



European Guide on Quality Improvement in Comprehensive Cancer Control

Tit Albrecht, Régine Kiasuwa and Marc Van den Bulcke



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Survivorship and rehabilitation: policy recommendations for quality improvement in cancer survivorship and rehabilitation in EU Member States

Tit Albreht, Josep Maria Borrás Andrés, Miriam Dalmas, Francesco De Lorenzo, Claudia Ferrari, Cora Honing, Riikka Huovinen, Stein Kaasa, Régine Kiasuwa, Anne Kari Knudsen, Winne Ko, Hilde Krogstad, Vittorio Mattioli, Ana Molina Barceló, Rosana Peiró Pérez, Graziella Pourcel, Joan Prades, Liisa Pylkkanen, Julien Tognetti, Luzia Travado, Ingrid van den Neucker and Wendy Yared

Main messages

- 1 Cancer survivors' follow-up, late effect management and tertiary prevention needs to be anticipated, personalized and implemented into care pathways, with active participation of survivors and relatives.
- 2 Improvement of early detection of patients' needs and their access to rehabilitation, psychosocial and palliative care services is required.
- 3 An integrated and multiprofessional care approach with a coordination of community care providers and services are needed to implement a survivorship care plan that enhances patient's self-management and quality of life.
- 4 For children, adolescents and young adults survivors, late health and psychosocial effects of cancer and its treatments need to be anticipated and addressed.
- 5 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.

Introduction

The new cancer survivorship challenge: going beyond quality of care and ensuring quality of life

Over past decades, the number of cancer survivors has increased substantially in Europe as well as in most high-income countries, as a result of the ageing population, progress in early diagnosis and effectiveness of therapies. Survival from cancer is improving and the five-year global prevalence of all cancers in Europe was about 9.7 million people in 2012 (1).

However cancer survival still varies widely within Europe, with lower rates in eastern countries compared with Nordic and central European countries (2).

Whether being cured (disease-free) or not, cancer survivors do experience late and long-term effects of treatment, emotional distress and potentially tumour recurrence. These effects represent challenges for health care systems, which have to ensure their appropriate follow-up care and quality of life: moving from "how long" people live after diagnosis to "how well" people can expect to live from diagnosis onward.

Recognizing this, the Council of the European Union invited Member States to "take into account the psycho-social needs of patients and improve the quality of life for cancer patients through support, rehabilitation and palliative care" (3). Eurostat defines quality of life as "the functional capabilities that citizens should have available to effectively pursue their self-defined well-being, according to their own values and priorities" (4). The patient-centred approach is, therefore, of high importance in the planning of (any type of) care provision.

Many studies have investigated the issues in the follow-up care of cancer survivors (5–7) and found the most impeding factors for the quality of cancer follow-up care were poor coordination of care, lack of communication among health care providers, uncertainties about "who is responsible" for the follow-up care and occurrence of many psychosocial unmet needs.

Based on the Institute of Medicine recommendations (5), the (site-specific) templates developed by the American Society of Clinical Oncology for the follow-up care of cancer survivors recommended the use of survivorship care plans to overcome these issues (8). Despite great values, survivorship care plans are still scarcely used because of two main barriers (7,9): the feasibility of integrating them into practice and the human and financial resources required to develop and manage these plans.

At the moment, no clear consensus exists regarding the content, format, management and implementation of long-term follow-up care plans for cancer survivors. This chapter aims at reviewing the existing knowledge and evidence about these plans and at providing policy recommendations for health administrators and policy-makers in charge of cancer control in EU Member States, in order to facilitate or engage in the improvement of the quality of cancer survivor's care and life.³

³ Work Package 8 leaders: Claudia Ferrari, Graziella Pourcel and Julien Tognetti; contributors: Neil Aaronson, Christine Berling, Xavier Castells Oliveres, Claudia Cormio, Angela De Boer, Peter Duncan, Francesco Florindi, Francesco Giotta, Adam Glaser, Christoffer Johansen, Andrea Lisi, Jane Maher, Caroline Oakley, Francesca Romito, Tiina Saarto, Jelka Skerjanc, Hildrun Sundseth, Michele Tiraboschi and Gilles Vassal.

The definition of cancer survivorship

The cancer care pathway or continuum has evolved alongside treatment innovations, as did attempts to define cancer survivorship. First definitions were based on the three key phases of cancer treatment: patients recently diagnosed, patients who completed their treatment and experience periodic examinations and patients considered as “cured” (10). This can be summarized as “the experience of living with, through and beyond a diagnosis of cancer” (11).

Cancer treatment improvements implied the appearance of patients living cancer free for many years but who experience recurrence or develop second primary cancer, patients with intermittent periods of active disease (chronic cancers), patients living for many years with advanced cancers and those who live after the expected death (12).

For the purpose of this chapter, a cancer survivor is defined as anyone with a diagnosis of cancer and who is still alive. This includes patients having completed primary therapy and who are free of disease as well as those patients living with recurrent and/or advanced disease.

According to WHO (13), rehabilitation (though not cancer specific) is defined as “a process aimed at enabling them [people with disabilities] to reach and maintain their optimal physical, sensory, intellectual, psychological and social functional levels.” In fact, cancer may be seen as a chronic illness with patients enduring physical and psychological symptoms years after treatment.

A new paradigm to be integrated in the cancer care pathway

Several reviews and surveys have been conducted in order to identify the best model of care for improving the cancer survivor’s quality of care and quality of life (5,6,9). The best approach appears to be the use of survivorship care plans that include the provision of medical and nonmedical care. Two main models are used: the shared care model (see below) and specialized survivorship clinics (7). The choice of which to use mainly depends on the national health care system, including the role of primary care and the reimbursement scheme (insurance coverage).

Even though evidence shows the important added-value for patients, health care providers and health care systems from survivorship care plans, these plans are scarcely used and few cancer patients have access to one.

The provision of policy recommendations for the content, format, management and implementation of survivorship care plans in EU Member States is the main purpose of this chapter.

Methods

Results of the preliminary work on existing guidelines or plans for long-term follow-up care for cancer patients reported that four countries can be recognized as pioneers: the United States, Canada and Australia, which follow the work achieved by the Institute of Medicine (5), and the United Kingdom (14).

Recommendations from the Institute of Medicine (5) for the United States and from the National Cancer Survivorship Initiative for the United Kingdom (14) and the content of their follow-up care plans were compared and five key areas were identified for investigation in the field of long-term follow-up care for cancer patients:

- medical follow-up: management of the late effects and tertiary prevention
- psychological support
- social rehabilitation including employment issues
- empowerment of cancer survivors
- multidisciplinary approach and coordination of care providers.

Four cross-cutting issues received particular attention:

- care for childhood cancer survivors
- inequalities in survivorship
- cancer information and data registration
- research.

In order to collect evidence about these nine issues and to translate it into policy recommendations for EU Member States, a three-fold methodology has been used (see supplemental information on methodology provided at www.cancercontrol.eu).

First, a literature review has been conducted using key words for the search and spread sheets to report outcomes.

Second, a critical appraisal exercise has been organized with a deliberative process involving invited EU experts to discuss the results and their applicability in EU Member States.

Third, in order to have insights into what is in use in EU Member States for cancer follow-up care, a survey was launched and 21 replies from nine EU countries have been analysed and compared (Annex 7.1).

Results

Content of long-term cancer follow-up care plans

A total of 151 publications (see supplemental information provided at www.cancercontrol.eu) have been retained and synthesized in the following to present key evidence related to the management of the late effects, tertiary prevention, psychological support and social rehabilitation in cancer follow-up care.

According to the National Cancer Institute in the United States (15), a survivorship care plan is “a detailed plan for a patient’s follow-up care after treatment for a disease ends. In cancer, the plan is based on the type of cancer and the treatment the patient received. A survivorship care plan may include schedules for physical exams and medical tests ... Follow-up care also checks for health problems that may occur months or years after treatment ends ... and may also include information to help meet the emotional, social, legal, and financial needs of the patient. It may include referrals to specialists and recommendations for a healthy lifestyle, such as changes in diet and exercise and quitting smoking.”

Medical follow-up: management of late effects

Cancer and its treatment have both direct and indirect effects, such as treatment-induced cardiotoxicity (16–18), bone loss, fatigue, pain, depression, endocrine and fertility problems (19), and these are important elements for follow-up surveillance (7,20). The challenge is to identify the patients at risk of encountering late effects and thereafter use preventive measures to mitigate these effects as much as possible. Deterioration of physical, mental and social quality of life in survivorship is strongly connected to precarious situation (i.e. low income, unemployment and other socially disadvantageous positions) (21).

The evidence in the literature is incomplete for childhood, adolescent and young adult cancer survivorship. For this population, the late and long-term effects that negatively affect their health and well-being include cardiovascular diseases, neurocognitive functioning (22), sexual and reproductive functions (23) and renal and endocrine functions.

Findings suggest that there is a need for deeper understanding of factors associated with increased morbidity susceptibility. This means that elements such as genomics, personalized and behavioural medicine, treatment-related toxicities, psychology, cardiology and endocrinology, as well as genetic predisposition, should be examined (24). The relationships between cancer treatments and the natural ageing process, as well as the interaction of multiple morbidities, are issues that should be further explored (25).

Medical follow-up: tertiary prevention

According to the IARC, tertiary prevention is “the use of treatment and rehabilitation programmes to improve the outcome of illness among affected individuals” (26).

Healthy lifestyle has positive effects on the prevention and management of late effects and cancer recurrence (5,27). Healthy food, adequate physical activity (28,29), avoidance of excessive sun exposure, limited alcohol consumption, stress reduction (30) and smoking cessation are important elements to consider for increased and quality survival.

Some physical activity is better than none and exercise can safely be undertaken by all cancer patients even during the advanced stage of the disease (31). Physical activity during treatment has shown to increase the percentage of patients completing therapy (32,33). It is effective in reducing both physiological and psychological treatment-related effects; speeds up recovery after treatment; improves pain in neck, shoulder and axillary region in breast cancer (34); and may prevent cancer recurrence (35,36). Incontinence, fatigue, body constitution and quality of life can be improved by physical exercise for patients during and after prostate cancer (37).

Stress is considered a risk factor for cancer recurrence. Stress-management interventions have been proved to reduce mortality and, therefore, may be beneficial in the prevention of recurrence (38,39).

Survivorship care for patients with advanced cancer

Medical advances have enabled cancer patients to live longer with active advanced-stage diseases. Although the symptoms and medical needs are similar to those of disease-free survivors, psychosocial concerns are different (40).

Most publications address the early integration of supportive and palliative care into cancer care pathways of patients diagnosed with advanced cancers (41–44).

Alongside the symptoms and side-effects of cancer treatment (e.g. incontinence, neuropathy, hair loss, nausea), patients with advanced-stage disease have to face physical and psychological well-being fluctuations that have a disruptive impact on their ability and willingness to cope with treatment and to plan for the future (45).

As for disease-free survivors, patients with advanced cancer report many unmet psychosocial needs but also additional unmet information needs, particularly related to euthanasia, living wills, financial and legal issue and hospices (46,47).

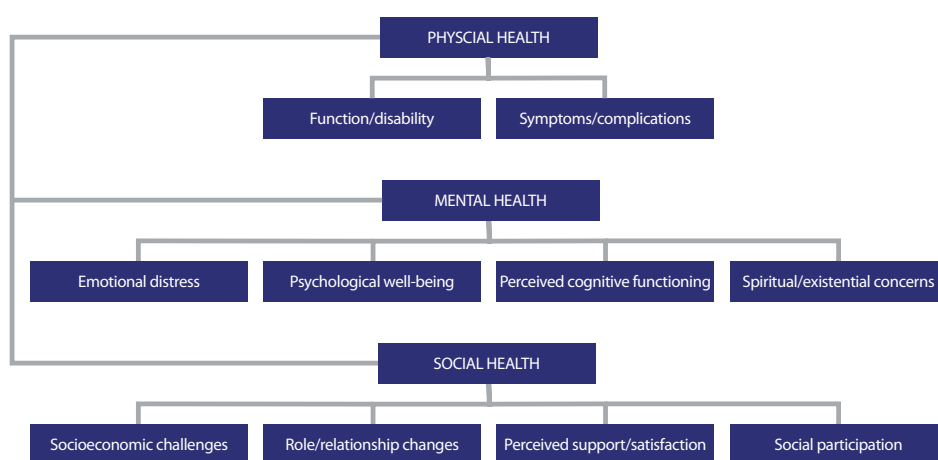
Patient-centred approach for long-term follow-up

Multidimensional needs' assessment as the starting point

The literature review showed that early and systematic detection of needs (Annex 7.2) in psychological support, social and physical rehabilitation, supportive and palliative care are necessary in order to orientate patients towards tailored health care interventions (48–50). It also demonstrated the necessity to anticipate certain issues that the patients and their relatives will face during the survivorship and rehabilitation period.

Measuring health-related quality of life should be integrated as an early, systematic and recurrent step in the long-term follow-up care of cancer survivors (51) (Fig. 7.1). Several tools already exist and can be used routinely.

Fig. 7.1 Health-related quality of life in cancer survivors



Source: Victorson et al., 2006 (51).

Psychological support

Diagnosis of cancer often generates major distress for patients and their families. Depression and other symptoms that impact quality of life during the entire cancer pathway are well documented, particularly among breast cancer survivors (52). Reviews highlight problems with fear of recurrence, fatigue, sexual health, depressive symptoms, pain and late or long-term effects because of cancer treatments. Individuals follow various trajectories of psychological adjustment during survivorship (53).

Evidence shows that psychological interventions reduce psychological morbidity and improve patients' adjustment to illness, quality of care and well-being (54–56). The access to psychological intervention during survivorship can be difficult, either because of patients' reluctance or because insufficient care is offered (57). Instruments for diagnosing psychosocial conditions, level of distress and psychosocial needs are not yet routinely used in all cancer settings (50,58). Several countries in Europe, the United States, Canada and Australia have developed clinical practice guidelines that assist clinicians in using evidence-based psychosocial care in their practice (49,59–62).

Inequalities are rarely mentioned in the selected articles from the review. However, geographical and social isolation may create greater difficulties in accessing quality psychosocial and palliative care for those living in rural areas and diagnosed with cancer (63). The mapping of psychosocial care resources in Europe shows that the provision of psycho-oncology services is very diverse, irregular and greatly depends on whether or not a country and its national cancer control plan or strategy considers psychosocial care as an element of multidisciplinary cancer care (64). Resources in this area are still scarce and widely variable across countries and type of hospital (cancer centre versus local hospital), mainly because of lack of financing and policy; in some countries they are even non-existent (65).

Professional reintegration

Results include issues such as employment and insurance that cancer patients have to face (5,66,67). The case study based on the VICAN 2 survey (68) illustrates these issues (Box 7.1).

Box 7.1 Case study examining employment issues: the VICAN 2 study

Background

The French national study VICAN 2 sheds light on people's daily life and the impact of cancer during the survivorship and rehabilitation period. This case study focuses on the inequalities on both the occupation rate and income two years after the first diagnosis of cancer.

Methodology

Computer-assisted telephone interviews of 40 minutes duration were conducted between January 2012 and June 2013 with about 4350 patients who had been diagnosed with cancer in 2010.

Outcome: cancer impact on income

At the diagnosis stage in 2010, 20.9% could be considered as poor compared with 14% in the general population (data from the French National Institute for Statistics and Economic Studies). Two years after the diagnosis, the gap had increased, with 25.1% of people living with a cancer being below the poverty threshold compared with 14.3% of the general population.

Losing one's job is not the only way the diagnosis of cancer has a financial impact on household income: most of the people who continued their employment during cancer diagnosis, treatment and survivorship had to face various important changes in their working time depending on their health status, which had impact on their income.

Outcome: professional situation two years after diagnosis of cancer

The professional situation of people diagnosed with cancer was shown to have considerably deteriorated two years after the diagnosis, with an activity rate decreasing from 88.2% in 2010 to 79.9% in 2012. The employment rate decreased to 61.3% and the unemployment rate was 11.1% (i.e. four points higher compared with 2010).

The most vulnerable people were mainly manual workers; the youngest and oldest; married people; people with an educational level below advanced level (A-level); those with fixed-term precarious working contracts; and those working in small and medium enterprises. This demonstrates a "double penalty", which brings together the unfavourable characteristics of the job market and the impact of the cancer diagnosis.

Most of the people aged between 18 and 57 years had lost their job 15 months after the diagnosis (91.6%) and 21.8% lost it at the moment of diagnosis. The waiting period before finding a new job was 11 months on average (i.e. an additional delay of 6 months compared with data for the general population).

Further research

A similar national study with the same methodology will be launched to assess people's quality of life 5 years after the diagnosis.

Recommendation

Similar studies should be conducted in different EU countries to better assess the impact of cancer on people's daily lives in order to address their needs and target sources of inequalities.

Source: Institut National du Cancer, 2014 (68).

Return-to-work support should be integrated early into the cancer care pathway, exploring the feasibility of adequate or progressive return to work and discussing with employers about working conditions (69,70). Both health care providers and employers have a role to play (63,71,72).

A strong emphasis is put on the positive effects of early psychosocial interventions in supporting cancer survivors with employment-related issues, ideally immediately after diagnosis and during treatment (73). Psychosocial and vocational rehabilitation need to take a person-centred approach based on each individual's situation: diagnosis and prognosis, medical and nonmedical treatments, intra- and interpersonal factors, patient values, aspirations and priorities, the attitude of colleagues, job demands, and so on. These determinants should be taken into account when planning reintegration into the working environment (70,74–79).

Supportive return-to-work interventions can be directed to employees or to the work environment and employers (80–82). The first approach aims at maintaining or enhancing the employability of cancer survivors. Work environment-directed interventions aim at adapting workplace environment, equipment, tasks and working time patterns to the needs of the cancer survivor. More evidence is needed on the effectiveness of return-to-work interventions and on work conditions for cancer survivors who do return to work (83).

Regarding employment and return-to-work issues, there are some good examples of regulation for the protection of cancer survivors and their relatives.

An Italian regulation passed in 2003 (decree-law n° 276/2003, article 46, as amendment of decree-law n° 61/2000, article 12 bis) prescribed the right for cancer patients working in the private sector to switch from full-time to part-time positions while under treatment, and to reverse to full-time 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, relatives (caregivers) 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. But it also includes important provisions to prevent discrimination arising from disability, indirect discrimination and discrimination against carers.

Other socioeconomic issues relate to health, disability and life insurances. European surveys (84) and the Institute of Medicine study (5) have reported that psychosocial workers should provide information on the potential insurance, employment and financial consequences of cancer through provision of a directory of cancer-related resources (e.g. online or telephone listings) and/or information in the form of general information brochures. Raising these issues with patients will at least let them know that help is available.

Children, adolescents and young adult survivors of cancer

For children, adolescents and young adults, the psychosocial experience of the illness is highly variable (85,86). It is sometimes years after the cancer is cured that the psychosocial impact of the illness occurs, leading to requests for support and psychosocial care (87,88). The utility of supportive and rehabilitation care has been proved, in particular adapted physical activity for children, to be associated with better health-related quality of life (89,90).

The literature suggests a routine yearly psychosocial assessment with attention to behavioural issues and educational and/or vocational progress to detect early signs of psychosocial suffering (91,92). Parents or relatives need to be involved in every step and are always considered as facilitators if they are properly educated, informed and coached by the health care providers (93).

Management of long-term follow-up care plans

Results from 55 publications have been retained, synthesized and discussed in order to present the key evidence regarding the management of survivorship care plans. There were three main issues: the role of multidisciplinary teams and the coordination of providers; the empowerment of cancer survivors; and the self-management perspective.

Multidisciplinary approach and coordination of cancer care providers

The clinical follow-up system as currently applied in survivorship shows low added-value. Multidisciplinary teams often disregard survivorship and rehabilitation issues. The main barriers with regards to their role in undertaking a survivorship care plan is lack of vision regarding redesigning the cancer patients' pathway and the team's workload (94). In addition, multidisciplinary teams also feel that they lack time and information about a follow-up plan. There is little evidence in the literature regarding follow-up care and the role of GPs (see Chapter 6).

The literature shows that survivorship care plans can be built upon the clinical management of a multidisciplinary team and could include addressing patients' late effects of treatment and psychosocial needs with a rehabilitation slant (95–98). Survivorship care plans can be managed according to different models of care coordination with a common starting point of a specialist in a multidisciplinary teams providing follow-up to create a holistic and integrated approach to survivors' health (70,99,100). Three conditions arise as core practices in the literature:

- GPs or a primary care team should play a relevant role in patients' follow-up
- the follow-up model should provide a rapid re-entry to specialized cancer care, if required; and
- a health care professional should assume the role of a coordinating case manager by being a point of reference and contact for the patient and the team.

Other components to be taken into account include the possibility of modifying health insurance coverage to include the follow-up as such and facilitating patient's access to community resources, patients' support groups and volunteers (101).

As 80% of young people with cancer are now surviving, all relevant stakeholders should be informed on possible risks or late effects of the cancer treatment received. The lack of information on many patients' medical history becomes particularly critical as children become adults. The Survivorship Passport initiative (102) can provide a solution to this problematic situation.

Education and empowerment of survivors

Involving patients in prevention, the follow-up and the management of late effects or the rehabilitation process (i.e. access to adapted information on self-management of late effects, on physical activities and dietary rules) is a major challenge. Satisfaction regarding the exchange of information with patients varied greatly among patients with low incomes (103). Online programs and e-health tools currently in development could help to improve the detection and evaluation of needs in supportive and palliative care (104,105). Online search for information, however, was lower for those who had lower education and socioeconomic status. Online programs and e-health may nevertheless offer a good alternative for educating survivors since they are considered cost-efficient and show equal impact with more conventional methods (106,107).

Education programmes are mainly targeted at specific subpopulations (e.g. patients with breast cancer, children, adolescents and young adults) but are also more effective for certain groups (e.g. white and well-educated patients, particularly women) (108).

Many programmes are implemented but not systematically evaluated. Costs and cost-effectiveness are hardly addressed in evaluation studies (109).

Self-management

Cancer survivors are requesting a more active role in their health care. Self-management programmes need to be offered to cancer survivors and provide advices on how to look after themselves after cancer diagnosis, for example with adequate information about potential late effects and their early identification and management (110–115). Health-promoting measures, including web-based programs and telephone counselling, are attractive options to help patient to self-manage.

Perspectives in survivorship and rehabilitation cancer research

The literature shows that more data are needed concerning the different components of survivorship care. The main unanswered issues are:

- the impact of clinical follow-up on medical outcomes in a wide-range of cancers;
- the clinical, biological and cellular mechanisms of late-effects;
- the impact of supportive care and psychological support on quality of life (short and long term), survival, return-to-work;
- the long-term impact of education programmes;
- the long-term follow-up of adults surviving a childhood cancer,⁴ even 10, 20 and 30 years after end of treatment.
- the determinants of cancer inequalities linked to survivorship; and
- the impact and management of comorbidities and other health care disparities.

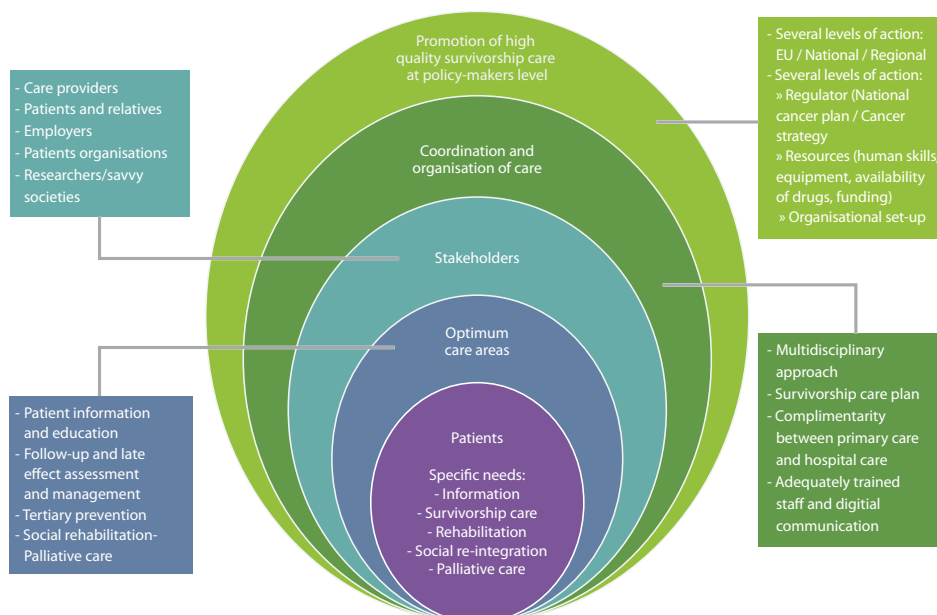
Furthermore, there is need for research networks and collaboration to initiate innovative clinical trials, such as intervention trials or RCTs.

Conclusions and recommendations

Based on the results obtained, the following section provides policy recommendations regarding three main aspects of the long-term follow-up care plans of cancer survivors: the content, and management and the implementation (Fig. 7.2).

⁴ Several large-scale cohorts of this population have been created in Europe, Canada and the United States. For example, the Childhood Cancer Survivor Study is a multicentre study from the United States for patients treated between 1970 and 1986. This generated the widest quantity of data ever collected on the subject. In France, the L.E.A programme initiated in the early 2000s by two centres, enabled the long-term follow-up of patients (more than 3000) cured from childhood leukemia in 13 oncopaediatric centres.

Fig. 7.2 Integrated survivorship and rehabilitation care model showing the different components of an effective European organizational survivorship care model with an integrated and personalized approach



Medical follow-up and tertiary prevention

- An early and personalized follow-up programme should be systematically planned and delivered to each survivor.
- Baseline screening should be performed prior to the start of any cancer-specific treatment. After the first screening regular updates should be performed on an individual basis and followed by adequate provision of psychosocial care.
- An adequate and multidimensional assessment should be made of the survivor's individual risk of late effects and respective rehabilitation or supportive needs (e.g. physical, psychological, social, cognitive, sexual, nutrition).
- Adequate and updated information on medium- and long-term effects of treatments should be available to survivors, their relatives and to care providers involved in the follow-up.
- In tertiary prevention, self-management should be emphasized, particularly on lifestyle recommendations and on avoiding risks of long-term effects by smoking cessation; weight control and healthy diet, including limited alcohol consumption; sufficient sustained physical activity at every phase of survivorship care; avoidance of excessive exposure to ultraviolet radiation; and stress management.

Patient-centred approach in long-term survivorship care

- Periodic screening of the physical condition, psychological distress and psychosocial needs should be conducted during the entire cancer pathway and integrated in routine cancer care.
- Rehabilitation and supportive care should be specifically offered to childhood, adolescent and young adult cancer survivors through a routine yearly psychosocial assessment with attention to social, psychological, behavioural and educational and/or vocational issues.
- Social and return-to-work issues should be integrated early into the cancer care pathway. The adaptation of working conditions for any patient returning to his/her previous work should be assessed at early stages.
- Public policies should be developed and implemented to safeguard cancer survivors' working lives, their employability, skills and capacity to work, as well as their motivation to work. Self-employed workers should be offered new skills to help them to achieve balance between health needs and work.

Management of long-term cancer follow-up care plans

- Psychosocial care, rehabilitation and palliative care should be integrated into the entire cancer pathway, including the survivorship and rehabilitation period. Psychosocial, rehabilitation and palliative care specialists should be members of (or associated with) the medical team in hospitals and in community care.
- The role of GPs and other PCPs should be actively supported to help them to manage all the care plan challenges. Their role should be clearly defined and tailored to the patient and the care plan needs. This role could evolve during the follow-up period.
- Communication between PCPs and health care specialists needs to be improved. Electronic patient records systems should be accessible to all health care providers treating patients. Communication between patients and health care providers needs to be improved.
- A key health care professional assuming a case management role should be assigned to each patient in accordance with medical and/or psychosocial specific requirements. This health care professional could play a main role in reducing the vulnerability of patients, for example with the management of adverse drug effects.
- Transition of care from paediatric oncology to adult medicine should be organized to guarantee adequate long-term follow-up and setting up of appropriate interventions.
- Empowerment of patients and their relatives should be enhanced to increase their participation in self-management, rehabilitation and return-to-work programmes. Online programs would facilitate this process together with the support of patient organizations.
- The use of digital methods (e-health supports) could facilitate sharing of information between patients and care providers and the uptake of the recommendations.

Perspectives in survivorship and rehabilitation cancer research

- An information and data collection system focused on late adverse effects (physical, psychological, cognitive, social and sexual), coupled with the surveillance of patients and involving PCPs, should be set up. More patient-reported outcome measures and their routine use are needed.
- The use of cancer registries in collecting data on survivors should produce stronger epidemiological data, including lifestyle, quality-of-life or socioeconomic information to better identify the causes of inequalities in survivorship. Moreover, registries should be expanded to additional factors that influence the quality of life (e.g. rehabilitation and employment issues). Patient-reported outcomes could also be a way to collect appropriate information.
- Clinical research should evaluate the feasibility, the efficacy and the cost-effectiveness (including the economical dimension) of non-drug related interventions such as self-management and e-health programs.
- Future research is needed to establish a multidimensional rehabilitation model focused on the quality of life and coordination of complex care to better address the management of late effects across the whole survivorship trajectory. More research would also be required to maximize the long-term follow-up and care of childhood cancer survivors and to identify the genetic risks associated with late effects and second cancers.
- More solid methodological RCTs and cohort studies are needed in order to reduce the intensity of cancer treatments while maintaining their efficacy, thus reducing the probability of late effects, particularly in childhood cancer survivors.

Implementation

Improving survivorship and rehabilitation care

- To enhance healthy lifestyles/behaviours in order to improve self-management of late effects with an equity perspective, public policies such as tobacco consumption restrictions, improving access to healthy food and developing actions to facilitate physical activity are needed. Actions targeted to specific vulnerable groups should be developed.
- Professional training and continuous education of health care providers is highly recommended for better information/communication/knowledge of survivorship and rehabilitation needs and management of late effects.
- Adequate financial and human resources should be allocated to the assessment and management of multidimensional late effects and tertiary prevention.
- Systematic screening of distress and physical and psychosocial needs is required for establishing adequate planning and implementation of psychosocial and rehabilitation care. A step-wise or tiered model of psychological care is recommended depending on the level of distress, psychological condition and morbidity of each patient. Interventions can range from basic information (level 1 and 2) to specialized psychological care (levels 3 and 4), as in the United Kingdom NICE guidelines. Interventions can range from:
 - information and psycho-education by primary oncology team to peer support;
 - e-health platforms for psychosocial support and self-management programmes;

- psychological interventions by psycho-oncology trained professionals (e.g. psychologists, social workers, psychiatrists);
 - complementary spiritual support;
 - psychotropic treatments by trained physicians (e.g. psychiatrists, oncologists); and
 - patient support groups
- For the diagnosis of psychological conditions, a specific assessment should be carried out by a psychological care professional: using validated and simple tools and according to clinical practice guidelines for the assessment and management of psychological distress and morbidity and anticipating the specific needs of populations at high risk, including young populations (e.g. children, adolescents, young adults) and relatives.
 - Education and self-management programmes should be developed and evaluated. Assessment of patients' needs should be systematically part of the development of an education programme. The evaluation of these programmes should assess the impact on the personal, organizational and health care policy levels, including cost-effectiveness and impact on health care quality.
 - Professional experts networking on specific late effects (e.g. post-radiation neurotoxicity or drug-related impaired immune function) could facilitate their identification and management and support the GP. Those expert networks could also contribute to improve data collection and research on late effects. GP should contribute to the collection of these data.

Improving the management of survivorship and rehabilitation care

- Information and communications technology support, such as telemedicine or interoperative patient files, should facilitate patient management and follow-up.
- An information system should be implemented in order to monitor the activity of multidisciplinary teams including multiprofessional involvement, thus enabling the collection of information on process indicators such as coverage (e.g. the number of patients discussed compared with the number of patients under treatment) and implementation of survivorship care plans (e.g. survivorship care plan recommendations effectively implemented).
- Psychosocial and rehabilitation services need to be identified and provided for adequate referral of patients.
- Structural financial resources dedicated to psychological care, rehabilitation and social reintegration services should be embedded in the budgets of national or regional cancer care services. Inequalities of access to these services for underserved populations (e.g. people living in geographical and social isolation) have to be addressed.
- A financing mechanism prioritizing multidisciplinary over monodisciplinary interventions, already existing in some European health systems, can be used to integrate survivorship into the cancer care continuum. Psychological care and rehabilitation resources need to be available and in the private sector needs to be considered eligible for reimbursement from health insurance plans/companies.
- Economic evaluation should be undertaken in order to assess cost-effectiveness of the model of care and inform policy-makers for the most efficient use of resources.

Ensure the visibility and recognition of survivorship and rehabilitation on the policy agenda

- Health care system and patients benefit from the inclusion of survivorship and rehabilitation issues in national cancer control plans and policies. Partnership development across different professional groups, patients and cancer survivors is beneficial. Enhancing collaboration between the different representatives of these groups to support and optimize work with cancer survivors is advisable.
- It is important to involve patients in advocacy activities for the development of survivorship care, whether they are engaged in a formal organization or not.
- The implementation of a long-term follow-up policy for childhood, adolescent and young adult cancer survivors would improve their QALY, which will have a positive economic impact of reduction of direct (medical care, treatments) and indirect (sick leaves, incapacity of work) costs linked to long-term morbidities in this population. More international and multicentre cooperation could enhance research activities in this area because of the limited number of cases.

Ensure equal opportunities to all cancer patients

- Opportunities should be created for socially disadvantaged people to fully engage in follow-up programmes.
- Better access to self-management programmes should be available for underserved and deprived populations (low income/low education).
- Public policies should be developed and implemented to support cancer patients from diagnosis to return to work. This would include financial aspects such as access to loans, mortgages and life insurance. Implementation of a pan-European strategy to tackle the differences between workers with cancer in different countries and to prevent discrimination would generate more evidence to better understand the living conditions of cancer survivors who return to work.
- Employers can also play an important role in supporting the survivors' return-to-work process: to explore possibilities of changes in job functions for cancer survivors and encourage them to acquire new skills; to facilitate the implementation of flexible working hours and options (remote working, part-time work); to offer economic benefits to employers who agree to adapt the workplace to the needs of cancer survivors; and to help self-employed workers to adapt their workplace and business to address health needs.
- Patient bills of rights including the right to work with special conditions (e.g. reduced hours of work or adapted working conditions) should be negotiated.

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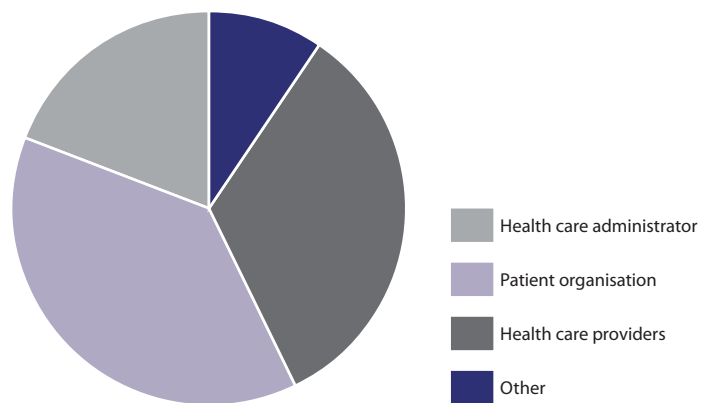
Annex 7.1. Results of the survivorship care plan survey

Details on data collected

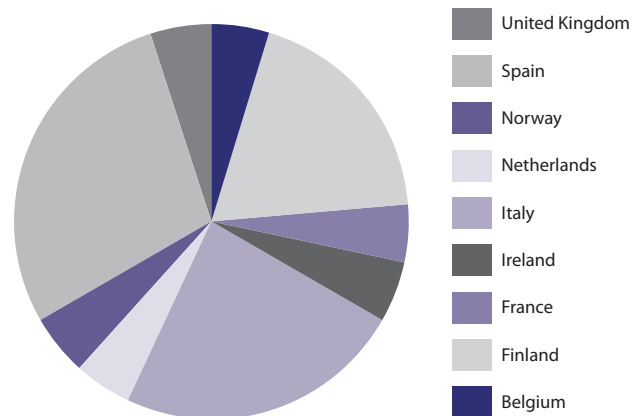
A total of 21 completed questionnaires have been collected. Fig. 7A.1 shows the origins of the data by category and by country.

Fig. 7A.1 Data collection

Origin per category



Origin per country



Note: A total of 21 questionnaires have been collected.

Summary of results

Answers varied a lot regarding how patient follow-up is organized and implemented in the EU countries and answers can differ even within the same country. However, all respondents agreed on what is the beginning of the follow-up period: being the period after the acute treatment phase. The length of this period depends on the type of cancer and on the treatment received, for example in Belgium this period lasts for five years and can be up to 10 years in Spain.

According to the results of the survey regarding the role of care providers, the oncologist remains the leader of follow-up care after completion of the treatment. Then in most countries the GP is usually responsible for monitoring the impact of cancer and its treatment on the patient's general health (comorbidities). The role of nurses differed a lot depending on the country, for example care coordinator in Belgium, in France and the United Kingdom, whereas the nurse may just be a contact point in Finland.

During the follow-up period, the identity of the patients, their ages and a record of the treatment(s) received are usually the minimum set of information available to care providers in all countries. In some countries, side-effect information is available (Finland, France Italy, the Netherlands, Spain) as well as rehabilitation care (the Netherlands) or medical history (Finland and Spain). In the majority of countries involved in the survey, supportive care is provided as part of the follow-up, except in Norway and Ireland, and variable in the United Kingdom and Spain. According to the results, pain management and psychological support for patients and their relatives against anxiety and depression are the common grounds for supportive care in EU countries. In addition to these services, symptom and late-effect management, sexuality and fertility support, as well as other supportive care such as nutrition, weight management and beauty care, are offered in a wide range of countries (Belgium, Finland, France, the Netherlands, Spain). Regarding social support and professional rehabilitation, the situation in EU countries is more heterogeneous; only France, Finland and the Netherlands provide services such as social needs evaluation, working ability evaluation and contact details of professionals in this area. In Finland and Spain, these services are only available if the patients ask for them.

The majority of the countries that took part in the survey (76%) claimed that there was no formal survivorship care plan, apart from France, the Netherlands and Finland (only for breast cancer). For patient follow-up, countries often used a mix of tools (paper documents, oral consultations and electronic files) that were commonly shared between all professionals involved with the patient. Only Finland used a nationwide electronic system.

However, 19 respondents out of 21 (two did not answer) thought that a survivorship care plan would be an efficient tool to organize follow-up care. A survivorship care plan, according to respondents, could potentially be an important communication tool between professionals and patients to manage and structure a global follow-up taking into account all aspects of survivorship care.

In addition, 18 respondents out of 21 (two did not answer and one responded "No") thought that a survivorship care plan would be an efficient way to improve quality of care. Not only would it improve the quality of care but it would also improve the access and continuity of care for patients.

Similarly, 18 respondents out of 21 (two did not answer and one responded "No") thought that a survivorship care plan would be an efficient way to better involve PCPs during this period.

Participants to this survey said that there is often no coordination protocol between specialized care and PCPs.

In terms of perceived barriers, the financial one came first (13 respondents), then the technical (9 respondents) and then the professional-related one (8 respondents).

Survivorship care plan

- A survivorship care plan should be delivered to all patients following a multidimensional needs' assessment and this survivorship care plan should be tailored and updated regularly according to the patient's health conditions.
- After the completion of the acute treatment phase, the patient should be given a survivorship care plan that would contain:
 - baseline information on the personal and medical profile of the patient (identity, age, summary of the treatment received), with additional data on possible late and long-term effects and medical history;
 - a minimum set of tailored supportive care services consisting of pain management and psychological support for patients and their relatives against anxiety and depression
 - possibly also healthy lifestyle issues, including for example tobacco cessation, physical activities, nutrition and weight management, beauty care, as well as sexuality and fertility support; and
 - social support and professional rehabilitation services.
- The survivorship care plan should be elaborated and implemented by the multidisciplinary team composed of:
 - an oncologist in collaboration with other professionals to plan the follow-up process;
 - a GP who deals with the impact of cancer and its treatment of the general health;
 - a (specialist) nurse or a support worker who is in charge of coordinating follow-up care among all services providers involved; and
 - a community care centre, which deliver information, educational activities about survivorship care.
- From a technical point of view, in order to meet its communication and care coordination objectives, the survivorship care plan should be:
 - accessible to all health care professionals having therapeutic relationships with the patient;
 - updated regularly; and
 - use a format that optimizes the understanding and the communication of information between patients and health care providers (and among health care providers).

Advice for implementation

Treatment Summary and Survivorship Care Plan from the American Society of Clinical Oncology or the National Comprehensive Cancer Network survivorship guidelines are good examples.

- Engage financial and professional resources.
- Ensure availability of dedicated resources for multidimensional cancer rehabilitation services.
- Appoint a patient navigator to guide the patient through existing rehabilitation resources.
- Evaluate the implementation (patient-reported outcome measures) and outcomes of the survivorship care plan.

Annex 7.2 Assessment of patient's symptoms and needs and the orientation to adequate intervention in psychological supportive care

The literature review showed that early and systematic detection of needs in psychological support, social rehabilitation (in particular for return-to-work issues), physical rehabilitation, supportive and palliative care is necessary in order to orientate patients towards tailored health care interventions. It also demonstrated the necessity to anticipate certain issues that the patients and their relatives will face during the survivorship and rehabilitation period.

In this context, one of the objectives of Chapter 7 was to set the basis of a common European process that would enable the assessment of patients' symptoms and needs in order to facilitate their guidance towards tailored interventions in supportive care. The process is presented via several questions that reveal the modalities of implementation.

Why?

The purpose of a qualitative assessment of symptoms and needs in cancer settings is about:

- improving the quality of health care (targeting each patient's needs and directing resources to optimize patient's clinical outcomes);
- improving clinician–patient communication; and
- regularly monitoring physical, social and psychological functioning to better address these needs.

The qualitative assessment of symptoms and psychosocial needs is not only useful for the orientation towards adequate care interventions but also for the patients themselves, who increasingly express their interest of being involved in their supportive care pathway.

When?

Symptoms and needs must be assessed as early as possible and at every "step" of the cancer journey: diagnosis, treatment, rehabilitation, follow-up and end of life.

Who?

The qualitative assessment of symptoms and needs should apply to all cancer patients and survivors. Health care professionals should incorporate the detection of patient-reported outcomes in their routine clinical activity.

What?

Qualitative assessment of symptoms and needs should cover:

- physical aspects (functional assessment and symptom burden)
- social aspects (family, relational, employment issues)
- psychological aspects (emotional, spiritual, sexual)
- perceived barriers to care
- satisfaction with cancer care.

How to assess?

Tools and measures should be defined at a local level, but they should share common characteristics agreed at the European level. They should be:

- very brief;
- validated in the local language (patient's language); and
- good performance parameters: validity, reliability, sensitivity, specificity, positive predictive value.

The literature emphasizes that tools should be accepted and shared by the front-line staff that will be using them in order to enhance the collaboration.

The qualitative assessment of symptoms and needs can be performed with traditional tools (paper and pencil tests) but also with the more recent digital tools, which have some limitations but also promising opportunities.

Personal interactions between health professionals and patients remain crucial to the process of obtaining valuable, reliable and viable information by which to initiate appropriate biomedical and/or psychosocial treatment.

Final objective

Every European cancer patient and survivor should have an assessment of symptoms and psychosocial needs that should be incorporated into the formal patient record system.