

Unemployment after cancer – a hidden driver of financial toxicity

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Abstract

While financial toxicity due to the high costs of cancer treatment is increasingly recognised as a significant challenge for cancer patients and survivors, the impact of reduced work participation as a major driver of financial toxicity is only just coming to light. Unemployment and reduced employment after a cancer diagnosis is associated with reduced financial reserves, impaired quality of life, and possibly reduced survival. Loss of work after cancer disproportionately impacts on those already more vulnerable, such as low income employees and the very young, with impact persisting for some for many years. Research needs to focus on quantifying and predicting the impact of reduced work participation on quality and quantity of survival, and development of interventions to assist with meaningful work participation for cancer survivors.

Financial toxicity, defined as financial distress or hardship experienced as a result of cancer treatment,¹ has attracted increasing attention in recent years as research shows that high costs associated with cancer treatment can lead to increased distress, reduced quality of life and even shortened survival.^{2,3} It is paradoxical that the great progress in development of better cancer treatments including rapid emergence of personalised medicines, new diagnostic approaches and novel surgical interventions, has led to reduced affordability of treatment by those who need them.⁴

While the focus of financial toxicity has traditionally been on escalating costs of treatments, tests and procedures, the financial burden is always the function of the cost of an item, such as a drug, surgical procedure, diagnostic test or even transport to attend the clinic, and the ability to pay, which reflects the financial reserves of an individual – their existing savings and their ability to generate new income through employment. Indeed, evidence shows that cancer patients often face a 'double whammy' of financial toxicity. At the time when cancer patients face the challenge of increased costs, they are often at their most vulnerable in regards to their ability to generate income to meet the additional expenses.⁵

This paper outlines the current knowledge regarding unemployment and reduced work participation after cancer, with a particular focus on their relationship to financial toxicity. It examines current strategies to improve work participation after cancer and discusses implications of this knowledge on cancer research and practice.

Work after cancer

Approximately half of cancer patients are younger than 65, when employment is an important part of their lives.⁶ Cancer diagnosis and cancer treatment can have profound impact on one's ability to continue employment because of physical, psychological and existential issues associated with the diagnosis and treatment. Symptoms like depression, fatigue, cognitive dysfunction or peripheral neuropathy may adversely affect one's ability to undertake work. This is particularly so in the setting of high demand professions and in situations where there is little flexibility in the workplace to accommodate temporary reduced capacity.⁷

Not surprisingly, evidence demonstrates that cancer survivors have reduced ability to maintain employment and experience reduced quality of employment when compared to cancer-free controls. Cancer survivors are 1.4 times more likely to be unemployed than controls, with approximately 30% of previously employed cancer survivors not returning to work at five years after diagnosis.^{8,9} Failure to

return to work in cancer survivors is associated with reductions in quality of life and poorer financial status.⁷ Cancer survivors are more likely to experience presenteeism (working while sick) within five years of cancer diagnosis, suggesting that the impact of cancer on work ability is not just on the quantity but also quality of work.¹⁰ While for cancer survivors, the impact of cancer on work is expected to lessen over time, patients with metastatic cancer are likely to face a fluctuating and ultimately deteriorating course of work ability, with increased symptom burden impacting on their ability to work.¹¹

Little is known about how much of the change in employment is driven by a change of life priorities and existential concerns about the value of work in the setting of potentially limited life expectancy versus inability to work, although studies suggest that cancer patients and survivors often feel that work is a financial necessity rather than existential choice.¹² This is not withstanding recognition of the non-financial benefits of employment including sense of normality, purpose, social connection and meaning, all very valuable in the otherwise disrupted universe of cancer.¹³

Financial impact of unemployment

Most of the research examining employment after cancer has focused on the social and existential impact of employment, with studies examining and quantifying the financial impact of unemployment emerging only recently. A systematic review by Altice and colleagues of financial hardship in cancer survivors reported 18 studies from the US that referred to productivity losses among cancer survivors with mean annual indirect costs to survivors ranging from \$US380 in prostate cancer to \$8236 in breast cancer.² An analysis of a national Medical Expenditure Panel Survey conducted in the US showed that compared to individuals without a cancer history, non-elderly colorectal and breast cancer survivors experienced statistically significant annual excess employment disability and productivity loss at work.¹⁴

In Australia, Paul and colleagues conducted a cross-sectional survey of oncology outpatients in two hospitals – metro and rural – with 255 responses returned. Of the respondents, 67% reported a change of employment, the most common being reduced hours, retirement or resignation/unemployment, and 63% reported reduced household income. The authors concluded that the data suggest that the financial impact of unemployment seemed to be the major driver of financial toxicity.¹⁵ Gordon and colleagues compared the self-reported financial hardship of colorectal cancer survivors in Queensland at six and 12 months following diagnosis with that of a matched general population group.¹⁶ After matching on seven socio-demographic variables, self-reported financial hardship among middle-aged workers with colorectal cancer was poorer at six months but had improved and was comparable to a general population comparison group at 12 months after diagnosis. Fifteen per cent of cancer survivors experienced a shortage of money to pay for living essentials. Middle-aged working cancer survivors who ceased or reduced work were more likely to perceive themselves as not being financially comfortable, compared with those who had continued work.

Who is affected by unemployment after cancer?

Similarly to financial toxicity in general, the impact of unemployment has a flow-on effect on the entire household. Zajacawa and colleagues reported on a large longitudinal study in the US and showed that the time after diagnosis was associated with reduction in probability of employment for cancer survivors, reduced working hours, reduced income and, most importantly, reduction in the overall household income.¹⁷ The impact appeared greater for men than women, reflecting men's greater paid workforce participation. In contrast, in a Swedish study of 3626 parents of survivors of childhood cancer, the financial impact was greater and longer lasting for mothers, with employment reduced for six years, than fathers, although both genders were affected.¹⁸ Thus, financial toxicity of unemployment was not just an acute toxicity – it had a late and long-lasting effect.

The impact of unemployment is greatest in those already most vulnerable, blue collar workers more than white collar workers,¹⁹ those on lower incomes,²⁰ or very young.²¹ There is very little data on patients from ethnically diverse, indigenous or rural and remote backgrounds, where job skills may be more limited and the job market smaller with fewer re-training opportunities.

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Unemployment after cancer is, of course, not just a function of an individual's abilities and cancer status, but is influenced by societal trends including the job market, and cultural expectation of who should work and what is expected of work after the cancer diagnosis. There is little known about how work after cancer is valued in different cultural and societal settings, and how work participation is further impacted by available alternatives to work, for example social security, disability support, retraining, insurance and support of friends and family.

Unemployment and survival

One of the most thought-provoking observations about unemployment after cancer is a suggestion of association with inferior survival. A large study by Maruthappu and colleagues examined World Bank and World Health Organisation data to correlated survival for different cancers categorised as treatable, as exemplified by breast, prostate, colon and untreatable, such as lung and pancreas, during the time of the global financial crisis with employment and changes in public expenditure on health.²² The study examined data from 75 countries representing over 2.106 billion people for unemployment analysis and 79 countries representing 2.156 billion for the public expenditure on health analysis. The study showed that the rise in unemployment was associated with increased mortality, especially for cancers in the treatable category, which may reflect limited access to care during the times of economic downturn.

Similarly, an Italian study of financial distress in participants of cancer clinical trials showed that worse financial difficulties were associated with a higher risk of death in this cohort of participants who, on the basis of trial participation and universal health coverage in Italy, were considered relatively protected from the threat of financial toxicity.²³ The authors postulated that the increased risk of death associated with financial distress was a reflection of employment loss and that in turn was a proxy for severity of underlying cancer and thus higher mortality.

Both studies present intriguing findings which, while unexpected, are consistent with the findings of increased mortality associated with inability to pay and bankruptcy after cancer reported elsewhere.³ To date no equivalent Australian data exists.

Addressing the challenge of work after cancer

As the financial and non-financial impact of reduced employment becomes apparent, there is a great need for effective strategies to address this issue. To do so, it is important to gain a greater understanding of the magnitude of the problem, predictors and comparisons in different settings. At present, most studies of work after cancer have a cross-sectional design and use a variety of measures, making comparison across countries and settings very difficult. The measures include return to work rates at six, 12 or 24 months, disability rates, time of work and sick leave and work status. While many studies examine quality of life as secondary endpoint, few focus specifically on work ability and quality of employment.²⁴ A greater harmonisation of measures would facilitate sharing knowledge from different countries and settings.

As already indicated, financial toxicity derived from unemployment relates to the costs, so one cannot be considered without the other. The rising costs of care are likely to unmask the hidden vulnerability of precarious employment. As such one should consider the two concepts as part of the same spectrum of financial vulnerability facing cancer patients and survivors (figure 1).

The factors that impact on financial costs of care are complex and multilevel (figure 2). Addressing them requires a broad consideration of not only physical and psychological dimensions of health, but also their social and cultural determinants. Healthcare providers need to consider financial wellbeing as an important aspect of wellness of a patient or survivor and consider the impact of cancer on work and financial security when discussing the impact of cancer treatment on the patient and their family. There is no doubt that this approach poses significant challenges to healthcare providers – while estimating a price for a new treatment is relatively straightforward, predicting impact of cancer treatment on employment depends on many variables – type of employment, type of cancer treatment, attitude to work, work flexibility, job market, cultural expectations regarding employment and societal support to those who cannot work and many others. Advising a patient regarding the impact of cancer treatment on their work requires close collaboration between healthcare providers

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and employers, often with input from specialists like occupational physicians and rehabilitation specialists. Clinicians need access to reliable information on work after cancer, skills in assessing work ability and ability to refer complex cases to specialised services like occupational physicians and rehabilitation physicians.

Figure 1: Relationship between financial toxicity, vulnerability and security as a function of cost and ability to pay.

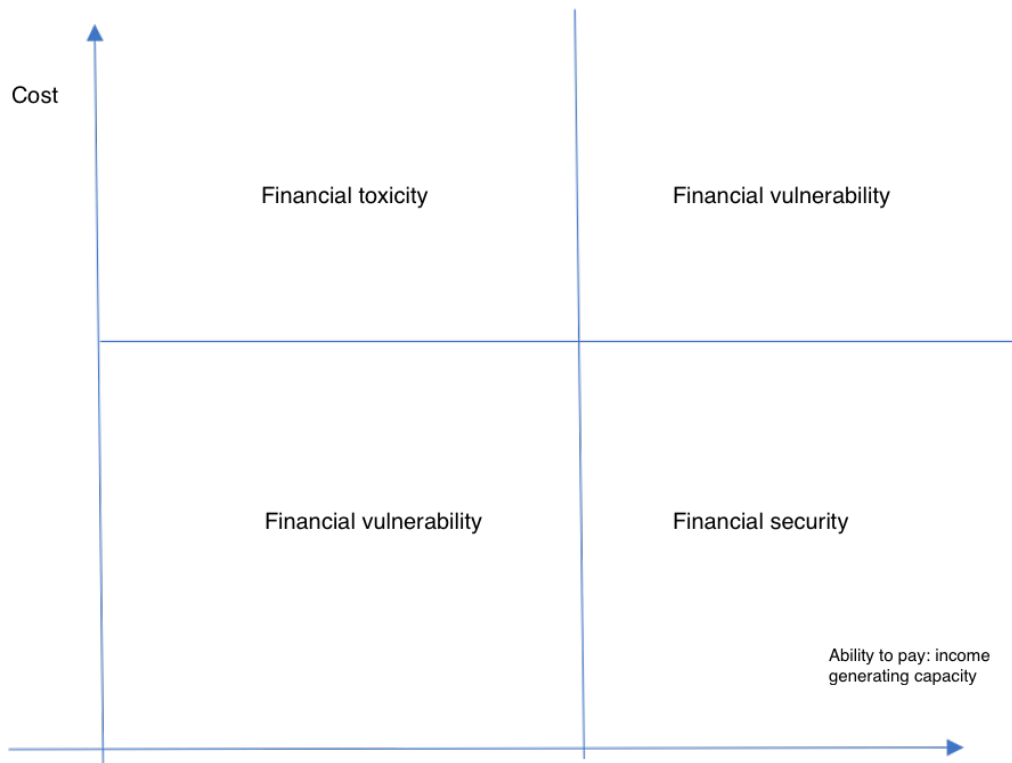
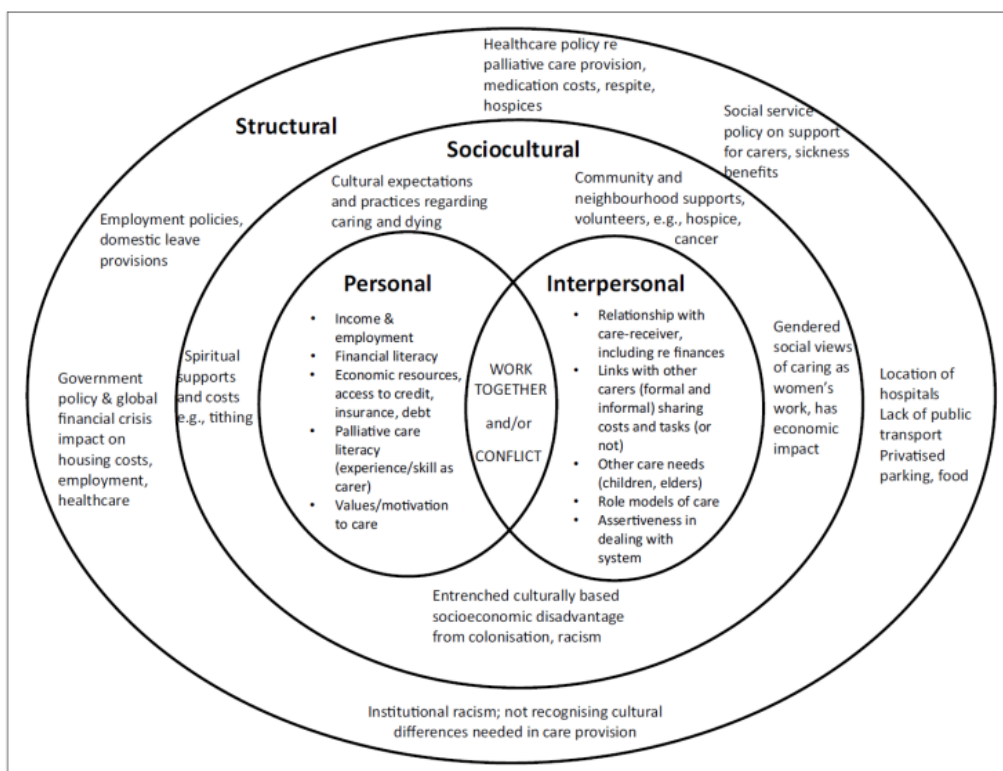


Figure 2: Dimensions that impact on cost of care. Adapted (with permission) from Gott et al.²⁵



Interventions to improve work participation after cancer

A 2015 Cochrane review by de Boer and colleagues updated the evidence on return to work interventions.²⁴ The review identified 15 randomised controlled studies of 1835 patients. All studies were conducted in high income countries and most focused on breast cancer (seven) and prostate cancer (two). The review found moderate evidence that multidisciplinary interventions incorporating physical training, psycho-education and vocational components improve return to work after cancer. Although most multidisciplinary interventions had a vocational component, the review identified no studies assessing vocational interventions focused on employment. All studies were aimed at the patients and there were no studies directed at the workplace. The authors recommended that more targeted, vocational interventions warranted further evaluation and that studies should examine the impact of interventions in other cancer groups and other ethnicities, and examine outcomes with longer follow-up focusing not just on numbers returning to work, but also the rates of work retention and productivity measures. The authors also identified missed opportunities in research where clinical trials evaluating complex interventions for cancer patients, for example exercise and healthy lifestyle interventions, currently do not include work participation as an endpoint.

To add to the authors' conclusions, it is notable that most of the studies of return to work interventions do not include data on cost-effectiveness of the interventions which would be critical to facilitate implementation. In contrast to Germany, Scandinavia and the Netherlands, Australia does not have established cancer rehabilitation programs with a focus on vocational rehabilitation. Introduction of such programs would require evidence, not only of effectiveness, but also cost-effectiveness to provide justification for funding from the public purse.

Both clinical practice and future research in this area requires a close collaboration between patients, healthcare providers, employers and insurers to ensure that the complex challenge of work after cancer is addressed at all levels where impact is required. But this approach requires a radical overhaul of how we support cancer patients, how we design research and who we see as key stakeholders in the process.

Conclusion

The issue of financial toxicity is emerging as a significant burden for patients and their families. It extends beyond the price of new treatments and reflects the subtle interplay between cost and ability to pay. It has disproportional impact on those most vulnerable to poor outcomes already. Addressing this emerging challenge requires a paradigm shift in how we see wellness of cancer patients and survivors, and the role of the health profession in ensuring wellness. Research and practice in this area requires collaboration with partners not traditionally engaged with healthcare professionals, like employers and insurers. Finally, the design of future cancer clinical trials needs to take into account the impact of unemployment and financial vulnerability on quality and quantity of survival.

References

1. de Souza JA, Wong Y-N. Financial distress in cancer patients. *J Med Person*. 2013;11(2):73–7.
2. Altice CK, Banegas MP, Tucker-Seeley RD, et al. Financial Hardships Experienced by Cancer Survivors: A Systematic Review. *J Natl Cancer Inst*. 2017;109(2).
3. Ramsey SD, Bansal A, Fedorenko CR, et al. Financial Insolvency as a Risk Factor for Early Mortality Among Patients With Cancer. *J Clin Oncol*. 2016;34(9):980-6.
4. Gordon LG, Merollini KM, Lowe A, et al. A Systematic Review of Financial Toxicity Among Cancer Survivors: We Can't Pay the Co-Pay. *Patient*. 2016;10:295-309
5. Mehnert A, de Boer A, Feuerstein M. Employment challenges for cancer survivors. *Cancer*. 2013;119 Suppl 11:2151-9.
6. AIHW 2017. Cancer in Australia 2017. Cancer series no. 101. Cat. no. CAN 100. Canberra: AIHW.
7. Mehnert A. Employment and work-related issues in cancer survivors. *Crit Rev Oncol Hematol*. 2011;77(2):109-30.
8. de Boer AG, taskila T, Ojajarvi A, et al. Cancer survivors and unemployment: a meta-analysis and meta-regression. *JAMA*. 2009;301(7):753-62.

9. Amir Z, Brocky J. Cancer survivorship and employment: epidemiology. *Occup Med* . 2009;59(6):373-7.
10. Soejima T, Kamibeppu K. Are cancer survivors well-performing workers? A systematic review. *Asia Pac J Clin Oncol*. 2016;12(4):e383-e97.
11. Tevaarwerk AJ, Lee JW, Terhaar A, et al. Working after a metastatic cancer diagnosis: Factors affecting employment in the metastatic setting from ECOG-ACRIN's Symptom Outcomes and Practice Patterns study. *Cancer*. 2016;122(3):438-46.
12. Knott V, Zrim S, Shanahan EM, et al. Returning to work following curative chemotherapy: a qualitative study of return to work barriers and preferences for intervention. *Support Care Cancer*. 2014;22(12):3263-73.
13. The Royal Australasian College of Physicians, Australasian Faculty of Occupational and Environmental Medicine Position Statement on Realising the Health Benefits Work, Sydney 2011. The Royal Australasian College of Physicians. 2011.
14. Zheng Z, Yabroff KR, Guy GP Jr, et al. Annual Medical Expenditure and Productivity Loss Among Colorectal, Female Breast, and Prostate Cancer Survivors in the United States. *J Natl Cancer Inst*. 2016;108(5).
15. Paul C, Boyes A, Hall A, et al. The impact of cancer diagnosis and treatment on employment, income, treatment decisions and financial assistance and their relationship to socioeconomic and disease factors. *Support Care Cancer*. 2016;24(11):4739-46.
16. Gordon LG, Beesley VL, Gabor M, et al. Reduced employment and financial hardship among middle-age individuals with colorectal cancer. Under review. *Eur J Cancer Care*.
17. Zajacova A, Dowd JB, Schoeni RF, et al. Employment and income losses among cancer survivors: Estimates from a national longitudinal survey of American families. *Cancer*. 2015;121(24):4425-32.
18. Lindahl Norberg A, Montgomery SM, Bottai M, et al. Short-term and long-term effects of childhood cancer on income from employment and employment status: A national cohort study in Sweden. *Cancer*. 2016;123:1238-48.
19. Mehnert A, Koch U. Predictors of employment among cancer survivors after medical rehabilitation--a prospective study. *Scand J Work Environ Health*. 2013;39(1):76-87.
20. Blinder V, Eberle C, Patil S, et al. Women with breast cancer who work for accommodating employers more likely to retain jobs after treatment. *Health Affairs*. 2017;36:274-81
21. Gunnes MW, Lie RT, Bjorge T, et al. Economic independence in survivors of cancer diagnosed at a young age: A Norwegian national cohort study. *Cancer*. 2016;122:3873-82.
22. Maruthappu M, Watkins J, Noor AM, et al. Economic downturns, universal health coverage, and cancer mortality in high-income and middle-income countries, 1990–2010: A longitudinal analysis. *Lancet*. 2016;388:684-95.
23. Perrone F, Jommi C, Di Maio M, et al. The association of financial difficulties with clinical outcomes in cancer patients: secondary analysis of 16 academic prospective clinical trials conducted in Italy. *Ann Oncol*. 2016;27(12):2224-9.
24. de Boer AG, Taskila TK, Tamminga SJ, et al. Interventions to enhance return-to-work for cancer patients. *The Cochrane database of systematic reviews*. 2015;(9):CD007569.
25. Gott M, Allen R, Moeke-Maxwell T, et al. 'No matter what the cost': A qualitative study of the financial costs faced by family and whanau caregivers within a palliative care context. *Palliat Med*. 2015;29(6):518-28.