OECI for Patients WG

Enhancing Patient Involvement in Cancer Care and Research

How patient perspectives are reshaping cancer care and research: FAVO's Experience

Laura Del Campo

11 June 2025

New needs, new rights: CHALLENGES

Information and Communication

Disparities

Rehabilitation (phisic, nutritional, sexual, cognitive and social

Mother and father after cancer

Patients and caregivers rights

Right to be forgotten

Pain therapy and pallaitive care

Rare cancers

Neglected tumors

Follow up and QoL for survivors

Life after cancer

Research

Umbrella Organization with over 300 federated Associations

F.A.V.O.
Federazione Italiana delle
Associazioni di Volontariato
in Oncologia

Regional Committees

FAVO **Lombardia**
FAVO **Lazio**
FAVO **Puglia**
FAVO **Piemonte-Liguria-Valle d’Aosta**
FAVO **Toscana**
FAVO **Campania**
FAVO **Sicilia**
FAVO **Triveneto**
FAVO **Calabria**
FAVO **Umbria Marche Abruzzo**

Cancer patients new needs

Cancer patients Associations

FAVO

Institutions

How FAVO involves Patient Organizations: Working Groups

F.A.V.O WOMAN

It consists of 56 federated Associations, united with the goal of ensuring the best quality of life through concrete initiatives to promote and implement the protection of the rights of women directly or indirectly affected by cancer, focusing on issues that cut across all types of cancer.

F.A.V.O RARE TUMORS

Fosters the active participation of associations in the National Rare Cancer Network; Contributes to the determination of Cancer pathways; Monitors the needs of patients; Promotes studies and research on rare cancers

F.A.V.O. PEDIATRIC CANCERS

Promotes joint awareness initiatives on the needs of children with childhood cancer and their families; supports surveys, studies and research on the topic of pediatric cancers and issues related to the needs of children, adolescents and family members; fosters the development of relationships with the relevant scientific community; creates permanent representativeness towards institutions; promotes specific Training activities for parents, volunteers, professionals;

How FAVO involves Patient Organizations: Working Groups

F.A.V.O HEMATOLOGICAL CANCERS

Promotes awareness-raising initiatives; Supports investigations, studies and research on the topic of hematologic malignancies; Fosters the development of relationships with the scientific community; Facilitates the exchange of information, experience and best practices; Implements patient empowerment and foster education; Creates permanent representativeness toward institutions.

F.A.V.O HEREDITARY TUMORS

The FAVO Hereditary Tumors Working Group focuses on carriers of hereditary syndromes (affected and healthy) and their related organs at risk. At an early stage, priority is on the two most prevalent syndromes (HBOC-HRD and LYNCH-MMR) and the following risk organs: breast, ovary, prostate, colorectum, endometrium, bladder, and urothelium.

F.A.V.O.
Federazione Italiana delle
Associazioni di Volontariato
in Oncologia

Tumori Genitourinari

AI TT
ANTURE
EUROPA UOMO
PaLiNUro

F.A.V.O GENITOURINARY TUMORS

Constantly monitors the evolving needs of patients with oncological diseases of the genito-urinary tract; shares best practices; fosters the development of relationships with the relevant scientific community; promotes studies and research on issues related to genito-urinary tract cancers; encourages the participation of associations in the process of determining PDTA.

NATIONAL CANCER SURVIVOR'S DAY

- Advocacy, research, Innvoation
- Networking
- Training
- Life celebration

DISPARITIES REDUCTION

Osservatorio sulla condizione assistenziale dei malati oncologici

17° Rapporto sulla condizione assistenziale dei malati oncologici

Roma, 15-18 maggio 2025
XX Giornata nazionale del malato oncologico

realizzato da:

Each year FAVO publishes a Report on the Care Condition of the Cancer Patient that:

- surveys and documents in a scientific and timely manner, the disparities in access by patients to diagnostic and therapeutic treatments in the various Italian regions;
- highlights the major critical issues related to diagnosis, treatment and care of cancer patients, at the various levels;
- proposes relevant initiatives from time to time, both at the legislative and management levels, always with respect to appropriateness and sustainability.

MAIN ACHIEVEMENTS

- The right of cancer patients to be able to continue working, in the public and private sectors, through the reversible transformation of full-time to part-time (2003)
- The reduction from one year to 15 days for the recognition also of the transitory oncological disability (2006)
- The right to immediate access of innovative drugs (2012) in all regions and reduction to 100 days of the time frame for AIFA approval of innovative drugs (2013)
- Contribution for the establishment of the National Rare Tumor Network (2017) and of the Regional Oncology Networks (2019 – 2023)
- FAVO’s designation as a component of the Observatory for Monitoring and Evaluation of Regional Oncology Networks (2019)
- Right to be forgotten: Provisions for the prevention of discrimination and protection of the rights of people who have been affected by oncological diseases (2023

FORMAL RECOGNIZATION OF CANCER PATIENTS ORGANIZATIONS INTO ONCOLOGICAL REGIONAL NETWORKS

Governance

Access points

Integration between Hospital and Territory

Design of cancer pathways

Research

Information & Communication

Ongoing EU Projects

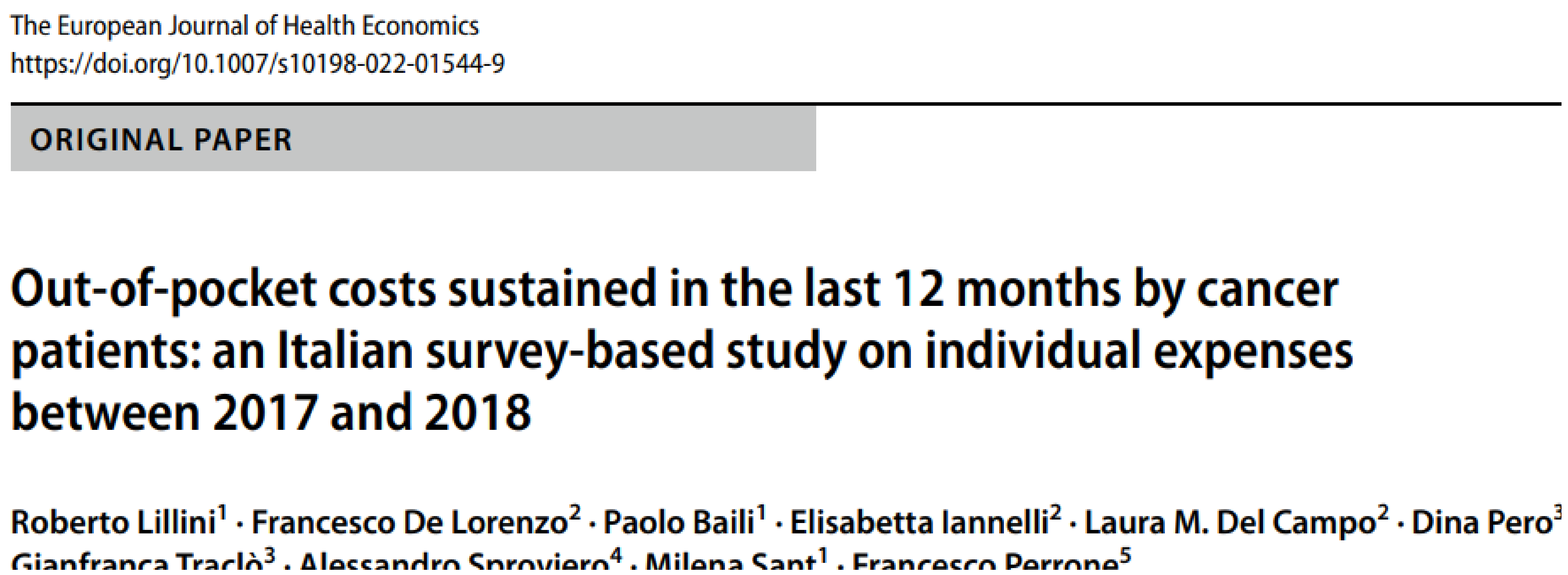
Integrated and Standardized NGS Workflows for Personalised Therapy – INSTAND NGS4: The project, EU-funded Pre-Commercial Procurement (PCP) project for improving cancer patient's benefit from Next Generation Sequencing (NGS) by developing an integrated and standardized NGS workflow.

Quality of Life in Oncology - EUonQoL: The project, funded by the EU Horizon Europe, is aimed to contribute to the EU initiatives against cancer, by developing the European Oncology Quality of Life Toolkit (EUonQoL-kit), a patient-centred unified tool for the assessment of quality of life among cancer patients and survivors.

EU Joint Action Networks of Expertise on Cancer – JANE 2: Jane 2 is a European 'Joint Action' funded by the EU Commission with the aim of creating seven new 'Networks of Competence' in oncology in Europe, capable of addressing as many areas of high complexity in the future by combining expertise and infrastructure present in different partner countries.

SUstaiNable inteRventions and healthy behavIours for adoleScent primary prEvention of cancer with digital tools - SUNRISE: The project, funded by Horizon-Miss-2023-cancer-01, will co-create, implement and evaluate a digitally-enhanced life-skills programme for primary prevention of cancer through sustainable health behaviour change in adolescents

Research


The European Journal of Health Economics
https://doi.org/10.1007/s10198-022-01544-9

ORIGINAL PAPER

Out-of-pocket costs sustained in the last 12 months by cancer patients: an Italian survey-based study on individual expenses between 2017 and 2018

Roberto Lillini[1] · Francesco De Lorenzo[2] · Paolo Baili[1] · Elisabetta Iannelli[2] · Laura M. Del Campo[2] · Dina Pero[3]
Gianfranca Traclò[3] · Alessandro Sproviero[4] · Milena Sant[1] · Francesco Perrone[5]


toxics MDPI

Case Report

Self-Reported Assessment of the Socio-Economic Impact of Anticancer Chemotherapy-Related Neurotoxicity

Guido Cavaletti [1,*], Alessia D'Acunti [2], Alessandro Porcu [2], Gabriella Masiello [2], Laura Del Campo [2],

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Annals of Oncology 19 (Supplement 9): ix11–ix23, 2008
doi:10.1093/annonc/mdn610

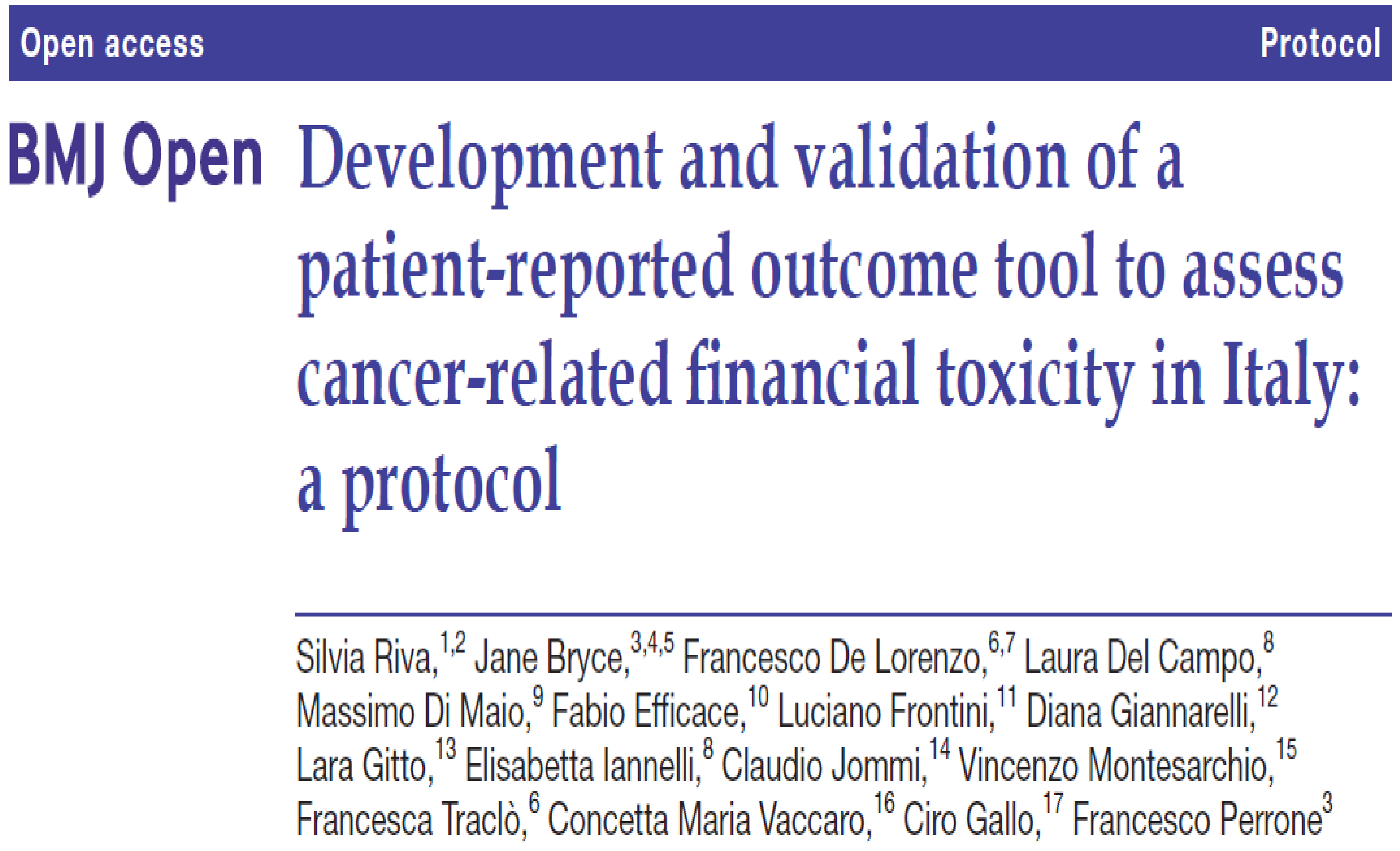
session B: rehabilitation, supportive and palliative care

B1* " NATIONAL SURVEY OF REHABILITATION CENTRES FOR CANCER PATIENTS IN ITALY"

Paola Varese*, Francesco De Lorenzo*, Rosaria Bufalino**, Maria Adelaide Bottaro*
*FAVO (Federazione nazionale delle Associazioni di Volontariato in Oncologia), INT Milano***

interim analysis after the enrolment of 204 pts showed arm 1 significantly less effective than the others for primary efficacy endpoints: it was withdrawn from the study. Statistical analysis at March 2008 showed a significant improvement of REE and fatigue in arms 3 and 5 and a significant decrease of TNF-α in arms 3 and 4. As for safety, only one severe toxicity (diarrhea) was observed in arm 3. In conclusion, the results so far seem to suggest that the most effective treatment for cancer pts with CACS should be either a combination regimen or L-carnitine alone.

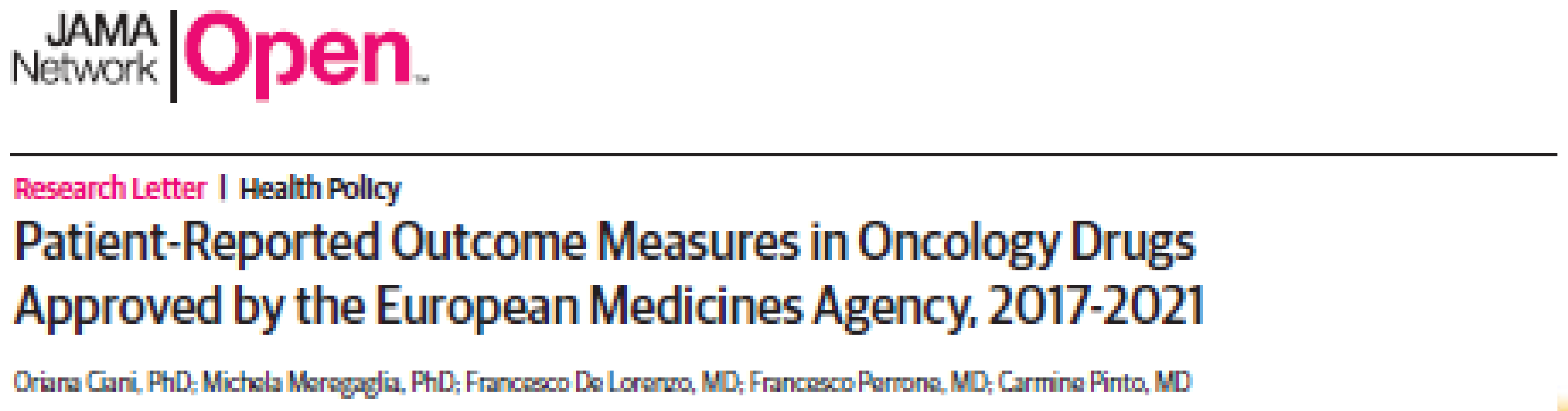
Supported by: MUR Project No. 2006067295


Open access Protocol

BMJ Open

Development and validation of a patient-reported outcome tool to assess cancer-related financial toxicity in Italy: a protocol

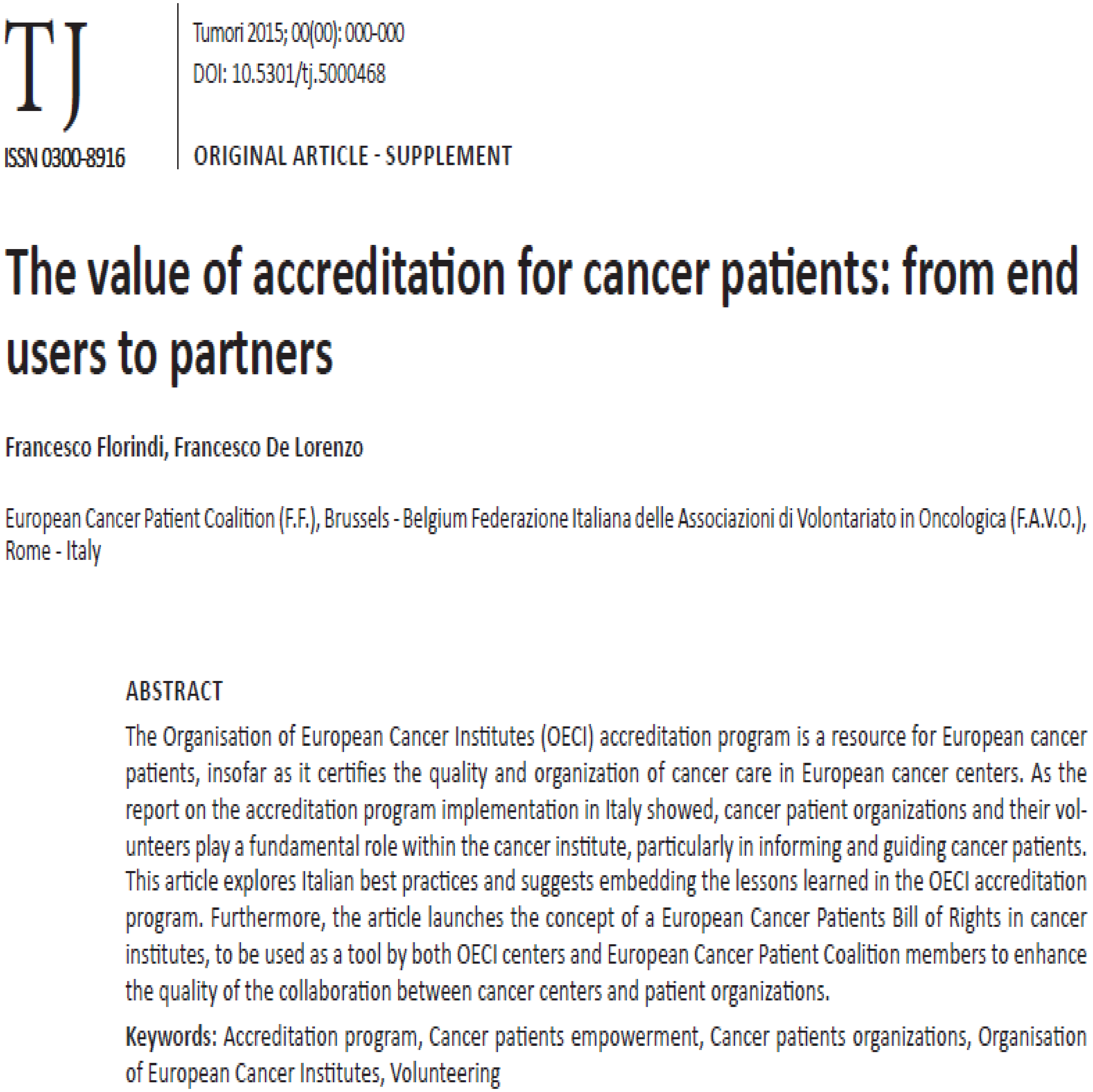
Silvia Riva,[1,2] Jane Bryce,[3,4,5] Francesco De Lorenzo,[6,7] Laura Del Campo,[8] Massimo Di Maio,[9] Fabio Efficace,[10] Luciano Frontini,[11] Diana Giannarelli,[12] Lara Gitto,[13] Elisabetta Iannelli,[8] Claudio Jommi,[14] Vincenzo Montesarchio,[15] Francesca Traclò,[6] Concetta Maria Vaccaro,[16] Ciro Gallo,[17] Francesco Perrone[3]


JAMA Network Open

Research Letter | Health Policy

Patient-Reported Outcome Measures in Oncology Drugs Approved by the European Medicines Agency, 2017-2021

Oriana Ciani, PhD; Michela Meregaglia, PhD; Francesco De Lorenzo, MD; Francesco Perrone, MD; Carmine Pinto, MD



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DOI: 10.5301/tj.5000468
ORIGINAL ARTICLE - SUPPLEMENT

The value of accreditation for cancer patients: from end users to partners

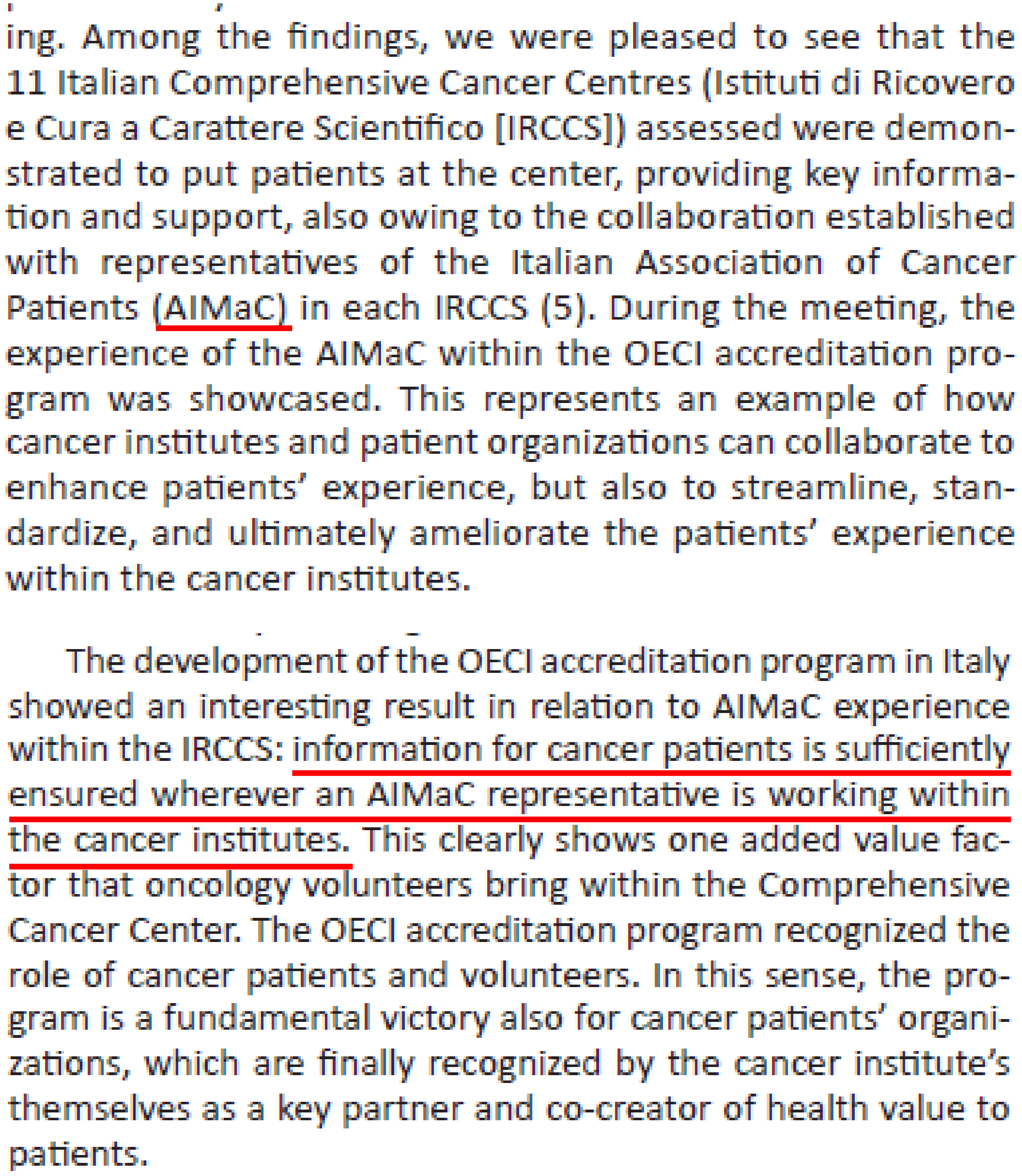
Francesco Florindi, Francesco De Lorenzo

European Cancer Patient Coalition (F.F.), Brussels - Belgium Federazione Italiana delle Associazioni di Volontariato in Oncologica (F.A.V.O.), Rome - Italy

ABSTRACT

The Organisation of European Cancer Institutes (OECI) accreditation program is a resource for European cancer patients, insofar as it certifies the quality and organization of cancer care in European cancer centers. As the report on the accreditation program implementation in Italy showed, cancer patient organizations and their volunteers play a fundamental role within the cancer institute, particularly in informing and guiding cancer patients. This article explores Italian best practices and suggests embedding the lessons learned in the OECI accreditation program. Furthermore, the article launches the concept of a European Cancer Patients Bill of Rights in cancer institutes, to be used as a tool by both OECI centers and European Cancer Patient Coalition members to enhance the quality of the collaboration between cancer centers and patient organizations.

Keywords: Accreditation program, Cancer patients empowerment, Cancer patients organizations, Organisation of European Cancer Institutes, Volunteering



ing. Among the findings, we were pleased to see that the 11 Italian Comprehensive Cancer Centres (Istituti di Ricovero e Cura a Carattere Scientifico [IRCCS]) assessed were demonstrated to put patients at the center, providing key information and support, also owing to the collaboration established with representatives of the Italian Association of Cancer Patients (AIMaC) in each IRCCS (5). During the meeting, the experience of the AIMaC within the OECI accreditation program was showcased. This represents an example of how cancer institutes and patient organizations can collaborate to enhance patients' experience, but also to streamline, standardize, and ultimately ameliorate the patients' experience within the cancer institutes.

The development of the OECI accreditation program in Italy showed an interesting result in relation to AIMaC experience within the IRCCS: information for cancer patients is sufficiently ensured wherever an AIMaC representative is working within the cancer institutes. This clearly shows one added value factor that oncology volunteers bring within the Comprehensive Cancer Center. The OECI accreditation program recognized the role of cancer patients and volunteers. In this sense, the program is a fundamental victory also for cancer patients' organizations, which are finally recognized by the cancer institute's themselves as a key partner and co-creator of health value to patients.

FROM 25 YEARS, AIMAC ENSURES TO CANCER PATIENTS AND THEIR FAMILIES PERSONALIZED INFORMATION, LISTENING AND RIGHTS THROUGH:

40 booklets on the main types of cancer, related treatments and their side effects, quality of life

50 Information desks in major Italian Cancer Centres providing personalized information and psychological support

National Helpline: Volunteers, assisted by oncologists, psychologists and lawyers, respond to questions regarding cancers, treatments, side effects, access to social benefits and welfare laws

aimac
associazione italiana malati
di cancro, parenti e amici

www.aimac.it: easy to read, provides up-to-date information on types of cancer, therapeutic treatments, complications, and support services.

Libretti informativi

Informazioni sui singoli tumori, su come affrontare la vita quotidiana, convivere con la malattia e migliorare la qualità della vita.

Oncoguida - Indirizzi utili

Oncoguida riporta gli indirizzi per aiutare i malati di cancro, i loro familiari e amici ad affrontare i disagi connessi con la malattia.

I diritti del malato

AIMaC ti informa su quali sono le tutele giuridiche e i benefici economici previsti dall'ordinamento a tutela dei malati e delle famiglie.

Forum

Scopri il forum di AIMaC, uno spazio libero dove condividere la propria storia, scambiando emozioni, sensazioni, informazioni e pensieri.

Social research for the identification of their new needs

The European Journal of Health Economics
https://doi.org/10.1007/s10198-022-01544-9

ORIGINAL PAPER

Out-of-pocket costs sustained in the last 12 months by cancer patients: an Italian survey-based study on individual expenses between 2017 and 2018

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Abstract

Purpose Out of Pocket costs (OOP) sustained by cancer patients also in public NHS contribute to disease-related financial toxicity. Aim of the study was to investigate the amount and the types of OOP sustained by Italian cancer patients for care services.

Methods A sample survey was conducted by FAVO in December 2017-June 2018, in 39 adhering hospitals and 1289 patients diagnosed from 1985 to 2018, by standardized questionnaire inquiring on: yearly expenditure by cancer service, age, year of diagnosis, disease phase, cancer site, sex, marital status, education, residence. Univariate and multivariable regression analyses were performed between OOP and each variable. Multilevel mixed-effects negative binomial regression was used to assess the combined effects of patients characteristics on the differences in acquiring health services.

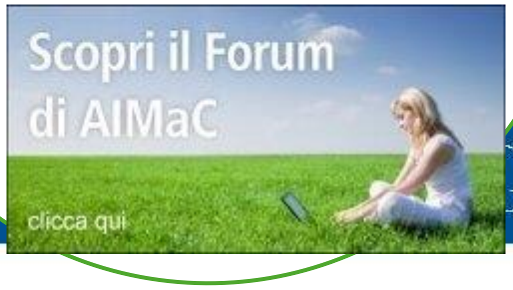
Results The yearly average OOP was 1841.81€, with the highest values for transports (359.34€) and for diagnostic examinations (259.82€). Significantly higher OOP were found in North and Centre than South and Islands (167.51 vs. 138.39). In the fully adjusted multivariable analysis, the variables significantly associated with higher than reference expenditure were: medium/high education (OR 1.22 [1.05–1.42], upper gastrointestinal tract cancer (OR 1.37 [1.06–1.77]), disease phase of treatments for cancer progression or pain therapy (OR 1.59 [1.30–1.93]).

Conclusion Italian cancer patients in 2018 sustained OOP quite similar to those measured in 2012 to supplement NHS services. The main component of the OOP costs were diagnostic examination and transportation. The NHS should pay attention to potentiate its ability to answer unmet needs of patients with advanced cancer who are the most fragile ones.

Implications for cancer survivors Reinforcing the services where the main OOP expenses are located can help in promoting public health actions and reduce socio-economic needs that could compromise the receipt of optimal care along the whole disease course, from diagnosis to rehabilitation.

Advocacy, defending their dignity and leading to the approval of

Forum: a virtual place where patients and caregiver can meet, share their experience, tell their stories



THANK YOU

for your attention

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FAVO