



Financial toxicity and symptom burden: what is the big deal?

Raymond Javan Chan^{1,2,3,4}  · Louisa Gordon^{1,5,6} · Syed Yousuf Zafar⁷ · Christine Miaskowski^{1,8}

Received: 29 August 2017 / Accepted: 4 February 2018 / Published online: 13 February 2018
© Springer-Verlag GmbH Germany, part of Springer Nature 2018

Keywords Financial toxicity · Symptom burden · Financial distress · Symptom cluster · Conceptual framework · Survivorship

Introduction

There is great interest currently on the issue of financial toxicity (FT) in cancer care with research papers, commentaries, and press articles on the topic substantially growing. The term ‘FT’ is used to describe the financial distress or hardship as an outcome of cancer treatment [1]. Alleviating the impact of FT requires knowledge of how health services are organised and funded within the respective health system and the efforts of numerous groups including policy makers, clinicians, advocacy groups, and industry. The supportive care community has taken the mission of lessening the negative impact of FT very seriously. Regardless of how it is measured, relatively high levels of FT are experienced by oncology patients and their caregivers [1]. Our recent systematic review of the FT literature

found that the frequency of FT ranged from 28 to 48% using monetary measures like percentage of household income, and 16 to 73% using self-report measures such as impacts on everyday living expenses [1].

While high financial burden reduces health-related quality of life, especially the emotional well-being domain [2–6], little is known about the relationship between FT and symptom burden, especially physical symptoms. We propose that increased knowledge of the experiences of having both FT and physical symptoms and, how they relate to each other, will inform the development and testing of interventions to decrease FT and/or symptom burden. This commentary discusses the importance of investigating the relationships between FT and symptom burden.

Why would increased knowledge of the relationships between FT and symptoms be helpful?

In an Irish study of 654 cancer survivors, participants who reported FT were three times more likely to develop depression and anxiety [7]. Similarly, in a US study of patients with advanced disease ($n = 149$), significant relationships were found between patient-reported FT and psychological distress, including anxiety and depression [8]. However, while the relationships between financial burden and psychological distress are becoming clearer, very few studies have evaluated the relationships between FT and physical symptoms or symptom clusters.

Research findings [9, 10] and clinical experience suggest that symptoms do not occur in isolation. In recent years, our understanding of the underlying biologic mechanisms for symptom clusters has increased [11]. With the increased knowledge of the impact of FT on cancer patients and their caregivers, researchers in the supportive care community must investigate the relationships between FT and symptom/symptom clusters. For example, one plausible research question could be ‘How does FT impact sleep disturbance, as well as a symptom cluster that include sleep disturbance?’.

✉ Raymond Javan Chan
Raymond.Chan@qut.edu.au

¹ School of Nursing, Queensland University of Technology, Kelvin Grove, Brisbane Q4059, Australia
² Institute of Health and Biomedical Innovation, Queensland University of Technology, Kelvin Grove, Brisbane Q4029, Australia
³ Metro North Hospital and Health Services, Herston, Queensland Q4029, Australia
⁴ School of Nursing, Queensland University of Technology, Level 3, N Block, Kelvin Grove Campus, Brisbane Q4059, Australia
⁵ QIMR Berghofer Medical Research Institute, 300 Herston Rd, Brisbane, QLD 4006, Australia
⁶ School of Medicine, The University of Queensland, Herston, Brisbane, Queensland 4006, Australia
⁷ Duke Cancer Institute, Sanford School of Public Policy, Duke University, Durham, NC, USA
⁸ Department of Physiological Nursing, University of California and San Francisco, 2 Koret Way – N631Y, San Francisco, CA 94143-0610, USA

Given the previous findings on the relationships between FT and psychological distress [7, 8], one would ask ‘How does FT influence a symptom cluster that includes anxiety and/or depression?’. For those patients who are experiencing FT and are struggling to meet the costs of cancer treatment, one could ask ‘How is FT associated with the costs of treatment for symptom management?’. We already know that caregivers experience significant symptom burden [12, 13]. Another question would be ‘What are the relationships between FT (that influence the entire household) and symptom burden in caregivers?’. When answered, these important clinical questions may assist with developing interventions to reduce the impact of FT as well as symptom burden.

Fatigue, pain, cognitive dysfunction, depression, and peripheral neuropathy may decrease patients’ function status and impede cancer survivors’ ability to return to work [14]. However, no studies have evaluated if effective management of these symptoms increases survivors’ ability to return to work. A 2015 Cochrane review of 15 RCTs ($n = 1835$) investigated the effects of interventions designed to enhance return to work in cancer patients. Of these 15 included studies, only one aimed to decrease fatigue and in turn enhance return to work [15]. While acknowledging that unemployment or restricted employment after cancer can be multifactorial, it would be important that future research determines *whether* and *how* symptom burden is responsible for unemployment or restricted employment which in turn worsens FT.

In addition to costs of anti-neoplastic drugs, it is essential that clinicians discuss with patients and caregivers the costs associated with supportive care treatments. Communication between physicians and patients about the costs of cancer treatment is sub-optimal [16, 17]. Therefore, robust discussions are taking place and expectations about the pivotal role that oncologists play in preparing patients for the costs associated with cancer treatments is increasing [18, 19]. However, research studies that examine the quality of health professional/patient communication around the costs of

supportive care and the financial impact for patients are limited. While oncology nurses often assume an important role in symptom management, our recent survey of 423 oncology nurses found that discussions with cancer survivors about employment and financial issues were one of the least frequently discussed topics [20, 21]. Furthermore, nearly half of the participants did not agree that these discussions were part of their role. Compared to other types of survivorship care interventions, cancer nurses expressed that they were the least confident in their ability to discuss these issues.

Conclusions

In conclusion, this paper highlights the importance of increasing the new knowledge of the relationships between FT and symptom burden. We recommend that future research tests the relationships between FT and symptom burden in different groups of oncology patients and caregivers at various stages of their survivorship journey. Based on the discussion above, we propose a theoretical framework that can serve as a guide for future testing (see Fig. 1). A variety of research methods such as big data study and mixed-methods designs may be useful to tease out the relationships among a variety of phenotypic characteristics and outcome measures.

Compliance with ethical standards

Conflict of interest The authors declare that they have no conflict of interest.

References

- Gordon LG, Merollini KMD, Lowe A, Chan RJ (2017) A systematic review of financial toxicity among cancer survivors: we can't pay the co-pay. *Patient* 10(3):295–309. <https://doi.org/10.1007/s40271-016-0204-x>
- Catalano PJ, Ayanian JZ, Weeks JC, Kahn KL, Landrum MB, Zaslavsky AM et al (2013) Representativeness of participants in the cancer care outcomes research and surveillance consortium relative to the surveillance, epidemiology, and end results program. *Med Care* 51(2):e9–15. <https://doi.org/10.1097/MLR.0b013e318222a711>
- Fenn KM, Evans SB, McCorkle R, DiGiovanna MP, Pusztai L, Sanft T et al (2014) Impact of financial burden of cancer on survivors’ quality of life. *J Oncol Pract* 10(5):332–338. <https://doi.org/10.1200/JOP.2013.001322>
- Kale HP, Carroll NV (2016) Self-reported financial burden of cancer care and its effect on physical and mental health-related quality of life among US cancer survivors. *Cancer* 122(8):283–289. <https://doi.org/10.1002/ncr.29808>
- Khera N, Chang YH, Hashmi S, Slack J, Beebe T, Roy V et al (2014) Financial burden in recipients of allogeneic hematopoietic cell transplantation. *Biol Blood Marrow Transplant* 20(9):1375–1381. <https://doi.org/10.1016/j.bbmt.2014.05.011>
- Sharp L, Timmons A (2016) Pre-diagnosis employment status and financial circumstances predict cancer-related financial stress and

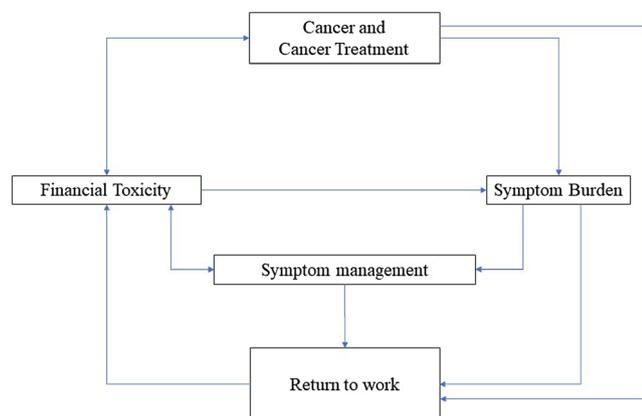


Fig. 1 Proposed theoretical framework for evaluating the relationships between financial toxicity and symptom burden

- strain among breast and prostate cancer survivors. *Support Care Cancer* 24(2):699–709. <https://doi.org/10.1007/s00520-015-2832-4>
7. Sharp L, Carsin AE, Timmons A (2013) Associations between cancer-related financial stress and strain and psychological well-being among individuals living with cancer. *Psychooncology* 22(4):745–755. <https://doi.org/10.1002/pon.3055>
 8. Delgado-Guay M, Ferrer J, Rieber AG, Rhondali W, Tayjasanant S, Ochoa J et al (2015) Financial distress and its associations with physical and emotional symptoms and quality of life among advanced cancer patients. *Oncologist* 20(9):1092–1098. <https://doi.org/10.1634/theoncologist.2015-0026>
 9. Illi J, Miaskowski C, Cooper B, Levine JD, Dunn L, West C et al (2012) Association between pro- and anti-inflammatory cytokine genes and a symptom cluster of pain, fatigue, sleep disturbance, and depression. *Cytokine* 58(3):437–447. <https://doi.org/10.1016/j.cyto.2012.02.015>
 10. Kim HJ, Barsevick AM, Beck SL, Dudley W (2012) Clinical subgroups of a psychoneurologic symptom cluster in women receiving treatment for breast cancer: a secondary analysis. *Oncol Nurs Forum* 39(1):E20–E30. <https://doi.org/10.1188/12.ONF.E20-E30>
 11. Miaskowski C, Barsevick A, Berger A, Casagrande R, Grady PA, Jacobsen P et al (2017) Advancing symptom science through symptom cluster research: expert panel proceedings and recommendations. *J Natl Cancer Inst* 109(4):djw253. <https://doi.org/10.1093/jnci/djw253>
 12. Fletcher BS, Paul SM, Dodd MJ, Schumacher K, West C, Cooper B et al (2008) Prevalence, severity, and impact of symptoms on female family caregivers of patients at the initiation of radiation therapy for prostate cancer. *J Clin Oncol* 26(4):599–605. <https://doi.org/10.1200/JCO.2007.12.2838>
 13. Swore Fletcher BA, Dodd MJ, Schumacher KL, Miaskowski C (2008) Symptom experience of family caregivers of patients with cancer. *Oncol Nurs Forum* 35(2):E23–E44. <https://doi.org/10.1188/08.ONF.E23-E44>
 14. Islam T, Dahlui M, Majid HA, Nahar AM, Mohd Taib NA, Su TT, My BCC study group (2014) Factors associated with return to work of breast cancer survivors: a systematic review. *BMC Public Health* 14(Suppl 3):S8. <https://doi.org/10.1186/1471-2458-14-S3-S8>
 15. Purcell A, Fleming J, Burmeister B, Bennett S, Haines T (2011) Is education an effective management strategy for reducing cancer-related fatigue? *Support Care Cancer* 19(9):1429–1439. <https://doi.org/10.1007/s00520-010-0970-2>
 16. Neumann PJ, Palmer JA, Nadler E, Fang C, Ubel P (2010) Cancer therapy costs influence treatment: a national survey of oncologists. *Health Aff (Millwood)* 29(1):196–202. <https://doi.org/10.1377/hlthaff.2009.0077>
 17. Schrag D, Hanger M (2007) Medical oncologists' views on communicating with patients about chemotherapy costs: a pilot survey. *J Clin Oncol* 25(2):233–237. <https://doi.org/10.1200/JCO.2006.09.2437>
 18. Aranda S, Currow D (2016) Financial toxicity in clinical care today: a “menu without prices”. *Med J Aust* 205(11):529–530
 19. Meisenberg BR (2015) The financial burden of cancer patients: time to stop averting our eyes. *Support Care Cancer* 23(5):1201–1203. <https://doi.org/10.1007/s00520-015-2664-2>
 20. Chan RJ, Wallace A, Downs E, Langbecker D, Ekberg S, Gates P et al (2016) Cancer nurses' provision of survivorship care for patients with haematological malignancy. *Support Care Cancer* 24(Suppl 1):S221
 21. Wallace A, Downs E, Gates P, Thomas A, Yates P, Chan RJ (2015) Provision of survivorship care for patients with haematological malignancy at completion of treatment: a cancer nursing practice survey study. *Eur J Oncol Nurs* 19(5):516–522. <https://doi.org/10.1016/j.ejon.2015.02.012>