“Aftermath”: Financial Resource Requirements of Young Adults Moving Forward After Cancer Treatment

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Purpose: Young adults (YAs) are at greater risk for cancer-related financial toxicity than other age groups. They are simultaneously dealing with cancer and normative developmental tasks (establishing independence, completing education, and beginning careers) and may go without needed medications, follow-up, and even food or housing because of cancer-related financial toxicity. This study explored the financial resources required for YAs to move forward after cancer treatment.

Methods: To identify and describe the financial challenges experienced by YA cancer survivors and the impact on their lives and overall development, we used secondary analysis of essays written by Samfund grant recipients. Directed content analysis allowed identification of salient categories from the essays of 104 YAs aged 17–39 years who received financial assistance between 2012 and 2013. Permission was secured before analysis.

Results: To move forward after cancer treatment, YAs state that they require enough financial resources to meet immediate needs, support future goals, facilitate self-care, and enable normative development.

Conclusions: Assessing the financial status of YAs with cancer is vital because many YAs lack resources to fund their basic needs and to move forward with independent living after cancer therapy. Interventions to identify and mitigate financial toxicity in YAs have the potential to reduce treatment nonadherence and poor follow-up due to insufficient financial resources in this at-risk population.

Keywords: survivorship, cost of illness, quality of life, financial toxicity

Introduction

THERE IS RISING AWARENESS of the myriad costs of cancer^{1,2} at both individual and societal levels,³ and of financial toxicity, defined as “...problems resulting from high medical payments combined with lower income because of job interruption.”¹ Direct costs include cancer treatment with follow-up monitoring for side effects and disease status, while indirect costs include lost productivity, travel, meals, and childcare.⁴ Insurance premiums, deductibles, and co-payments for both treatment and prescription medications are rising.^{3,5} Young adults (YAs), aged 15–39, are particularly vulnerable to financial toxicity because of their developing financial independence compared to children and lack of financial stability compared to older adults.⁶ There are currently only a few reports describing the financial challenges of YAs in the United States.^{6,7}

The Samfund helps YAs move forward from the financial challenges of cancer (from 2003 to 2019, The Samfund was a

standalone nonprofit providing financial assistance to YA cancer survivors. (As of July 1, 2019, The Samfund is a program of Expect Miracles Foundation). YA cancer survivors are eligible to apply for modest grants averaging \$1500–2000. Assistance can be directed toward reduction of debt or help with expenses associated with medical care/insurance (bills, premiums, co-pays), rent/mortgage/utilities, health/wellness (gym memberships, counseling), education, car payments, repairs, or insurance, family building, and miscellaneous other needs (professional apparel, home modifications).⁶ YAs write essays as part of the application process telling of their concerns and plans related to both finances and the future.

Methods

A quantitative analysis of data from the applications of 2007–2013 SamFund grant recipients who electronically consented to analysis of their de-identified data was

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completed in 2014–2015.⁶ This was followed by a qualitative analysis of data from a subset of that sample who had an application essay from 2012 to 2013 (the most recent grant year data available before beginning the qualitative analysis).

Data included in this analysis included an initial essay describing the cancer experience, financial impact, and request for funding and at least one 6 or 12 month follow-up essay describing what the grant enabled them to do and their goals for the upcoming year. Although the essays were not analyzed as prefunding/postfunding pairs, analysis of prefunding essays provided description of the financial impact of cancer and the postfunding essays provided description of moving forward from that impact. We explored the conditions needed for YAs to financially move forward after cancer treatment using an exploratory descriptive design with directed content analysis, as described by Hsieh & Shannon.⁸ Qualitative content analysis goes beyond word count to explore language use for the purpose of classifying text into an efficient number of categories that represent similar meanings.⁸

Data were extracted from essays of 104 Samfund grant recipients. All resided in the United States, were cancer free, more than 1 year following cancer therapy completion with stable disease, or in remission on maintenance therapy, and were aged 17–35 years for 2012 applications and 21–39 years for 2013 applications as the Samfund's eligibility criteria changed from 2012 to 2013.

The aim of the analysis was to explore the conditions needed for YAs to move forward financially after cancer treatment. This aim was defined collaboratively by two clinicians experienced in YA oncology and research (R.J. & C.F.M.) and two senior members of the Samfund staff (S.W. & M.L.) familiar with the data to be analyzed. The clinicians developed a list of predetermined categories pertinent to analysis. This deductive approach operationalized definitions based on the published literature and clinician knowledge of the population and problem under study. The Samfund staff then endorsed the initial category list (12 categories, 1 comprised of 4 subcategories). The clinicians refined the initial category list by renaming, redefining, and merging categories to maximize conceptual clarity and minimize overlap. The Samfund staff agreed upon the refined category list (seven categories, no subcategories).

One clinician (C.F.M.) independently coded the dataset with attention to consistent application of the existing categories. Another researcher with experience in YA oncology and qualitative research (K.S.) independently reviewed all the coding inductively to assess fit of categories as a confirmability audit. An example of the difference in approach would be seeing a statement “*feels like I am swimming in debt and there is no escape*” deductively fitting this to the predetermined category of insufficient financial resources. Then with inductive coding reading the statement and coding it is a vivid description of an inability to meet financial needs.

Coding was then compared and discrepancies addressed via discussion (C.F.M. & K.S.) until consensus was reached. Categories were refined for clarity, codes reassigned where necessary, and categories further merged to yield four distinct categories. Written summaries were generated with accompanying exemplar quotes. An audit trail was maintained throughout the process to track decision-making. Categories were redefined for clarity, codes reassigned, and categories further merged to yield two distinct categories

focused on immediate and future needs. Written summaries were generated with accompanying exemplar quotes. An audit trail was maintained throughout the process to track decision making.

Results

Data analysis revealed that for YAs to move forward after cancer treatment they need financial resources enough to (1) meet immediate needs, and (2) support future goals—including future goals that (a) facilitate survivor self-care, and (b) enable normative development. These categories are described below with exemplar quotes for both YAs experiencing current sufficiency and insufficiency (Table 1).

Meet immediate needs

Insufficient financial resources to meet immediate needs led YAs to report “*depression, extreme stress, and an overall feeling of despair*.” Many compared their financial distress to sinking or treading water, just trying to stay afloat, such as “*I am sinking*” and “*only treading water because I... add more to my debt each month than I am able to pay*.” Financial obstacles seem impassable (one YA wrote that it “*feels like I am swimming in debt and there is no escape*”), with future financial status also a source of distress: “*It makes you feel helpless to watch your bank account slowly plummet and to know that soon, there will be nothing coming in to replenish it*.”

YAs report that cancer treatment causes both additional costs and decreased ability to work/termination of employment, resulting in income insufficient to meet their expenses. Many refer to “*living paycheck to paycheck*” and being “*forced...to rely on my credit card*.” They report that they “*make sacrifices*” and “*live minimally*.” Some reported homelessness resulting from the costs associated with cancer treatment.

Many report that their “*debt is financially devastating*” and they have to choose which bills to pay: “*At times there is a toss up between what gets paid for that month because I can't pay all of my bills on my current monthly income*.” They describe making choices between paying bills, doctors' appointments, and having adequate food: “*I have gone without eating...because I paid my last dollar to a bill just so it wasn't late*.”

YAs describe consequences of debt, including damaged or ruined credit, collections, wage garnishment, bankruptcy, eviction, and repossession: “*I lost my apartment, my vehicle was repossessed and I was faced with wage garnishments. My credit has been destroyed. Bankruptcy is now my only option*.” For some, cancer exacerbated preexisting debt: “*I had credit card debt before my illness from putting myself through school and living expenses to start a career, but during and after my credit card bills have been affected even more as I lean on them to get me through*.” For others, debt was a new experience: “*I had very good credit before all of this*.”

Debt distress was very real with challenges such as “*the shame of collection calls and debtors*” and “*mounting debt terrifies me- it will permanently affect my credit, thus impacting my life forever*.” While these are challenges that can occur for any cancer patient, YAs are particularly vulnerable because they might still be in school or training and have a shorter history of work.

TABLE 1. CATEGORIES AND EXEMPLAR QUOTES

Category	Exemplar quotes
Meet immediate needs	<p>I am trying to recover but it's much more difficult when you get rid of the cancer in your body but it still is very prominent in your financial life... my financial situation is my new cancer.</p> <p>There's just nothing left after I've paid my normal person bills of rent, car payments, grocery bills, school loans, and so on, so the bills have accumulated. The hospital calls regularly to urge me to pay more. I always pay what I can, but that leaves me with nothing to help re-build my savings account, to visit friends, to buy a pair of shoes or get ahead.</p> <p>Instead of focusing on getting healthy so I can get back to work and start a family, I am stuck all day trying to figure out what I can sell so I can keep the electricity on.</p>
Support future goals	<p>It is so wonderful to be free of medical debt. I can now begin to look at the future and not have to live with constant reminders to the past.</p> <p>I am so financially stuck, unable to save up for the next scan because I don't have anything left to pay for the one I just had....Knowing that these scans will go on and on for years and that I will reach my out of pocket maximum for my health insurance every year for the foreseeable future, is enough to keep me awake at night. How does a person ever get ahead, when there is always another bill coming?..How can I put cancer into my past, when my credit card gets denied at the end of the month because I had blood tests to pay for?</p>
Facilitate survivor self-care	<p>To practice yoga, and to get stronger in my upper body, has been amazing. It is the only time that is given to my head and my body alone, and the amount of psychological healing that takes place is magical. It has the added benefit of keeping my arm swelling and pain (due to treatment induced lymphadema) down to a minimum.</p> <p>I will likely have to give up my rock climbing gym membership due to the cost of my upcoming reconstructive surgeries and my limited savings. Exercising has always been incredibly important to me, but by the end of my yearlong intensive treatments I was unable to do most activities. Therefore, when I ended treatment, building my strength back up was my first priority. My rock climbing gym has been an invaluable aid in this process. Thanks to climbing, my strength has returned, and I feel like myself again. Cancer was also an incredibly isolating experience for me, and climbing has given me a much-needed sense of community and a social outlet. Continuing to rock climb would significantly benefit me both physically and emotionally.</p>
Enable normative young adult development	<p>I am trying to re-enter the real world and be a self sufficient person. I have lost so much time and I am desperate to be independent and no longer a burden to the people that have sacrificed so much for me. I really feel that a significant part of my recovery is tied to being as self sufficient as possible</p> <p>I no longer live with mom. Even though I'm indebted to her for being my sole caregiver during my entire cancer experience, I felt stunted. Being in the same room before, during, & after treatments was triggering. While I was lucky enough to have such a support system, my bedroom continually reminded of my inability to cope & process the trauma. I attempted to regain a sense of normalcy by rearranging the furniture, joining a support group for young adult cancer survivor, & returning to work as well as extracurricular activities I once enjoyed. Nothing worked. I had to remove myself from a physical location that kept me tied to the psychic trauma. Now I live with my partner, & even though my monthly obligations & expenses have increased, I insist on it. I pay what my modest salary allows.</p>

Many YAs described lack of insurance coverage affecting their ability to access necessary care: *"I qualify for health coverage through Medicaid, but the hospital where I receive my cancer care does not accept Medicaid,"* and *"co-pays for specialists are beyond the scope of what I can afford."* Many YAs admitted to foregoing medications or follow-up cancer care due to cost: *"(I) had to stop taking several medications because I couldn't afford to pay out of pocket"* and *"not willing to get the PET scan and make all of my medical appts because I can't afford to pay any of them back... so I just don't go."*

Planned aspects of post-treatment care, such as reconstruction following breast cancer treatment, may remain unfinished because of cost: *"[I am] unable to continue with*

my nipple reconstruction because I have past due bills. I tried making payments but I did not pay enough of the bill to continue the reconstruction process." This is a challenge, not only to financial resources but also to the sense of self. YAs are just developing that sense of self and this can affect self-esteem and intimacy as well.⁹

Some YAs reported financial assistance from family and friends *"During treatment, I temporarily moved back home with my parents. I relied on them not only for my caregiving and emotional support but for financial supplementation,"* *"My friends and family had a fundraiser that helped pay for some of the medical costs."* However, YAs reported that although family and friends may have offered financial

assistance there were often limits on this support: *"During my cancer treatment my parents helped me the best they could, however, they are no longer able to do so. They have given me everything they could," "my boyfriend has been helping me with my bills although he has very little money himself,"* and *"my family wasn't able to help me financially so I have been on my own with the help of some friends and loans."*

Conversely, sufficient financial resources allow YAs to *"spend less time scrambling for money, and feel 'more confident about my financial outlook and feel more financially stable.'"* They report paying debts such as credit card, car, school, mortgage, and previous cancer care with positive consequences: *"I was able to pay the remainder of my medical bills down, lessening my stress level"* and *"(I) stopped the medical collection agency from calling."* They describe both *"working on rebuilding my savings account,"* and also funding future endeavors: *"[I was] able to finish my graduate degree program this past December because I didn't have to choose between paying my bills and finishing my classes."*

Support future goals

Support for future goals is particularly salient in the YA life stage. YAs without sufficient financial resources to support future goals reported that they were *"barely getting by"* and *"constantly playing catch up."* They report that *"cancer has caused a debilitating financial strain that is seemingly impossible to recover from."* They feel *"burdened"* by debts and expenses that are *"crushing"* and *"holding me back from moving forward with my life."* Employment options were limited: *"(I) have to change career, location, or continue to work two jobs. In a sense that feels like cancer is winning because it is still controlling my life."* The need for health insurance also dictates job choices: *"company provided medical insurance is a must... self-employment would not be possible."*

With sufficient financial resources, YAs describe feeling confident in their ability to resume life: *"I can focus on moving forward with my life in whichever path I want to take."* They reported plans to reestablish educational and professional goals interrupted by cancer: *"I have 2 courses to complete before I get my Bachelor's degree. It's been extremely slow going the past 2 years and all extra money has been going to medical bills so I haven't been able to save up for those last 2 courses. I hope to do so soon."*

YAs were also able to establish new goals: *"I am not going to be the person that stays on disability just 'because' there was an excuse to obtain it! I'm putting myself through nursing school and I plan to make a wonderful life for me and my children... I have so much drive to complete this goal of mine and become a transplant nurse so I can give young adult patients just like myself hope when I know all too well how hopeless it can sometimes seem."* In some cases, personal goals require long-term modification to accommodate post-cancer life: *"[I want to] start my own tutoring business, so that I can still teach but at my own pace and with some flexibility for [doctor] visits and sick days."*

Facilitate survivor self-care. YAs describe a desire to optimize their health through self-care, ranging from eating

healthier food to mental health therapy, but often struggle with finding the necessary financial resources: *"cancer has made me angry, depressed and self-conscious... My therapist charges me whatever I can afford at the moment (which is a very low amount), but by next week I will not be able to afford to see him."* Many express interest in exercise: *"I feel less stress when I go to the gym."* They also identify the use of complementary and alternative medicine as helpful: *"massages, acupuncture, meditation to help me relax from anxiety and depression,"* but note, *"It is hard to justify paying for a gym membership when I have outstanding amounts of debt."*

Enable normative development. Normative development, comprising achievement of milestones related to education, work, independence from family of origin, intimate partner relationships, and family building is of importance to YAs. YAs describe how cancer has impacted their ability to be independent and self-sufficient: *"Of all the things that I have grieved for or been angry and frustrated with throughout this journey, it is the lack of independence and sense of self-sufficiency. These are things that I always prided myself on and are part of my self-identity."* They view the ability to live independently as key: *"I am unable to live on my own and can barely support myself...cancer has taken... my independence."* They describe the inability to meet their own needs as distressing. *"I have tried to pay my medical expenses on my own but sadly have failed. I have tried to continue working while in treatment so I wouldn't make myself a burden to others financially."*

YAs describe recovery from losses due to cancer in terms of *"trying to get back to a normal lifestyle."* The availability of opportunities to engage in what YAs regard as normal educational, professional, and personal activities may need to include accommodation of any physical or psychosocial limitations due to cancer and cancer treatment (i.e., fatigue, muscle weakness, pain, neuropathy, neurocognitive impairment, and an immunocompromised state) for YAs who report *"I still feel the daily effects from treatment and getting through a day is challenging for me."*

A few YAs report receiving support: *"My employer was gracious enough to hold my position and I was able to step in right where I left off. They were as thrilled to have me back as I was to be back. Working gave me a new focus and really helped to lift my spirits."* They compare themselves to non-cancer peers: *"people my age should be getting their career started to pay off their student loans or saving for a wedding, not be working 2-3 jobs to make minimum payments on medical treatments."* However, inability to move forward with career is often reported: *"my long term side effects prevent me from returning to my old occupation and limit what I can do now."*

YAs report that achievement of developmentally appropriate milestones requires sufficient financial resources: *"I'm not able to pay for continuing education due to depleting any extra funds that I have had over the past year to pay for medications, office visit co-pays and personal bills."* Financial resources are necessary to take next steps in intimate partner relationships, such as cohabitation independent from family of origin: *"I am preparing to move out of my parents' house, with my boyfriend."*

Additionally, financial resources are vital to family building after cancer because both assisted reproduction and

adoption are expensive: “*I am unable to conceive on my own due to high-dose chemotherapy... and my medical insurance will not pay,*” and “*we simply cannot afford to save any money to adopt a child, or position ourselves as more financially attractive to potential birth parents, with the medical bills that loom over us.*”

Discussion

The ability to manage challenges related to cancer treatment/survivorship is entwined with the need for financial self-sufficiency. Underinsurance and lack of insurance remain challenges, even with the advent of the Affordable Care Act.¹⁰ For YAs, the ability to move forward after cancer treatment depends intimately on the ability to meet their own financial needs (Table 1). Lack of financial self-sufficiency is a direct threat to obtaining the independence that is the hallmark of the YA life stage.⁹

The American Society of Clinical Oncology (ASCO) has provided the recommendation that health care providers discuss cost with their patients.¹¹ However, there is great variability in the occurrence of these discussions. In one study, only 24% of oncology encounters had a cost conversation of any type.¹² This may be because many cancer patients do not think this is the physician's role.¹³ Studies exploring this perception do not specifically analyze the YA age group compared to older counterparts.

Regardless of YAs' perceptions about the need to discuss finances with their health care providers, our data clearly demonstrate that YAs are making choices regarding treatment and follow-up based on cost and affordability. Encouraging discussions with health care providers will enable YAs to make informed choices about the implications for their health, both currently and in the future.

Study limitations include selection bias, as this was a purposive sample of YAs with sufficient financial need to both self-identify as requiring assistance and be awarded assistance on application for it, and lack of opportunity to clarify thoughts or feelings with the anonymized essay authors. However, there was rich, poignant data related to the financial impact of cancer on YA lives. Continued research into the financial toxicity experienced by YAs with cancer is warranted to guide future intervention with this high-risk group.

Conclusion

YAs with cancer are at significant risk for life-altering financial toxicity. Just as there has been a concerted effort toward cure of cancer in this population, now attention must turn to assessment and intervention to decrease the financial toxicity associated with survival. The difference between simply surviving cancer and thriving in future endeavors is inherently entwined with financial solvency. Facilitating dialog about financial toxicity is a first step in the development of jointly crafted solutions from health care providers, patients, and insurers.

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