The Socioeconomic Consequences of Cancer for Patients: Actions Needed and Feasible

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AT A GLANCE

BACKGROUND AND OBJECTIVES:

Even in countries providing universal health care, cancer patients and long-term survivors experience burdensome socioeconomic impacts (SEI), many of which are driven by out-of-pocket expenses and reduced earnings due to reduced or lost work capacity.[1,4,6,7] The SEI of cancer is associated with impaired quality of life, poorer clinical outcomes, and increased mortality. In 2021, a multi-stakeholder Task Force was inaugurated within the framework of the Health Economics Working Group of the Organisation of European Cancer Institutes (OECI), with the objective to produce actionable recommendations for research, clinical practice, and policy to address the SEI of cancer from the perspective of patients and their relatives.

METHODS:

Building on the OECI conceptual model of SEI (see right side), capturing the multi-dimensional nature of SEI, and informed by primary research, targeted literature reviews, and extensive deliberation, the Task Force is developing a consensus on actionable steps to address the SEI of cancer, an often overlooked consequence of the disease.

EMERGING RECOMMENDATIONS:

Recommendations will span research, clinical practice, and policy.
There is a need

- to better understand **determinants of vulnerability** to and severity of SEI,
- to overcome current **fragmentation of research** into SEI,
- and to establish **systematic recording** of SEI, beyond purely health-related patient-reported outcomes.

In routine health care,

- the currently **low awareness among providers** (including cancer specialists[7]) should be addressed,
- as well as the disintegration of responsibilities and **support systems**,
- and the **financial navigation of patients** should be improved;
- standard **screening** for financial and social distress should be integrated.

Consideration of SEI should be enhanced in

- **decision-making processes**,
- **official guidelines**,
- and **Health Technology Assessments**,

and patients – especially young adults – should be involved in policy making around these issues.

A «**right to be forgotten**», i.e., the right to live without discrimination due to a past cancer diagnosis, should be granted to long-term survivors.

CONCLUSIONS:

Immediate action is needed and feasible;[3,4,6,7] it should be accompanied by further research into prevalence, severity, and implementation effectiveness.

LITERATURE

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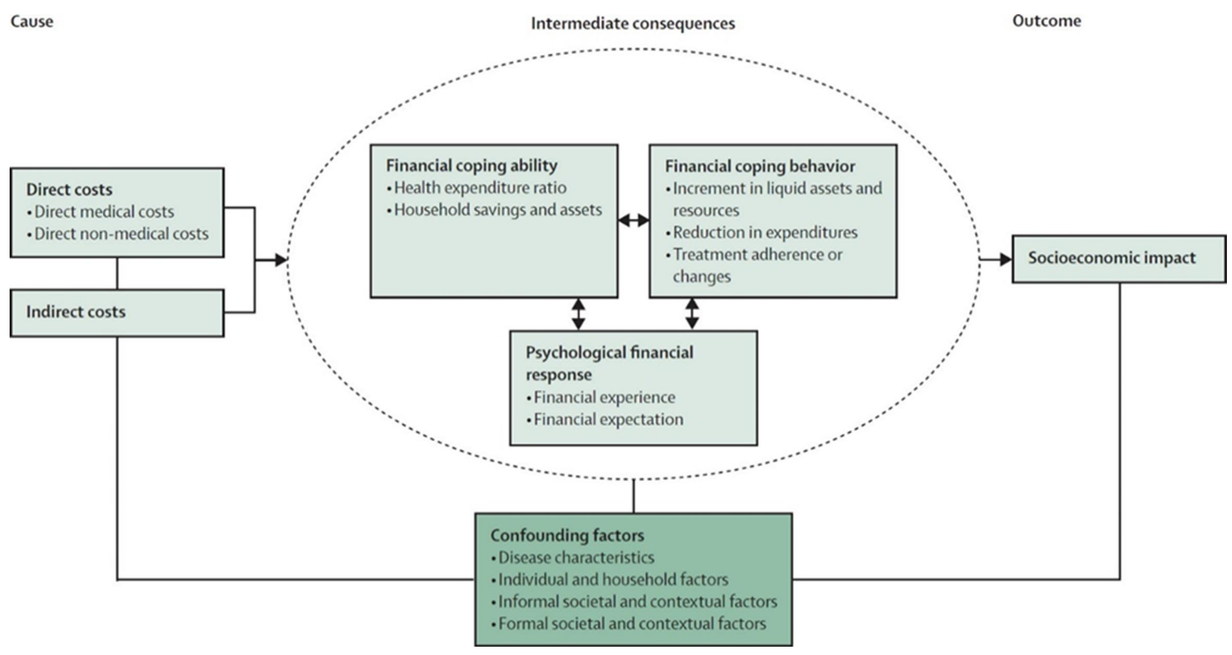
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CONCEPTUAL FRAMEWORK



OBSERVATIONS

WHO IS AFFECTED?

- Not all cancer patients are affected equally. Our research indicates that divorced, self-employed patients who are younger, lower educated, with a lower household income, or with dependents, especially school-age children, are among the most vulnerable groups.

HOW SEVERE IS IT?

- Income loss after a cancer diagnosis affects 51-66% of patients in Europe, with about 10% experiencing a monthly income loss exceeding 1,200 euros.[6] Most patients also face additional treatment-related expenses, with travel costs and co-payments being leading causes.
- Many cancer patients experience psychological distress, and decreased quality of life due to financial problems. Underutilization of medical services – in some cases including discontinuation of therapies – has been found to be associated with impaired clinical outcomes and higher mortality.[4]

TAKE-AWAYS

- **A serious and broadly underestimated problem**

The socioeconomic consequences of cancer are not a marginal issue; they are frequently severe and **extend beyond the patients themselves**, with a negative impact not only on household members, carers, and dependents, including children, but also affecting many long-term cancer survivors.

- **Addressing Inequalities**:

Out-of-pocket costs and income loss create financial burdens for cancer patients and families, highlighting the need to provide targeted support to vulnerable groups. The **European Union** and its member states need a coherent strategy to address this critical gap in their social support systems.

- **Research Priorities**:

A unified approach enhances research comparability, harmonizes terminology, and supports validated measurement tools. Future studies should **validate the framework and develop robust measurement instruments**[2-5] to guide clinical practice, support patients, and inform policy.

- **Next Steps**:

The Task Force is in the process of finalizing a **White Paper** with specific policy recommendations at the European level. The Task Force will be **open to partnering** with interested parties wishing to join the OECI initiative.

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