



# Goals of Survivorship Care

# 2

Francesco De Lorenzo, Kathi Apostolidis, Adela Maghear, Stefano Guzzinati, Luigino Dal Maso, Enkeleint A. Mechili, and Nikolaos Mitsimponas

---

## Cancer Survivorship Care

Cancer survivor is defined as anyone with a diagnosis of cancer and who is still alive [1]. In recent years cancer survivorship has increased significantly and around 25% of people surviving after a cancer diagnosis have the same life expectancy as the general population. In Europe and in the United States, the number of individuals

---

F. De Lorenzo

European Cancer Patient Coalition - ECPC, Brussels, Belgium

Italian Federation of Cancer Patients Organizations, Rome, Italy

K. Apostolidis (✉)

European Cancer Patient Coalition - ECPC, Brussels, Belgium

Hellenic Cancer Federation, Athens, Greece

e-mail: [kathi.apostolidis@ecpc.org](mailto:kathi.apostolidis@ecpc.org)

A. Maghear

European Cancer patient Coalition (ECPC), Brussels, Belgium

e-mail: [adela.maghear@ecpc.org](mailto:adela.maghear@ecpc.org)

S. Guzzinati

Registro Tumori Veneto, Azienda Zero, Padova, Italy

e-mail: [stefano.guzzinati@azero.veneto.it](mailto:stefano.guzzinati@azero.veneto.it)

L. Dal Maso

Epidemiologia Oncologica, Centro di Riferimento Oncologico (CRO), IRCCS, Aviano, Italy

e-mail: [dalmaso@cro.it](mailto:dalmaso@cro.it)

E. A. Mechili

Clinic of Social and Family Medicine, School of Medicine, University of Crete, Crete, Greece

Department of Healthcare, Faculty of Public Health, University of Vlora, Vlora, Albania

e-mail: [mechili@univlora.edu.al](mailto:mechili@univlora.edu.al)

N. Mitsimponas

HYGEIA Hospital, Athens, Greece

living after a cancer diagnosis (i.e., cancer prevalence) is growing by approximately 3% annually. They currently represent more than 5% of the overall population in high-income countries (i.e., at least 20 million in Europe and 17 million in the USA) [2–4].

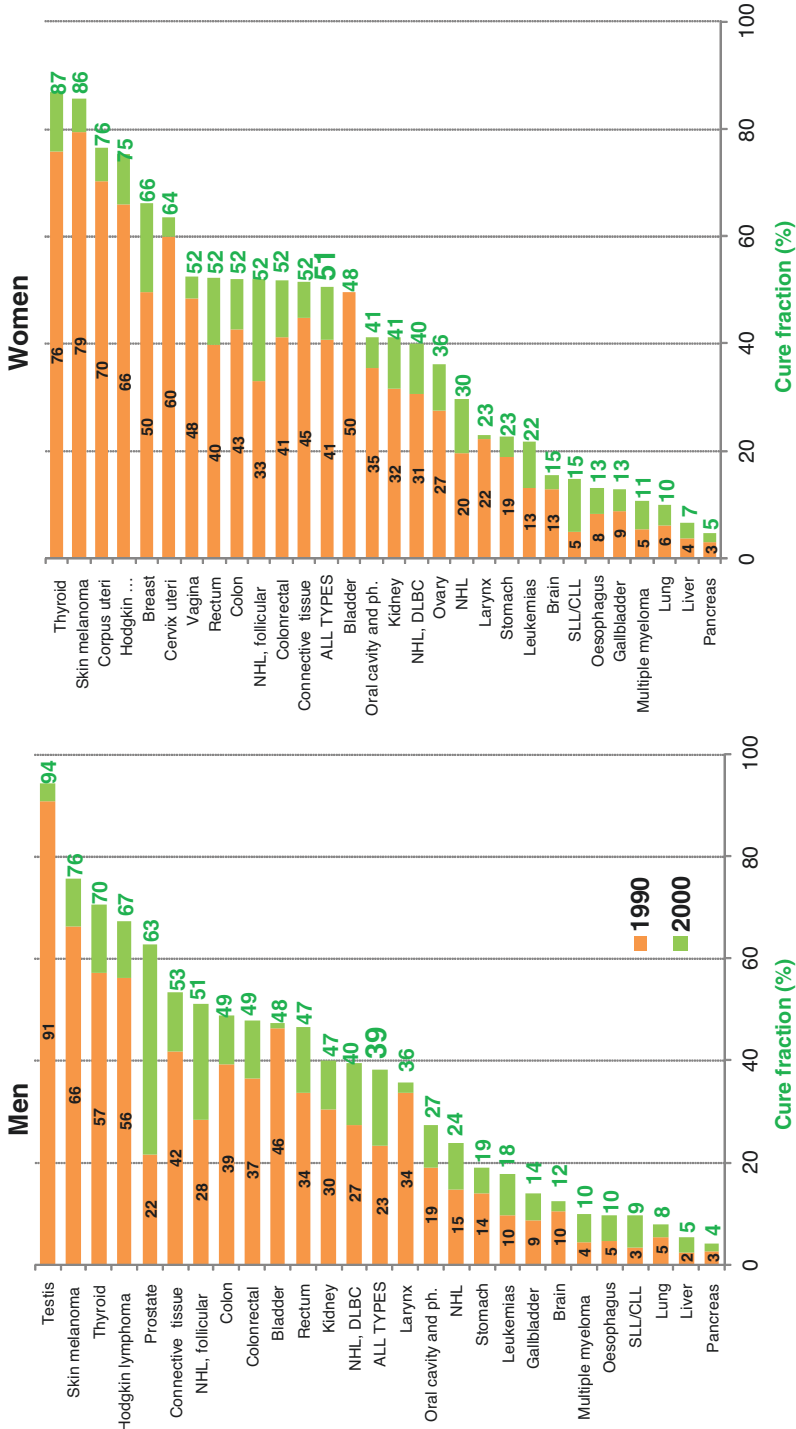
A recent study has estimated population-based indicators of cancer cure in Europe by type, sex, age, and period [5]. The study used information from the EURO CARE-5 dataset, including 7.2 million cancer patients (42 population-based cancer registries in 17 European countries) diagnosed at ages 15–74 years in 1990–2007 and at least 18 years of follow-up. Cure fraction was defined as the proportion of cancer patients having the same mortality rates as those observed in the general population of the same sex and age.

The cure fraction of European cancer patients increased in the 10 years examined, in both sexes (Fig. 2.1) reaching 39% among men and 51% among women, for all cancer types combined, diagnosed in 2000 at all ages (15–74 years). The cure fraction was 94% in men, when the diagnosis was testicular cancer, 76% in men and 86% in women with skin melanoma, 70% in men and 87% in women with thyroid cancer, 67% in men and 75% in women with Hodgkin lymphomas. Cure fraction was also 76% for patients with cancers of corpus uteri, 66% for those with cancer of the breast, 64% for those with cancers of the cervix uteri, and 63% for those with cancers of the prostate. On the other hand, the proportion of cure was very low (below 15%) when the diagnosis was a cancer of the pancreas, liver, esophagus, lung, brain, chronic leukemia, and myelomas.

Notably, two-thirds of cancer patients, diagnosed at age 15–44 years (65% in men and 69% in women), were expected to be cured, while the proportion was approximately one-third for patients aged 65–74 years (33% in men and 38% in women).

Further studies explored other indicators of cancer cure [6, 7]. In particular, an Italian study [7] reported that, up to 2010, 27% of all prevalent cases (20% in men and 33% in women) could be considered as “already cured cancer patients” since their life expectancy (mortality rates) had become indistinguishable from that of the general population of the same age and sex. Assuming similar proportions for the European population, people living after a cancer diagnosis in 2020 who can be considered as already cured are at least five million, 1% of the overall population.

These results confirm the need to reconsider the current paradigm of survivorship as a never-ending experience. To recognize the increasing number of patients who will reach or have already reached a life expectancy similar to that of the general population provides an opportunity to improve quality of life by changing the way “former” patients view themselves, and it allows patients to return to their regular lives. The European Commission has recently acknowledged this need through the “Mission on Cancer” and “European Cancer Plan,” currently under approval. Currently, it is more important than ever to develop a concrete plan for the support of cancer patients after treatment. At the moment they will be considered free of disease (i.e., cured), we need to have a roadmap for future follow-up, if needed, and rehabilitation.



**Fig. 2.1** Cure fraction after a cancer diagnosis in Europe, according to cancer type and year of diagnosis (adapted from [5])

## Domains of Cancer Survivorship Care

According to the National Academy of Medicine report, titled “From Cancer Patient to Cancer Survivor: Lost in Translation” a cancer survivor’s experience entails the entire range of the cancer pathway, i.e., diagnosis, treatment, remission, surveillance, after-cancer care, and end of life. As a definition and provision of care, survivorship pertains to the problems that are related to the capacity of a patient to obtain healthcare and follow-up treatment, late effects of treatment, second cancers, and quality of life. In the same report, it is highlighted that the essential goal of survivorship care is to shift cancer care from a model of illness to one of wellness.

For the delivery of survivorship care, the National Academy of Medicine defines four different components of healthcare provision to cancer survivors:

- **Cancer surveillance and screening:** In this level, surveillance is performed in order to identify possible recurrence of the primary malignancy and evaluate the likelihood of any second cancer.
- **Late effects and side effects management:** Regarding the late effects’ management, there is ongoing research both for childhood and adult patient’s types of cancer. The main aim of this research is to identify the potential late effects of cancer treatment and provide clinicians and caregivers with the tools to identify them promptly, and support more efficiently cancer survivors. The relevant body of research monitors the level of health maintenance and vital organs function that may be related to each treatment received.
- **Risk reduction and cancer prevention:** Regarding the risk reduction and prevention of future cancer occurrence, various behavioral interventions are suggested, in order to promote lifestyle changes, that have the possibility to reduce cancer incidence, but also several other illnesses, such as smoking cessation, healthy living, energy balance, and dietary changes.
- **Psychosocial functioning:** The psychosocial and economic consequences of surviving cancer treatments are equally important with the aforementioned, physical late effects. Cancer survivors and their families have to address many challenges, including economic burden, loss or interruption of social relationships, as well as emotional suffering that can last for a long time after a therapy is completed [8].

As someone can understand from the components, the healthcare support that is needed for cancer survivors requires the involvement of many different disciplines. Even more, depending on the age, cancer survivors may need support from even a more complex web of different healthcare services and practitioners. Among elderly people, we can have the existence and interaction between multiple chronic conditions and different medications, occasionally the absence of social support, as well as particular goals of therapy (e.g., aggressive—and many times more effective—types of therapies are not suitable for this cohort of cancer survivors). Survivorship care needs to be a healthcare service that will continuously evolve to adapt to older adults’ health needs.

According to the summary of evidence by Halpern et al., there are various models describing the delivery of such survivorship care [9]. These different models of survivorship care can be disease-specific or general, dependent on different types of cancer care professionals, as well as focusing on the care provided in separate survivorship clinics where cancer treatment was received or focusing on integrating survivorship care into a broader oncology practice.

Depending on whom among the clinicians (e.g., oncologists, primary care providers (PCP), or a combination of both) is managing survivorship care, a cancer survivor may get different types and intensity of care. Primary care providers and cancer specialists may have different priorities and scope on how they deliver cancer survivorship care; they may also have differing knowledge and clinical skills. In a similar fashion, cancer survivors may have different views about the importance of their various healthcare providers. In this manner, the models of survivorship that have been proposed were primary care-based (e.g., a primary care provider manages the survivorship care), specialty care-based (e.g., an oncologist takes ownership of survivorship care), and shared care models (e.g., joint management and responsibility of survivorship care).

Among these, the shared care model has been suggested to be the best way to optimize care for cancer survivors and guarantee high-quality care. Shared care allows for flexibility in providers' roles and responsibilities over time. It can also be flexible and efficient to the different needs of cancer survivors, which are dependent on time since diagnosis and completion of treatment, as well as recurrence status, and presence of other chronic conditions. It is noteworthy to mention, that a successful shared care model needs a tailored integration of primary care and specialty multidisciplinary healthcare providers with expertise in oncology, as well as in geriatric care for older cancer patients. The follow-up of cured and disease-free cancer patients will be at best delivered within cancer centers or oncological hospitals but separately from the oncology department to avoid that the specialized human resources are diverted from treating cancer patients in the acute phase of treatment. A crucial element of the shared care model is the need to have an established, interactive communication channel (e.g., with the use of well-designed e-health interventions) between primary care and specialty care providers. Many diseases such as nutritional and metabolic problems are common for cancer patients. Many oncologists seem to focus just on the disease (cancer) treatment while neglecting other health issues [10].

Finally, another model of cancer survivorship care delivery is risk-stratified care. In this model, the frequency of encounters with cancer specialists is directly related to patients' clinical needs, including the risk of recurrence and their late effects. For example, an older woman diagnosed with early-stage breast cancer treated with excision alone might not need to see a medical oncologist for ongoing care. Instead, she could transition to being managed exclusively by her PCP unless she experiences a recurrence for which she will receive specialty care. Integration of both psychosocial and somatic rehabilitation for cancer survivorship is clearly proposed under the fourth pillar of the Europe Beating Cancer Plan. Provision of patient-centered services from a multidisciplinary team and focusing on education, increase

of patient involvement in research, and dissemination of information should be at the core of survivorship care strategy. The active involvement of patients in their care is critical to better understand their needs, wishes, and preferences.

---

## **Cancer Survivorship Care Plan and Rehabilitation Targets**

### **Cancer Survivorship Care Plan**

In Recommendation 7, the Mission on Cancer calls for an “EU-wide research programme and policy support to improve the quality of life of cancer patients and survivors, family members and caregivers, and all persons with an increased risk of cancer” [11].

Such a program should aim to:

- develop a methodology to assess the health-related quality of life;
- develop tools to enable patient involvement in decision making;
- establish comprehensive programs at the international level based on patient-reported outcomes to monitor the physical and psychosocial needs of cancer survivors (e.g., return to work, fertility, sexuality, reconstruction surgery, dental health, cognitive functioning, fear of recurrence, etc.);
- support research to close the knowledge gaps regarding the negative consequence that a cancer diagnosis or treatment has on a patient’s physical, mental, and social health, both in the short and long term;
- develop long-term follow-up programs to better understand the needs and challenges of pediatric and young cancer patients;
- initiate research to assess the discrepancies and discrimination that cancer survivors face in different countries, including their access to legal and financial services (e.g., loans, mortgages, life insurance);
- support research into prediction models for the side effects of cancer therapies;
- assess the efficacy of the survivorship care programs initiated by different health systems;
- develop research to assess both the direct and indirect economic consequences that cancer survivors and their relatives have to cope with [12].

Cancer survivors are a vulnerable population that requires medical and nonmedical interventions and is particularly at risk not only of having a low quality of life due to the long-term side effects of treatment with consequences for patients’ physical, mental, and social health but also, as the majority of cancer survivors are above 65 years of age, they are at risk of developing another cancer. Other factors that influence the quality of life of cancer survivors are the cancer-related comorbidities, reaction to stress, stigmatization, the survivor’s socioeconomic status, and access to quality healthcare and rehabilitation services [13].

For many people it is very difficult to remember all the details of cancer treatment, to record the needs that are rising during the treatment, and afterward to have

steadily on mind the plan of the follow-up care [14]. This need of survivorship care can be fulfilled with the existence of a structured and detailed survivorship care plan. Keeping a personal healthcare record can be useful and facilitate all the process.

Using this tool in survivorship care can facilitate the everyday life of cancer survivors and can reduce the pressure and the amount of work from the healthcare professionals.

Survivorship care plan should be individualized to the needs of each patient. The survivorship care plan should be customized to the needs of each cancer survivor, and should include basic information about the cancer type, the type of therapy received (biologic therapy, chemotherapy, surgery, radiotherapy, etc.), the possible side effects experienced from the therapy/ies and the other needs that possibly can arise during the period of therapy and afterward.

Furthermore, the essential role of survivorship care plan can be highlighted through the fact that survivorship care plan can be a useful tool for the oncology team of each cancer survivor as for the other healthcare professionals that are related with the cancer survivors. Healthcare professionals can use the survivorship care plan in order to carry out a structured and detailed follow-up [14].

Summary of cancer treatment consists of details about the personal medical history of the patient, the family medical history and a possible genetic counseling, information about the time of diagnosis, and the kind and sequence of treatment/s. The main contributors to the cancer treatment are basically the oncology team (medical oncologist, radiation oncologist, surgeon, nurses).

The after-treatment care plan includes the follow-up care plan (when should patient perform the suitable follow-up exams like computer tomography or laboratory exams, or other tests) and taking advice from your care team about tasks of the everyday life like sleep, exercise, sunscreen, immunizations, healthy weight programs, and helping to quit with smoking. Moreover, in the after-care plan are included other issues like providing psychosocial support to those who need it, financial planning, money and job problems, and problems in the relationship with friends and family. All the abovementioned parts of survivorship care plan are aspects of everyday life, that strongly concern most of the cancer survivors and that probably seek to be resolved [14–22].

## Rehabilitation Targets

Cancer and its treatment produce a multidimensional impact on patients' lives, affecting the physical, sensorial, cognitive, psychological, family, social, and spiritual functional level of each individual cancer survivor. The problems that can arise through this situation can affect the daily activities or the procedure of returning back to work or even have a long-lasting effect on the health of cancer survivors. Cancer rehabilitation is one of the most important milestones in cancer survivorship care. It can help cancer survivors cope in a comfortable way with the problems that can arise during and after the cancer treatment or problems that can arise through

the disease itself and it can help cancer survivors in optimizing the quality of life and recovering the normalcy of their lives.

Rehabilitation programs can be organized as separate outpatient programs delivered by a multidisciplinary team of healthcare professionals within cancer centers or oncological hospitals or can be delivered by specialized clinics. The goal of such rehabilitation programs is mainly to help as many people as possible to recover from the physical or psychological problems, that can be caused during the cancer trajectory and through the phase of the main treatment and support patients to become as productive and independent as possible.

Rehabilitation is useful not only for the patient's life but also for their families. Provision of psychological support for the entire family and the patient is a crucial aspect in survivorship. Such support can contribute to better management of different emotions and can improve quality of life. To achieve this, accredited infrastructures should be built, with geographical distribution, such as the Comprehensive Cancer Centers (CCCs) [1]. The 34 CCCs that currently are in operation in Europe cannot cope with the present demand for cancer care, and, therefore, measures should be taken to ensure that such centers will be established in all countries, while in bigger countries there should be one CCC per five million inhabitants. Structuring the collaboration between accredited CCCs will support innovation and cover the entire cancer research continuum for both cancer care and early detection methods. This impacts early translational research, clinical trials, outcomes research, and health economics [1].

- As a milestone of cancer survivorship care cancer rehabilitation has multidimensional targets, which consist of many aspects of the everyday life of cancer survivors such as:
- Overcoming as soon as possible the side effects that can be caused through the cancer treatment or learning to manage possible side effects and coping with them.
- Improving physical and psychological conditions in order to offset any limitations caused through the cancer trajectory.
- Getting back a good physical condition in order to return to everyday life.
- Improving or even regaining self-confidence and self-awareness.
- Learning to manage and whenever it is possible to overcome mobility problems (getting out of a chair, walking, getting dressed, etc.) or cognitive problems (difficulty thinking clearly, memory problems, etc.).
- Becoming more independent and less reliant on physicians and reducing the number of hospitalizations.
- Learning how to adopt healthy everyday habits like exercise, balanced and healthy diet, and preserving or achieving a healthy weight.
- Getting advices and ideas on how to cope with problems like family issues, problems in the relationship with friends, partner, or kids.

The goal of cancer rehabilitation at the end of the day is to help cancer survivors stay as active as possible in order to go back to work and to regain the most if not



every aspect of the everyday life before cancer, to improve the quality of life, to reduce the possible side effects and symptoms of cancer or its treatment, and to help the cancer survivors to be more independent and confident. Toward this direction establishment of survivorship cancer clinics could help significantly. These clinics should include a multidisciplinary staff that can provide person-centered services. This is of paramount significance because patients after the acute care are usually left. These centers except those that can be used for further survivorship research can also help in provision of psychosocial interventions and rehabilitation. Additionally, patient empowerment can take place in these comprehensive clinics [13].

Despite the high number of cancer patients who survive, most of the EU countries have a lack of integrated rehabilitation policies. On the one hand, we have the lack of knowledge and experiences of healthcare personnel on cancer patient rehabilitation while on the other hand research data lacks on late effects of cancer and its treatment [14–23].

---

## The Different Needs for Survivorship Care

Cancer survivors range from cured people, free of disease 5 or 10 years after completion of treatment, to people who continue to receive treatment to reduce the risk of recurrence, and people with well-controlled disease and few symptoms, who receive treatment to manage cancer as a chronic disease. Cancer survivors can be people from all age groups including kids, adolescents and young adults, adult, and elderly people.

Survivorship care covers issues related to follow-up care, to the management of late side effects of treatment, to the improvement of quality of life, psychological, and emotional health. Survivorship care includes also future anticancer treatment where applicable. Family members, friends, and caregivers should also be considered as part of the survivorship experience.

Following the policy recommendations on cancer survivorship of the EU Joint Action on Cancer Control [20, 23], the European Cancer Patient Coalition-ECPC has collaborated with the European Society of Medical Oncology-ESMO in developing the Patient Guide on Survivorship. The Guide offers to patients and their families information in coping with the new reality of survivorship, on preventive health, follow-up care and most importantly, it includes the Survivorship checklist, care plan, and treatment summary that each oncology specialty clinician should fill in at the completion of each acute treatment modality for cancer patients free of disease (Fig. 2.2).

The collaboration of ECPC with ESMO was also extended to the clinical guidelines thus new and revised guidelines include also survivorship information that helps oncologists understand that cancer care after acute treatment enters a new phase: survivorship with its own requirements for care and follow-up.

Different key factors can explain the heterogeneity of needs among cancer survivors. The time of the survivorship caregiving, the type and stage of cancer, and the



status of treatment and in many cases the different age between cancer survivors are some of these factors. Furthermore, in the needs of survivorship care should be included the needs of family caregivers.

The role of a supportive network around the cancer patient cannot be emphasized enough: family, friends, colleagues, and community can play a significant role in managing emotional problems and assist patients to return to normal life. Some patients find it easier to discuss their concerns with people who experienced same cancer. A critical issue for this is patient empowerment which should be a role of healthcare professionals.

The type and stage of cancer and the consequent therapeutic procedures can significantly affect the type of needs, that a cancer survivor can have. Patients at the end of acute care treatment worry about the possible current or future side effects of their treatments. Furthermore, they possibly worry about the return to their normal habits and normal life.

People who completed their treatment and are considered cured after 5 or 10 years from the end of their treatment have different concerns and needs, like maintaining a healthy lifestyle, making their regular annual screening, returning to work, assuring their financial sustainability, regaining control of their life. People, who cope with cancer as a chronic disease, have different worries and different priorities focused on keeping the disease under control, maintaining the quality of life, and assuring the possibility to work [14].

Among cancer survivors, there are different views concerning essential needs of survivorship care. Some consider physical rehabilitation and regaining of the physical strength that they may have had before the cancer diagnosis, as the goals of the survivorship care. Others consider essential the psychological aspects of their lives that were affected by cancer and seek solutions through survivorship care. Others may have employment or financial issues as their main priority and as a result, their needs in the survivorship period will be heavily affected.

Cancer incidence is higher in the population around +65 years; however, cancer affects also children, adolescents, and young adults. Cancer is experienced differently by patients in different age groups which, consequently, have different needs during cancer survivorship.

Children and their parents may have worries about how cancer can affect their relationship with brothers, sisters, and friends. Young adults most often may have concerns about sexual life, relationship status, their education and job finding, as well as fear of recurrence.

Family caregivers are also a crucial part of the cancer pathway and of the survivorship experience and their needs are most often overlooked. Caregivers' needs differ depending on their age, employment status, their own health condition, and depending on whether the patient is in the acute phase of treatment or in survivorship status. Former caregivers (caregivers of patients who are in remission) could have different needs from current caregivers or bereaved caregivers. Former caregivers' basic needs consist of issues like managing interpersonal relationships or reintegration to family and social life and work. Current caregivers could have as main concerns issues like meeting patients' complex demands, maintaining

intimacy with partners, balancing own and patient's needs, and making decisions in the context of uncertainty. On the other hand, bereaved family caregivers have different needs like managing psychological distress and managing the loss of the patient, often struggling with financial issues that the disease has generated. Research into survivorship issues that will examine the variety of needs that can arise during the survivorship period will contribute to improving survivorship care [1, 24–29].

---

## The Impact of National Disparities on Survivorship Care

Disparities in access to survivorship care are evident and are based on gender, age, ethnicity, geographical location, health status, etc. [30–32]. Different strategies exist for merging these disparities and they have been presented in official documents [33, 34]. Among European countries, different inequalities (between and within countries) exist in early detection, diagnosis, management, treatment, rehabilitation, adequate information, and bureaucratic issues that cancer patients have to deal with [34]. These inequalities are reflected in cancer outcomes, with the underprivileged having worse health outcomes due to worse access to healthcare services during and after the disease.

During the last decades, significant improvements have been achieved in health technology, which have impacted significantly in health outcomes. However, the rate of cancer incidence increases annually. Around 20% and 16.7% of male and female world population respectively will develop cancer in their lifespan and 12.5% and 9% of them will die of cancer [35].

Cancer inequalities, as highlighted in “Challenging the Europe of Disparities in Cancer-A Framework for Improved Survival and Better Quality of Life for European Cancer Patients” [35, 36] divide Europe from East to West and from North to South. Such disparities must be addressed to ensure that the provisions of the EU Beating Cancer Plan can be met and that they can benefit all European citizens.

Western and Northern countries are doing much better than the Southern and Eastern countries [37]. The Western and Northern European countries have better healthcare systems and provide better access to early detection programs and services and try to decrease the financial impact of the disease [38]. In Bulgaria for instance, only 6% of cancer diagnosis was the result of screening programs while the 94% was the result of a medical appointment for another health problem [39]. These disparities exist not only at the screening or diagnosis level but also with cancer treatment. After being disease-free, patients lack sufficient rehabilitation, psychosocial support services, and continuity of care. Cancer survivors report lower health status than before cancer experience, less health information, as well as that their family members do not look for information on cancer and that their income is low [40]. Inequalities in cancer are also illustrated by the fact that survival rates are also much lower in the Southern and Eastern European countries compared to the Northern and Western ones.

Survivorship research is of paramount importance to address the gaps and inequalities in survivorship care. As A. Berns et al. (2020) mention, we need first of all the appropriate infrastructure to translate research into actions. Many times, research just remains in published papers and is not implemented to respond to the needs of people. Involvement of different actors (stakeholders, policymakers, patient coalitions, etc.) in research is a key component of implementation. Implementation of clinical and prevention trials that would include also health economics, therapeutic interventions, and tertiary prevention measures should be a high priority of both researchers and policymakers.

In order to eliminate inequalities, different actions have been undertaken by CDC [41], while the EU Joint Action on Cancer Control (CanCon) has made clear recommendations in this area [42]. Some of the key recommendations proposed by the Joint Action on Cancer Control (CanCon) are [42]:

1. Embed equity within the cancer prevention and control policies in all European Union Member States.
2. Align cancer prevention and control policies with a Health in all Policies approach.
3. Adopt a Health Equity Impact Assessment framework.
4. Engage and empower communities and patients in cancer prevention and control activities.
5. Support the development of European research programs that help deliver equity in cancer prevention and control in all European Union Member States.
6. Improve equitable access and compliance with cancer screening programs.
7. Ensure equitable access to timely, high-quality, and multidisciplinary cancer care.
8. Ensure equitable access to high-quality surgical care in all European Union Member States.
9. Ensure that all patients have timely access to appropriate systemic therapy.
10. Develop national cancer rehabilitation and survivorship policies, underpinned by an equity perspective.

---

## The Cancer Stigma and Cancer Advocacy

Despite the improvements in diagnosis, treatment, technology, and life expectancy, cancer continues to be seen as a stigmatizing disease. Stigma relates to cancer as a life-threatening condition [43–45]. Thinking about the disease can remind patients about their feelings at the time of diagnosis and treatment, such as fear, stress, depression, awkwardness, self-criticism, shame, guilt, and low self-esteem. [46, 47]. These feelings emerge because of still prevailing beliefs that a cancer diagnosis is a death sentence [48]. However, stigma does not affect only cancer patients themselves, but it also permeates into and impacts society.

The Joint Action on Cancer Control (CanCon) has paved the way toward reducing the cancer burden within the European Union by proposing policy

recommendations aimed at improving the delivery of cancer care and the quality of life of cancer patients and survivors. The policy recommendations coupled with the policy papers that accompany the main deliverable can support EU member states to prioritize cancer on their health agendas and to plan and implement high-quality rehabilitation and survivorship care for their citizens [49].

The focus points proposed by the Joint Action on Cancer Control cover the following aspects:

1. The need for a personalized follow-up program for each cancer survivor that includes the management of late effects and foresees the patient's needs for tertiary prevention; such programs should be implemented with the active involvement of survivors and their relatives.
2. The need to rethink the early detection of patients' needs and to improve their access to rehabilitation, psychosocial, and palliative care services.
3. The need for an integrated and multidisciplinary care framework that would enable the implementation of a survivorship care plan that can enhance patient empowerment and quality of life.
4. The need to foresee and address the late effects of cancer and its associated treatments pose to children, adolescents, and young adult survivors.
5. The need for enhanced research in survivorship in order to provide data on late effects and to assess the impact and cost-effectiveness of supportive care, rehabilitation, palliative, and psychosocial care interventions [50].

On the other hand, survivorship features high on both current European Commission emblematic initiatives: the European Cancer Plan and the Cancer Mission in Horizon Europe. The EU Cancer Plan was published in February 2021 and aims to deal with the whole disease pathway. The policy document focuses on four core areas, on which the European Commission will concentrate its efforts: prevention, early detection, diagnosis, cancer treatment and quality of life. The EU Cancer Plan aims to foster European collaboration and support EU member states to strengthen their national cancer plans as well as to be better prepared for future challenges. The EU Cancer Plan focuses more on new approaches to cancer with a specific focus on new technologies, research, and innovation, in order to provide better patient-centered services [51]. Patient-centeredness is also closely connected with the "Cancer Mission", the new research and innovation program in health, included in Horizon Europe [52].

To impact society at large, the Mission on Cancer aims at bringing countries together to achieve a significant reduction of the enormous EU cancer burden and improve the quality of life of patients by promoting cost-effective, evidence-based best practices in cancer prevention, treatment, and care [1]. The main goal for the implementation of a mission-oriented approach to cancer in Horizon Europe was to achieve a 10-year cancer-specific survival for three-quarters of the adult patients diagnosed in the year 2030 in the Member States with a well-developed healthcare system [1, 12]. However, achieving this goal poses significant medical, socioeconomic, legal, and political challenges.

Positioned as the last component of the cancer research continuum and an integral part of translational research, survivorship research can influence the assessment of multiple patient outcomes, including the health-related quality of life and the socioeconomic factors impacting survivorship. Any data collection from cancer survivors may be useful to detect and reduce long-term side effects of treatment, as well as to improve rehabilitation and psychosocial services [49].

The development of pertinent strategies, aiming to address the long-term effects of cancer treatment and to improve the health-related quality of life of cancer patients, should pay particular attention to the gaps between research and cancer care and prevention that can be found in areas such as psychosocial oncology, supportive care, rehabilitation, palliative care, and survivorship. Outcomes research is key for both therapeutic interventions and the effectiveness of public health services and interventions. A high-quality cancer care requires multidisciplinary expertise and adequate resources, together with high-quality data. Furthermore, due to the expansion of new evidence for diagnostics and therapy, innovation is essential and should be tailored to the individual needs of patients. Integrating cancer care and prevention with research and education will boost innovation and deliver a comprehensive multidisciplinary cancer care framework [1, 11, 12, 35, 36, 46–55].

---

## Concluding Remarks

Europe counts currently 20 million cancer survivors and cured patients who, in most EU member states, do not receive any rehabilitation and survivorship care. The EU Cancer Plan sets an ambitious goal to be reached by 2030: a 10-year survival of 75% for cancer patients and living well after cancer.

Improvement of research and decrease of health inequalities in cancer care by improving cancer screening, early detection, equal access to treatment, and follow-up care are key strategies for European countries to reach the above goal. Provision of patient-centered services that focus on research, empowerment, education, and multidisciplinary care delivery should be the standard cancer care approach. Synergies among patients, researchers, civil society, stakeholders, and policymakers can help in establishing the patient-centric approach in the years to come, which is our key recommendation, which is also the core of the EU Cancer Plan.

Despite the high incidence of cancer, and abundant literature on health-related quality of life, patient-centricity, patient involvement in their care, there is a lack of concrete policies to ensure rehabilitation and lifelong survivorship care. Establishment of survivorship clinics in cancer centers, where multidisciplinary teams provide services can help in better rehabilitation and reintegration in social life and work. The multidisciplinary teams of these clinics can empower patients and provide tertiary prevention. Adaptation of patients to a healthier lifestyle can improve survivorship and health-related quality of life. Provision of detailed information and self-management education will decrease stress and make patients feel more confident and relying more on information from their medical team rather than from various Internet sources. The cancer survivorship care plan offering

information about the patient's diagnosis, treatment, and follow-up care [14] should become integrated into the discharge instructions of cancer patients across Europe. It will help any healthcare provider whom the cancer survivor will consult to have a clear picture of the patient's prior cancer experience, adverse events, and follow-up care. Digital health can play an important role, particularly in cancer supportive care settings, aiming to offer to cancer patients and survivors tools and assistance to cope with cancer care issues, and at the same time, improving the efficiency of the healthcare system and liberating health professionals time for taking care of patients in the acute phase [1, 2, 7]. Survivorship research and care will become increasingly important in the following years, as a result of the increasing numbers of "cured" patients and cancer survivors.

---

## References

1. Berns A, Ringborg U, Celis JE, Heitor M, Aaronson NK, Abou-Zeid N, Adami HO, Apostolidis K, Baumann M, Bardelli A, Bernards R. Towards a cancer mission in Horizon Europe: recommendations. *Mol Oncol*. 2020;14(8):1589–615.
2. Guzzinati S, Virdone S, De Angelis R, et al. Characteristics of people living in Italy after a cancer diagnosis in 2010 and projections to 2020. *BMC Cancer*. 2018;18:169.
3. Colonna M, Boussari O, Cowppli-Bony A, et al. Time trends and short term projections of cancer prevalence in France. *Cancer Epidemiol*. 2018;56:97–105.
4. National Cancer Institute. <https://www.cancer.gov> Accessed on 6 March 2021.
5. Dal Maso L, Panato C, Tavilla A, et al. The cure of cancer in Europe: results from the EURO CARE-5 study for 32 cancer types. *Int J Epidemiol*. 2020; <https://doi.org/10.1093/ije/dyaa128>.
6. Dal Maso L, Guzzinati S, Buzzoni C, et al. Long-term survival, prevalence, and cure of cancer: a population-based estimation for 818,902 Italian patients and 26 cancer types. *Ann Oncol*. 2014;25:2251–60.
7. AIRTUM Working Group. Italian cancer figures, report 2014. Prevalence and cure of cancer in Italy. *Epidemiol Prev*. 2014;38(Suppl 1):S1–S144. <https://www.registri-tumori.it/cms/pubblicazioni/i-tumori-italia-rapporto-2014-prevalenza-e-guarigione-da-tumore-italia>
8. Forum NC, National Academies of Sciences, Engineering, and Medicine. Long-Term Survivorship Care After Cancer Treatment: Proceedings of a Workshop.
9. Halpern MT, Viswanathan M, Evans TS, Birken SA, Basch E, Mayer DK. Models of cancer survivorship care: overview and summary of current evidence. *J Oncol Pract*. 2015;11(1):e19–27.
10. de Lorenzo F, Apostolidis K. The European Cancer Patient Coalition and its central role in connecting stakeholders to advance patient-centric solutions in the mission on cancer. *Mol Oncol*. 2019;13(3):653–66.
11. European Commission. Conquering cancer: mission possible. 2020.
12. Celis JE, Pavalkis D. A mission-oriented approach to cancer in Europe: a joint mission/vision 2030. *Mol Oncol*. 2017;11:1661–72.
13. Berns A, Ringborg U, Celis JE, Heitor M, Aaronson NK, et al. Towards a cancer mission in Horizon Europe: recommendations. *Mol Oncol*. 2020;14:1589–615.
14. ESMO Patient guide on survivorship. European Society of Medical Oncology.
15. Survivorship. Doctor approved patient information from American Society for Clinical Oncology.
16. Survivorship Care Plans. American Cancer Society.
17. Cancer treatment & survivorship facts & figures. American Cancer Society.
18. Ganz PA, Casillas J, Hahn EH. Ensuring quality care for cancer survivors: implementing the survivorship care plan. *Semin Oncol Nurs*. 2008;3(24):208–17.



19. Stout NL, Silver JK, Alfano CM, Ness KK, Gilchrist LS. Long-term survivorship care after cancer treatment: a new emphasis on the role of rehabilitation services. *Phys Ther*. 2019;99(1):10–3. <https://doi.org/10.1093/ptj/pzy115>.
20. Survivorship and Rehabilitation from CanCon (Cancer Control Joint Action).
21. Dennett AM, Elkins MR. Cancer rehabilitation. *J Physiother*. 2020;66(2):70–2. <https://doi.org/10.1016/j.jphys.2020.03.004>. Epub 2020 Apr 11
22. Hunter EG, Gibson RW, Arbesman M, D'Amico M. Systematic review of occupational therapy and adult cancer rehabilitation: part 1. Impact of physical activity and symptom management interventions. *Am J Occup Ther*. 2017;71(2):7102100030p1-7102100030p11. <https://doi.org/10.5014/ajot.2017.023564>.
23. Albrecht T, Andrés JB, Dalmas M, De Lorenzo F, Ferrari C, Honing C, Huovinen R, Kaasa S, Kiasuwa R, Knudsen AK, Ko W. Survivorship and rehabilitation: policy recommendations for quality improvement in cancer survivorship and rehabilitation in EU Member States. *European Guide on Quality Improvement in Comprehensive Cancer Control*. Scientific Institute of Public Health, National Institute of Public Health, Brussels. 2017.
24. Mayer DK, Nasso SF, Earp JA. Defining cancer survivors, their needs, and perspectives on survivorship health care in the USA. *Lancet Oncol*. 2017;18(1):e11–e18. [https://doi.org/10.1016/S1470-2045\(16\)30573-3](https://doi.org/10.1016/S1470-2045(16)30573-3). PMID: 28049573.
25. Ganz P. Survivorship: adult cancer survivors. *Prim Care Clin Office Pract*. 2009;36:721–41.
26. Cancer treatment & survivorship facts & figures 2016–2017. American Cancer Society.
27. Shakeel S, Tung J, Rahal R, Finley C. Evaluation of factors associated with unmet needs in adult cancer survivors in Canada. *JAMA Netw Open*. 2020;3(3):e200506. <https://doi.org/10.1001/jamanetworkopen.2020.0506>. PMID: 32142127; PMCID: PMC7060489
28. Jacobsen PB, Nipp RD, Ganz PA. Addressing the survivorship care needs of patients receiving extended cancer treatment. *Am Soc Clin Oncol Educ Book*. 2017;37:674–83. [https://doi.org/10.1200/EDBK\\_175673](https://doi.org/10.1200/EDBK_175673).
29. Kim Y, Carver CS, Ting A. Family caregivers' unmet needs in long-term cancer survivorship. *Semin Oncol Nurs*. 2019;35(4):380–3. <https://doi.org/10.1016/j.soncn.2019.06.012>. Epub 2019 Jun 20. PMID: 31230929; PMCID: PMC6660396
30. National Research Council. From cancer patient to cancer survivor: lost in transition. National Academies Press; 2005.
31. Yabroff KR, Lawrence WF, Clauser S, Davis WW, Brown ML. Burden of illness in cancer survivors: findings from a population-based national sample. *J Natl Cancer Inst*. 2004;96(17):1322–30.
32. Weaver KE, Geiger AM, Lu L, Case LD. Rural-urban disparities in health status among US cancer survivors. *Cancer*. 2013;119(5):1050–7.
33. US Department of Health and Human Services. National Prevention Council, National Prevention Strategy. Washington, DC: US Office of the Surgeon General; 2011.
34. European Cancer Patient Coalition (2015) Challenging the Europe of disparities in cancer. <http://www.ecpc.org/activities/policy-and-advocacy/policy-initiatives/europeof-disparities> (accessed 6 March 2021).
35. Lawler M, Le Chevalier T, Murphy MJ, Banks I, Conte P, De Lorenzo F, Meunier F, Pinedo HM, Selby P, et al. A catalyst for change: the European cancer patient's bill of rights. *Oncologist*. 2014:1–8.
36. Challenging the Europe of disparities in cancer—a framework for improved survival and better quality of life for European cancer patients on behalf of the Europe of disparities in cancer—Working Group (Chair: Lawler M, Members: Apostolidis K., Banks I., Florindi F., Militaru M., Price R., Sullivan R., de Lorenzo F).
37. De Angelis R, Sant M, Coleman M, Francisci S, Baili P, Pierannunzio D, et al. Cancer survival in Europe 1999–2007 by country and age: results of EURO CARE-5—a population-based study. *Lancet Oncol*. 2014;15(1):23–34.
38. Solar O, Irwin A. A conceptual framework for action on the social determinants of health. Geneva: World Health Organization; 2010.

39. Euractive. Tackling disparities in cancer care across the central and eastern European region. [https://www.euractive.com/section/health-consumers/opinion/tackling-disparities-in-cancer-care-across-the-central-and-eastern-european-region/#\\_blank](https://www.euractive.com/section/health-consumers/opinion/tackling-disparities-in-cancer-care-across-the-central-and-eastern-european-region/#_blank) Accessed on 6 March 2021.
40. Jung M, Ramanadhan S, Viswanath K. Effect of information seeking and avoidance behavior on self-rated health status among cancer survivors. *Patient Educ Couns*. 2013;92(1):100–6.
41. Smith JL, Hall IJ. Advancing health equity in cancer survivorship: opportunities for public health. *Am J Prev Med*. 2015;49(6):S477–82.
42. Peiró Pérez R, Molina Barceló A, De Lorenzo F, et al. Policy paper on tackling social inequalities in cancer prevention and control for the European population. [https://cancercontrol.eu/archived/uploads/PolicyPapers27032017/Policy\\_Paper\\_4\\_Tackling.pdf](https://cancercontrol.eu/archived/uploads/PolicyPapers27032017/Policy_Paper_4_Tackling.pdf).
43. Yılmaz M, Dissiz G, Usluoğlu AK, Iriz S, Demir F, Alacacioglu A. Cancer-related stigma and depression in cancer patients in a middle-income country. *Asia Pac J Oncol Nurs*. 2019;7(1):95–102. [https://doi.org/10.4103/apjon.apjon\\_45\\_19](https://doi.org/10.4103/apjon.apjon_45_19).
44. Ernst J, Mehnert A, Dietz A, et al. Perceived stigmatization and its impact on quality of life - results from a large register-based study including breast, colon, prostate and lung cancer patients. *BMC Cancer*. 2017;17:741. <https://doi.org/10.1186/s12885-017-3742-2>.
45. Williamson TJ, Choi AK, Kim JC, Garon EB, Shapiro JR, Irwin MR, Goldman JW, Borynayan K, Carroll JM, Stanton AL. A longitudinal investigation of internalized stigma, constrained disclosure, and quality of life across 12 weeks in lung cancer patients on active oncologic treatment. *J Thorac Oncol*. 2018;13(9):1284–93.,ISSN 1556-0864. <https://doi.org/10.1016/j.jtho.2018.06.018>.
46. Vrinten C, Gallagher A, Waller J, Marlow LA. Cancer stigma and cancer screening attendance: a population based survey in England. *BMC Cancer*. 2019;19(1):1.
47. Margetic BA, Kukulj S, Galic K, Zolj BS, Jakšić N. Personality and stigma in lung cancer patients. *Psychiatr Danub*. 2020;32(4):S528–32.
48. Agustina E, Dodd RH, Waller J, Vrinten C. Understanding middle-aged and older adults' first associations with the word “cancer”: a mixed methods study in England. *Psycho-Oncology*. 2018;27(1):309–15.
49. Cancer Control Joint Action (CanCon), 2017. <https://www.cancercontrol.eu/>, Accessed on 6 March 2021.
50. European Guide on Quality Improvement in Comprehensive Cancer Control, Chapter 7—Survivorship and Rehabilitation, 2017.
51. European Commission. Communication from the commission to the European parliament and the council Europe’s beating cancer plan. Brussels, 3.2.2021.
52. European Commission. Horizon Europe. The Commission’s proposal for Horizon Europe, strategic planning, implementation, news, related links. [https://ec.europa.eu/info/horizon-europe\\_en](https://ec.europa.eu/info/horizon-europe_en), Accessed on 6 March 2021.
53. Sontag S. *Illness as metaphor and AIDS and its metaphors*. Macmillan; 2001.
54. Dumas A, Allodji R, Fresneau B, Valteau-Couanet D, El-Fayech C, Pacquement H, Laprie A, Nguyen TD, Bondiau PY, Diallo I, et al. The right to be forgotten: a change in access to insurance and loans after childhood cancer? *J Cancer Surviv*. 2017;11:431–7.
55. Lagergren P, Schandl A, Aaronson NK, Adami H-O, de Lorenzo F, Denis L, Faithfull S, Liu L, Meunier F, Ulrich C. Cancer survivorship: an integral part of Europe’s research agenda. *Mol Oncol*. 2019:1–12. <https://doi.org/10.1002/1878-0261.12428>.