

«The **Socioeconomic Impact** of Cancer»

[«**Krebs und Armut**»]

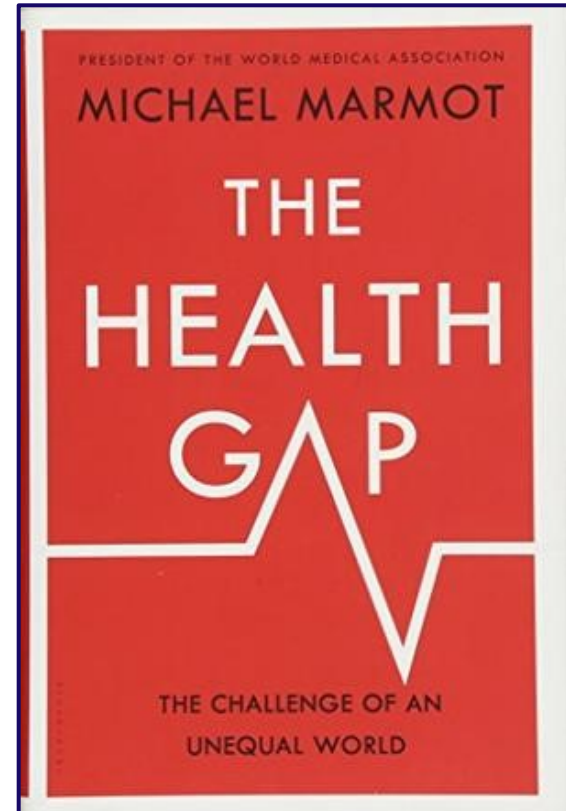
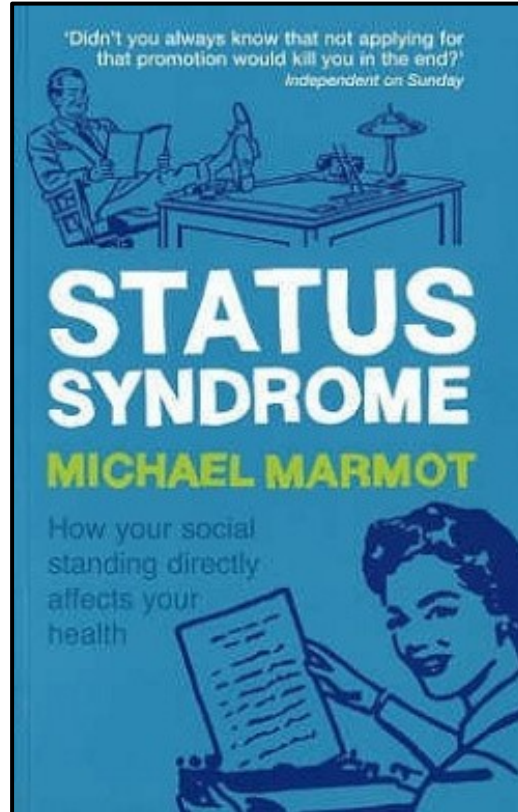
OECD Task Force
OECD SEC-Studie

Prof. **Michael Schlander**, MD, PhD, MBA

DKK 2024, Berlin, 21. – 24. Februar 2024

«Krebs und Armut»

Not Specific for Cancer: «A Cycle of Poverty»?



¹Sir Michael Marmot (*1945)

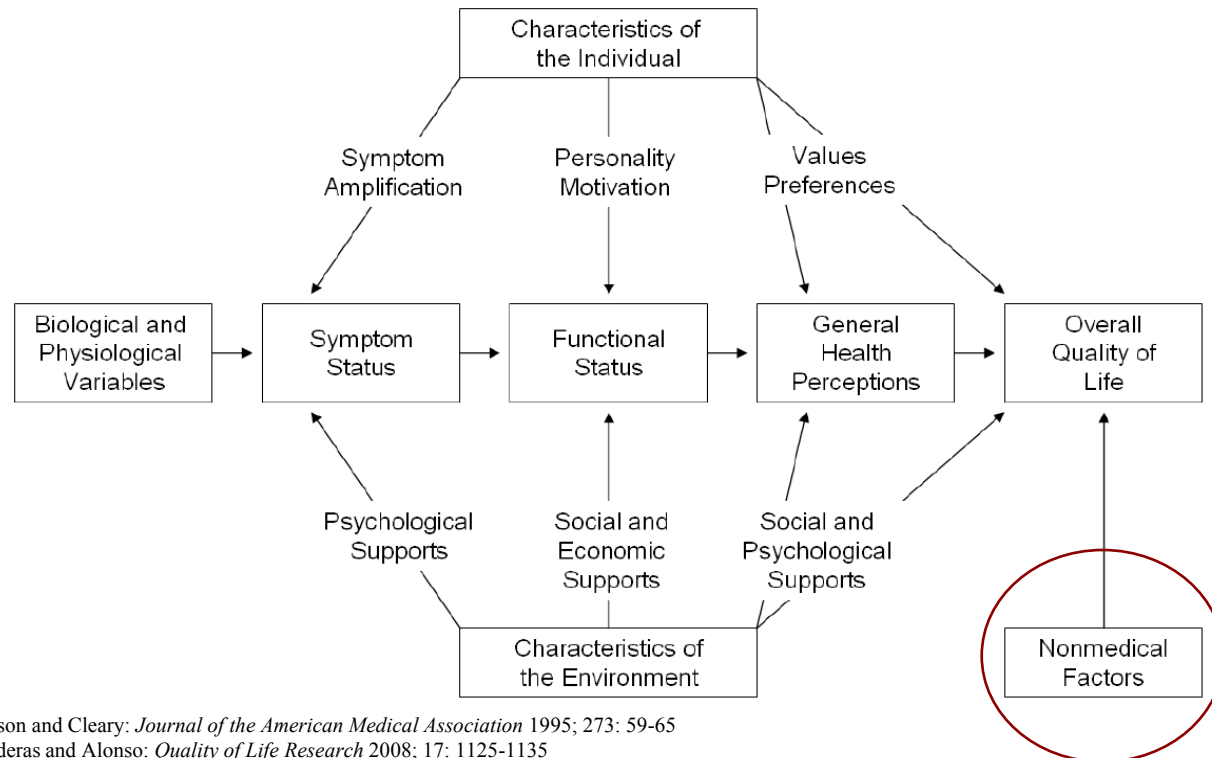
Professor of Epidemiology and Public Health at University College London (UCL)

«Krebs und Armut»

The Traditional Perspective on PROs

Wilson and Cleary (1995)¹

=> *far-reaching de facto exclusion of non-health-related outcomes*



¹Wilson and Cleary: *Journal of the American Medical Association* 1995; 273: 59-65

²Valderas and Alonso: *Quality of Life Research* 2008; 17: 1125-1135



«Financial Toxicity» & The Need for a Broader Definition

«Financial Toxicity»
is not a neutral term!

National Cancer Institute (NCI, up until Sept. 2022):

Problems a **patient** has related to the **cost of medical care** such as not having health insurance or having a lot of costs for medical care not covered by health insurance can cause financial problems and may lead to debt and bankruptcy.

Financial toxicity can also affect a patient's **quality of life** and access to medical care. For example, a patient may not take a prescription medicine or may avoid going to the doctor to save money.

1. adopting the perspective of patients
2. what about impact of / on household members and or relatives (caregivers, dependents, etc.)?

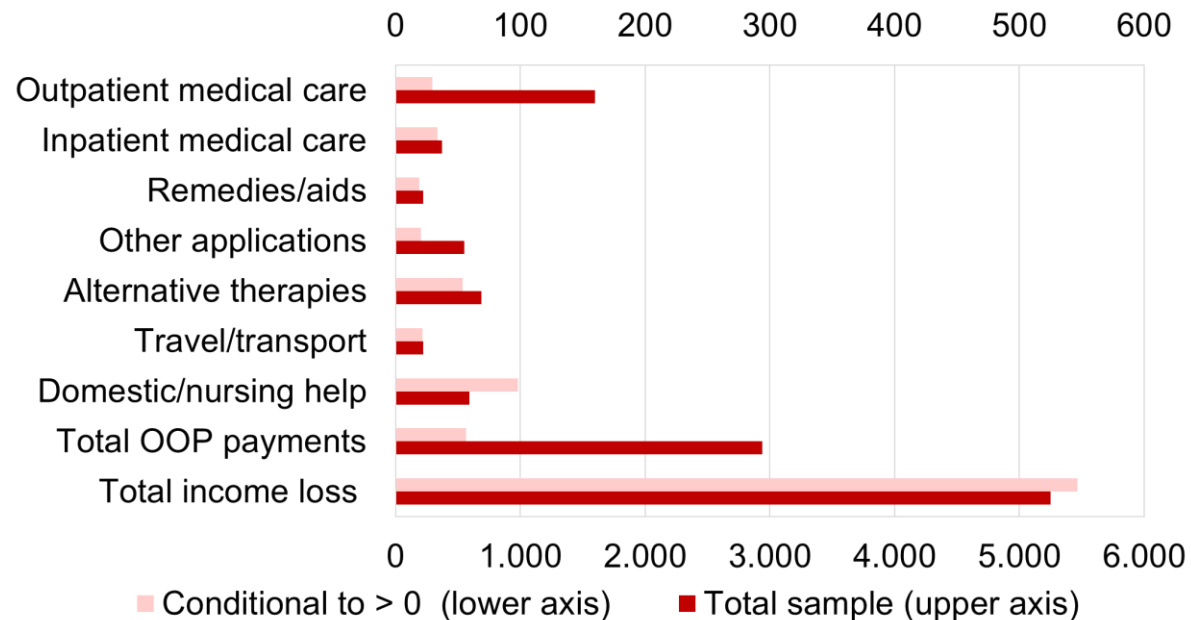
1. reflecting the traditional focus on (presumably “health-related”) quality of life
2. what about other constructs (and their valuation), capturing the full range of “intangible costs” incurred by patients (such as loss of capabilities / impaired functional status, health perceptions, psychological well-being / distress, social networks, life satisfaction, etc.)

1. focus on «out-of-pocket» («oop») costs, i.e., direct medical & non-medical costs from the perspective of patients
2. what about [net] income loss, i.e., indirect costs from the perspective of patients?
3. ... negative (and positive?) impact on patients and relatives ...
4. ... of the disease *per se* and of medical care?

Socioeconomic Impact of Cancer: Some German Data

Income Loss and Out-of-Pocket Expenditures [Breast Cancer Survivors]

For the present study, we examined data from 2,654 long-term breast cancer survivors in Germany that participated in the population-based CAESAR study and who were at least five years post-diagnosis.¹



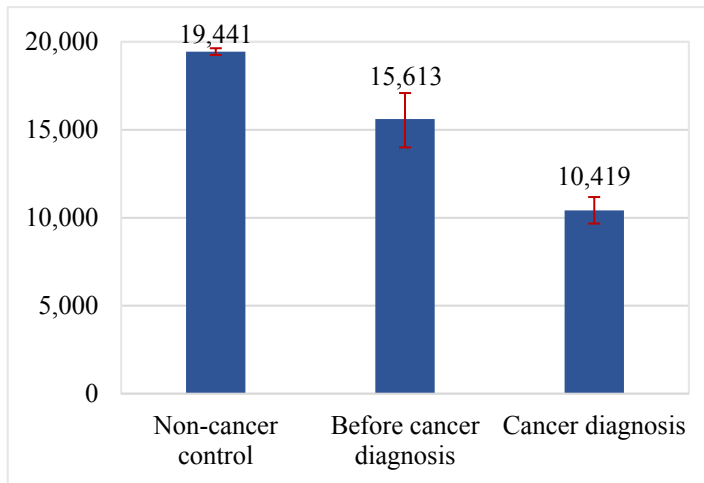
¹J. Schneider; D. Hernandez; CAESAR Study Group; M. Schlander; V. Arndt. Out-of-pocket payments and loss of income among long-term breast cancer survivors in Germany: A multi-regional population-based study. *Journal of Cancer Survivorship* 2023; 17 (6): 1639-1659.

Socioeconomic Impact of Cancer: Some German Data

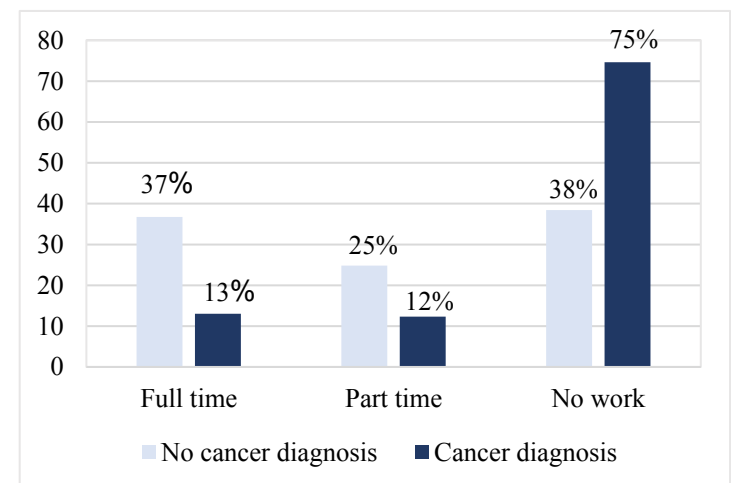
Income Loss associated with a Cancer Diagnosis

For the study, we analyzed data from the **Socio-Economic Panel (SOEP)**, consisting of approximately 20,000 individuals, who are traced annually.¹

Job Income Average [€ 2016]



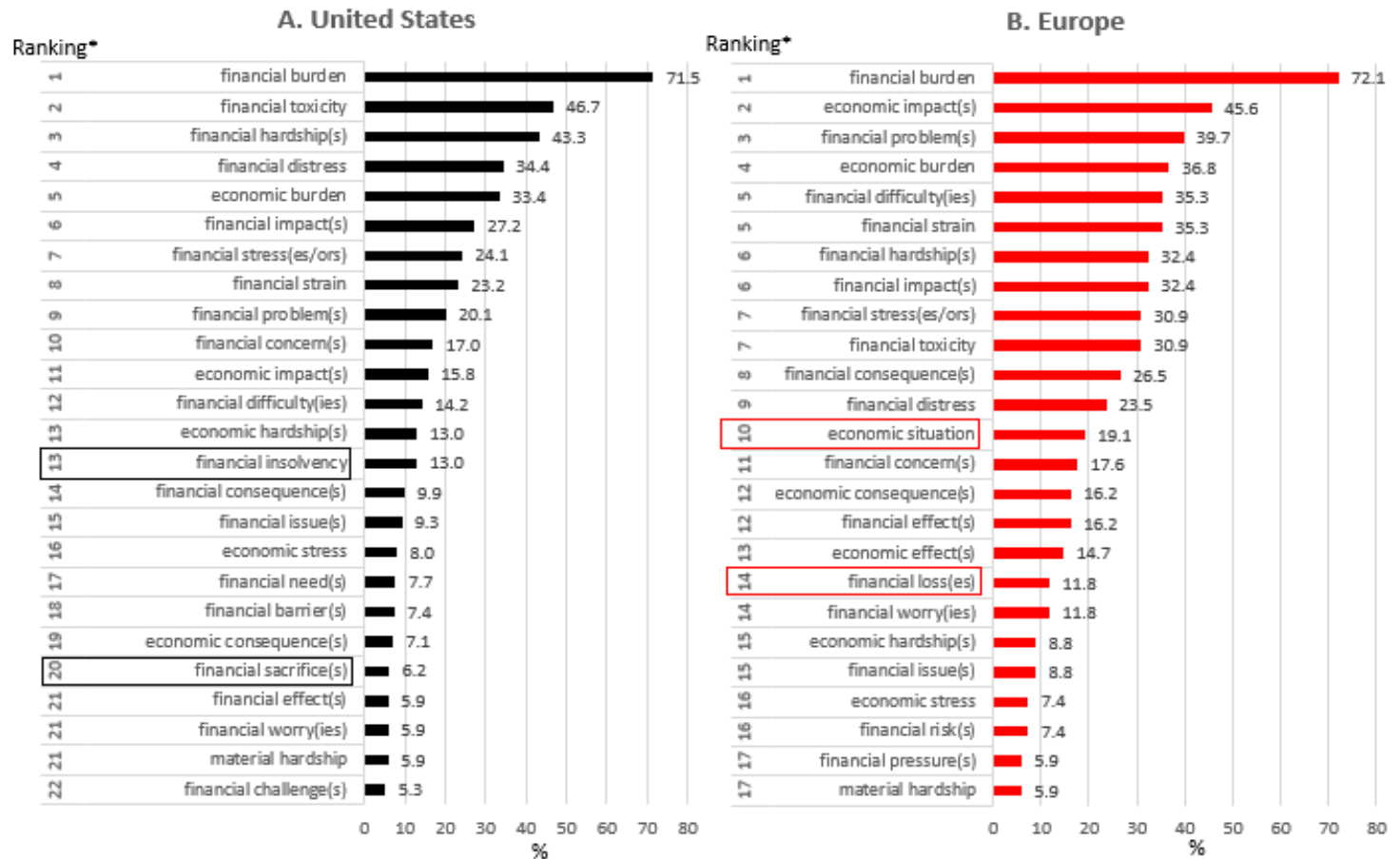
Work Status (Period from 2009 – 2015)



¹D. Hernandez and M. Schlander. Income loss after a cancer diagnosis in Germany: An analysis based on the socio-economic panel survey. *Cancer Medicine* 2021; 10 (11): 3726-3740.

Socioeconomic Impact or «Financial Toxicity»

Inconsistent Use of Terminology



*Rankings are based on the number of articles (original articles, literature reviews and abstracts) that mentioned the term at least one time. More than one term can have the same ranking if the number of articles that mentioned the terms is the same. Boxes highlight the terms that only appear among the 25 most frequently used terms in that particular region. Source: DKFZ Analysis (K. Hernandez-Villafuerte, R. Eckford, et al., 2021)

The largest network
of Cancer Centres
and Institutes across
Europe and beyond its
borders

AUSTRIA / BELGIUM / BULGARIA / CHILE
CYPRUS / COLOMBIA / CROATIA / CZECH REPUBLIC
DENMARK / ESTONIA / FINLAND / FRANCE
GERMANY / GREECE / HUNGARY / IRELAND / ITALY / JORDAN
LATVIA / LITHUANIA / NORWAY / POLAND / PORTUGAL / ROMANIA
RUSSIA FEDERATION / SERBIA / SLOVAKIA / SLOVENIA / SPAIN
SWEDEN / SWITZERLAND / TANZANIA / THE NETHERLANDS
TURKEY / UKRAINE / UNITED KINGDOM / VIETNAM



– **Cancer Economics Working Group**

– Lead: Wim van Harten (Chair)



– **Task Force on Socioeconomic Impact Research**

– Lead: Michael Schlander (Chair)

Task Force Membership

- **Netherlands Cancer Institute (NKI-AVL), *The Netherlands***
Wim van Harten (*TF Co-Chair*), Valesca Retèl, Nora Franzen, Julie Vancoppenolle
- **Centre Henri Becquerel, *France***
Artus Paty, Thomas Vermeulin
- **Institut Curie Paris, *France***
Philip Thierry
- **Humanitas Research Hospital (IRCCS), *Italy***
Elena Vanni
- **Instituto Catalán de Oncología, *Spain***
Olaya Seoane, Agustín Escobedo, Sandra Foix
- **Hospital de Braga, *Portugal***
João Porfírio Oliveira
- **Klinika za tumore Klinicki bolnicki centar Sestre milosrdnice, *Croatia***
Iva Kirac
- **Patient Representative, *Croatia***
Sinisa Varga (Former Minister of Health)
- **University of Oslo, Institute of Health and Society, *Norway***
Eline Aas
- **Oslo University Hospital, *Norway***
Sigbjørn Smeland
- **King's College London, *England***
Richard Sullivan
- **Arturo López Pérez Foundation, *Chile***
Camila Quirland Lazo, Felipe Maza, Jeanette Alejandra Fuentes
- **Patient Representative, *Germany***
Bernd Crusius (Haus der Krebshilfe)
- **German Cancer Research Center (DKFZ) / Health Economics, *Germany***
Michael Schlander (*TF Chair*), Rachel Eckford, Diego Hernandez, Karla Hernandez-Villafuerte, Phu Duy Pham, Jasper Ubels

Task Force Objectives

To Support Future Socioeconomic Impact Research in Europe

– Rationale:

- Need to better understand the extent of the problem, including predictors and moderators of **vulnerability** of patients (and their relatives), such as
 - Individual factors (e.g., personal values, preferences, general perceptions)
 - Environmental and social factors (e.g., psychological and economic support)
 - Characteristics of the respective health and social security system
 - Access to, as well as organization, location, and modality of medical care
- Research to date in Europe has been heterogeneous,
 - characterized by inconsistent use of terminology
 - impaired by a shortage of validated instruments
 - lacking a coherent and comprehensive conceptual framework

Task Force Objectives

Rationale, Objectives, and Anticipated Outcomes

– Objectives:

- To fill the gap in standards and guidance for studies exploring the socioeconomic impact of cancer and cancer care on patients and their relatives;
- To reduce or eliminate the risk of wasted research efforts due to redundant, overlapping, and incomparable work owing to unnecessarily heterogeneous use of terms and definitions,
and
- To support and facilitate further research in the field, including a potential platform for future collaborative projects by members of the Task Force,
- such as, but not limited to, the pan-European OECD/NKI SEC Trial

Task Force on «Socioeconomic Impact Research»

Outcomes of Task Force

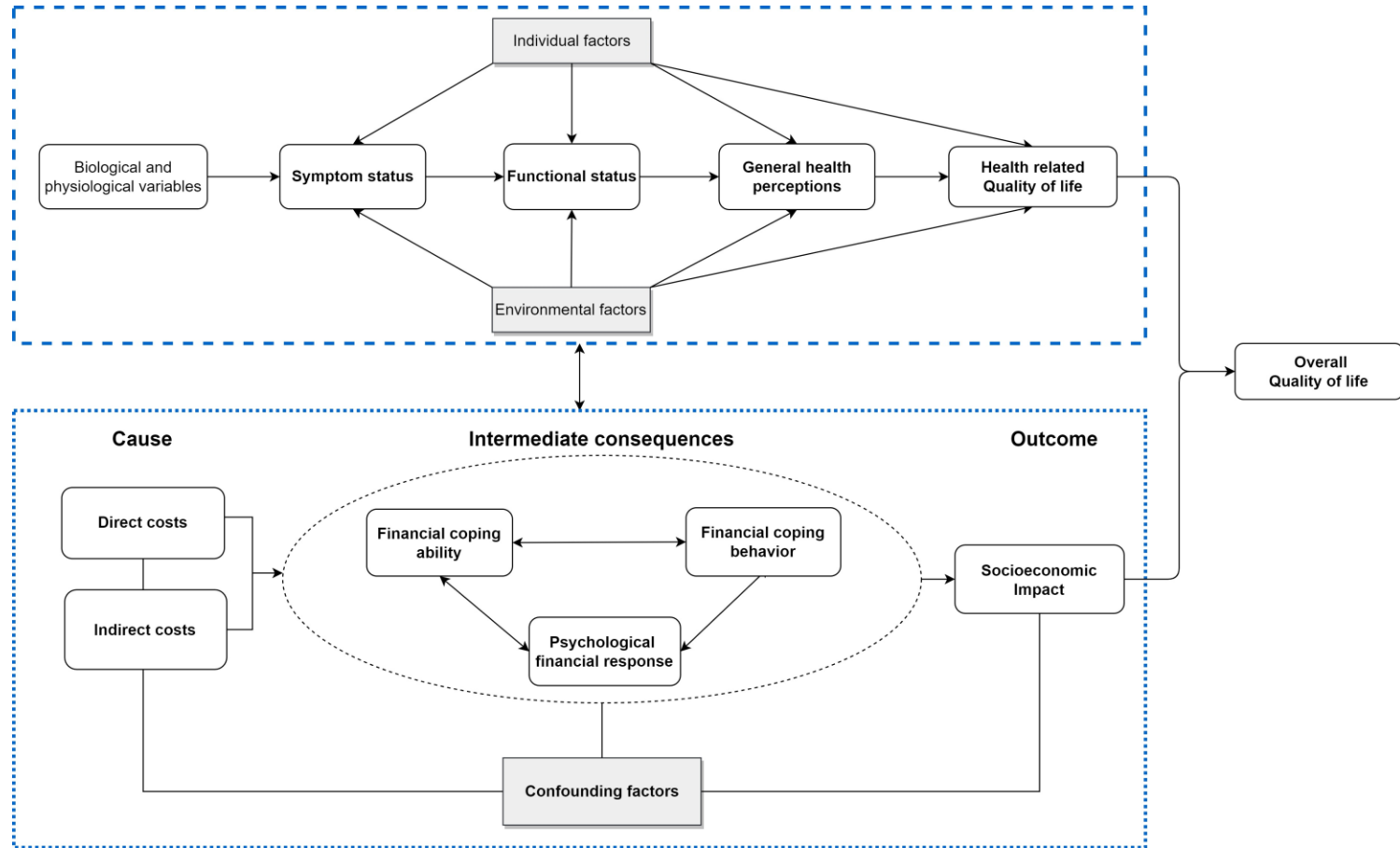
Phases 1 & 2


- ▭ A **European Consensus** on a comprehensive **conceptual framework**
- ▭ **European Recommendations** for a consistent **taxonomy & terminology** and

Phase 3

- ▭ **Instrument Development & Validation** for **measuring the socioeconomic impact of cancer** from the perspective of patients and their relatives

«Socioeconomic Impact» – An Integrated Framework



 Health outcome model (adapted from Valderas and Alonso, 2008)

 Socioeconomic Impact framework

«Socioeconomic Impact» – An Integrated Framework

forthcoming:

The socioeconomic impact of cancer on patients and their relatives: Organisation of European Cancer Institutes task force consensus recommendations on conceptual framework, taxonomy, and research directions

Michael Schlander, Wim van Harten†, Valesca P Retèl, Phu Duy Pham, Julie M Vancoppenolle, Jasper Ubels, Olaya Seoane López, Camila Quirland, Felipe Maza, Eline Aas, Bernd Crusius, Agustín Escobedo, Nora Franzen, Jeanette Fuentes-Cid, Diego Hernandez, Karla Hernandez-Villafuerte, Iva Kirac, Artus Paty, Thierry Philip, Sigbjørn Smeland, Richard Sullivan, Elena Vanni, Sinisa Varga, Thomas Vermeulin, Rachel D Eckford*

The Lancet Oncology 2024 (in press)

The European SEC Study¹

– Primary Objective

- To explore the socio-economic consequences for patients resulting from cancer diagnosis in European countries

– Secondary Objectives

- To measure the relation between the FIT (& subscales) score per residence country
- To measure the relation between the FIT (& subscales) score and cancer category
- To measure the relation of the FIT (& subscales) score to socio-economic demographics of the patients

¹J. Vancoppenolle, N. Franzen, L. Azarang, T. Juslin, M. Krini, T. Lubbers, J. Mattson, D. Mayeur, R. Menezes, J. Schmitt, F. Scotte, O. Seoane Lopez, T. Skaali, J. Ubels, M. Schlander, V. Retel, W. van Harten, OECD Working Group Health Economics

The European SEC Study¹

– The Financial Index of Toxicity («FIT») Instrument

- Initially believed to be the most suitable instrument in the European setting
- Focus on psychological and practical elements of financial toxicity
- Score between 0 (lowest toxicity) and 100 (highest toxicity)
- Measuring three domains:

Financial stress score	Financial strain score	Lost productivity score
<ul style="list-style-type: none"> • Inability to pay for food, housing of medication 	<ul style="list-style-type: none"> • Satisfaction of financial situation • Worrying about financial situation • Financial situation when young • Borrowing money for treatment related expenses 	<ul style="list-style-type: none"> • Quitting of job patient • Quitting of job caregiver

¹J. Vancoppenolle, N. Franzen, L. Azarang, T. Juslin, M. Krini, T. Lubbers, J. Mattson, D. Mayeur, R. Menezes, J. Schmitt, F. Scotte, O. Seoane Lopez, T. Skaali, J. Ubels, M. Schlander, V. Retel, W. van Harten, OECD Working Group Health Economics

The European SEC Study¹

– Survey Design

- **41 items**
- **Topics covered**
 - Sociodemographic variables
 - Age, country, education, type of cancer & treatment
 - Financial Index of Toxicity (FIT score) & consequences
 - General and subscale scores
 - Loss of income & household income
 - Additional treatment related expenses
 - Employment status before & after diagnosis
- **Coping behaviors among patients**
 - Delay in doctor visits, not or partly fill prescriptions
- **Health-related quality of life**
 - EQ-5D questionnaire
- **Translated in 16 languages**

¹J. Vancoppenolle, N. Franzen, L. Azarang, T. Juslin, M. Krini, T. Lubbers, J. Mattson, D. Mayeur, R. Menezes, J. Schmitt, F. Scotte, O. Seoane Lopez, T. Skaali, J. Ubels, M. Schlander, V. Retel, W. van Harten, OECD Working Group Health Economics

The European SEC Study¹

– Respondents

– Inclusion criteria

- All cancer patients that have been/are treated with systemic therapy and/or invasive surgery
- Max. 2 years after treatment
- Living in European country

– Distribution of questionnaire

- Hospitals
 - Pseudo-anonymous or Anonymous pathway
 - Ethical committee approval
- Patient organizations
 - Anonymous pathway

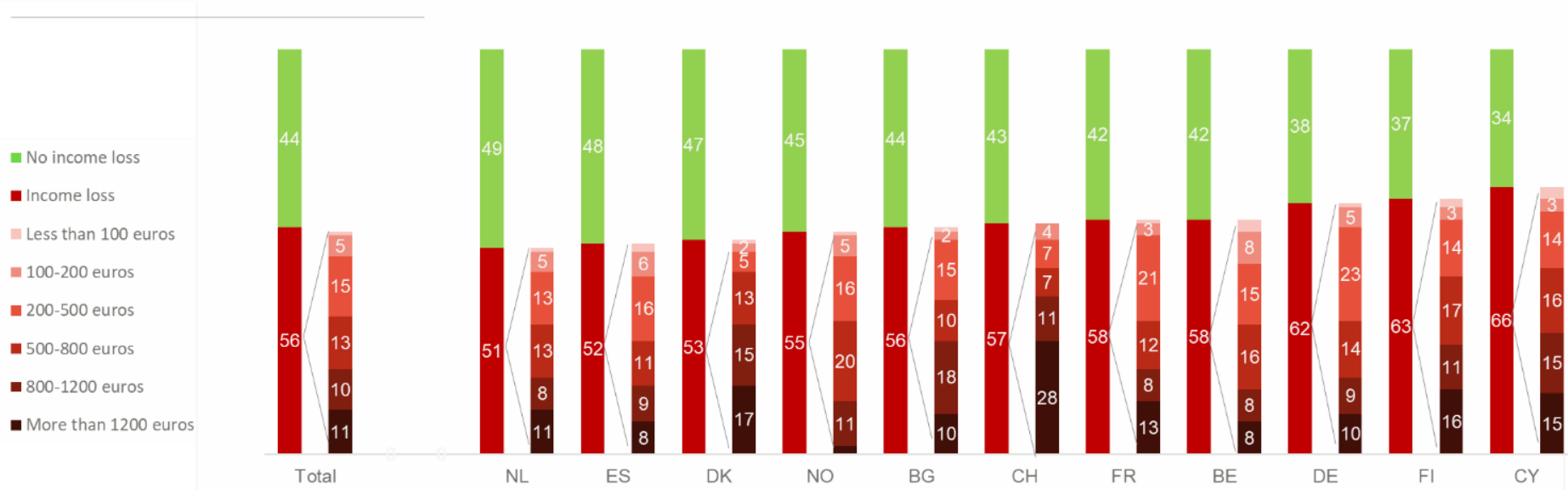
– Participation / evaluable questionnaires

- N=2507 (ES, 520; NL, 413; F, 241; D, 208; BG, 201;...)
- hereof, female 1832 (73.1%); breast cancer, 1181 (47.1%)

¹J. Vancoppenolle, N. Franzen, L. Azarang, T. Juslin, M. Krini, T. Lubbers, J. Mattson, D. Mayeur, R. Menezes, J. Schmitt, F. Scotte, O. Seoane Lopez, T. Skaali, J. Ubels, M. Schlander, V. Retel, W. van Harten, OECE Working Group Health Economics

The European SEC Study¹

Income loss and its severity (%), total N=2281

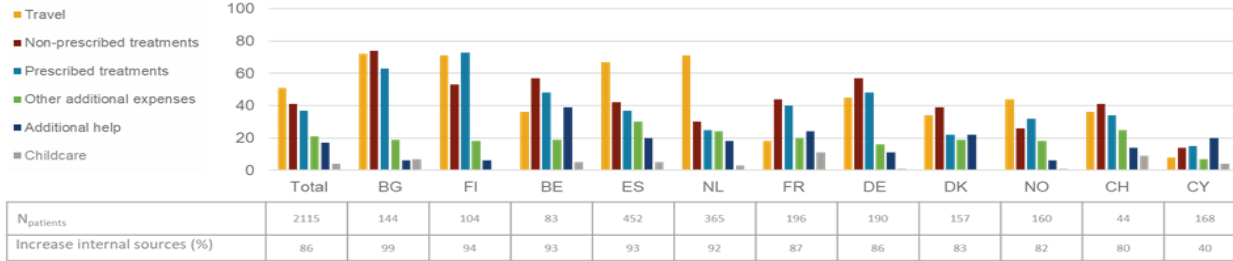


Median monthly earnings (€)	2739	1708	4057	442	4279	5625	3092	2369	2891	2958	1477
N _{patients}	393	478	165	183	154	46	226	90	198	117	176

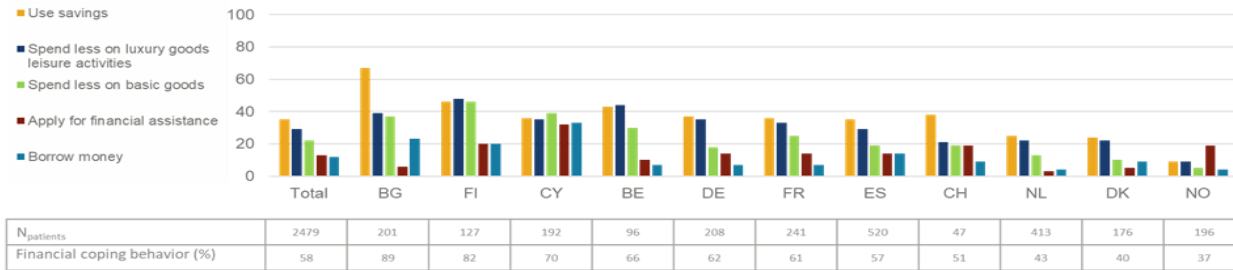
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SEC Study: Additional Treatment-Related Expenses

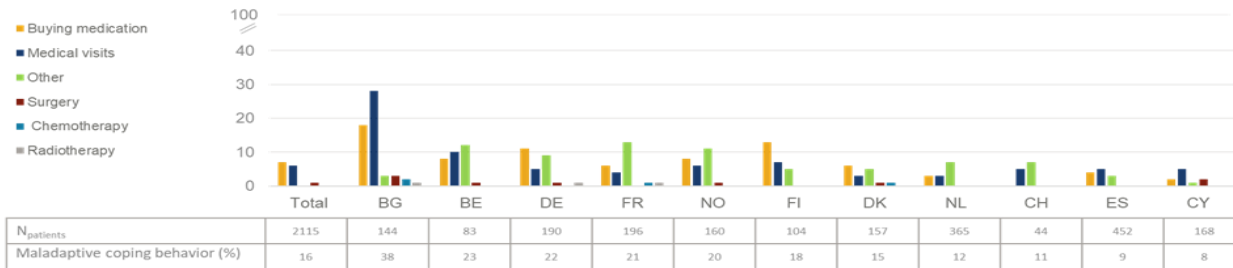
A. Additional treatment related expenses*



B. Financial coping behavior to manage the financial consequences of their cancer diagnosis*



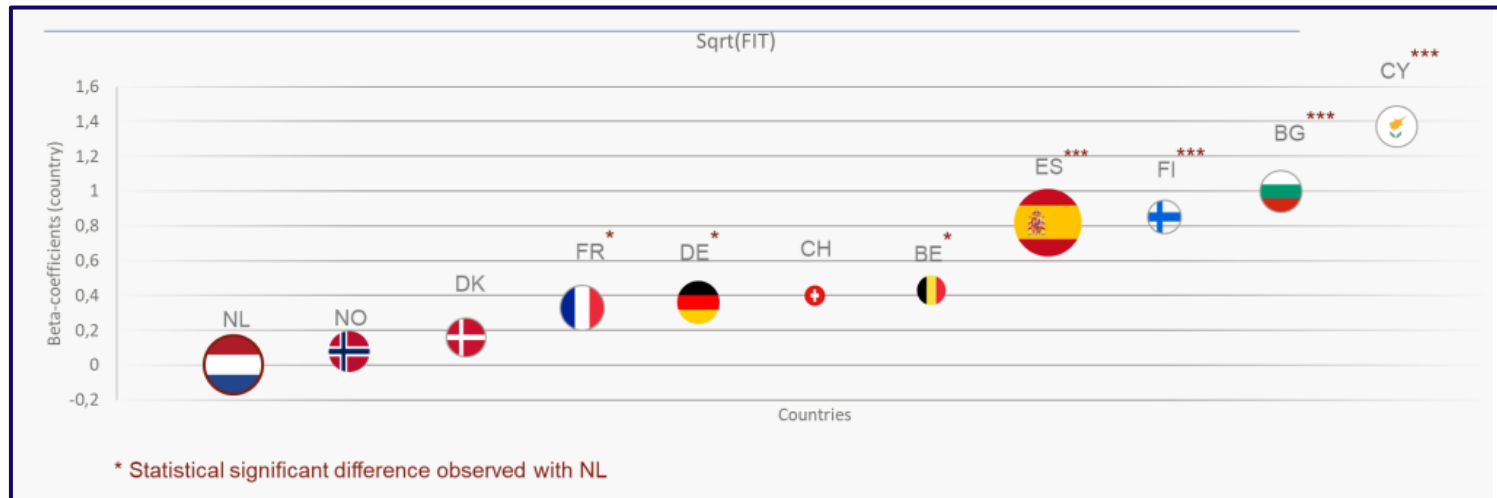
C. Maladaptive coping behavior (delaying or avoiding medical treatment/attention): *



*Double counting

The European SEC Study¹

Association between the patients' country of residence and the overall Financial Index of Toxicity (FIT) scores:



¹J. Vancoppenolle, N. Franzen, L. Azarang, T. Juslin, M. Krini, T. Lubbers, J. Mattson, D. Mayeur, R. Menezes, J. Schmitt, F. Scotte, O. Seoane Lopez, T. Skaali, J. Ubels, M. Schlander, V. Retel, W. van Harten, OECD Working Group Health Economics

Summing Up: The European SEC Study¹

- A multinational study to explore the socio-economic impact and financial toxicity among patients with cancer across Europe.
- 56% of patients suffered from income loss and 86% reported additional treatment-related expenses.
- 16% of patients delayed or avoided medical visits, buying medication, surgery or other health services.
- Divorced, self-employed, younger patients and patients with children are especially vulnerable for financial toxicity after a cancer diagnosis.
- In every EU country, a substantial number of patients with cancer report serious financial consequences and stress.

¹J. Vancoppenolle, N. Franzen, L. Azarang, T. Juslin, M. Krini, T. Lubbers, J. Mattson, D. Mayeur, R. Menezes, J. Schmitt, F. Scotte, O. Seoane Lopez, T. Skaali, J. Ubels, M. Schlander, V. Retel, W. van Harten, OECD Working Group Health Economics

«Krebs und Armut»

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