

Supplementary file 1. ESMO Expert Consensus Statements on the Screening and Management of Financial Toxicity in Patients with Cancer: Further discussion of statements

METHODS

A Delphi panel of international experts was assembled with members identified by the European Society for Medical Oncology (ESMO), thru Giuseppe Curigliano, Daniele Santini and Carla Ida Ripamonti, with the first author, Pricivel Carrera (PC). Research relevant to/on financial toxicity, multi-disciplinarity, and diversity in health system contexts were taken into account in the formation of the Delphi panel as headed by PC. Nineteen experts accepted the invitation to work on financial toxicity statements for the Delphi survey within working groups (WGs) based on the current evidence-base.¹ Four WGs were established; each of the four WG was assigned themes to focus on, which are pertinent to the experience of financial toxicity among patients with cancer, their care-givers, and its management, including screening as well as in the context of survivorship.

The WGs were convened from March 2022 and worked on their proposed statements until October 2022. During the first round of the Delphi survey, which ran from November 28, 2022 to December 6, 2022, the experts evaluated 28 statements. Through the ESMO, each expert was independently asked to state if they agree, disagree or abstain to each statement and provide any comments. Consensus was reached in 89% (n=25) of statements with 100% agreement in 8 (29%) of the statements. Consensus was defined as >75% of participants agreeing/ strongly agreeing with a statement. The cut-off was based on a systematic review of Delphi studies which found 75% as the median threshold to define consensus.²

Following revisions to the statements based on feedback from individual experts, and discussions within each WG, all statements were re-voted on with the exception of 5 statements that received a 100% consensus on the first round and which had not been revised. The second round of Delphi ran from December 23, 2022 until January 12, 2023. Consensus was reached in 96% (n=26) of statements with 100% agreement in 37% (n=10) of the statements. One statement which received <75% of consensus was dropped from the final list of statements.

The following sections report on the findings of the expert panel discussions, consensus statements and a summary of evidence supporting each one. Planning, preparation and execution of the consensus process was conducted according to the ESMO standard operating procedures (<https://www.esmo.org/content/download/729269/17224532/1/ESMO-ECS-Standard-Operating-Procedure.pdf>).

WP1: Patients with cancer at risk of financial toxicity

Discussion Statement 1A

Regarding age, while younger age has repeatedly been reported as a risk factor associated with financial toxicity^{3,4,5,6} it is important to note that elderly patients have also been reported to face catastrophic health expenditures.^{7,8} They are less able to engage in economic activities and are more vulnerable to suffer other comorbidities and health problems requiring health expenditure. However, in many cases, they may also have greater financial reserves and may not experience as high financial distress.⁹ Questions remain whether younger people are more likely to participate in financial toxicity research studies) and report distress compared to their older counterparts.

Discussion Statement 1B

Financial toxicity is often linked to employment status. Data from several systematic reviews show fairly consistently that unemployment – either at the time of cancer diagnosis or afterwards – increases the risk of financial toxicity (measured in various ways); conversely, employment or being actively at work reduces the risk.^{10,11,12,13,14} Similar findings relate to lower workforce participation indicators – such as part-time work at diagnosis and changes in employment or reduced employment (e.g. reduced hours, forced leave) after cancer diagnosis.^{12,15,16}

Qualitative data support these quantitative associations.¹⁷ The main exception is some studies from Ireland, suggesting employed individuals at the time of diagnosis have higher financial toxicity risk than retirees;^{18,19,20} this may relate to healthcare system specifics and co-payments model⁹. It is unclear whether unemployment or reduced employment effects are independent of low income (consistently linked with increased financial toxicity^{21,22}). A further gap relates to self-employment; limited evidence suggests the self-employed may more often experience negative financial changes post-cancer or be more vulnerable to financial hardship.^{20,23} Employer or social welfare mitigation strategies (e.g. paid sick leave) may help people return to work more quickly following a cancer diagnosis.¹⁸

Discussion Statement 1C

Living alone or being single may also link with financial toxicity, but evidence is less extensive. Family and friends may play a role in alleviating financial hardship due to cancer, but evidence on this is currently limited. In a few studies in high-income countries, people with cancer who are unmarried or live alone more often face financial toxicity or financial barriers.^{20,22} This could reflect more limited financial resources in single-person households.

A small number of qualitative studies highlight how financial and practical (e.g. transport) support from family and friends may help alleviate out-of-pocket (OOP) costs experienced by patients.^{24,25,26} A UK study noted the importance to patients with cancer of being able to depend on a partner's income.²⁷ In one qualitative study, cancer survivors who had loans from family or friends had significantly increased risk of objective financial stress;²⁸ the cross-sectional design and suggests objective hardship likely resulted in the need to borrow money.

Discussion Statement 2A

Mixed results were found for stage of disease. A non-significant association of metastatic vs. local stage of disease has been found among Japanese cancer patients on treatment.²⁹ Among patients with advanced disease in France and the US, patients with metastatic disease have reported a significant impact on family distress from costs of cancer compared to those who had advanced disease defined based on recurrence, local advanced disease, or second line of chemotherapy.³⁰ Patients with distant disease have been found to have highest probability of bankruptcy.³¹ Another study reported that patients with advanced cancer were more likely to have financial catastrophe (OOP costs > 30% income) than those with no advanced cancer.³² Moreover, among patients who incurred time costs, costs were found to be higher in those with metastatic disease than in those with no metastatic disease.³³ In a review of 22 studies from India,³⁴ 3 studies found that advanced-stage disease was a risk factor for high treatment costs among patients of any cancer,³⁵ breast cancer³⁶ and oral cancer³⁷.

Breast cancer stage 4 patients were found to have worse financial toxicity than stage 1 patients in the US.³⁸ Among French patients with advanced disease, breast cancer patients have been found to be more

likely to report financial distress.³⁹ Breast cancer patients who had recurrent disease have been found with worse financial decline than breast cancer patients with no recurrence, while no significant association with stage has been found.⁴⁰ Recurrent cancer has been reported as a risk factor for financial toxicity among brain cancer patients.⁴¹ A study in South Korea found that thyroid cancer patients had OOP costs three times higher than breast cancer patients.⁴² Another study, meanwhile, did not find significant associations for disease severity or cancer stage among head and neck cancer patients.⁴³

Discussion Statement 2B

A significant association was found for surgery for advanced lung, breast, colorectal, or prostate cancer and financial toxicity in France and the US³⁵. Focusing on prostate cancer treatment, radical prostatectomy and current androgen deprivation therapy were associated with increased time and OOP cost in Canada,³³ while there were higher reported OOP costs for those who had radical prostatectomy compared to those who had watchful waiting or androgen deprivation therapy in Australia.²

Discussion Statement 2C

Two studies found a significant association of high OOP costs (>20% of income) with physical limitations,⁴⁴ and higher time and OOP costs for prostate cancer symptoms including low urinary and bowel function.³³ In addition to these studies, a systematic review found an association of financial toxicity with non-cancer comorbid conditions and functional physical and mental status.¹⁵ A financial toxicity indicator (using up savings due to cancer) was, meanwhile, found to be associated with indicators of physical and cognitive symptoms (i.e. high level of need for “dealing with feeling tired” and “coping with bad memory or lack of focus”).⁴⁵

A study on advanced cancer patients found that patients with financial distress were more likely to have higher depression scores and lower functional and social well-being, but not lower physical well-being.³⁵ In a similar study of advanced cancer patients in Italy financial distress was found to be associated with higher levels of anxiety and overall symptom burden.⁴⁶ One study examined the association of financial distress and physical symptoms in French advanced cancer patients and found that financial distress was associated with a higher symptom burden in the last 24 hours.³³

Among cancer survivors in the Netherlands, current financial difficulties due to cancer were associated in adjusted analysis with emotional, social and cognitive functioning, but not associated with survivorship symptoms such as fatigue, pain, nausea/vomiting etc.⁴⁷ Overall, while these studies found significant associations of financial toxicity with some measure of psychological and physical symptom burden, the cross-sectional study design or the timing of assessment of financial toxicity and symptoms, do not allow to ascertain whether these symptoms are risk factors or consequences of financial toxicity.

Discussion Statement 2D

A significant higher likelihood of financial difficulties in the past week was found for those who were 10 or more years post diagnosis compared to those who were 5-9 years post diagnosis.^{48,49} This result, however, was not consistent across age groups, but was significant in survivors who were 30-49 years old. If patients are not able to work and since replacement income, such as sickness pay is limited in time, they suffer from loss of income. Meanwhile, among 387 gynecologic cancer patients in Germany followed up to 12 years post diagnosis, the likelihood of financial difficulties in the past week due to

disease or treatment was found lower at 3 years post-diagnosis compared to one year post diagnosis or compared to 5 or more years post diagnosis.⁵⁰ Finally, costs of cancer care, and consequently OOP costs, increase again at end of life, i.e. in the year before death.⁵¹ Therefore, financial toxicity may be high at this time as well as closer to diagnosis.

Discussion Statement 3A

A review of the literature on OOP payments per patient and their caregivers found that the average monthly OOP costs in 2018 US dollar (USD) in the US were up to 12 times more than those in Canada, 45 times than those Western Europe, and 6 times than in Australia.⁵² The average monthly OOP costs per patient in terms of transportation and caregiver costs, however, was found to be three times higher in Canada, Australia and Western Europe compared to the US. In low and middle-income countries (covering China, Malaysia, India, Haiti, Brunei, Thailand, Indonesia, Philippines, Vietnam, Laos, Cambodia, and Myanmar) OOP expenditures have been estimated to account for over 40% of annual incomes on average.⁵² In contrast, in high-income countries (such as the US, Canada, and Australia) OOP costs account for less than 20% of annual incomes income on average.^{53,54} This discrepancy may be due to the lack of comprehensive health insurance coverage for cancer treatments, or the limited inclusion of cancer interventions in publicly-funded, assured benefit packages.

Discussion Statement 3B

In some publicly-funded systems, including partially funded ones such as the Medicare and Medicaid in the United States, there is substantial OOP to cover prescription drugs and outpatient and inpatient services alone.⁵⁵ Although supplementary private health insurance may provide additional financial risk protection for OOP, it should be noted that premium payments may be high since they are risk-based.⁵⁶ Consequently, in spite of health insurance, the patient may be underinsured, and thus, forgo treatment. A recent study found that 28.3% of patients with cancer, despite having Medicare coverage did not fill their prescriptions for specialty drugs.⁵⁷ In these publicly-funded health systems, social welfare benefits are important to manage financial toxicity. Finally, in low and middle-income countries (LMICs), publicly funded healthcare is limited and tied with significant OOP, thereby exposing patients with cancer to high financial toxicity.^{52,53}

Discussion Statement 3C

A study in the US has shown that wealthier and more educated patients may travel longer distances to specialized cancer centers but have less financial toxicity possibly because of better social or economic resources of patients.⁴ In addition, there is some, limited, evidence that rural patients are more likely to forego treatment due to costs.⁵⁸ The link between SES (discussed in Question 4) and location of residence needs to be studied in detail, given insights into the associations of social deprivation (via area deprivation indices) and health outcomes.⁵⁹

WP2: Management of financial toxicity during the initial phase of treatment at the hospital/ambulatory settings

Discussion Statement 4

In addition to being a simple screening tool, an advantage of using instruments developed to measure QoL is that they also lend themselves to being acted on in real time. An example is the secondary analysis of 16 prospective trials performed in Italy showing that financial toxicity was reported by around one-fourth of 3670 patients and was associated with worse survival and QoL outcomes.⁶⁰ The disadvantage of having one or few items measuring financial toxicity, however, is the limited capacity to graduate financial toxicity and to understand its determinants and, therefore, the inability to plan actions to contrast financial toxicity and its negative effects on patients' outcome.

If only one question is used a number of patients at risk to experience financial toxicity might be overlooked. Thus, even for the purpose of rapid screening for financial toxicity, a short set of questions may be warranted. Research to develop a short, comprehensive and validated screening tool should be supported which may build upon the instruments developed for financial toxicity, namely, COST (comprehensive score for financial toxicity), (patient-reported outcome for fighting financial toxicity) PROFFIT and (subjective financial distress questionnaire) SFDQ.

COST is the most widely-used instrument globally, which was developed in the USA where high co-payments for treatment are observed, and its particular the organization of cancer care and drug approval environment.^{61,62} A different scenario may apply in Europe where most of the health systems provide cancer care with no (or modest) direct cost for patients. This consideration seems to be supported by the fact that items measuring material conditions (that may be considered as determinants of financial toxicity) are more represented in the PROFFIT instrument developed within the Italian public health system than in the COST instrument notwithstanding a strong similarity in methodology applied in developing both instruments, including participation of patients and caregivers within focus groups.^{63,64} Consistently, only three of the 14 items of the Subjective Financial Distress Questionnaire (SFDQ) questionnaire developed in India fall within the psychological domain, all the other items being substantially based on material causes.⁶⁵

Whether the instrument was developed to measure QoL or financial toxicity specifically, taking a PROMs format implies that psychometric properties should be tested and validated; this matter has been described in detail by Zhu et al.⁶⁶ Finally, it may be worth considering that tools measuring financial toxicity should also be made available in electronic formats, as is happening for most of the available PROMs.⁶⁷

Discussion Statement 5

Appropriateness of the diagnostic process is a crucial element in containing costs. "Physicians have a societal responsibility to provide care that minimizes waste and is evidence based".⁶⁸ The diagnostic process is optimized when the whole diagnostic team is involved, and patients are offered a navigation system into services. When they are left alone in seeking referrals and planning times are longer, the quality of examinations is not optimal and costs are increased due to redundancy of examinations and wasted resources.

Discussion Statement 6

There is now robust evidence from multiple large clinical trials that early palliative care improves QoL, reduces depression, and improves satisfaction with care. Early palliative care also reduces the use of chemotherapy near end of life, inpatient admissions and more broadly, health resources.⁶⁹ The American Society of Clinical Oncology (ASCO) recommends that all advanced cancer patients be seen by a multidisciplinary palliative care team within eight weeks of diagnosis.⁷⁰ The impact of this strategy on patient level financial burden needs to be studied systematically.

Discussion Statement 7

It is advisable that the physician responsible for the medical treatment of a specific cancer patient delegates the assessment of patient's financial situation and management of the financial challenges to a professional. Social workers as well as other professionals trained in financial navigation currently facilitate increased patient access to care and assist with OOP expenses.⁷¹ These processes should be included in the national and hospital-based treatment protocols. Receiving financial assistance during the initial treatment improves QoL of cancer patients and makes them feel more in control of financial decision-making.⁷² A few promising studies have been carried out that developed educational intervention tools for emotional, instrumental, and informational support of patients suffering from financial distress for use in the clinical setting.^{28,73}

WP3: Financial toxicity during the continuing phase and during end-of-life

Discussion Statement 8

Individual financial exposure is dependent on the health care system and the availability, or not, of a national insurance program covering the OOP cost of anti-cancer therapies and associated genomic testing.^{74,75} Even in countries with national insurance, health technology assessment (HTA) requirements and processes determine coverage for medicines leaving others, uncovered and available only if purchased privately or if the patient has some form of additional insurance.^{76,77} In addition to limited coverage the requirement for co-payment, in some countries, expose many patients to financial toxicity for OOP expenses.⁷⁹

Discussion Statement 9

Management strategies need to address both the objective financial burden and the subjective financial distress.⁵³ Since financial distress contributes to anxiety and depression,⁷⁸ patients and their family members may need augmented psychological support.^{79,80} Different therapeutic approaches may be required for financial worry (which is often associated with anxiety) as distinct from financial rumination which is more closely associated with depression.⁸¹

WP4: Financial risk protection for survivors of cancer, and in cancer recurrence

Discussion Statement 10

The European Academy of Cancer Sciences,⁸² working through its Survivorship Subgroup has highlighted the dearth of research studies that specifically address the needs of cancer survivors and has proposed the creation of a European Cancer Survivorship Research and Innovation Plan⁸³ that would be embedded within the EU Cancer Mission. This Plan has three pillars – the Medical Cancer Survivorship Research and Innovation Pillar, the Socio-Economic Cancer Survivorship Research and Innovation Pillar and the Politico-Legal Cancer Survivorship Research and Innovation Pillar.⁸⁴ Financial challenges and toxicities are specifically addressed within the Socio-Economic and Politico-Legal Pillars.

Financial challenges can adversely impact on (quality of life) QoL and survival of those living beyond cancer, their families and their caregivers.^{40,78,85,86,87,88} Periodic assessment of financial challenges at multiple time points during the cancer continuum is crucial.⁸⁹ More research is needed to select the best measure for assessing financial hardship in all its facets and develop an easy-to-integrate “tool” for routine practice. Systematic evaluation of financial challenges should be part of comprehensive patient-reported outcomes assessments to identify cancer survivors and families most vulnerable to long-term financial hardship and in need targeted support. Clinical care pathways and provider, clinic, and/or system-level strategies must also be developed to connect at-risk patients identified during assessment with appropriate resources to address their specific challenges. Unintended patient-level economic consequences of germline testing, or of hereditary cancer syndrome diagnosis should be considered during therapeutic decision-making to recommend risk-reducing strategies, including providing financial assistance to patients at high risk of bankruptcy.

Discussion Statement 11

France pioneered addressing potential financial discrimination against cancer survivors by introducing Right to be Forgotten (RTBF).⁹⁰ This ensures long-term cancer survivors are not discriminated against or penalized when accessing financial services such as loans and mortgages. In addition to France, Belgium, the Netherlands, Portugal, Romania and Spain have enacted the RTBF legal framework.^{91,92,93} Four other EU countries are working on similar legal frameworks to mitigate financial discrimination for cancer survivors.⁹³

By protecting long-term cancer survivors from financial discrimination, the RTBF empowers them to return to their professional activities and reintegrate into social and economic life. Healthcare providers, especially oncologists, must promptly inform patients about potential financial discrimination risks and guide them on utilizing the RTBF. Many European healthcare professionals are currently unaware of this issue, necessitating awareness efforts within the medical community.

The RTBF has been prioritized for implementation within the European Beating Cancer Plan⁹⁴ and the EU Cancer Mission.⁹⁵ An exploratory study commissioned by Directorate-General for Health and Food Safety (DG SANTE) on the access to financial products for persons with a history of cancer in EU Member States found that most Member States and key stakeholders are positive about further exploration of EU-level action supporting access to financial products for cancer survivors.

The RTBF for cancer survivors was integrated into the EU’s Consumer Credit Directive approved in September 2023. The Directive states: “(41a) Because of their medical history, many cancer survivors in

long-term remission often experience an unfair treatment in accessing to financial services. They often face prohibitively high premiums, although they have been cured for many years, even decades. For the purpose of giving consumers who survived cancer equal access to insurance related to credit agreements, Member States should require that the insurance policies are not based on health data of consumers after a relevant period of time following the end of the consumer's medical treatment. Such period of time determined by the Member States may not exceed a period of 15 years counting from the end of the medical treatment of the consumer.”⁹⁶

The (RTBF) entitles cancer survivors deemed "cured" by oncologists to lead normal lives without discrimination based on past cancer diagnoses. Regarding financial discrimination, the RTBF advocates disregarding oncological history by insurance companies and banks after a specified duration following the completion of treatment, reflecting survivors' health status post-treatment health status. This approach asserts that, beyond a defined post-treatment period, cancer survivors no longer pose heightened risks to financial institutions, justifying the oversight of their cancer history. This facilitates financial assessments aligning with their current health status during service applications.

Jurisdiction-specific RTBF laws and regulations vary. In countries like France, the Netherlands, Portugal, Romania, and Spain, survivors are generally exempt from disclosing their cancer history after 5 to 10 years post-treatment and in the absence of relapse. In Belgium, disclosure is mandatory, but legal provisions prevent its use to deny services or impose special conditions.⁸⁷ Unlike General Data Protection Regulation (GDPR) application, the RTBF in cancer emphasizes disregarding rather than deleting data. Balancing the RTBF in cancer with accurate medical records for healthcare providers and researchers, who depend on comprehensive histories for care and research, is crucial.

Discussion Statement 12

England's National Cancer Survivorship Initiative model focuses on developing risk-stratified pathways of care, employing treatment summaries and care plans, supporting efforts to improve self-management, ensuring extensive ambulatory care – in some cases but not all, empowering remote monitoring etc. with the goal of improving survivorship experiences, while using health-care services efficiently.⁹⁷ This survivor-centred approach could have positive implications for addressing financial challenges in those living beyond cancer.

References

- 1 Curigliano G, Banerjee S, Cervantes A, et al. Managing cancer patients during the COVID-19 pandemic: an ESMO multidisciplinary expert consensus. *Ann Oncol*. 2020;31(10):1320-1335. doi:10.1016/j.annonc.2020.07.010.
- 2 Diamond IR, Grant RC, Feldman BM, et al. Defining consensus: a systematic review recommends methodologic criteria for reporting of Delphi studies. *J Clin Epidemiol*. 2014;67(4):401-409. doi:10.1016/j.jclinepi.2013.12.002.
- 3 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):2224-2229. doi:10.1093/annonc/mdw433.
- 4 Gordon LG, Merollini KMD, Lowe A, Chan RJ. A Systematic Review of Financial Toxicity Among Cancer Survivors: We Can't Pay the Co-Pay. *Patient*. 2017;10(3):295-309. doi:10.1007/s40271-016-0204-x.
- 5 Ripamonti CI, Chiesi F, Di Pede P, et al. The validation of the Italian version of the COmprehensive Score for financial Toxicity (COST). *Support Care Cancer*. 2020;28(9):4477-4485. doi:10.1007/s00520-019-05286-y.
- 6 Voleti SS, Warsame R, Mead-Harvey C, et al. Assessing Patient-Reported Financial Hardship in Patients With Cancer in Routine Clinical Care. *JCO Oncol Pract*. 2022;18(11):e1839-e1853. doi:10.1200/OP.22.00276.
- 7 Choi JW, Cho KH, Choi Y, Han KT, Kwon JA, Park EC. Changes in economic status of households associated with catastrophic health expenditures for cancer in South Korea. *Asian Pac J Cancer Prev*. 2014;15(6):2713-2717. doi:10.7314/apjcp.2014.15.6.2713.
- 8 Zhao T, Cheng J, Chai J, et al. Inpatient care burden due to cancers in Anhui, China: a cross-sectional household survey. *BMC Public Health*. 2016;16:308. doi:10.1186/s12889-016-2995-z.
- 9 Chan R, Cooper B, Paul S, et al. Distinct financial distress profiles in patients with breast cancer prior to and for 12 months following surgery. *BMJ Support Palliat Care*. 2022;12(3):347-354. doi:10.1136/bmjspcare-2020-002461.
- 10 Doshmangir L, Hasanpoor E, Abou Jaoude GJ, Eshtiagh B, Haghparast-Bidgoli H. Incidence of Catastrophic Health Expenditure and Its Determinants in Cancer Patients: A Systematic Review and Meta-analysis [published correction appears in *Appl Health Econ Health Policy*. 2021 Oct 7;:]. *Appl Health Econ Health Policy*. 2021;19(6):839-855. doi:10.1007/s40258-021-00672-2.
- 11 Mols F, Tomalin B, Pearce A, Kaambwa B, Koczwara B. Financial toxicity and employment status in cancer survivors. A systematic literature review. *Support Care Cancer*. 2020;28(12):5693-5708. doi:10.1007/s00520-020-05719-z.
- 12 Smith GL, Lopez-Olivo MA, Advani PG, et al. Financial Burdens of Cancer Treatment: A Systematic Review of Risk Factors and Outcomes. *J Natl Compr Canc Netw*. 2019;17(10):1184-1192. doi:10.6004/jnccn.2019.7305.
- 13 Bygrave A, Whittaker K, Paul C, Fradgley EA, Varlow M, Aranda S. Australian Experiences of Out-of-Pocket Costs and Financial Burden Following a Cancer Diagnosis: A Systematic Review. *Int J Environ Res Public Health*. 2021;18(5):2422. doi:10.3390/ijerph18052422.
- 14 Pauge S, Surmann B, Mehlis K, et al. Patient-Reported Financial Distress in Cancer: A Systematic Review of Risk Factors in Universal Healthcare Systems. *Cancers (Basel)*. 2021;13(19):5015. doi:10.3390/cancers13195015.

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- 15 Yabroff KR, Dowling EC, Guy GP Jr, et al. Financial Hardship Associated With Cancer in the United States: Findings From a Population-Based Sample of Adult Cancer Survivors. *J Clin Oncol*. 2016;34(3):259-267. doi:10.1200/JCO.2015.62.0468.
 - 16 Jagsi R, Pottow JA, Griffith KA, et al. Long-term financial burden of breast cancer: experiences of a diverse cohort of survivors identified through population-based registries. *J Clin Oncol*. 2014;32(12):1269-1276. doi:10.1200/JCO.2013.53.0956.
 - 17 Zhu Z, Xing W, Zhang X, Hu Y, So WKW. Cancer survivors' experiences with financial toxicity: A systematic review and meta-synthesis of qualitative studies. *Psychooncology*. 2020;29(6):945-959. doi:10.1002/pon.5361.
 - 18 Hanly P, Maguire R, Ceilleachair AO, Sharp L. Financial hardship associated with colorectal cancer survivorship: The role of asset depletion and debt accumulation. *Psychooncology*. 2018;27(9):2165-2171. doi:10.1002/pon.4786.
 - 19 Lu L, O'Sullivan E, Sharp L. Cancer-related financial hardship among head and neck cancer survivors: Risk factors and associations with health-related quality of life. *Psychooncology*. 2019;28(4):863-871. doi:10.1002/pon.5034.
 - 20 Sharp L, Timmons A. Pre-diagnosis employment status and financial circumstances predict cancer-related financial stress and strain among breast and prostate cancer survivors. *Support Care Cancer*. 2016;24(2):699-709. doi:10.1007/s00520-015-2832-4.
 - 21 Udayakumar S, Solomon E, Isaranuwachai W, et al. Cancer treatment-related financial toxicity experienced by patients in low- and middle-income countries: a scoping review. *Support Care Cancer*. 2022;30(8):6463-6471. doi:10.1007/s00520-022-06952-4.
 - 22 Fitch MI, Sharp L, Hanly P, Longo CJ. Experiencing financial toxicity associated with cancer in publicly funded healthcare systems: a systematic review of qualitative studies. *J Cancer Surviv*. 2022;16(2):314-328. doi:10.1007/s11764-021-01025-7.
 - 23 Torp S, Paraponaris A, Van Hoof E, et al. Work-Related Outcomes in Self-Employed Cancer Survivors: A European Multi-country Study. *J Occup Rehabil*. 2019;29(2):361-374. doi:10.1007/s10926-018-9792-8.
 - 24 McGrath P. "It's horrendous--but really, what can you do?" Preliminary findings on financial impact of relocation for specialist treatment. *Aust Health Rev*. 2000;23(3):94-103. doi:10.1071/ah000094.
 - 25 Céilleachair AÓ, Costello L, Finn C, et al. Inter-relationships between the economic and emotional consequences of colorectal cancer for patients and their families: a qualitative study. *BMC Gastroenterol*. 2012;12:62. doi:10.1186/1471-230X-12-62.
 - 26 Timmons A, Gooberman-Hill R, Sharp L. "It's at a time in your life when you are most vulnerable": a qualitative exploration of the financial impact of a cancer diagnosis and implications for financial protection in health. *PLoS One*. 2013;8(11):e77549. doi:10.1371/journal.pone.0077549.
 - 27 Moffatt S, Noble E, Exley C. "Done more for me in a fortnight than anybody done in all me life." How welfare rights advice can help people with cancer. *BMC Health Serv Res*. 2010;10:259. doi:10.1186/1472-6963-10-259.
 - 28 Khera N, Kumbamu A, Langer SL, et al. Developing an Educational Intervention to Address Financial Hardship in Cancer Patients. *Mayo Clin Proc Innov Qual Outcomes*. 2020;4(4):424-433. doi:10.1016/j.mayocpiqo.2020.04.004.

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- 29 Honda K, Gyawali B, Ando M, et al. Prospective Survey of Financial Toxicity Measured by the Comprehensive Score for Financial Toxicity in Japanese Patients With Cancer. *J Glob Oncol*. 2019;5:1-8. doi:10.1200/JGO.19.00003.
 - 30 Barbaret C, Delgado-Guay MO, Sanchez S, et al. Inequalities in Financial Distress, Symptoms, and Quality of Life Among Patients with Advanced Cancer in France and the U.S. *Oncologist*. 2019;24(8):1121-1127. doi:10.1634/theoncologist.2018-0353.
 - 31 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):980-986. doi:10.1200/JCO.2015.64.6620.
 - 32 ACTION Study Group, Kimman M, Jan S, et al. Catastrophic health expenditure and 12-month mortality associated with cancer in Southeast Asia: results from a longitudinal study in eight countries. *BMC Med*. 2015;13:190. doi:10.1186/s12916-015-0433-1.
 - 33 de Oliveira C, Bremner KE, Ni A, Alibhai SM, Laporte A, Krahn MD. Patient time and out-of-pocket costs for long-term prostate cancer survivors in Ontario, Canada. *J Cancer Surviv*. 2014;8(1):9-20. doi:10.1007/s11764-013-0305-7.
 - 34 Boby JM, Rajappa S, Mathew A. Financial toxicity in cancer care in India: a systematic review. *Lancet Oncol*. 2021;22(12):e541-e549. doi:10.1016/S1470-2045(21)00468-X.
 - 35 Mohan L, Arya A, Pandey KC, et al. An Observational Analysis of Financial Toxicity Inflicted on Patients and Their Family in Cancer Treatment: A Study From the Kumaon Region of India. *Asian Journal of Medical Research*. 2018; 7(2):MC04-MC06. <https://ajjournals.com/index.php/ajmr/article/view/>.
 - 36 Jain M, Mukherjee K. Economic burden of breast cancer to the households in Punjab, India. *International Journal of Medicine and Public Health*. 2016;6(1):13-8. doi:10.4103/2230-8598.179754.
 - 37 Goyal S, Tiwari VK, Nair KS, Raj S. Risk factors and costs of oral cancer in a tertiary care hospital in Delhi. *Asian Pac J Cancer Prev*. 2014;15(4):1659-1665. doi:10.7314/apjcp.2014.15.4.1659
 - 38 Wheeler SB, Spencer JC, Pinheiro LC, Carey LA, Olshan AF, Reeder-Hayes KE. Financial Impact of Breast Cancer in Black Versus White Women. *J Clin Oncol*. 2018;36(17):1695-1701. doi:10.1200/JCO.2017.77.6310.
 - 39 Barbaret C, Brosse C, Rhondali W, et al. Financial distress in patients with advanced cancer. *PLoS One*. 2017;12(5):e0176470. doi:10.1371/journal.pone.0176470.
 - 40 Jaggi R, Pottow JA, Griffith KA, et al. Long-term financial burden of breast cancer: experiences of a diverse cohort of survivors identified through population-based registries. *J Clin Oncol*. 2014;32(12):1269-1276. doi:10.1200/JCO.2013.53.0956.
 - 41 Kalra D, Menon N, Singh G, et al. Financial toxicities in patients receiving systemic therapy for brain tumors: A cross-sectional study. *Ann Oncol*. 2020;3(4):724-9. doi: 10.4103/crst.Crst_265_20.
 - 42 You CH, Kang S, Kwon YD, Choi JH. Time trend of out-of-pocket expenditure among cancer inpatients: evidence from Korean tertiary hospitals. *Asian Pac J Cancer Prev*. 2013;14(11):6985-6989. doi:10.7314/apjcp.2013.14.11.6985.
 - 43 Chauhan AS, Prinja S, Ghoshal S, Verma R. Economic Burden of Head and Neck Cancer Treatment in North India. *Asian Pac J Cancer Prev*. 2019;20(2):403-409. doi:10.31557/APJCP.2019.20.2.403.
 - 44 Davidoff AJ, Erten M, Shaffer T, et al. Out-of-pocket health care expenditure burden for Medicare beneficiaries with cancer. *Cancer*. 2013;119(6):1257-1265. doi:10.1002/cncr.27848.

-
- 45 Hall AE, Sanson-Fisher RW, Lynagh MC, Tzelepis F, D'Este C. What do haematological cancer survivors want help with? A cross-sectional investigation of unmet supportive care needs. *BMC Res Notes*. 2015;8:221. doi:10.1186/s13104-015-1188-7.
 - 46 Mercadante S, Aielli F, Adile C, Bonanno G, Casuccio A. Financial distress and its impact on symptom expression in advanced cancer patients. *Support Care Cancer*. 2021;29(1):485-490. doi:10.1007/s00520-020-05507-9.
 - 47 Pearce A, Tomalin B, Kaambwa B, et al. Financial toxicity is more than costs of care: the relationship between employment and financial toxicity in long-term cancer survivors. *J Cancer Surviv*. 2019;13(1):10-20. doi:10.1007/s11764-018-0723-7.
 - 48 Arndt V, Koch-Gallenkamp L, Jansen L, et al. Quality of life in long-term and very long-term cancer survivors versus population controls in Germany. *Acta Oncol*. 2017;56(2):190-197. doi:10.1080/0284186X.2016.1266089.
 - 49 Doege D, Thong MS, Koch-Gallenkamp L, et al. Health-related quality of life in long-term disease-free breast cancer survivors versus female population controls in Germany. *Breast Cancer Res Treat*. 2019;175(2):499-510. doi:10.1007/s10549-019-05188-x.
 - 50 Koch L, Jansen L, Herrmann A, et al. Quality of life in long-term breast cancer survivors - a 10-year longitudinal population-based study. *Acta Oncol*. 2013;52(6):1119-1128. doi:10.3109/0284186X.2013.774461.
 - 51 Yabroff KR, Mariotto A, Tangka F, et al. Annual Report to the Nation on the Status of Cancer, Part 2: Patient Economic Burden Associated With Cancer Care. *J Natl Cancer Inst*. 2021;113(12):1670-1682. doi:10.1093/jnci/djab192.
 - 52 Irigorri N, de Oliveira C, Fitzgerald N, Essue B. The Out-of-Pocket Cost Burden of Cancer Care-A Systematic Literature Review. *Curr Oncol*. 2021;28(2):1216-1248. doi:10.3390/curroncol28020117.
 - 53 Donkor A, Atuwu-Ampoh VD, Yakanu F, et al. Financial toxicity of cancer care in low- and middle-income countries: a systematic review and meta-analysis. *Support Care Cancer*. 2022;30(9):7159-7190. doi:10.1007/s00520-022-07044-z.
 - 54 Coumoundouros C, Ould Brahim L, Lambert SD, McCusker J. The direct and indirect financial costs of informal cancer care: A scoping review. *Health Soc Care Community*. 2019 Sep;27(5):e622-e636. doi: 10.1111/hsc.12808.
 - 55 Baird K. High Out-of-Pocket Medical Spending among the Poor and Elderly in Nine Developed Countries. *Health Serv Res*. 2016;51(4):1467-1488. doi:10.1111/1475-6773.12444.
 - 56 Carrera PM, Kantarjian HM, Blinder VS. The financial burden and distress of patients with cancer: Understanding and stepping-up action on the financial toxicity of cancer treatment. *CA Cancer J Clin*. 2018;68(2):153-165. doi:10.3322/caac.21443.
 - 57 Dusetzina SB, Huskamp HA, Rothman RL, et al. Many Medicare Beneficiaries Do Not Fill High-Price Specialty Drug Prescriptions. *Health Aff (Millwood)*. 2022;41(4):487-496. doi:10.1377/hlthaff.2021.01742.
 - 58 Palmer NR, Geiger AM, Lu L, Case LD, Weaver KE. Impact of rural residence on forgoing healthcare after cancer because of cost. *Cancer Epidemiol Biomarkers Prev*. 2013;22(10):1668-1676. doi:10.1158/1055-9965.EPI-13-0421.
 - 59 Singh GK. Area deprivation and widening inequalities in US mortality, 1969-1998. *Am J Public Health*. 2003;93(7):1137-1143. doi:10.2105/ajph.93.7.1137.

-
- 60 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):2224-2229. doi:10.1093/annonc/mdw433.
- 61 de Souza JA, Yap BJ, Wroblewski K, et al. Measuring financial toxicity as a clinically relevant patient-reported outcome: The validation of the COmprehensive Score for financial Toxicity (COST). *Cancer*. 2017;123(3):476-484. doi:10.1002/cncr.30369.
- 62 de Souza JA, Yap BJ, Hlubocky FJ, et al. The development of a financial toxicity patient-reported outcome in cancer: The COST measure. *Cancer*. 2014;120(20):3245-3253. doi:10.1002/cncr.28814
- 63 Riva S, Arenare L, Di Maio M, et al. Cross-sectional study to develop and describe psychometric characteristics of a patient-reported instrument (PROFFIT) for measuring financial toxicity of cancer within a public healthcare system. *BMJ Open*. 2021;11(10):e049128. doi:10.1136/bmjopen-2021-049128.
- 64 Riva S, Efficace F, Di Maio M, et al. A qualitative analysis and development of a conceptual model assessing financial toxicity in cancer patients accessing the universal healthcare system. *Support Care Cancer*. 2021;29(6):3219-3233. doi:10.1007/s00520-020-05840-z.
- 65 Dar MA, Chauhan R, Murti K, Trivedi V, Dhingra S. Development and Validation of Subjective Financial Distress Questionnaire (SFDQ): A Patient Reported Outcome Measure for Assessment of Financial Toxicity Among Radiation Oncology Patients. *Front Oncol*. 2022;11:819313. doi:10.3389/fonc.2021.819313.
- 66 Zhu Z, Xing W, Wen H, et al. Psychometric properties of self-reported financial toxicity measures in cancer survivors: a systematic review. *BMJ Open*. 2022;12(6):e057215. doi:10.1136/bmjopen-2021-057215.
- 67 Gordon S, Crager J, Howry C, et al. Best Practice Recommendations: User Acceptance Testing for Systems Designed to Collect Clinical Outcome Assessment Data Electronically. *Ther Innov Regul Sci*. 2022;56(3):442-453. doi:10.1007/s43441-021-00363-z.
- 68 Meropol NJ, Schrag D, Smith TJ, et al. American Society of Clinical Oncology guidance statement: the cost of cancer care. *J Clin Oncol*. 2009;27(23):3868-3874. doi:10.1200/JCO.2009.23.1183.
- 69 Jordan K, Aapro M, Kaasa S, et al. European Society for Medical Oncology (ESMO) position paper on supportive and palliative care. *Annals Oncol*. 2018;29: 36–43. doi:10.1093/annonc/mdx757
- 70 Ferrell BR, Temel JS, Temin S, et al. Integration of Palliative Care Into Standard Oncology Care: American Society of Clinical Oncology Clinical Practice Guideline Update. *J Clin Oncol*. 2017;35(1):96-112. doi:10.1200/JCO.2016.70.1474.
- 71 Yezefski T, Steelquist J, Watabayashi K, Sherman D, Shankaran V. Impact of trained oncology financial navigators on patient out-of-pocket spending. *Am J Manag Care*. 2018;24(5 Suppl):S74-S79.
- 72 Semin JN, Palm D, Smith LM, Ruttle S. Understanding breast cancer survivors' financial burden and distress after financial assistance. *Support Care Cancer*. 2020;28(9):4241–4248. doi:10.1007/s00520-019-05271-5.
- 73 Shankaran V, Leahy T, Steelquist J, et al. Pilot Feasibility Study of an Oncology Financial Navigation Program. *J Oncol Pract*. 2018;14(2):e122-e129. doi:10.1200/JOP.2017.024927
- 74 Fitch MI, Sharp L, Hanly P, Longo CJ. Experiencing financial toxicity associated with cancer in publicly funded healthcare systems: a systematic review of qualitative studies. *J Cancer Surviv*. 2022;16(2):314-328. doi:10.1007/s11764-021-01025-7.

-
- 75 Carrera P, Yousuf Zafar, S. Financial Toxicity. In I Olver, ed., *The MASCC Textbook of Cancer Supportive Care and Survivorship*. Cham, Switzerland: Springer International Publishing; 2018. p127-143.
- 76 Ezeife DA, Morganstein BJ, Lau S, et al. Financial Burden Among Patients With Lung Cancer in a Publically Funded Health Care System. *Clin Lung Cancer*. 2019;20(4):231-236. doi:10.1016/j.clcc.2018.12.010.
- 77 Tur-Sinai A, Urban D, Azoulay D, Bar-Sela G, Bentur N. Understanding out-of-pocket spending and financial hardship among patients who succumb to cancer and their caregivers. *Isr J Health Policy Res*. 2022;11(1):1. doi:10.1186/s13584-021-00511-8.
- 78 Sharp L, Carsin A-E, Timmons A. Associations between cancer-related financial stress and strain and psychological well-being among individuals living with cancer. *Psychooncology*. 2013;22(4):745-755.
- 79 Patel MR, Jagsi R, Resnicow K, et al. A Scoping Review of Behavioral Interventions Addressing Medical Financial Hardship. *Popul Health Manag*. 2021;24(6):710-721. doi:10.1089/pop.2021.0043.
- 80 Jones SM, Henrikson NB, Panattoni L, Syrjala KL, Shankaran V. A theoretical model of financial burden after cancer diagnosis. *Future Oncology*. 2020. 16(36): 3095-3105. doi: 10.2217/fon-2020-0547.
- 81 Khera N, Zhang N, Hilal T, et al. Association of Health Insurance Literacy With Financial Hardship in Patients With Cancer. *JAMA Netw Open*. 2022;5(7):e2223141. doi:10.1001/jamanetworkopen.2022.23141.
- 82 European Cancer Academy. Available at <https://www.europeancanceracademy.eu/>. Accessed on 9 November 2023.
- 83 Lawler M, De Lorenzo F, Lagergren P, et al. Challenges and solutions to embed cancer survivorship research and innovation within the EU Cancer Mission. *Mol Oncol*. 2021;15(7):1750-1758. doi:10.1002/1878-0261.13022.
- 84 Altice CK, Banegas MP, Tucker-Seeley RD, Yabroff KR. Financial Hardships Experienced by Cancer Survivors: A Systematic Review. *J Natl Cancer Inst*. 2016;109(2):djw205. doi:10.1093/jnci/djw205.
- 85 Fenn KM, Evans SB, McCorkle R, et al. Impact of financial burden of cancer on survivors' quality of life. *J Oncol Pract*. 2014;10(5):332-338. doi:10.1200/JOP.2013.001322.
- 86 Sadigh G, Switchenko J, Weaver KE, et al. Correlates of financial toxicity in adult cancer patients and their informal caregivers. *Support Care Cancer*. 2022;30(1):217-225. doi:10.1007/s00520-021-06424-1.
- 87 Lai DWL. Effect of Financial Costs on Caregiving Burden of Family Caregivers of Older Adults. *SAGE Open*, 2012;2(4). doi.:10.1177/2158244012470467.
- 88 Kent EE, Forsythe LP, Yabroff KR, et al. Are survivors who report cancer-related financial problems more likely to forgo or delay medical care? *Cancer*. 2013;119(20):3710-3717.
- 89 Khera N, Holland JC, Griffin JM. Setting the stage for universal financial distress screening in routine cancer care. *Cancer*. 2017;123(21):4092-4096. doi:10.1002/cncr.30940
- 90 Scocca G, Meunier F. Towards an EU legislation on the right to be forgotten to access to financial services for cancer survivors. *Eur J Cancer*. 2022;162:133-137. doi:10.1016/j.ejca.2021.12.001

-
- 91 The Official Gazette of Romania, Part I no. 682 of July 8, 2022, Law no. 200/2022 for the completion of the Patient Rights Law no. 46/2003.
 - 92 Lawler M, Meunier F. Don't make cancer survivors pay twice-the right for them to be "forgotten" should be law everywhere. *BMJ*. 2022;378:o2197. doi:10.1136/bmj.o2197.
 - 93 Overview of legislation at the national level. <https://endingdiscrimination-cancersurvivors.eu/>. Accessed on 9 November 2023.
 - 94 Europe's Beating Cancer Plan. Available at: https://health.ec.europa.eu/system/files/2022-02/eu_cancer-plan_en_0.pdf. Accessed on 9 November 2023.
 - 95 EU Missions Cancer. Available at https://research-and-innovation.ec.europa.eu/system/files/2021-09/cancer_implementation_plan_for_publication_final_v2.pdf. Accessed on 9 November 2023.
 - 96 Proposal for a directive of the European Parliament and of the Council on consumer credits (COM/2021/347 final). – C9-0244/2021 – 2021/0171(COD)). Available at: https://www.europarl.europa.eu/meetdocs/2014_2019/plmrep/COMMITTEES/IMCO/AG/2023/05-22/1277771EN.pdf. Accessed on 9 November 2023.
 - 97 Jefford M, Rowland J, Grunfeld E, Richards M, Maher J, Glaser A. Implementing improved post-treatment care for cancer survivors in England, with reflections from Australia, Canada and the USA. *Br J Cancer*. 2013;108(1):14-20. doi:10.1038/bjc.2012.554.