



Published in final edited form as:

Cancer. 2018 August ; 124(16): 3284–3289. doi:10.1002/cncr.31588.

The Intersection of Financial Toxicity and Family Building in Young Adult Cancer Survivors

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Précis

Financial toxicity and family building difficulties may co-occur in young adult cancer survivors. We describe this intersection and propose steps to alleviate associated distress.

Keywords

financial toxicity; young adult; family building; survivorship; fertility

The convergence of financial toxicity and family building difficulties after cancer creates unique challenges for young adult (YA; 18-39 years old) cancer survivors. Financial toxicity, the economic distress or hardship resulting from cancer treatment, has been reported among YA survivors at alarming rates; at the same time, YAs who experience fertility impairment as a result of treatment may additionally face costly family building options. These combined financial pressures can have significant effects on family building decisions and financial outcomes in both the short- and long-term. Here, we describe how financial toxicity and fertility-related side effects of treatment can co-occur among YA cancer survivors and propose steps to alleviate distress associated with this intersection.

Financial Toxicity of Cancer in Young Adults

Researchers have come to view financial toxicity as yet another treatment-related effect, in the same vein as common biological toxicities.¹ It is rooted, in part, in the high cost of treatment and medication; the impact of disease and treatment on the ability to work and/or attend school; and increased cost sharing between patients and insurers (e.g., higher

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The authors have no conflicts of interest.

Author Contributions:

Thom: Conceptualization, writing—original draft, writing—review and editing
Benedict: Conceptualization, writing—original draft, writing—review and editing
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premiums, deductibles, and co-payments/co-insurance).¹⁻⁴ Predictably, financial toxicity can yield a variety of negative effects on survivors' quality of life, including increased risk for bankruptcy, asset depletion, medical debt, and high levels of finance-related anxiety, worry, and stress.^{5,6} Even among survivors who are insured, cost-coping strategies to reduce the financial burden of cancer include depleting savings, borrowing money, failing to adhere to prescribed treatment and medications, and delaying or forgoing follow-up care—all of which can lead to overall lower quality of life, poor disease outcomes, and increased risk for depression, anxiety, and distress.^{5,7-9} Rates of financial toxicity after cancer vary widely: a recent systematic review found 12-62% of survivors report debt from treatment, 47-49% report some level of cancer-related financial distress, and 4-45% report finance-related medication nonadherence.⁵ Factors associated with financial toxicity include higher comorbidity, lower income at diagnosis, female gender, and younger age.^{3,4,10} Indeed, YA survivors report cancer-related financial toxicity more frequently than older survivors.¹¹⁻¹³ In the Adolescent and Young Adult Hope Study, a population-based cancer registry of adolescent and young adults with cancer, 90% of young survivors reported a need for financial support for medical care, and 62% wanted professional advice on managing healthcare payments.¹¹

A cancer diagnosis may interrupt key developmental transitions and milestones during young adulthood, including educational pursuits and graduation, workforce entry/advancement, and achieving financial independence from parents, and these interruptions may limit survivors' long-term earnings, contributing to financial toxicity.¹⁴⁻¹⁶ Survivors may also face treatment-related cognitive, physical, and/or psychosocial impairments into adulthood: over 50% of patients working or in school full-time before diagnosis report problems with return to school/work after treatment because of issues with attention and memory, missed days due to health or medical visits, and difficulty "keeping up."^{12, 15} About a quarter of YA survivors have not returned to full-time school/work three years after their diagnosis, and 12% report being "completely unable" to work at a job, do housework, or go to school.^{12,15}

Young survivors also face higher out-of-pocket medical costs than their peers, with current estimates suggesting they spend, on average, an extra \$3170 per year in medical costs over non-survivors (\$7417 vs \$4247).¹⁵ Additionally, 44% of YA cancer survivors in their 20s, and 26% in their 30s, report avoiding medical care because of its cost, compared to 16% and 18% in an age-matched non-cancer sample, respectively, with no difference in demographics or insurance coverage between the two groups.¹⁷ YA cancer survivors are more likely to be unable to afford medication (18.3% vs 11.9%; $p<.002$), request cheaper prescriptions (32.2% vs 24.5%; $p=.004$), and use lower-cost alternative therapies (9.3% vs 5.4%; $p=.01$), compared to peers.¹⁸

These effects may have very real consequences for survivors' long-term financial outlook and access to care. Compared to age-matched peers and siblings, YA survivors report lower income and net worth, and they are more likely to be under- or unemployed, lack insurance coverage or be covered by Medicaid, have debt, and declare bankruptcy.^{15,19,20} A recent analysis found YA survivors are also more likely than siblings to experience "job lock," in which they stay in a job to maintain employer-sponsored medical coverage.¹⁰ This practice

has the potential to limit survivors' future earnings and career progress, and ultimately, as the authors suggested, overall quality of life.¹⁰

Financial Costs of Family Building After Cancer

Amidst cancer's economic burden, YAs may also experience infertility, impaired fertility, or other associated hurdles in pursuit of parenthood, which can result in additional costs when trying to build their families. Due to the effects of gonadotoxic treatments, survivors may need assisted reproductive technology (ART) to achieve pregnancy in the female partner/survivor, using fresh, frozen, or donated gametes. If unable to carry a pregnancy, female survivors may need to consider surrogacy with a gestational carrier. Alternatively, survivors may choose to adopt a child. Each option has significant associated financial costs that may cause or exacerbate cancer-related financial toxicity. These costs can be difficult to predict, given uncertainty surrounding the exact procedures needed (e.g., number of in vitro fertilization [IVF] cycles), the occurrence of unexpected medical costs, and the agency, travel, and legal fees associated with adoption and surrogacy.^{21,22} In the U.S., cost estimates range from \$12,000–\$15,000 per IVF cycle (or \$40,000–\$60,000 per live birth using IVF, as patients often require multiple cycles) and \$100,000–\$150,000 for gestational carrier, with limited insurance coverage available. Adoption cost estimates range from \$30,000–\$40,000 but depend on situational factors, such as domestic versus international adoption.^{23–27}

Financial assistance programs are available for patients seeking to undergo *pre*-treatment fertility preservation to help offset costs of medication and egg/embryo or sperm storage. As of this writing, only two states (Connecticut and Rhode Island) have mandated insurance coverage laws for fertility preservation for cancer patients prior to initiation of cancer-directed therapy,²⁸ with others (California, Hawaii, Maryland, Massachusetts, New York, New Jersey) proposing similar measures. Financial assistance programs for *post*-treatment family building, however, are largely non-existent. While it is possible to negotiate lower rates with individual reproductive medicine centers, and there are a few opportunities to apply for financial grants to support family building costs from patient organizations such as The Samfund, these opportunities are limited. Thus, the onus for covering the majority of family building costs when ART, surrogacy, or adoption is needed will likely fall upon the YA survivor (and his/her partner).

Financial and Family Building Decision-Making

Given that YA cancer survivors rank fertility and family building as among their most pressing post-treatment concerns and that fertility concerns can impact quality of life,^{29,30} it is important to understand how survivors approach decisions and plan financially for ART, surrogacy, and/or adoption, if needed. A number of factors may affect family building decisions, including current reproductive health, prior fertility preservation, financial resources, and the preferences and values of the prospective parents.^{31,32} Through an online survey of 346 YA female cancer survivors, we previously demonstrated that uncertainty and distress, measured as decisional conflict and concerns about reproduction, arise when considering family building decisions after treatment and that higher decisional conflict was influenced by unmet information needs ($\beta = .43$; $p < .001$).³¹ Few studies, however, have

explored how cost or financial toxicity factors impact survivors' decision-making or their need for financial counseling.^{32,33} Although cost has been cited as a barrier to undergoing fertility preservation before treatment,^{22,34} there is no indication that cancer or its financial effects dissuade survivors (or their partners) from wanting to have children after cancer.³⁵

Given their age, it is also critical to consider that YAs may not yet possess the financial aptitude to optimize decision-making and appropriately plan for post-treatment family building costs. The Developmental Model of Financial Capability, which integrates concepts from Developmental Theory, Social Cognitive Theory, and empirical findings related to financial education and behaviors,³⁶ posits that "financial capability" is a developmental task, and increasing objective financial knowledge alone is not enough to change financial behaviors. YA cancer survivors may also lack "health cost literacy," or the ability to understand financial concepts related to care, to discuss financial burden with clinicians as a part of treatment decision-making, and to access appropriate resources to address financial stress.³⁷ This lack of knowledge and skills may lead YA survivors to make uninformed care decisions, which can leave them unprepared for large bills or deductibles. To date, we are unaware of any study that has explored YA survivors' financial decision-making processes in the context of family building after cancer therapy.

For many survivors, achieving parenthood has significant potential to yield positive outcomes, and decision-making about how to spend limited financial resources will depend on individuals' (and couples') values, priorities, and goals. Our previous qualitative analysis of financial difficulties related to family building suggests some survivors are willing to take on significant economic burden and debt to achieve parenthood, while others are surprised and unprepared for the costs they incur.³⁵ In both scenarios, we found that prospective parents are often anxious about the long-term implications of the financial steps taken to cover costs (e.g., depleting savings and assets, incurring debt), particularly as they prepare for the cost of a new child.³⁵ These data suggest the importance of ensuring survivors receive adequate information to make informed decisions about family building, so they may plan for the associated costs, as needed. Financial planning strategies could potentially mitigate long-term financial strain and distress and allow survivors to avoid unexpected bills. We propose the need for comprehensive support services to help YA cancer survivors make decisions about family building options, including strategies to promote financial capability, health cost literacy, and early financial planning.

Tailoring Interventions

Recently, various stakeholders in cancer care, including healthcare systems/providers, pharmaceutical companies, payers, and patient advocacy groups, have sought to address the financial toxicity related to cancer treatment. Proposed interventions at a systemic level include lowering the price of drugs, allowing the Centers for Medicare and Medicaid Services to negotiate costs, and addressing the proportion of costs that fall to patients. However, it is unlikely that such policy changes will be implemented in the foreseeable future.³⁸

Oncologists and allied health providers can become key players in addressing the immediacy of financial toxicity, a responsibility the oncology care community has acknowledged.³⁹ The role of the provider should include discussing treatment costs with patients and referring to support services for financial assistance as needed.

The need for providers to educate patients and/or make referrals to financial support services extends to fertility-related services as well, and it is critical for providers to initiate these discussions early enough to ensure patients have time to prepare before they are ready to start a family.³⁸ Although research has shown that over half (52%) of patients want to discuss financial issues with their care providers,⁶¹ medical professionals are often uncomfortable and ill-prepared to have financial discussions. Empirically-based resources are needed to facilitate financial discussions and support providers in assessing patients' need for financial support and in making appropriate referrals.

Potential strategies to support these discussions include patient navigation services, peer-to-peer mentoring, and topic-specific support groups for patients interested in post-treatment family building options. While financial navigation interventions are being tested in the research setting,⁴⁰ we are not aware of any targeted toward YA cancer survivors, despite data highlighting this group's interest in such interventions.⁴¹ Likewise, general interventions focusing on *post*-treatment fertility preservation and family building decisions are limited; the majority of research in this area has focused on fertility preservation decisions *before* treatment begins,^{42–47} and to our knowledge, none have included financial counseling or educational content aimed at building financial skills. We are also unaware of any existing decision support interventions regarding fertility preservation or family building decisions for males.⁴⁸

Ideal interventions targeting family building and financial toxicity should thus focus on providing basic information about the healthcare and insurance systems; detailing expected costs in the treatment and survivorship settings, highlighting the potential for unforeseen expenditures; educating patients on the skills needed to navigate current and future finances; and instructing survivors about the intersection between financial toxicity and family building costs. In the pre-treatment setting, financially-focused fertility information should address the short-term costs associated with fertility preservation, including medication and retrieval procedures, as well as the long-term costs associated with gamete/embryo freezing and storage; the eventual use of the specimens, be it through the survivor's (or partner's) own pregnancy or surrogacy; and/or adoption. In the post-treatment setting, topics should include the costs associated with post-treatment fertility preservation (if applicable); use of previously stored gametes/embryos; and alternative family building options such as adoption. In both settings, it is vital for these discussions to occur within the context of the survivor's ongoing medical care and healthcare costs, and with consideration for the survivor's developmental age and for the effects of treatment on his or her ability to work or attend school.⁴¹ It is equally important for the patient to evaluate and incorporate his or her values related to finances and family building into the conversation.

Next Steps

The long-term psychosocial burden of cancer-related fertility problems is well-established, and addressing fertility is now considered a key aspect of cancer care.^{31,49–52} As such, leading medical organizations have issued guidelines highlighting the need for clinicians to inform patients about their risks of infertility, discuss options for fertility preservation, and refer interested patients to reproductive specialists before treatment begins.^{53–57} Importantly, issues surrounding fertility, reproductive health, and family building must be revisited post-treatment as well, as a lack of fertility-specific information, misconceptions, anxiety, and distress are common in this population.^{58–60}

Further work is needed to examine YA cancer survivors' financial capability and the impact of financial knowledge, perceptions, and practices on family building decisions and financial outcomes. This can lead to the development of evidence-based resources to help survivors manage the financial effects of cancer and make decisions about family building. While several decision support interventions have been developed for pre-treatment fertility preservation, we argue that similar support services are needed in the post-treatment setting. This support may help mitigate undue financial burden and the exacerbation of subsequent financial toxicity and its psychosocial impact while ensuring patients have the opportunity to make informed, values-based decisions regarding family building and plan and prepare for the associated costs of ART, surrogacy, and adoption.

Acknowledgments

Funding: This review was funded in part through the NIH/NCI Cancer Center Support Grant P30 CA008748.

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