European Journal of Cancer 65 (2016) 150–155

Available online at www.sciencedirect.com

ScienceDirect

journal homepage: www.ejcancer.com

Original Research

Cancer in Europe: Death sentence or life sentence?

Lifang Liu [a,*], Peter O'Donnell [b], Richard Sullivan [c],
Alexander Katalinic [d], Lotte Moser [e], Angela de Boer [f],
Francoise Meunier [a] on behalf of the Scientific and Organizing Committee

[a] *The European Organisation for Research and Treatment of Cancer (EORTC), Avenue Emmanuel Mounier 83/11, 1200 Brussels, Belgium*
[b] *POLITICO, Brussels, Belgium*
[c] *Institute of Cancer Policy, King's College, London, United Kingdom*
[d] *Institute for Social Medicine and Epidemiology, University of Lubeck, Germany*
[e] *Champalimaud Foundation, Lisbon, Portugal*
[f] *Coronel Institute of Occupational Health, Amsterdam Medical Center, Amsterdam, The Netherlands*

Received 30 June 2016; accepted 5 July 2016

KEYWORDS
Survivor summit;
Long-term survivorship;
Social economic impact;
Data merging

Abstract With so many adults and children receiving successful treatment for their cancer, survivorship is now a 'new' and critical issue. It is increasingly recognised that the growing numbers of survivors face new challenges in their bid to return to 'normal' life. What is not yet so widely recognised is the need for a broad response to help them cope—with stigmatisation, misunderstanding, lifelong issues of confidence and social adaptation, and even access to employment and to financial services. As a further stage in its programme of attention to this aspect of cancer, the European Organisation for Research and Treatment of Cancer (EORTC) brought survivors, researchers, carers, authorities and policymakers together at a meeting in Brussels in March/April 2016, to learn at first hand about the posttreatment experience of cancer survivors. The meeting demonstrated that while research is well advanced in many of the medical consequences of survivorship, understanding is still lacking of many non-clinical, personal and administrative issues. The meeting raised the discussion of survivorship research beyond the individual to a population-based approach, exploring the related socioeconomic issues. Its exploration of initiatives across Europe countries provoked new thinking on the need for effective collaboration, with a new focus on non-clinical issues, including effective

---

* *Corresponding author.*
E-mail address: Lifang.liu@eortc.be (L. Liu).

http://dx.doi.org/10.1016/j.ejca.2016.07.007

dialogue with financial service providers and employers, improvements in collecting, exchanging and accessing data, and above all, ways of translating research outcomes into action. This will require wider recognition that, as Françoise Meunier, Director Special Projects, EORTC, said, ‘It is time for a new mind set’.

This summary captures the 2-d program of presentations, panel discussions and interactive dialogues at the 2nd Cancer Survivorship Summit hosted by the European Organisation for Research and Treatment of Cancer (EORTC) on 31st March–1st April 2016, Brussels, which provided an update of progress on the EORTC survivorship agenda since earlier meetings (http://www.eortc.org/survivorship2014/).

Some 150 attendees from 12 European countries and the United States of America, including cancer survivors, clinicians, patients advocates, governmental agencies, politicians, payers, insurers, bankers, health officials, researchers and journalists, reviewed medical and non-medical issues relating to the increasingly recognised societal challenges faced by survivors of cancer. Each of the sessions offered a perspective from survivors and reactions from participants.

It complemented the literature of the increase in cancer survival and gave sharp focus to the challenges with touching personal testimony. It highlighted the merits of bringing data together from a wider range of sources. It explored new methodologies developed for data aggregation, and—extending beyond the medical realm—it explored new data on societal issues, such as employment, insurance and obtaining mortgages. Options for proactive harmonisation of data were also discussed.

A major innovation was the discussion of survivorship not just in terms of risk assessment and intervention at the individual level, but at the wider society level, exploring issues such as the inequalities resulting from the diversity of national circumstances, and the cost to the community of excluding cancer survivors from work, insurance or loans.

In parallel, the meeting recorded progress at a technical level in moving from discussion to action in new data collection, collation with other data sources, and new methodology development.

1. Section 1: key issues addressed

The first day of the summit was devoted to societal issues faced by cancer survivors, including job loss after cancer, barriers to resuming work after treatment and hurdles in obtaining life insurance and mortgages. The discussion was opened by Sir Peter Jonas—who in the 45 years since he was diagnosed with Hodgkin’s disease has been successively the Director of the Chicago Symphony Orchestra, the English National Opera and the Bavarian State Opera and who celebrated his recent 70th birthday by completing a walk across the length of Europe from the northern tip of Scotland to Palermo in Sicily. He said that he had been repeatedly unable to obtain health insurance anywhere in the world and urged insurance companies and employers to wise up to the reality that people survive cancer. His experience was echoed in different registers among participants, young and old, whose comments conveyed a sense of victimisation (as one put it, the questioning when she tried to obtain life insurance for a mortgage was so intense that she ‘felt accused of something’ and she abandoned her bid) and a frustration at inappropriate decision-making criteria. Refusal of insurance or bank loans often aggravates the loss-of-income challenges that arise from barriers to returning to work. The repercussions on survivors from these accumulated barriers are serious at the level of the individual. For those with family responsibilities, the hardship can be multiplied accordingly, impacting on the social well-being of spouses and children.

At the level of society as a whole, new diagnoses of cancer far outstrip the annual figures for cancer mortality, auguring continuing increases in survivorship: there are 3.7 million new cases a year in the World Health Organisation Europe region, but deaths from the disease are 1.9 million. In Europe, an estimated 10–12 million patients have survived the fifth year after diagnosis, and of these nearly half (3 million women and 2 million men) are under the age of 60 years. These figures conceal variations between cancer types and countries: mortality rates remain higher in Southern and Eastern Europe, and survival for cancer of the pancreas is less than 10%, while it is higher than 90% for cancer of the prostate or testis [1].

Variations are also marked between return-to-work rates—although the general picture is starkly negative. As many as 20–30% of women surviving breast cancer become unemployed within 4 years [2], and return-to-work rates are at best 24% and can be as low as 6%, depending on the cancer site and disease stage [3]. Regional surveys suggest that 55% of chronically ill patients do not have a job, despite 80% of them wanting to work. Among all diseases, cancer has the highest prevalence of work loss and return to work—only 64% after 18 months, with a 37% higher chance of unemployment, and three times higher chance of disability unemployment. For survivors of childhood cancer, the figures are even worse: they are 85% more likely to be