthood; that is, the themes were framed so that they emphasized specific age-related concerns.

Results

Participants

Fifty-two EA cancer survivors (ages 18–29, M age = 25.29 years, SD = 2.88) were selected from the original two studies. There were no significant demographic differences between those with testicular versus hematologic cancer, with the exception of gender, which was related to cancer site. Table 1 presents participant characteristics.

Emergent Themes

Descriptions of financial stress and its psychological sequelae emerged across interview topics. Participants described stressors common across the lifespan [17], including burden of medical bills and difficulty managing treatment expenses. Participants also described how they experienced cancer-related financial stress within the context of their life stage: specifically, illness-related financial stress interrupted developmental tasks. These themes are discussed below in more detail, with illustrative quotes identifying participant identification number, age, gender, and type of cancer: testicular cancer (TC) or hematological cancer (HC).

Managing health care costs with limited funds

Managing health care costs depended on one's financial situation before diagnosis. At the most basic level, worry about paying for medical treatment focused on the availability of health insurance. A few participants did not have health insurance at the time of their diagnosis because they were in school, were unemployed, or could not afford insurance. Before being diagnosed, many participants had believed that they were too young to need health insurance. A 26-year-old male with Hodgkin's lymphoma (HC-126) gives voice to this belief in his advice to other young adult cancer survivors:

“One thing I would advise [...] is to make sure to have health insurance. [...] You know, most young adults don't think [about] having it. ‘Nothing's going to happen to me. Why do I need health insurance?’”

For those with insurance, concern arose about whether the insurance was sufficient to cover the full cost of treatment. This sometimes resulted in a feeling that having health insurance, though helpful, was burdensome to navigate as an EA cancer survivor:

“I’m 26 and I’m realizing how much it sucks to deal with insurance being a young adult cancer patient [...] they can’t deny you coverage for a preexisting condition, but they have nice little loopholes” (HC-160, 26-year-old woman).

Worries about covering medical costs had implications for care. Some participants expressed reluctance to see a doctor when they first started noticing symptoms if they did not have health insurance, as they could not afford the cost of an appointment. As severity of the symptoms increased, however, participants were more inclined to either pay out-of-pocket, depleting their funds, or to seek public assistance (e.g., Medicaid). One participant even went as far as to ask to have two procedures performed together to reduce treatment costs:

“I was really kind of pressuring my doctor to stick the implant in at the same time as removing the other one [...] Which wouldn’t have been good medically speaking, but I still wanted him to do that just because I knew I wasn’t going to be able to afford the price of doing it out-of-pocket myself.” (TC-115, 28-year-old man).

The financial burden of these illness-related expenses was experienced as uniquely difficult because of the lack of having a “nest egg to fall back on” (HC-158, 29-year-old woman) that EA cancer survivors imagined many older adult cancer survivors have after years of employment and accumulated savings. Prior to cancer, acquiring health insurance or understanding the nuances of having medical care funds were not well integrated into the developmental tasks of emerging adults.

Limiting future possibilities of employment and education

As some participants were employed and others unemployed, we heard a variety of ways in which financial stress from cancer diagnosis and treatment resulted in obstacles to pursuing educational or professional goals. Beyond physical limitations of illness or treatment (e.g., extreme fatigue or isolation to avoid infection) that often abruptly interrupt schooling, some participants indicated they took time off from school specifically because the cost of cancer made it difficult to afford tuition or make student loan payments. As one participant explained, the “cancer was not a good enough medical reason to defer my loans” (HC-154, 24-year-old woman). The competing costs of education and treatment was experienced as frustrating for some participants, who expressed concerns about the impact of not meeting educational costs:

“[T]he main reason for my frustration [...] is because of college [...] because I didn’t finish, and I didn’t have a job [...] they [the student loan company] are on us [...] because there’s other bills that need to be paid.” (HC –115, 27-year-old man).

Another concern was employability *after* treatment. Such worries were salient for those who had not yet achieved job security or established long-standing professional networks. For a few employed participants, taking medical leave had resulted in being laid off. In cases

where participants were seeking employment, concern was expressed about disclosing cancer diagnosis:

“My mom’s paranoid that like an employer’s going to [...] be like, “You have—you have cancer. What if it relapses? We don’t want to hire you, because we don’t want to pay the extra insurance and stuff.” (HC-120, 29-year-old woman).

Developing independence while being financially dependent

One distinctive developmental task of emerging adulthood is gaining independence [9]. Participants described how illness-related financial stress prevented them from becoming independent:

“It was a really stark contrast to all my friends [...] here I was really dependent on my family for things [...] like all the medications I couldn’t afford. Thankfully my parents were able to pay for that, plus my health insurance, but I felt really, really dependent when I was looking forward to being independent” (HC-162, 23-year-old woman).

Underlying concerns about establishing independence was a broadly held belief that financial security is crucial to this developmental task. When discussing long-term goals and (an imagined) life after cancer, many participants included financial stability when speaking about the life they eventually hoped to have:

“[G]etting married, starting a family, and hopefully finding a successful career that makes me some money and keeps me happy and wanting to go to work every day would be the long-term major goals.” (TC-103, 27-year-old man).

Managing social relationships while paying for cancer

Emerging adulthood is a time for developing and solidifying intimate relationships or for starting a family [8]. Similar to EA’s without a cancer diagnosis who are struggling to manage their relationships on a budget, many participants indicated that socializing, dating, and being in an intimate relationship are contingent upon the ability to spend money on social activities:

“[W]henever I wanted to be social, I went out to different places or whatever, and it costs money, money which I don’t have” (HC-115, 27-year-old man).

Cancer-related financial stress often involves making financial sacrifices due to debt, and this debt places limitations and strains on social relationships [3]. Participants with limited financial means had to rely on friends and family to afford the cost of treatment. Because of this, many participants felt like a “financial burden” on their family (HC-115, 27-year old man).

Navigating fertility decisions with finances in mind

Fertility preservation is a focal stressor for many young adults with cancer, particularly if the treatment is likely to impair fertility [22; 27]. Participants mentioned how the cost of medical care extends to the coverage of fertility preservation procedures, which can range from \$150 to \$15,000 [28]. However, the cost of fertility preservation procedures is not the

major determinant of this type of financial stress. Consistent with the developmental context of emerging adulthood, starting a family was not on the present agenda of many participants, regardless of whether the participant was in an intimate relationship:

“[My mother is] kind of putting pressure on me to have kids sooner, but I decided to wait until we have like financial ability to do it” (HC-120, 29-year-old woman).

For some, the cost of the fertility preservation procedures, combined with the sense of limited time to acquire necessary funds, was not worth the trade-off for a future not yet fully imagined:

“How [was] I going to get \$3000, \$4000 to pay to get my sperm frozen? And on top of that, I didn’t even have a chance to save, to do it. [...] They gave me three weeks and that’s that, come up with your decision.” (TC-108, 25-year-old man).

This was especially crucial for EA women who needed in vitro fertilization within their next cycle to preserve eggs:

“I chose not to do fertility saving [...] I don’t have ten grand to sink on doing this. I am too young to do that kind of investment, especially with my insurance, who viewed that kind of fertility saving as a—as an optional choice procedure, like they weren’t gonna help pay for it.” (HC-133, 28-year-old female).

Although some funds are available to support fertility preservation, this quote highlights the fact that many did not feel like they had any option to cover the costs. Participants who were able to access financial resources (e.g., health insurance or family) generally indicated being able to afford fertility preservation methods, although exploring these options was another “off-time” task [22].

A surprising finding: The potential benefits of financial stress

Despite the fact that financial stress was often appraised as stressful in EA cancer survivors’ lives, it also was seen as yielding benefits. Specifically, a number of participants recognized cancer-related financial stressors but, as a result of having financial support from friends, family, or workplace, felt a sense of financial security amidst the instability of being an EA cancer survivor.

Financial support was described in multiple ways, from parents who managed medical bills to friends that “went food shopping” without expecting to be paid back (HC-120, 29-year-old female). This support was often accompanied by a deep gratitude, as expressed by a 29-year-old man talking about how his father helped manage bills:

“If [my father] wasn’t there to help [...] I would’ve had the debt all on me. [...] so I’m just fortunate that he helped.” (TC-112).

A supportive work environment was valued among participants who were employed. Participants praised their place of employment and their colleagues for allowing them to take time off to recover after treatment and donating their vacation days, respectively:

“[I] had to take three weeks off, but my job was cool with it. [...] I had paid vacation I was able to use and I had a week extra that I needed to take off and they were just like, “Ah, don’t worry about it.” (HC-124, 24-year old man).

“I was trying not to take as much sick leave [...] some other people donated leave, that way I didn’t have to use all of mine” (HC-136, 24-year-old female).

Finally, for some, cancer-related financial stress was part of the larger illness experience that provided a new outlook to life. Having access to sources of support led to the feelings of gratitude described above:

“[O]ther people might not have been financially secure enough to [preserve fertility by banking sperm], and so I was thankful that we can still have kids, and I was thankful that I was not impotent. And I was thankful that I was alive.” (HC-116; 29-year-old man).

For other participants, the experience of financial stress involved a newfound maturity with respect to developmental tasks:

“Before I would be more open to talking to more girls, now it’s like I value the type of relationship that I have. Like now I won’t put up with certain things in a relationship [...] So I think as long as I have the financial thing settled, I think I can do the whole social thing with that mindset now, going into the future. So it hasn’t stopped me, it’s just, I think it forces maturity in that space.” (HC-115, 27-year-old man).

Summary

In sum, financial stress affects many interconnected developmental tasks of emerging adulthood. This integration is expressed by a 25-year-old man with testicular cancer:

“[O]nce you get told that you have testicular cancer you have to put your life on hold [...] you’re having to pay medical bills like crazy [...] you come to the point where you’re having to count your bills with like your two hands and your toes [...] And on top of that, what are you getting out of it, you know what I mean? You’re not getting a house. You’re not getting a nice white picket fence or anything like that. You’re not building a relationship with your wife, you’re building a relationship with the nursese you don’t even know.” (TC-109).

Financial stress plagued many of the EA cancer survivors in the sample, affecting progress through the many developmental tasks of this life stage. At the same time, the perception of benefits from cancer-related financial stress may reflect an optimism about present circumstances, often expressed as gratitude for financial support and a newfound perspective as a cancer survivor.

Discussion

This study examined how financial stress is experienced by cancer survivors within the developmental context of emerging adulthood. Consistent with the literature [29–32], the findings suggest that financial stress of young adult cancer survivors must be seen beyond

the stressors related to cost of medical care, insurance, and lost wages, and understood in the context of how they limit goals, priorities, and strivings. As such, managing illness-related financial stress is considered an important adaptive task of illness adjustment [33] that must be balanced with age-normative developmental tasks.

Financial stress was clearly a concern for the EA cancer survivors in this study, as many spontaneously spoke of financial concerns when talking about other topics. Although, within the United States, cancer creates financial stress for cancer survivors at any life stage, examining financial stress within developmental context allows us to go beyond identifying whether hardships exist to understanding why they are distressing for some, to be able to seek psychological solutions. The “unique challenge” [10] of financial hardships for EA cancer survivors is embedded in the way in which cancer-related financial stress intersects with developmental tasks. These include accomplishing relationship and career goals [13, 15, 21], accepting the possibility of an uncertain future [22], and solidifying beliefs about the self as an independent adult agent [34]. EA cancer survivors who have fewer tangible resources, less flexibility to accept goal change, and stronger visions of the self as an independent adult agent may be at greater risk to experience psychological distress as a result of cancer-related financial stress.

The results also suggest that not all financial stressors are experienced as distressing. A number of participants described benefits from their cancer-related financial stress, citing gratitude for resources and support and a positive outlook for the future [see also 35]. This may reflect an optimism about future possibilities typical of EA’s [9] or unrealistic optimism, which is frequently reported by young adults [36]. Taken together, the findings suggest that EA cancer survivors may be less distressed if they do not view financial hardships as limiting them from moving forward into adulthood.

Strengths and Limitations

This study is a secondary analysis of data not collected to understand financial stress; participants spoke about financial stress spontaneously. Specific data about financial resources may have been informative. Similarly, data on survival expectations would have allowed us to address whether participants preoccupied with survival might dwell less on interrupted developmental tasks of young adulthood. Finally, because participants were well enough to participate in a lengthy interview, it is possible the sample reflects higher functioning cancer survivors; these data cannot answer this question.

Despite these limitations, there are strengths worth noting. Combining data from studies of two different types of cancer with similar prevalence among emerging adults captured greater diversity in cancer experiences while looking for common themes across cancer sites. Hearing about stress organically (versus questioning) provides a stronger sense of how financial stress affects younger adults and impact quality of life.

Implications for Psychosocial Oncology Practice

Research on the financial impact of cancer has almost exclusively focused on identifying the types of financial stressors that arise [37] or strategies for ameliorating them [10]. To improve psychosocial oncology practice for EA cancer survivors, it is important to

understand not only *what* stressors they face, but also *how* these cancer-related stressors are experienced in conjunction with normative development tasks.

Health care practitioners are likely aware that many young adults do not have the financial resources to afford the cost of treatment and other cancer-related expenses (e.g., fertility preservation). Offering information about alternate resources (e.g., thesamfund.org) is an obvious first step [10]. The data suggest that practitioners take a minute to understand how younger adult survivors frame the illness and its financial consequences within their current life context. Emerging adulthood is a time already fraught with uncertainty; financial stress may intensify that uncertainty.

Along similar lines, future research exploring should explore how financial stressors interact with other developmental stressors, as well as beliefs about the value of money in one's life. Some EA cancer survivors experience financial stress that affects a particular development task (e.g., they become unemployed and unable to make a living), but are able to capitalize on another development task (e.g., relying on family to help cover the cost of medical bills), specifically because of their unique life stage in-between adolescence and adulthood [7].

Conclusion

As evidenced in the voices of EA cancer survivors, financial stress represents a non-specific, multi-component variable that impacts quality of life by intersecting with developmental life tasks. The findings make a case for the consideration of developmental life stage in understanding the stress and adjustment among cancer survivors.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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Table 1.

Participant Characteristics

	Total Sample		Testicular cancer sample		Hematologic cancer sample		X ²	df	p
	N	%	N	%	N	%			
Sex							22.02	1	.00
Female	21	40.4%	0	0	21	65.6%			
Male	31	59.6%	20	100%	11	34.4%			
Race/Ethnicity									
White ^a	35	67.3%	10	50%	25	78.1%			
Latino ^b	8	15.4%	8	40%	0	-			
Black ^c	3	5.8%	0	-	3	9.4%			
API ^d	2	3.8%	1	5%	1	3.1%			
AI/AN ^e	1	1.9%	1	5%	0	-			
Relationship status							1.55	1	.21
Partnered	18	34.6%	9	45%	9	28.1%			
Not Partnered	34	65.4%	11	55%	23	71.9%			
Graduated from college?							1.85	1	.17
Yes	27	51.9%	8	40%	19	59.4%			
No	25	48.1%	12	5%	13	40.6%			
Age	M	SD	M	SD	M	SD	t	df	p
	25.29	2.88	25.00	2.68	25.75	3.19	-0.91	50.00	.37
Months since diagnosis	31.25	17.12	35.35	13.25	28.69	18.89	-1.40	31.78	.17

Note:

^aWhite/Caucasian^bLatino/Hispanic^cBlack or African-American^dAsian/Pacific Islander

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