european
cancer
ORGANISATION

Free from Cancer: Achieving Quality of Life for All Cancer Patients and Survivors

Survivorship and Quality of Life Network

The Survivorship and Quality of Life Network is one of the European Cancer Organisation’s Focused Topic Networks, established as part of our Strategy for 2020-2023. The Survivorship and Quality of Life Network was launched in May 2020.

More information is available on our website.

If you would like to find out more about the Survivorship and Quality of Life Network, please contact us at: info@europeancancer.org

Member
SOCIETY OF THE
EUROPEAN
CANCER
ORGANISATION

Patient
ADVOCACY GROUP OF
EUROPEAN
CANCER
ORGANISATION

Community 365
INITIATIVE OF THE
EUROPEAN CANCER
ORGANISATION

Contents

Acknowledgements

This document was produced by European Cancer Organisation's Survivorship and Quality of Life Network. It was compiled via a number of processes of outreach and consultation with European Cancer Organisation's Member Societies, Patient Advisory Committee andCommunity 365[a], in particular with participants in the Survivorship and Quality of Life Network and in line with the European Cancer Organisation's policy decision-making process.

Principal Authors

Andrew Davies, Co-Chair, Survivorship and Quality of Life Network, European Cancer Organisation
Csaba L. Dégi, Co-Chair, Survivorship and Quality of Life Network, European Cancer Organisation
Matti Aapro, President, European Cancer Organisation

Coordinators

Richard Price, EU Affairs Policy Manager, European Cancer Organisation
Norbert Couespel, Policy & Advocacy Team, European Cancer Organisation

Contributors

Enormous thanks are due to all those members of the Survivorship and Quality of Life Network, and other members of the European Cancer Organisation and its Patient Advisory Committee, who took the time to comment on various drafts of this report, provide reference material, advice and other commentary.

Riccardo Asteggiano, European Society of Cardiology
Sebastian Arias, Roche
Sarah Collen, European Association of Urology
Maria Die Trill, International Psycho-Oncology Society
Vincent Dufauret, Sanofi
Faith Gibson, Multinational Association for Supportive Care in Cancer
Hugo Katus, European Society of Cardiology
Daniel Kelly, European Oncology Nursing Society
Alessandro Laviano, European Society for Clinical Nutrition and Metabolism
Julie Ling, European Association for Palliative Care
Sara Mac Lennan, European Association of Urology
Françoise Meunier, European Cancer Patient Coalition
Nadia Pellanda, MSD
Kathy Oliver, International Brain Tumour Alliance
Anna Prokupkova, Association of European Cancer Leagues
Cobi Reisman, European Society for Sexual Medicine
Isabel-Teresa Rubio, European Society of Breast Cancer Specialists
Grazia Scoppa, European Cancer Patient Coalition
Darina Sedláková, Association of European Cancer Leagues
Eva-Maria Strömsholm, Gynecological Cancerpatients in Finland
Roberta Ventura, ABC Global Alliance
Jamie Wilkinson, European Pain Federation
Barbara Wilson, Working With Cancer
Theresa Wiseman, European Oncology Nursing Society

Suggested citation: Davies A, Dégi CL, Aapro M, Price R, Couespel N (2020). Free from Cancer: Achieving Quality of Life for All Cancer Patients and Survivors. European Cancer Organisation; Brussels

---

[a] Community 365 is group of charity, philanthropy and industry contributors to the Focused Topic Networks of the European Cancer Organisation. Community 365 provide ideas, guidance, practical support and resources for our work in convening stakeholders and building consensus in the European cancer community. Community 365 contributors do not have a decision-making role in our policy work. Rather, policies of the European Cancer Organisation, such as those represented in this document, are agreed by our Board after consultation with our Member Societies and Patient Advisory Committee, via our Policy Pathway process. More information here: www.europeancancer.org/community-365

Introduction

Nearly 3 million new people are diagnosed with cancer every year in the European Union (EU)[1]. As a result of progress in early diagnosis, innovation in all treatment modalities and growing access to multidisciplinary cancer care, cancer survival rates have increased significantly, so that there are now almost 10 million people surviving more than five years after cancer diagnosis in Europe[2,3.] Due to the extreme heterogeneity of cancer, precisely defining cancer survivors remains difficult and controversial in the cancer community (see Box 1). However, it appears clearly that, in the coming years in Europe, there will be not only more and more disease-free (cured) patients, having successfully completed their cancer therapy, but also increasing numbers of patients affected by cancer in the long term. The latter include those living with advanced or metastatic cancer for many years, experiencing cancer recurrence, intermittent periods of active cancer, or a second cancer[4.] It is therefore time now for European health systems to improve their readiness for the present and future realities of increased cancer survivorship.

Improvements in cancer survival rates represent a great achievement for health systems and the European cancer community as a whole. However greater attention is now required to ensure cancer patients and survivors, as far as may be possible, are able to benefit from a higher quality of daily life and look forward to a life free of cancer and its effects, both physically and psychologically.

The challenges to address in this respect are significant, as in many cases, this improved survival is associated with a wide range of ongoing, long-lasting issues, either as a consequence of their cancer itself, or of the treatment they receive(d). Importantly, such issues include both psycho-social aspects, such as cancer distress, cancer stigma, professional and financial difficulties, and physical aspects, such as cancer treatment side-effects, long-term chronic pain and cancer complications and comorbidities[5]. In its 2008 conclusions on reducing the burden of cancer, 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*"[6]. However, more than ten years later, there still exist a number of hurdles impeding the access of cancer patients and survivors to the care they need, including poor coordination of care and occurrence of many psychosocial unmet needs[7.]

Additionally, these hurdles come in combination with significant inequalities across Europe. Access of cancer patients and survivors to adapted care and management of the long-term impacts of their cancer and cancer treatment is highly unequal across European countries. This can be evidenced in major discrepancies in both cancer survival rates and cancer patients' and survivors' quality of life, and shows the need to ensure equal access to survivorship care across Europe. Furthermore, unequal implementation of regulations protecting cancer patients, survivors and caregivers against financial and professional discrimination across European countries leads to further inequalities in their chances of reintegration into the society.

Collectively, this demands an overall reorientation of cancer systems in Europe. Cancer is not an 'acute' disease, but rather a disease of the long term. Cancer systems should therefore move from a cure vs end-of-life care dichotomy to a more patient-centred approach, focused on continuously achieving optimal quality of life throughout the entire cancer journey, and through recognition and incorporation of the concepts of supportive care and survivorship care planning (see Box 2 & Box 3). To help achieve this reorientation, the European Cancer Organisation has established a Survivorship and Quality of Life Network, bringing together healthcare professionals, patients, researchers, academics and others to precisely delineate the challenges to be met and produce recommendations on the most critical policy needs to be addressed[8].

Our Network proposes the following seven priorities to National Governments, the European Union, WHO Europe and others in order to bring about a paradigm change in how health systems take better account of the Survivorship and Quality of Life challenge in cancer care:

1. Take action on cancer distress
2. Elevate management of pain and other symptoms: core parts of the cancer patient pathway
3. Cancer patients and survivors have sex lives too: recognise sexuality in health system approaches
4. Cancer comorbidities and complications: an ever-growing challenge in need of additional focus
5. Empower cancer patients and survivors: the importance of education and information.
6. Provide cancer patients and survivors with the right to reintegration into the workplace
7. Cancer survivors have a right for their cancer to be forgotten by financial service providers

BOX 1: The Challenge of Defining Cancer Survivors

Currently, there is a lack of consensus on the definition of a "cancer survivor" (or cancer survivorship), with some authorities and stakeholders suggesting that a person becomes a cancer survivor after the diagnosis is confirmed (irrespective of the stage of the disease)[9], and others suggesting that a person only becomes a cancer survivor after a specified period with no active disease (e.g. five years)[10].

The Survivorship and Quality of Life Network of the European Cancer Organisation has decided not to adopt a specific definition, but to acknowledge the different definitions, which relate to some degree overlapping populations. The rationale for this decision is that the Network wants to focus on the difficulties encountered by such cancer patients as a result of either their cancer and/or their cancer treatment(s), i.e. physical problems and psycho-social needs, including in respect to financial toxicity, and health-related discrimination.

BOX 2: Supportive Care

Supportive care in cancer is defined as the prevention and management of the adverse effects of cancer and its treatment. This includes management of both physical and psychological challenges and side effects across the continuum of the cancer experience from diagnosis, through cancer treatment, to post-treatment care. The concept of supportive care can therefore be seen as an "umbrella", covering all of the needs of cancer patients in addition to their anticancer therapy and maximising their quality of life. Enhancing rehabilitation, secondary cancer prevention, survivorship, and end-of-life care are all integral to supportive care[11].

Beyond medical oncologists and oncology nurses, any organ-related specialist, geriatrician, palliative care clinician, pain specialist, nutritionist, psycho-oncologist, social worker, physiotherapist, nurse or allied health worker who is required to relieve a patient's symptoms or side effects may be involved in the provision of supportive care in a multidisciplinary way. Among essential components of supportive care is the adoption of a patient-centred approach. A patient-centred approach gives close attention to the provision of relevant care across the entire cancer timeline, from diagnosis to survival or end-of-life, in a multidimensional and holistic manner, attending to physical and functional, psychological, social and spiritual well-being of the patients, as well as of their family and carers[12,13].

BOX 3: Survivorship Care Planning

A number of initiatives within the European cancer community have contributed to develop the concept of survivorship care planning, which was further delineated by the recent EU-co-funded Cancer Control Joint Action (CanCon) final report[14].

Each cancer patient should be provided, after the completion of the acute treatment phase, with a survivorship care plan. This plan should contain information regarding both physical and psycho-social impacts of cancer and cancer treatment, and aim at organising their management, as well as the cancer patient's rehabilitation, through access to relevant services and interventions.

In spite of clear evidence showing the added-value of Survivorship Care Plans for patients, healthcare providers and healthcare systems, there are too few cancer patients securing access to survivorship care planning[15,16,17,18,19,20,21].

The provision of individual survivorship plans is a key component of the Organisation of European Cancer Institutes (OECI) Standards for Cancer Centres[22]. Simultaneously, the European Cancer Organisation's Essential Requirements for Quality Cancer Care series outline follow-up, support and care for long-term survivorship as fundamental elements of the cancer care pathway[23].

The European Code of Cancer Practice states the right of every cancer patient in Europe to "Receive and discuss with your care team a clear, managed and achievable plan for your survivorship and rehabilitation."[24]

1. Take Action on Cancer Distress

Cancer distress can be defined as "*an unpleasant emotional experience of a psychological, social and/or spiritual nature which extends on a continuum from normal feelings of vulnerability, sadness and fears to disabling problems such as depression, anxiety, panic, social isolation and spiritual crisis*" [2526]. Cancer distress is therefore a major factor of poor quality of life, whose wide-ranging detrimental consequences can affect not only cancer patients and survivors, but also their caregivers, families, partners and friends. Beyond the trauma represented by cancer and its treatment, the burden of cancer distress can be reinforced by additional elements, including:

- Cancer stigma, particularly present in the case of certain cancer types, such as lung cancer;
- Fear of cancer recurrence, very frequently experienced by cancer survivors; and
- Anticipatory grief and survival guilt, faced by caregivers, families, partners and friends ahead of and/or after losing a loved one.

Importantly, it may also be associated with delayed or denied treatment, reluctance to disclose cancer status, difficulties in attending support groups and lower survival as a whole[27,28,29].

Against this background, psycho-oncology interventions have been demonstrated to be effective in improving psychosocial outcomes in cancer patients[30,31,32,33,34,35,36]. Key components of psycho-oncological care include:

- Early, systematic and regularly updated psychosocial screening and monitoring in all phases of the cancer disease trajectory[37,38,39,40,] notably through digital means, allowing to capture issues which affected individuals will typically not report spontaneously;
- Comprehensive and stepped psychosocial assessment, taking into account physical, emotional, practical, family and spiritual/religious concerns[41,42,43]; and
- Treatment of cancer distress through provision of relevant forms of psychological support, such as individual and group psychotherapies, psychoeducation, cancer coaching and counselling, relaxation training, and a broad range of self-directed interventions made available to affected individuals through digital means, of particular relevance during the ongoing COVID-19 pandemic[44].

Psycho-oncology is regularly identified by cancer patients as an area of unmet care need. This notably relates to long-lasting under-recognition of psycho-oncology by health systems and chronic mismatch between generated care needs and allocated resources[45,46].

Crucially, cancer distress does not stop at the end of the cancer patient's active treatment phase. Instead, it may last during the entire survivorship phase, leading to detrimental impacts on quality of life in the long-term, including for caregivers, families, partners and friends, independently from the outcome of the cancer[47]. However, even when psycho-oncology services are in place, and as a result of poor coordination of care, the transition between these two phases often results in psycho-oncology care needs being neglected or inconsistently managed, and in affected individuals being thereby left uncertain or exposed to conflicting messages across the care pathway.

Recommendations

Health systems should incorporate psycho-oncology services as an integral component of the comprehensive multidisciplinary care that needs to be provided to cancer patients and survivors throughout the cancer journey. In this aim, we recommend urgent action around four priorities:

Firstly, European countries must seek to ensure the provision of sustained financial resources to psycho-oncology services. At the national level, this can be achieved through dedicated provisions within national cancer control plans. At an EU level, support could be provided through the EU4Health Programme, the EU Cancer Mission and other funding instruments. **Access to psycho-oncology services could be monitored via a new European Cancer Dashboard.**

Secondly, the EU and its Member States must act to elevate education and training in cancer survivorship and psycho-oncology, by:

- Supporting the establishment of **a European survivorship professional certification**, with a strong psycho-oncology core;
- Sharing, identifying and implementing best practices to ensure that all primary care and oncology professionals have at least a basic education and training in cancer survivorship; and,
- Examining opportunities for the Professional Qualification Directive to support better integration of survivorship within minimum training requirements of relevant healthcare professionals.

Thirdly, European- and national-level guidance should be produced to allow for a consistent and a coordinated management of psycho-oncology care needs throughout the entire care pathway. Such guidance must include strong components on such elements as:

- Supporting the setup of multidisciplinary teams including psycho-oncologists;
- Defining the roles and responsibilities of the different groups of healthcare professionals in the provision of psycho-oncology;
- Ensuring provision of consistent advice and information to affected individuals; and
- Establishing smooth communication procedures as well as robust referral pathways from primary care providers and oncological treatment specialists to trained psycho-oncologists.

Finally, the EU must make best use of important ongoing initiatives, such as the European Health Data Space and the EU Cancer Mission’s Patient Digital Centre, to enable broad and consistent monitoring of long-term outcomes of cancer patients, including psychological impacts.

2. Elevate Management of Pain and Other Symptoms: Core Parts of the Cancer Patient Pathway

Further to psychological impacts of cancer, cancer patients and survivors are also faced with a wide range of physical problems, as a consequence either of the cancer itself, or of the cancer treatment(s) they receive(d), creating a tremendous burden at every stage of the disease[48]. In the context of improvements in cancer survival and of the need for health systems to move their focus from a cure vs end-of-life care dichotomy to the achievement of optimal quality of life throughout the entire cancer journey, particular attention is needed to the steeply increasing challenge of those physical problems affecting patients and survivors in the long term, much beyond the end of their active treatment phase. Significant gaps exist in respect of their management, in terms of knowledge, practice and infrastructure. Furthermore, the continuous evolutions in cancer treatment technologies and the development of new medical agents, such as immunotherapies, are likely to create completely new toxicities and symptoms in long-term cancer patients and survivors, which will require appropriate and specific management by health systems.

These long-lasting physical problems are very variable, and relate to the type of cancer, the type of cancer treatment(s), and coexisting risk factors. They can affect every organ and function of the patient. Prominent examples include chronic pain, chronic fatigue, difficulties to speak, sexual dysfunction and gastrointestinal and urinary disorders[49]. These problems may either date from the time of the cancer treatment, such as immunosuppression due to chemotherapy and neuropathic effects of cancer surgery, or may be a so-called "late effect" of the cancer treatment, such as salivary gland dysfunction ("dry mouth") caused by radiotherapy[50] and autoimmune or autoinflammatory disorders arising from immunotherapy[51.] Collectively, for many patients these problems have a significant impact on their quality of life, with resultant psychological and social complications.

Of all such symptoms, pain is one of those which cancer patients and survivors fear and experience the most. According to recent studies, it affects more than half of patients receiving cancer treatment[52] and more than one third of adult cancer survivors[53,54]. Uncontrolled cancer pain has a huge impact on patients' quality of life, significant psychological, social and health economic implications (for the patients, their families, and the health system), and may also have a negative impact on patient survival (and vice versa). Moreover, inadequate management of cancer pain may also result in morbidity, and occasionally in mortality, notably due to adverse effects of opioid analgesics. However, at least one third of cancer patients currently have inadequate pain control[55]. While some patients have inherently difficult-to-control pain, in many cases the problem relates to a reversible barrier to pain control (e.g. inadequate assessment/re-assessment of patients' pain, limited availability of pain services, restricted availability or access to opioid analgesics and other drugs used for the management of pain)[56].

The management of long-term physical impacts of cancer requires the development of specialist symptom control, supportive and palliative care services, ensuring access of cancer patients to:

- Early, systematic and regularly updated assessment for physical impacts of cancer and cancer treatment; and
- Treatment of those long-term cancer patients and survivors with severe, life-changing physical problems through specific medical expertise possessed by highly trained supportive and palliative care specialists.

This relates to specificities in both the biological mechanisms underlying the presentation of these symptoms in the context of cancer survivorship, and in the particular accompanying health condition of long-term cancer patients and cancer survivors. For instance, chronic cancer pain encountered by long-term cancer patients and cancer survivors differs significantly from acute cancer pain typically faced by patients with advanced, metastatic or terminal disease. Treatments that are effective for acute cancer pain may be less effective, and/or less well tolerated in the former case. As a result, the management of chronic, difficult-to-control, cancer pain is known to require individualised, multimodal interventions, provided by relevant specialists[57]. Furthermore, severe symptoms most often differ radically between patient populations, according to age, cancer type, or received treatment, further highlighting the need for specialist services and workforce to appropriately treat them.

However, in many cases the specialist workforce possessing this particular medical expertise is not available to cancer patients, due to systemic gaps in recognition, training and investment in cancer supportive care services, so that there is persisting inequitable access to supportive and palliative care across Europe.

Recommendations

In the context of ongoing important initiatives in cancer policy, such as the Europe's Beating Cancer Plan, we call for the adoption of a holistic approach to cancer survivorship and quality of life, giving attention to all impacts of cancer and cancer treatment on long-term patients and survivors, including those of physical nature.

The EU, its Member States, WHO Europe and others should come together to urgently accelerate the dthe development of the provision of specialist, cancer supportive and palliative care. Key actions to be conducted include:

- Fostering the adoption of appropriate education and training initiatives in the field of cancer supportive and palliative care in European countries, guided by European-level advice to health systems, and sharing of good practices;
- Providing sustained investment to the development of specialist, cancer supportive and palliative care services in European countries, through national and European funding mechanisms;
- Promoting quality assurance mechanisms for the provision of supportive and palliative care to cancer patients, through the recognition of European guidelines and accreditation systems developed by relevant expert communities;
- Stimulating further research into the development, assessment and optimisation of supportive and palliative care interventions in Europe, notably through the EU Cancer Mission.

Further to the management of these long-term impacts of cancer and cancer treatment, their high and increasing human and economic cost for the community calls for them to be better taken into account by health systems as a whole. As part of a paradigm change of healthcare systems towards the achievement of ooptimal quality of life throughout the entire cancer journey and in the context of relevant initiatives, such as the European Semester processes, the '*State of Health in the EU*' and the new EU Pharmaceutical Strategy, opportunities should be explored to build on existing instruments in order to define, establish and/or use long-term physical impacts of cancer and cancer treatment, such as pain, as indicators in the assessment of healthcare systems' quality[58].

National efforts to improve supportive cancer care should be included within a European Cancer Dashboard.

3. Cancer Patients Have Sex Lives Too: Recognise Sexuality in Health System Approaches.

Sexuality is recognised as an important component of quality of life[59,60,61] and is known to be associated with longer longevity[62,63]. In short, cancer patients, survivors, and their partners, have sex lives too[64,65]. All of us should be able to enjoy relationships of intimacy. Yet, all too often, discussion on such topics can be hampered by lingering taboo. Any remaining taboo on this must now be broken. Data, for example, shows that cancer patients and survivors suffer from significant dissatisfaction when it comes to their sex lives. This relates both to sexual dysfunction, which affects an estimated half of cancer patients[66] and a third of childhood cancer survivors[67,68,69], often as a result of cancer treatments rather than from the cancer itself[70], and to psychological and social elements[71,72]. Crucially, sexual dissatisfaction can be encountered by all cancer patients, not only by those suffering from a tumour affecting their sexual organs[73,74].

Sexuality-related issues are particularly detrimental to the quality of life of cancer patients and survivors. Such issues lead to significant cancer distress[75,76], both for patients and their partners, endangering their mental health and their relationships[77,78,79,80,81], and potentially even impacting the cancer treatment itself. Yet, in spite of this, accumulating reports identify sexual medicine as one of the greatest areas of unmet care needs for cancer patients and survivors[82,83,84], especially in younger adults[85]. Sexual medicine can be integral to improved care for cancer patients in respect to a wide range of complications, including body image and fertility challenges. These can be sensitive issues for discussion with patients and too often healthcare professionals do not benefit from substantial training to make the provision of advice and support in these areas a standard part of cancer care. Remaining problems in access to sexual medicine are, in large part, due to long-lasting gaps in training and education of sexual medicine specialists and healthcare professionals as a whole.

Importantly, sexual minorities are particularly affected by these deficiencies in care provision. Data clearly shows a strong association between sexuality-related issues and long-term mental and physical problems for LGTBQ individuals. These individuals may give different meanings to sexuality-related matters, which may, for example, threaten their sexual identity. Reactions to sexual complications may also differ, such as some individuals being potentially more likely to engage in novel practices as a means of managing sexual challenges[86,87]. Healthcare professionals therefore need to be specifically primed to the provision of sexual medicine to LGBTQ individuals, in order to avoid making heteronormative assumptions and to provide them with relevant information and support[88].

Preservation of sexual function and satisfaction needs to be recognised as an integral part of cancer care and should be addressed as a matter of routine, before, during and after provision of cancer treatment, even in the case of cancers not physically affecting sexual or reproductive organs.

This should be achieved by ensuring the provision of relevant information and interventions, destined to both cancer patients and their partners. Restoration of sexual function does not ensure restoration of sexual satisfaction[89]. Sexual medicine interventions in cancer need to be multidisciplinary, integrating both specialist medical components, aiming at tackling sexual dysfunction, and professional psychological counselling, in order to support the restoration and preservation of a satisfying sex life.

Simple measures health systems can take include promotion of the great array of well-formed, easy-to-read and digest, information on cancer and sex and sexuality matters that have been made available online by patient associations[90] and medical societies, at both national and international levels[91].

Recommendations

Elevating provision of sexual medicine and addressing unmet needs of cancer patients and survivors in sexuality-related issues need to be made an integral part of the development of a holistic European agenda for cancer survivorship and quality of life.

Sexual medicine should be included in all initiatives aimed at developing provision of supportive care in Europe. This should be achieved through investments in training, education, relevant services and research.

The awareness of all healthcare professionals, including oncology specialists and primary healthcare providers, should be raised about the sexuality-related issues faced by cancer patients and survivors, as well by their partners. This educational and awareness raising effort should include dedicated attention to the needs of sexual minorities.

The EU Cancer Mission and Horizon Europe research programme should include parameters of sexual orientation in relevant aspects of its supported research and rehabilitation studies.

4. Cancer Comorbidities and Complications: An Ever-Growing Challenge Demanding Focus

Further to the range of physical and psycho-social challenges resulting from their cancer and cancer treatment, cancer patients and survivors may also be faced with distinct health conditions in parallel to their cancer journey, in the form of comorbidities and complications. Comorbidities are defined as the co-existence of long-term health conditions in the presence of a primary disease of interest, while complications correspond to health conditions resulting from this primary disease or from its treatment[92,93].

Owing to shared risk factors, average age of patients as well as to systemic impacts of disease and treatment, comorbidities and complications are particularly common in cancer patients and represent a highly significant and increasing burden for healthcare and social welfare systems[94,95]. Research shows that the majority of cancer patients, even up to 90% depending on age and cancer type, report at least one comorbid condition[96,97]. Such comorbidities and complications are very diverse, and can typically include pulmonary disorders, diabetes, obesity and dietary disorders, cardiovascular diseases such as heart failure, myocardial infarction, arrhythmias, hypertension and thrombosis, stroke, liver diseases, neurological and mental health disorders[98,99].

Comorbidities and complications can have a dramatic impact on cancer patient's prognosis for their tumour, as well as on their overall survival and long-term quality of life. In addition to being responsible for potential delays in cancer diagnosis, such conditions may cause affected patients to suffer higher levels of toxicity from cancer treatment and can prevent optimal cancer treatment.
Owing to lack of consensus on how to record, interpret or manage cancer comorbidities and complications, patients with relevant comorbidities are also less likely to receive cancer treatment with curative intent. They are also often excluded from randomised clinical trials, further reducing their chances of survival[100]. Consistently, data clearly indicates a higher mortality in cancer patients affected by comorbidities and complications[101], as well as a strong association with indicators of poorer quality of life, including nutritional status, physical functioning, general health and pain[102,103].

As a result of lack of recognition of the issue and typically siloed organisation of health systems[104], there are still significant gaps in all aspects of the management of cancer comordibities and complications in Europe. This includes the prevention of comorbidities and complications in cancer patients and survivors through health promotion, the detection of these conditions, the assessment of the risk of cancer patients to develop them, as well as the provision of adapted treatment and care to address them[105]. This also relates to the many patients treated for a chronic severe disorder who develop cancer as a second life-threatening disorder.

Recommendations

Dedicated attention is needed to meet the growing challenge of cancer comorbidities and complications. This includes resolving current systemic deficiencies that hamper access of affected patients to adapted and comprehensive treatment and care. The following actions should be urgently considered:

- Leverage existing EU funding programs for research on cancer to include complications and comorbidities related to cancer and cancer treatment, aiming at improving understanding of their causation and impact, as well as at establishing adapted treatment and care strategies to address them, and at better preventing them through optimisation of cancer treatment;
- Foster sharing and implementation of best practices to take better account of comorbidities and complications within cancer clinical trials, as well as to ensure the access of affected cancer patients to curative treatment;
- Upscale efforts to bring about coordination and integration of primary and secondary care for cancer patients, with a particular attention to the management of comorbidities and complications; and
- Embed a provision dedicated to cancer comorbidities and complications within a new European professional survivorship certification, and support the inclusion of this aspect in education and training opportunities for oncologists and healthcare professionals as a whole.

5. Empower Cancer Patients and Survivors: The Importance of Education and Information

As elaborated above, cancer patients and survivors suffer from a wide range of issues as a consequence of their cancer and their cancer treatment, often significantly detrimenting their quality of life. Beyond the need for health systems to address these issues, cancer patients and survivors also deserve to receive relevant and adapted information to help them meet the challenges they face. Such information should cover all the aspects of their cancer survivorship, including access to specialist care and support services addressing both physical and psycho-social impacts of cancer and cancer treatment. Provision of such information can be embedded within survivorship care plans (see Box 3).

Furthermore, carefully adapted and relevant information should be provided at each stage of their journey as a cancer patient. Since decisions regarding treatment and care options received by patients at the early stages of their cancer journey can impact their quality of life decades later, cancer patients must be offered clear and understandable information concerning the possible consequences of each option for them. In doing so, health systems will allow cancer patients to participate in information-based shared-decision-making and to give a truly informed consent to the provision of cancer treatment and care options to them.

Information needs relate not only to treatment of course, by many connected areas, such as general health and wellbeing promotion, and also key aspects of personal nutrition and diet.

The advance of digital technology, including portable digital devices and smartphone applications, is creating bountiful new opportunities and fresh practices to learn from when it comes to innovative means of providing timely advice and information to cancer patients and survivors. Though care must be continually paid to prevent misinformation also being conveyed by these means. This emphasises the need for health systems to be actively engaged in this arena and not to leave the area open to individuals and organisations with an interest in conveying unscientific and potentially harmful information.

Beyond being only informed, the understood aim should be to ensure cancer patients are truly empowered. Patient empowerment is defined by the World Health Organization as '*a process through which people gain greater control over decisions and actions affecting their health*'[106]. There is substantial evidence that patient engagement and empowerment have the potential to improve not only patient satisfaction with care but also the quality of care provided, as well as patient outcomes[107].

Thus, developing and supporting health literacy and empowerment tools tailored to cancer patients and survivors concerning the long-term consequences of their cancer and their cancer treatment is of particular relevance to meet the European cancer survivorship and quality of life challenge. The European Code of Cancer Practice recently launched by the European Cancer Organisation represents a prominent example of a patient empowerment tool in this regard. Co-produced by a team of cancer patients, patient advocates and oncology professionals, the Code is a simple, accessible, widely disseminated statement of the core general requirements for best cancer practice in order to improve outcomes for all of Europe's cancer patients.

The Code sets out a series of ten key overarching rights to support European citizens and patients, and in particular signposts what they should expect from their health system, in order to achieve best possible outcomes. Translated into more than 20 European languages, among the Code's ten rights, three of them focus more specifically on later stages of the cancer journey and are therefore of particular relevance to long-term cancer patients and survivors:

- The right to receive optimal supportive and palliative care, as relevant, during any part of the patient's cancer journey;

- The right to receive and discuss with the patient's care team a clear, managed and achievable plan for his/her survivorship and rehabilitation; and

- The right to be fully reintegrated into society and protected from cancer-related stigma and discrimination, so that, in so far as is possible, patients can return to work and a normal life[108].

Patient advocacy and support organisations have become an ever-growing source of high quality information for individuals with cancer, and their carers, in addition to what may be received directly from healthcare professionals and health systems. Patient organisations can be especially important in respect of helping address needs that a given health system may not be adequately covering for cancer patients. Simple measures - without high investment cost - for addressing these gaps on the patient journey should include patient and carer referral by healthcare institutions and healthcare professionals to patient organisations at the first diagnosis stage and additionally, later on, at various crossroads on the cancer patient pathway. During the current COVID-19 period, it's particularly vital that the sustainability of patient organisations is not jeopardised by the pandemic. A financial safety net during this crisis should urgently be put in place by governments to help secure the viability of patient organisations, many of which rely on in-person events to raise vital funding for cancer research and patient support. During the pandemic, such events have had to be cancelled, resulting in significant funding reductions for patient organisations to use for their crucial work.

Recommendations

Patient empowerment and information should be central considerations and points of response for the EU, WHO Europe and any other European or international organisation formulating guidance, advice or best practices to be applied by national health systems in respect to cancer survivorship and quality of life.

Support should be provided to patient organisations and others to conduct and build on patient empowerment and patient information initiatives. This could notably be achieved through official endorsement of such initiatives, support to dissemination efforts and provision of funding through mechanisms such as the EU4Health Programme.

6. Providing Cancer Patients and Survivors with the Right to Reintegration Into the Workplace

It is estimated that around half of the people diagnosed with cancer are of working age[109]. Any cancer diagnosis is likely to result in long periods of sickness absence because of the need to undergo medical treatments and attend appointments, as well as endure functional restrictions as a result of treatment. Indeed, a 2009 estimate, suggested the total economic loss to the EU due to lost working days as a result of cancer at EUR 9.5 billion[110]. With further increases in the number of cancer diagnoses in the population expected, and as many countries increase retirement age, the numbers of people working with, and/or surviving from, cancer will increase[111].

Furthermore, even after treatment ends, many cancer survivors must live with long-term symptoms and impairments, often related to the treatment they receive, which may include fatigue, pain and other work relevant side effects. Other implications of cancer and its treatment that influence occupational safety and health are impaired mental health, including depression and anxiety, diminished physical functioning and symptoms such as pain and reduced cognitive capacities, including attention and memory problems. Each on their own, and often in combination, have clear employment-related impacts for the individuals concerned, including job retention, limitation of promotion and development opportunity, and even reduced ability to enter, re-enter or move in the job market. Particular impacts from a cancer diagnosis occur for the self-employed, with studies suggesting a higher negative impact to personal finances than for salaried cancer patients and survivors[112].

In total, the overall risk of unemployment among cancer survivors is estimated to be 40% times higher than among people who have never been diagnosed with cancer[113]. A country-specific study from the Netherlands in 2014 found that the employability of cancer patients and survivors is the lowest among all chronically-ill patient groups in the country[114].

Fighting cancer at European level means also fighting for an improved environment for cancer patients and survivors to return to work, and to enjoy the same chances of economically productive and fulfilling work lives as the rest of the population.

In some countries in Europe, protecting cancer patients and survivors from workplace discrimination has included utilisation of disability discrimination legislation. For example, in the UK, the law considers having cancer to be a disability, meaning the individual with cancer cannot be treated less favourably than other people (who do not have cancer) because of their cancer, or for reasons connected to the cancer[115].

Primary care has a significant role to play in improving the chances of cancer patients and survivors to attain successful reintegration into the workplace. General practitioners, community pharmacists, community nurses, psychosocial professionals (psychologists, social workers, counsellors, etc.), physiotherapists, dieticians, and occupational specialists from a range of professions all can help address the personalised support needs individuals have in achieving successful readjustment after diagnosis and treatment.

But too often, primary care is not sufficiently strong within national health systems to perform this supporting role to the level of need that exists. Optimal integration between primary and secondary care also remains a significant challenge. Ultimately, what is required is the delivery of a collective role by primary care, secondary care and occupational care in assisting individuals with return to work, but too often, coordination is lacking.

A significant challenge is also presented when it comes to securing and protecting the rights of carers in respect to cancer care and survivorship. Many informal cancer caregivers make employment changes to provide care during survivors' treatment and recovery. These employment changes can lead to reduced income and financial difficulties.

Recommendations

In line with the European Code of Cancer Practice (Rights 7, 9 and 10), European cancer initiatives, at EU and WHO Europe level, should give significant attention to the Return to Work needs of cancer patients, survivors and carers. Monitoring, assessment and sharing of national best practices in this area should be a strong element of pan-national action. The mandate of, and instructions to, the European Agency for Safety and Health at Work (OSHA) to conduct such activity should be refreshed in the context of the Europe's Beating Cancer Plan. The EU Pillar of Social Rights, and its Action Plan expected in 2021, provide a further opportunity in this respect.

All national cancer plans should include components to address Return to Work and rehabilitation needs, including the strengthening of primary care, and further actions to better coordinate primary and secondary care.

Large employer organisations should have in place clear guidance and systems to ensure employees with, or who have survived cancer, or are caring for someone with cancer, are fully supported and enabled to continue their work, ensuring reasonable, flexible workplace adjustments[116].

Further research efforts in this space are called for, including in respect to cancer patients and survivors who return to work and then leave the workforce soon after, and the reasons for this.

7. Cancer Survivors have a Right for their Cancer to be Forgotten by Financial Service Providers

Further to a wide range of above described physical, psychological and professional impacts of cancer and cancer treatment, a significant obstacle faced by cancer survivors to return to a normal life is the one of financial discrimination.

When applying for insurance, cancer survivors are often asked to disclose their full medical history, including their cancer diagnosis. Based on this information, insurers may exclude certain risks, including cancer, from their policy, increase insurance premiums by up to 300% or reject applications altogether. This significantly affects people's ability to obtain travel, health and life insurance. It also affects their access to loan-related insurance, which covers outstanding payments on a loan in the case of death, sickness or unemployment, and is, in some countries where mortgages are rare, often mandatory when applying for loans, for example to buy property. Altogether, these issues significantly increase the socioeconomic burden placed on cancer survivors, acting as financial obstacles in every aspect of their professional and personal lives, even years after the successful completion of cancer treatment[117].

To address this issue, three European countries (France, Belgium and Luxemburg), likely soon joined by Netherlands, have implemented specific legislative initiatives, recognizing a 'Right to Be Forgotten' for cancer survivors. The provisions state that in the context of accessing financial services, the period beyond which no medical information relating to the previous cancerous disease can be collected by insurance organisms may not exceed ten years after the end of treatment or, for cancers occurring in children and young adults (before age 18 in Belgium and Luxemburg, before age 21 in France and Netherlands), five years after the end of treatment. The laws also include a list of exceptions for cancers with an excellent prognosis having shorter delays to exercise the Right to Be Forgotten[118].

These regulations represent a great milestone for the European cancer community, which has long been unanimously calling and advocating for their implementation. A prominent example of such calls is the European Cancer Summit 2018 resolution on financial discrimination of cancer survivors. Developed together with Member Societies of the European Cancer Organisation and its Patient Advisory Committee, this resolution set a target of 2025 for delivery of the 'Right to be Forgotten' for cancer survivors in all European countries and was agreed on, following public consultation, by 400 leading representatives of healthcare professional, patient, research and other stakeholder communities. In spite of the progress achieved since then, exhaustive implementation of relevant regulations protecting cancer survivors from financial discrimination is still far from complete in Europe[119].

Concerns about the socio-economic issues experienced by survivors of cancer across Europe have been raised also by EU Institutions. In this regard, an important step forward was the inclusion of the 'Right to Be Forgotten' as a measure of best practice to ensure the best possible quality of life for cancer survivors in the roadmap for the EU Beating Cancer Plan, promoted by the EU Commission in February 2020[120]. Lately, the Interim Report of the Mission Board for Cancer included the 'Right to be Forgotten' among the recommendations to the EU Member States to counteract discrimination and to ensure equality[121]. In this context, a pan-European solution based on the implementation of the 'Right to be Forgotten' would be a relevant approach to tackle the issue. The EU Action would provide a common regulatory framework among the Member States to avoid discrimination and ensuring equality among EU citizens who experienced cancer.

Recommendations

Based on established consensus within the European cancer community, we repeat our call for the right of cancer survivors, when accessing financial services, not to declare their cancer ten years after the end of the active treatment and five years if they had cancer under 18, to be codified across European countries by 2025.

To achieve this goal, following actions should be urgently considered:

- The European Insurance and Occupational Pensions Authority should issue guidance to insurers about the ethical principles that should apply in respect to cancer patients and cancer survivors insurance applications. This should include travel insurance, critical illness policies and definitions of cancer used by insurance companies.
- An EU level comparative study of EU Member States approaches towards ensuring the rights of cancer survivors to access financial services in a fair manner should be conducted.
- National Governments should recognise the inequities and disparities that exist within the financial service landscape in respect to cancer survivors, have assessed their national legal frameworks accordingly, and proposed remediating measures, learning from the experience of France, Belgium, Luxemburg and Netherlands in this respect. This recognition could be expressed via a set of European Council conclusions.

Additionally, in the context of the forthcoming Europe's Beating Cancer Plan and EU Cancer Mission, urgent consideration should be given to the possibilities of a pan-European solution for the implementation of the 'Right to Be Forgotten' for cancer survivors, such as through a revision of the EU Consumer Rights Directive.

References

1 Data retrieved from IARC Global Cancer Observatory https://gco.iarc.fr/.

2 Survivorship – the next frontier of cancer care improvement, on the European Organisation for Research and Treatment of Cancer website (2018): https://www.eortc.org/blog/2018/09/04/survivorship-the-next-frontier-of-cancer-care-improvement/ (accessed April 2020).

3 Couespel, N., et al., Strengthening Europe in the fight against cancer, Study for the committee on Environment, Public Health and Food Safety, Policy Department for Economic, Scientific and Quality of Life Policies, European Parliament, Luxembourg, 2020.

4 Albreht T, Borrás Andrés JM, Dalmas M, et al. Survivorship and rehabilitation: policy recommendations for quality improvement in cancer survivorship and rehabilitation in EU Member States IN Albreht T, Kiasuwa R, Van den Bulcke M. European Guide on Quality Improvement in Comprehensive Cancer Control. Cancer Control Joint Action (Chapter 7); 2017.

5 Albreht T, Borrás Andrés JM, Dalmas M, et al. Survivorship and rehabilitation: policy recommendations for quality improvement in cancer survivorship and rehabilitation in EU Member States IN Albreht T, Kiasuwa R, Van den Bulcke M. European Guide on Quality Improvement in Comprehensive Cancer Control. Cancer Control Joint Action (Chapter 7); 2017.

6 Council of the European Union. 2876th Employment, Social Policy, Health and Consumer Affairs, Council meeting: conclusions on reducing the burden of cancer. Luxembourg, Employment, Social Policy, Health and Consumer Affairs Council; 2008:

https://register.consilium.europa.eu/doc/srv?l=EN&f=ST%209636%202008%20INIT (accessed April 2020).

7 Couespel, N., et al., Strengthening Europe in the fight against cancer, Study for the committee on Environment, Public Health and Food Safety, Policy Department for Economic, Scientific and Quality of Life Policies, European Parliament, Luxembourg, 2020.

8 For more information concerning the European Cancer Organisation Survivorship and Quality of Life Network, please visit: https://www.europeancancer.org/topic-networks/6:survivorship-and-quality-of-life-network.html

9 US National Cancer Institute's definition of a cancer survivor: https://www.cancer.gov/publications/dictionaries/cancer-terms/def/survivor

10 Rowland J, Kent E, Forsythe L, et al. Cancer survivorship research in Europe and the United States: where have we been, where are we going, and what can we learn from each other? Cancer. 2013 Jun 1;119 Suppl 11(0 11):2094-108. doi: 10.1002/cncr.28060.

11 Multinational Association of Supportive Care in Cancer (MASCC)'s definition of supportive care: https://www.mascc.org/mascc-strategic-plan (accessed July 2020).

12 Olver I, Keefe D, Herrstedt J, et al. Supportive Care in Cancer-A MASCC Perspective. Support Care Cancer. 2020 Apr 27.

13 Couespel, N., et al., Strengthening Europe in the fight against cancer, Study for the committee on Environment, Public Health and Food Safety, Policy Department for Economic, Scientific and Quality of Life Policies, European Parliament, Luxembourg, 2020.

14 Albreht T, Borrás Andrés JM, Dalmas M, et al. Survivorship and rehabilitation: policy recommendations for quality improvement in cancer survivorship and rehabilitation in EU Member States IN Albreht T, Kiasuwa R, Van den Bulcke M. European Guide on Quality Improvement in Comprehensive Cancer Control. Cancer Control Joint Action (Chapter 7); 2017.

15 Albreht T, Borrás Andrés JM, Dalmas M, et al. Survivorship and rehabilitation: policy recommendations for quality improvement in cancer survivorship and rehabilitation in EU Member States IN Albreht T, Kiasuwa R, Van den Bulcke M. European Guide on Quality Improvement in Comprehensive Cancer Control. Cancer Control Joint Action (Chapter 7); 2017.

16 Hewitt M, Greenfield S, Stovall E. From cancer patient to cancer survivor: lost in transition. Washington, DC, US National Academy of Sciences; 2006.

17 Wolff SN. The burden of cancer survivorship. a pandemic of treatment success. In Feuerstein M, ed. Handbook of cancer survivorship. New York, Springer; 2006:7–18.

18 Earle CC. Quality of care. In Feuerstein M, ed. Handbook of cancer survivorship. New York, Springer; 2006:19–42.

19 American Society of Clinical Oncology. ASCO cancer treatment and survivorship care plans. Alexandria, VA, American Society of Clinical Oncology; 2016 (http://www.cancer.net/survivorship/follow-care-after-cancer-treatment/asco-cancer-treatment-and-survivorship-care-plans; accessed April 2020).

20 Keesing S, McNamara, Rosenwax L. Cancer survivors' experience of using survivorship care plans: a systematic review of qualitative studies. Journal of Cancer Survivorship, 2015 ;9: pp.260–268.

21 Couespel, N., et al., Strengthening Europe in the fight against cancer, Study for the committee on Environment, Public Health and Food Safety, Policy Department for Economic, Scientific and Quality of Life Policies, European Parliament, Luxembourg, 2020.

22 https://www.oeci.eu/accreditation/Page.aspx?name=OECI_STANDARDS

23 https://www.europeancancer.org/2-content/8-erqcc

24 https://www.europeancancer.org/2-standard/89-the-code-survivorship-and-rehabilitation

25 Holland JC, Reznik I. Pathways for psychosocial care of cancer survivors. Cancer 2005; 104: 2624-2637. doi:10.1002/cncr.21252.

26 NCCN (National Comprehensive Cancer Network). Distress management practice guidelines. J Natl Compr Canc Netw. 2003; 1: 344–374.

27 Chambers SK, Dunn J, Occhipinti S, et al. A systematic review of the impact of stigma and nihilism on lung cancer outcomes. BMC Cancer. 2012 May 20; 12: p.184.

28 Henningfield MF, Adjei AA. Lung Cancer Awareness Month - A Lot of Progress, But More Work Needs to Be Done. J Thorac Oncol. 2017 Nov; 12(11): pp.1603-1605.

29 Vodermaier A, Lucas S, Linden W, et al. Anxiety after diagnosis predicts lung cancer-specific and overall survival in patients with stage III non-small cell lung cancer: a population-based cohort study. J Pain Symptom Manage. 2017 Jun;53(6):1057-1065.

30 Carlson L, Bultz B. Efficacy vs. cost of psychosocial interventions: an evidence-based call for action. Oncol Exchange. 2002; 1(2): pp.24-29.

31 Carlson L, Bultz BD. Efficacy and medical cost offset of psychosocial interventions in cancer care: making the case for economic analyses. Psychooncology. 2004; 13(12): pp.837-849.

32 European Cancer Organisation. Position Statement - Integrated Cancer Care: Bringing Primary Care and Secondary Care Together. https://www.europeancancer.org/resources/57:integrated-cancer-care-bringing-primary-care-and-secondary-care-together.html (accessed July 2020).

33 Gysels M, Higginson IJ, Rajasekaran M, et al. Improving supportive and palliative care for adults with cancer: research evidence. London: National Institute for Health and Clinical Excellence; 2004.

34 Jacobsen PB, Shibata D, Siegel EM. Evaluating the quality of psychosocial care in outpatient medical oncology settings using performance indicators. Psychooncology. 2011 Nov; 20(11): pp.1221-1227.

35 Raingruber B. The Effectiveness of Psychosocial Interventions with Cancer Patients: An Integrative Review of the Literature (2006–2011). ISRN Nursing, 2011, 638218.

36 Faller H, Schuler M, Richard M, et al. Effects of Psycho-Oncologic Interventions on Emotional Distress and Quality of Life in Adult Patients With Cancer: Systematic Review and Meta-Analysis. J Clin Oncol. 2013 Feb 20; 31(6): pp.782-93.

37 Albreht T, Kiasuwa R, Van den Bulcke M. European Guide on Quality Improvement in Comprehensive Cancer Control. Cancer Control Joint Action (Chapter 4); 2017.

38 Gysels M, Higginson IJ, Rajasekaran M, et al. Improving supportive and palliative care for adults with cancer: research evidence. London: National Institute for Health and Clinical Excellence; 2004.

39 Loscalzo M, Clark KL, Holland J. Successful strategies for implementing biopsychosocial screening. Psychooncology. 2011 May; 20(5): pp. 455-462.

40 Sussman J, Baldwin LM. The Interface of Primary and Oncology Specialty Care: From Diagnosis Through Primary Treatment. J Natl Cancer Inst Monogr. 2010;2010(40):18-24.

41 CPAC, Bultz B. Canadian Partnership Against Cancer - Guide to Implementing Screening for Distress, the 6th Vital Sign Moving Towards Person-Centered Care; 2009. Retrieved from Toronto: http://www.virtualhospice.ca/Assets/Distress-%20CPAC_20150713161546.pdf (accessed July 2020).

42 Gysels M, Higginson IJ, Rajasekaran M, et al. Improving supportive and palliative care for adults with cancer: research evidence. London: National Institute for Health and Clinical Excellence; 2004.

43 Nekhlyudov L, O'Malley DM, Hudson, SV. Integrating Primary Care Providers in the Care of Cancer Survivors: Gaps in Evidence and Future Opportunities. Lancet Oncol. 2017 Jan; 18(1): e30-e38.

44 NCCN Clinical Practice Guidelines in Oncology, Distress Management 2.2017- Sept 2017

45 Jacobsen PB, Shibata D, Siegel EM. Evaluating the quality of psychosocial care in outpatient medical oncology settings using performance indicators. Psychooncology. 2011 Nov; 20(11): pp.1221-1227.

46 Couespel, N., et al., Strengthening Europe in the fight against cancer, Study for the committee on Environment, Public Health and Food Safety, Policy Department for Economic, Scientific and Quality of Life Policies, European Parliament, Luxembourg, 2020.

47 Kim Y, Shaffer KM, Carver CS. (2016). Quality of life of family caregivers 8 years after a relative's cancer diagnosis: Follow-up of the National Quality of Life Survey for Caregivers. Psycho-Oncology, 25, 266-274.

48 Couespel, N., et al., Strengthening Europe in the fight against cancer, Study for the committee on Environment, Public Health and Food Safety, Policy Department for Economic, Scientific and Quality of Life Policies, European Parliament, Luxembourg, 2020.

49 https://www.macmillan.org.uk/_images/cured-but-at-what-cost-report_tcm9-295213.pdf

50 Davies AN, Thompson J. Parasympathomimetic drugs for the treatment of salivary gland dysfunction due to radiotherapy. Cochrane Database of Systematic Reviews 2015, Issue 10. Art. No.: CD003782.

51 Rapoport BL, van Eden R, Sibuad V, et al. Supportive care for patients undergoing immunotherapy. Support Care Cancer 2017 Oct.; 25(10): pp.3017–3030.

52 van den Beuken-van Everdingen MH, Hochstenbach LM, Joosten EA, et al. Update on prevalence of pain in patients with cancer: systematic review and meta-analysis. J Pain Symptom Manage 2016; 51: 1070-90.

53 Brown MR, Ramirez JD, Farquhar-Smith P. Pain in cancer survivors. Br J Pain 2014; 8: 139-153.

54 Jiang C, Wang H, Wang Q et al. Prevalence of Chronic Pain and High-Impact Chronic Pain in Cancer Survivors in the United States. JAMA Oncol 2019; 5: 1224-6.

55 Bennett MI, Eisenberg E, Ahmedzai SH, et al. Standards for the management of cancer-related pain across Europe – a position paper from the EFIC Task Force on Cancer Pain. Eur J Pain 2019; 23: 660–8

56 Cherny NI, Baselga J, de Conno F, et al. Formulary availability and regulatory barriers to accessibility of opioids for cancer pain in Europe: a report from the ESMO/EAPC Opioid Policy Initiative. Ann Oncol 2010; 21: 615-26.

57 Bennett MI, Kaasa S, Barke A, et al. The IASP classification of chronic pain for ICD-11: chronic cancer-related pain. Pain 2019; 160: 38-44.

58 https://www.sip-platform.eu/resources/details/sip-presents-its-cancer-position-paper

59 WHO's factsheet on sexual health: https://www.who.int/health-topics/sexual-health#tab=tab_2

60 The World Health Organization Quality of Life assessment (WHOQOL): position paper from the World Health Organization. Soc Sci Med. 1995 Nov;41(10):1403-9. doi: 10.1016/0277-9536(95)00112-k.

61 Flynn KE, Lin L, Bruner DW, et al. Sexual Satisfaction and the Importance of Sexual Health to Quality of Life Throughout the Life Course of U.S. Adults. J Sex Med. 2016 Nov;13(11):1642-1650. doi: 10.1016/j.jsxm.2016.08.011.

62 Kashdan TB, Goodman FR, Stiksma M, et al. Sexuality leads to boosts in mood and meaning in life with no evidence for the reverse direction: A daily diary investigation. Emotion. 2018 Jun;18(4):563-576. doi: 10.1037/emo0000324.

63 Palmore EB. Predictors of the longevity difference: a 25-year follow-up. Gerontologist. 1982 Dec;22(6):513-8. doi: 10.1093/geront/22.6.513.

64 Jackson SE, Wardle J, Steptoe A, et al. Sexuality after a cancer diagnosis: A population-based study. Cancer. 2016 Dec 15;122(24):3883-3891. doi: 10.1002/cncr.30263.

65 Traa MJ, De Vries J, Roukema JA, et al. The sexual health care needs after colorectal cancer: the view of patients, partners, and health care professionals. Support Care Cancer. 2014 Mar;22(3):763-72.

66 Bonini Colmano CM, Molnar S, Salvano LM, et al. Sexual dysfunction in patients with cancer. J Clin Oncol. 2007 Jun;25(18_suppl):19653. DOI: 10.1200/jco.2007.25.18_suppl.19653

67 Bober SL, Zhou ES, Chen B, et al. Sexual function in childhood cancer survivors: a report from Project REACH. J Sex Med. 2013 Aug;10(8):2084-93. doi: 10.1111/jsm.12193.

68 Zebrack BJ, Foley S, Wittmann D, et al. Sexual functioning in young adult survivors of childhood cancer. Psychooncology. 2010 Aug;19(8):814-22. doi: 10.1002/pon.1641.

69 Sukhu T, Ross S, Coward RM. Urological Survivorship Issues Among Adolescent Boys and Young Men Who Are Cancer Survivors. Sex Med Rev. 2018 Jul;6(3):396-409. doi: 10.1016/j.sxmr.2017.12.007.

70 Perz J, Ussher JM, Gilbert E, et al. Feeling well and talking about sex: psycho-social predictors of sexual functioning after cancer. BMC Cancer. 2014 Mar 28;14:228. doi: 10.1186/1471-2407-14-228.

71 Dobkin PL, Bradley I. Assessment of Sexual Dysfunction in Oncology Patients. J Psy Oncology 1991; 9(1): 43-74.

72 Ussher JM, Perz J, Gilbert E, et al. Perceived causes and consequences of sexual changes after cancer for women and men: a mixed method study. BMC Cancer. 2015 Apr 11;15:268. doi: 10.1186/s12885-015-1243-8.

73 Ussher JM, Perz J, Gilbert E, et al. Perceived causes and consequences of sexual changes after cancer for women and men: a mixed method study. BMC Cancer. 2015 Apr 11;15:268. doi: 10.1186/s12885-015-1243-8.

74 Perz J, Ussher JM, Gilbert E, et al. Feeling well and talking about sex: psycho-social predictors of sexual functioning after cancer. BMC Cancer. 2014 Mar 28;14:228. doi: 10.1186/1471-2407-14-228.

75 Matthew AG, Goldman A, Trachtenberg J, et al. Sexual dysfunction after radical prostatectomy: Prevalence, treatment, restricted use of treatment and distress. J Urology 2005; 174:2105-2110. Doi: 10.1097/01.ju.0000181206.16447.e2.

76 Twitchell DK, Wittmann DA, Hotaling JM, et al. Psychological Impacts of Male Sexual Dysfunction in Pelvic Cancer Survivorship. Sex Med Rev. 2019 Oct;7(4):614-626. doi: 10.1016/j.sxmr.2019.02.003.

77 Loeb S, Salter CA, Nelson CJ, et al. A Call to Arms: Increasing Our Understanding of the Impact of Prostate Cancer on the Sexual Health of Partners. J Sex Med. 2020 Mar;17(3):361-363. doi: 10.1016/j.jsxm.2019.11.262.

78 Hawkins Y, Ussher J, Gilbert E, et al. Changes in sexuality and intimacy after the diagnosis and treatment of cancer: The experience of partners in a sexual relationship with a person with cancer. Cancer Nursing 2009; 32(4): 271–280. doi :10.1097/NCC.0b013e31819b5a93

79 Hodges LJ, Humphris GM, Macfarlane G, et al. A meta-analytic investigation of the relationship between the psychological distress of cancer patients and their carers. Soc Sci Med. 2005 Jan;60(1):1-12.

80 Maughan K, Heyman B, Matthews M, et al. In the shadow of risk: How men cope with a partner's gynaecological cancer. Int J Nurs Stud. 2002 Jan;39(1):27-34. doi: 10.1016/s0020-7489(01)00004-9.

81 Rolland JS. In sickness and in health: the impact of illness on couples' relationships. J Marital Fam Ther 1994; 20: 327-347. doi: 10.1111/j.1752-0606.1994.tb00125.x.

82 DeSantis CE, Lin CC, Mariotto AB, et al. Cancer treatment and survivorship statistics, 2014. CA Cancer J Clin. Jul-Aug 2014;64(4):252-71. doi: 10.3322/caac.21235.

83 Ream E, Quennell A, Fincham L, et al. Supportive care needs of men living with prostate cancer in England: a survey. Br J Cancer. 2008 Jun 17;98(12):1903-9. doi: 10.1038/sj.bjc.6604406.

84 Bond CB, Jensen PT, Groenvold M, et al. Prevalence and possible predictors of sexual dysfunction and self-reported needs related to the sexual life of advanced cancer patients. Acta Oncol. 2019 May;58(5):769-775. doi: 10.1080/0284186X.2019.

85 Mutsch J, Friedrich M, Leuteritz K, et al. Sexuality and cancer in adolescents and young adults - a comparison between reproductive cancer patients and patients with non-reproductive cancer. BMC Cancer. 2019 Aug 22;19(1):828. doi: 10.1186/s12885-019-6009-2.

86 Ussher JM, Perz J, Rose D, et al. Sexual Rehabilitation After Prostate Cancer Through Assistive Aids: A Comparison of Gay/Bisexual and Heterosexual Men. J Sex Res. 2019 Sep;56(7):854-869. doi: 10.1080/00224499.2018.1476444.

87 Rosser BRS, Kohli N, Polter EJ, et al. The Sexual Functioning of Gay and Bisexual Men Following Prostate Cancer Treatment: Results from the Restore Study. Arch Sex Behav. 2020 Jul;49(5):1589-1600. doi: 10.1007/s10508-018-1360-y.

88 Quinn GP, Sanchez JA, Sutton SK, et al. Cancer and lesbian, gay, bisexual, transgender/transsexual, and queer/questioning (LGBTQ) populations. CA Cancer J Clin. Sep-Oct 2015;65(5):384-400. doi: 10.3322/caac.21288.

89 Terrier JE, Masterson M, Mulhall JP, et al. Decrease in Intercourse Satisfaction in Men Who Recover Erections After Radical Prostatectomy. J Sex Med. 2018 Aug;15(8):1133-1139. doi: 10.1016/j.jsxm.2018.05.020.

90 https://www.europeancancerleagues.org/wp-content/uploads/ECL-Cancer-and-Sexuality-Leaflet-Patients_September-2020.pdf

91 https://www.europeancancerleagues.org/wp-content/uploads/ECL-Cancer-and-Sexuality-Leaflet-HCP_September-2020.pdf

92 https://ecpc.org/wp-content/uploads/2020/07/Final-Cancer-Comorbidities-Joint-statement.pdf

93 https://bmccancer.biomedcentral.com/articles/10.1186/s12885-019-6472-9

94 Søgaard M, Thomsen RW, Bossen, KS, et al. The impact of comorbidity on cancer survival: a review. Clinical epidemiology 2013, 5 (Suppl. 1), 3–29. doi:10.2147/CLEP.S47150

95 Zamorano J.L. et al (2016). 2016 ESC Position Paper on cancer treatments and cardiovascular toxicity developed under the auspices of the ESC Committee for Practice Guidelines: The Task Force for cancer treatments and cardiovascular toxicity of the European Society of Cardiology (ESC). European Journal of Heart Failure. 19: 9-42. doi: 10.1002/ejhf.654

96 Koroukian SM, Murray P, Madigan E. Comorbidity, disability, and geriatric syndromes in elderly cancer patients receiving home health care. J Clin Oncol. 2006; 24(15):2304-10. doi: 10.1200/JCO.2005.03.1567

97 Lee L, Cheung WY, Atkinson E, et al. Impact of Comorbidity on Chemotherapy Use and Outcomes in Solid Tumours: A Systematic Review. Journal of Clinical Oncology 2011; 29:1, 106-117. doi: 10.1200/JCO.2010.31.3049

98 https://ecpc.org/wp-content/uploads/2020/07/Final-Cancer-Comorbidities-Joint-statement.pdf

99 https://bmccancer.biomedcentral.com/articles/10.1186/s12885-019-6472-9

100 Sarfati D, Koczwara B, Jackson C. The Impact of Comorbidity on Cancer and Its Treatments. A Cancer Journal for Clinicians 2016; 66:337-350. doi: 10.3322/caac.21342

101 Piccirillo JF, Feinstein AR. Clinical symptoms and comorbidity: significance for the prognostic classification of cancer. Cancer. 1996;77(5):834–842. doi: 10.1002/(SICI)1097-0142(19960301)77:5<834::AID-CNCR5>3.0.CO;2-E.

102 Malik M, Vaghmare R, Joseph D, et al. Impact of Comorbidities on Quality of Life in Breast Cancer Patients. Indian Journal of Cardiovascular Disease in Women 2006 WINCARS. doi: 10.1055/s-0038-1656491.

103 https://ecpc.org/wp-content/uploads/2020/07/Final-Cancer-Comorbidities-Joint-statement.pdf

104 https://bmccancer.biomedcentral.com/articles/10.1186/s12885-019-6472-9

105 https://ecpc.org/wp-content/uploads/2020/07/Final-Cancer-Comorbidities-Joint-statement.pdf

106 https://journals.sagepub.com/doi/10.1177/0269216318783919

107 Patient Engagement and Empowerment: Key Components of Effective Patient-Centred Care, Butcher H, Selby P. In Problem Solving in Patient Centred and Integrated Cancer Care. Eds Velikova G, Fallowfield L, Younger J, Board R, Selby P. EBN Health, Oxford, 2018.

108 For more information concerning the European Code of Cancer Practice, please visit: https://www.europeancancer.org/code

109 https://osha.europa.eu/en/publications/rehabilitation-and-return-work-after-cancer-instruments-and-practices

110 https://osha.europa.eu/en/publications/rehabilitation-and-return-work-after-cancer-instruments-and-practices

111 https://www.ncbi.nlm.nih.gov/pmc/articles/PMC7182621/

112 https://pubmed.ncbi.nlm.nih.gov/29946813/

113 https://osha.europa.eu/en/publications/rehabilitation-and-return-work-after-cancer-instruments-and-practices

114 http://www.startfoundation.nl/profielacceptatie

115 https://www.macmillan.org.uk/cancer-information-and-support/impacts-of-cancer/work-and-cancer/cancer-and-employment-rights

116 https://www.sip-platform.eu/resources/details/sip-thematic-network-2018-joint-statement-now-available-in-several-languages

117 https://www.all-can.org/efficiency-hub/the-right-to-be-forgotten-improving-access-to-loans-and-insurance-for-cancer-survivors/

118 Scocca G. and Meunier F. (2020) A right to be forgotten for cancer survivors: A legal development expected to reflect the medical progress in the fight against cancer. J. Cancer Policy 25: 1-4.

119 https://www.europeancancer.org/resources/115:resolution-survivorship-financial-discrimination.html

120 https://ec.europa.eu/info/law/better-regulation/have-your-say/initiatives/12154-Europe-s-Beating-Cancer-Plan

121 https://ec.europa.eu/info/publications/conquering-cancer-mission-possible_en

Participants in the Survivorship and Quality of Life Network

Member Organisations Part of this Network

CIRSE

EANM
EUROPEAN ASSOCIATION OF NUCLEAR MEDICINE

EAPC
VZW

eau
European Association of Urology

ECL
Association of European Cancer Leagues

EFIC
EUROPEAN PAIN FEDERATION

EORTC
European Organisation for Research and Treatment of Cancer
The future of cancer therapy

European Society for Sexual Medicine
ESSM

esso
The European Society of Surgical Oncology

Flims Alumni Club

IPOS
INTERNATIONAL PSYCHO-ONCOLOGY SOCIETY

MASCC™
Multinational Association of Supportive Care in Cancer
WWW.MASCC.ORG

OECI
ORGANISATION OF EUROPEAN CANCER INSTITUTES
EUROPEAN ECONOMIC INTEREST GROUPING

To view the latest list of the participants to the Survivorship and Quality of Life Network, visit our website.

If you would like to find out more about the Survivorship and Quality of Life Network, please contact us at: info@europeancancer.org

Patient Organisations Part of this Network

Childhood Cancer International
EUROPE

DIGESTIVE CANCERS
EUROPE

European Cancer Patient Coalition

IBTA
INTERNATIONAL BRAIN TUMOUR ALLIANCE

LuCE
Lung Cancer Europe

THE MDS ALLIANCE
ALLIANCE • ALLIANZ • ALIANZA

MPE
Myeloma Patients Europe

Charities and Foundations Part of this Network

ABC
GlobAlliance

Community 365
INITIATIVE OF THE EUROPEAN CANCER ORGANISATION

Invited Stakeholders in this Network

Suomen Gynekologiset Syöpäpotilaat ry
Gynekologiska Cancerpatienterna i Finland rf

ESPEN
European Society for Clinical Nutrition and Metabolism

As the not-for-profit federation of member organisations working in cancer at a European level, the European Cancer Organisation convenes oncology professionals and patients to agree policy, advocate for positive change and speak up for the European cancer community.

Publication: November 2020.

european
cancer
ORGANISATION

Rue d'Egmont 13
B-1000 Brussels, Belgium

+32 2 775 02 00

europeancancer.org

FOLLOW US:
@EuropeanCancer