



Improving European policy to support cancer survivors

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ABSTRACT

Due to increasing investment in health, earlier diagnosis, timely treatment, and new therapies, more people are surviving a diagnosis of cancer. While it is encouraging to observe a substantially increase in the number of cancer survivors, people with acute cancer, those with chronic cancer, and those cured of cancer all have different needs and preferences.

The “European Guide on Quality Improvement in Comprehensive Cancer Control”, produced by the European Commission’s Joint Action on Cancer Control, includes a specific chapter on survivorship. This chapter was developed in collaboration with patient organisations, and provides a set of recommendations for the development of quality national survivorship care plans.

Patient organisations have demonstrated the ability to link the policy environment to the reality of cancer care. For example, the “Patient Guide on Survivorship”, produced by the European Society for Medical Oncology in collaboration with the European Cancer Patient Coalition, is the first practical implementation of the Joint Action on Cancer Control survivorship recommendations. The guide provides actionable information on follow-up care, setting the foundation for a personalised survivorship care plan. A checklist of key interventions completes the document. Exercise, increased fruit and vegetable consumption, smoking cessation, and cognitive behavioural therapy have all demonstrated beneficial effects on the lives of cancer survivors. This guide is a practical tool to empower people with cancer to engage with their healthcare team.

The return to an active and normal life, for all cancer survivors who can reasonably achieve this goal, must be a priority of all healthcare systems.

1. Cancer survivorship: a ticking bomb

In the European Union, the burden of cancer keeps growing, together with the associated social and economic implications. In the 1970s, almost no man with testicular cancer would survive the disease, while today more than 95% of men diagnosed with testicular cancer at a regional stage are alive 5 years after diagnosis [1]. There are similar exceptional improvements in 5 year survival rates of childhood cancers (up to 79% in 2007 [2]) and breast cancer (now at over 80% [3]). But how can the healthcare systems respond to the growing needs of cancer survivors? To meet cancer survivors needs, the European Cancer Patient Coalition has promoted initiatives and research projects aimed at developing an EU Survivorship Care Plan, which should provide a benchmarking for the care after the acute treatment. Key priorities for action are timing and content of follow-up, rehabilitation, raising awareness of both short-term and long-term treatment – related effects, health maintenance, information regarding legal protections and psychological support.

Due to increasing investment in health, earlier diagnosis, timely treatment and new therapies, more and more people are surviving a diagnosis of cancer. The cancer survival rates in Europe have been steadily increasing. Age and case-mix standardised relative survival has increased from 44% in 1999–2001 to 49% in 2005–2007 for men, and from 53% in 1999–2001 to 56% in 2005–2007 for women [4]. In 2007, it was estimated that there were approximately 8.7 million cancer survivors in Europe [5].

It is very encouraging to see substantially more people surviving cancer, especially as many of these will have a positive effect on society by returning to work. However, people with acute cancer, those with chronic cancer, and those cured all have different needs and preferences. The needs of cancer survivors have long been neglected from public policy and national cancer control plans. Furthermore, the increased number of cancer survivors is likely to have a substantial impact on the health system.

Many cancer survivors have unmet needs, especially when it comes to improving the quality of life, in addition to extending the duration of

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life [6]. At least one quarter of cancer survivors report long-term poor health and disability [7]. Some cancer survivors have levels of fatigue that are three-fold greater than the general population [8], and many carry a life-long fear of cancer recurrence [9]. Cancer survivors from vulnerable populations or with a low-socioeconomic status are particularly at risk of having a lower quality of life compared to the general population [10]. Returning to work is also difficult for many cancer survivors, with one recent global survey reporting that more than one-third of employers described concerns about workplace discrimination against cancer survivors [11].

Even though exercise [12], increased fruit and vegetable consumption, smoking cessation [13], and cognitive behavioural therapy [8] have demonstrated beneficial effects on the lives of cancer survivors, few survivors are able to meet all of these recommendations [13].

However, notwithstanding this important body of evidence, cancer survivors' needs remain neglected by healthcare systems. This increases the already unacceptable impact of inequalities in cancer care, adding a particularly vicious component, that affects not only the individual cancer survivor, but also their relatives and carers, as well as society as a whole.

The return to an active and normal life, for all survivors who can reasonably achieve this goal, must be a priority of all healthcare systems. It should not be simply left to the good will and initiative of individual patients or doctors. In this sense, healthcare systems must ensure a seamless continuum between acute treatment phase and rehabilitation, as well as a seamless transition from hospital to home care.

2. National cancer survivorship plans: the CanCon recommendations

In light of these facts, it is of the utmost importance to develop national plans to ensure that the healthcare system can fully support cancer survivors' specific needs. Such plans can be included or ancillary to existing National Cancer Control Programmes and we will refer to them as Survivorship Care Plans. Survivorship Care Plans, also known as aftercare plans, describe medical and non-medical interventions for people with cancer once the acute treatment phase has been finalised. Survivorship plans are a means of helping people with cancer return to a normal life, to prevent secondary tumour and relapses, and to prevent late effects from cancer treatment. They must recognise the diverse needs of people with cancer, which may include rehabilitation, monitoring, and palliative care [14].

Currently, there are few efforts to develop system-wide strategies to address the needs of cancer survivors. For example, the self-assessment tool from the WHO's National Cancer Control Programme includes only a brief mention of aftercare and omits the support of long-term cancer survivors [15].

Fortunately, however, the European Commission and the European oncology community have already demonstrated interest in producing guidelines to help EU governments in the production of Survivorship Care Plans. In particular, the European Commission's Joint Action on Cancer Control (CanCon) analysed how survivorship is included in all European national cancer plans, using a detailed survey and an accurate literature review.

The "European Guide on Quality Improvement in Comprehensive Cancer Control" [16], CanCon's main deliverable, includes a specific chapter on survivorship, which was co-authored by the European Cancer Patient Coalition, and also benefitted from the contribution of many EU experts on cancer control and survivorship. This chapter, "Survivorship and rehabilitation: policy recommendations for quality improvement in cancer survivorship and rehabilitation in EU Member States" [17] provides a set of comprehensive recommendations for the development of national survivorship care plans.

The main messages are:

1. Cancer is not a death sentence anymore. A cultural shift is needed to

fight the stigma associated with cancer.

2. Cancer survivors' follow-up, late effect management, and tertiary prevention needs to be anticipated, personalised, and implemented into care pathways, with active participation of survivors and relatives.
3. Improvement of the early detection of patients' needs and their access to rehabilitation, psychosocial, and palliative care services is required.
4. An integrated and multi-professional care approach, with a co-ordination of community care providers and services, is needed to implement a survivorship care plan that enhances the patient's self-management and quality of life.
5. For children, adolescents, and young adult survivors, late health and psychosocial effects of cancer and its treatments need to be anticipated and addressed.
6. More research in the area of survivorship is needed to provide data on late effects, as well as the impact and cost-effectiveness of supportive care, rehabilitation, palliative, and psychosocial care interventions.

The document is a valuable source for all countries within the European Union, and provides actionable solutions to the rising number of people surviving cancer. They include late effect management and tertiary prevention, and recognise people with cancer as active partners in care. An integrated care approach is recommended in order to ensure an efficient, effective, and multi-disciplinary care pathway is implemented.

3. Beyond survivorship care plans

The inherently cross-disciplinary nature of survivorship care calls for the commitment and action not only of healthcare systems, but also of other socio-economic actors, like employers, insurance and bank product providers, and EU ministries of finance and employment.

One issue is the recognition of disability for cancer survivors who cannot return to an active life. The process of request and recognition of the disability status should be as streamlined and simple as possible to ensure that patients and survivors can have effective access to services and support.

The CanCon guide provides a few interesting examples of best practices from EU countries that can be used as a model for the development of patient-oriented solutions for the socio-economic problems derived from long term cancer survivorship.

One of such examples is the Italian regulation passed in 2003 (decree-law n° 276/2003, article 46, as amendment of decree law n° 61/2000, article 12 bis) prescribing the right of cancer patients working in the private sector to switch from full-time to part-time positions while under treatment, and then to revert to full-time employment according to their needs and capability. The same right was extended to public employees in 2007 (law n° 247/2007, article 1, subsection 44). Within the same legal framework, carers of cancer patients are given priority over part-time applications as long as there are positions available.

In the United Kingdom, the employment provisions of the Equality Act 2010 protect anyone who has, or has had, a disability (including people affected by cancer). The Act requires employers to make reasonable adjustments for employees with a disability. It also includes important provisions to prevent discrimination arising from disability, indirect discrimination, and discrimination against carers.

These examples show that change is possible and adaptations of the legal framework can be achieved to satisfy the new needs and new rights of cancer survivors.

Adopting forward-looking socio-economic legislation is not sufficient. It is also necessary to measure the impact of those measures. In the context of survivorship care and return to normal life, it is crucial to understand how many cancer patients obtaining a disability pension could be able to return to an active life if properly followed up after the

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