

COMMENTARY

Open Access



Policy Brief – Survivorship is cancer survivorship the poor cousin of cancer control within the EBCP?

Régine Kiasuwa Mbengi^{1*} , Gabrielle Schittecatte¹ and Sofie Theys¹

Abstract

Background There is an increasing number of cancer survivors, including children, adolescents, young adults, individuals of working age, and the elderly, within the Belgian and European population. Yet, survivorship care and rehabilitation are often treated as an afterthought in care organisation. This not only directly affects the quality of life of survivors and carers, but also puts the sustainability of the healthcare and social security systems at risk.

Methods We analysed the ongoing Europe Beating Cancer Plan (EBCP) to identify the actions supporting survivorship (care) developments, then compared their weight in the EBCP to the other domains of cancer control. Following this analysis, and comparison with related ongoing projects, and current infrastructure in Belgium, several unmet needs were identified.

Conclusion To better address these unmet needs, we recommend that Belgium incorporates survivorship care and long-term follow-up in clinical guidelines and care pathways, and considers including indicators related to cancer survivorship in the planning and design of quality insurance schemes, including certification of comprehensive cancer centres. Furthermore, we suggest further investment and support for research and knowledge exchange in the field of survivorship.

Keywords Cancer survivorship, Survivorship care, Quality of life, Quality of care

Introduction

The prevalence of cancer survivors is growing every year (around 3% per year), and is now estimated at over 12 million survivors in Europe, with about 300.000 childhood cancer survivors [1]. The five year survival rates for all cancers combined is 71% for the 2014–18 period in Belgium [2].

Cancer survivors experience a wide range of problems related to physical and mental functioning, including symptoms such as fatigue and pain, sexual problems,

issues related to body image, distress, fear of recurrence, in addition to cognitive, social and physical functioning [3].

Improvements in prevention, diagnostics and treatment are key elements for cancer control, leading to increases in survival. However, relative to the medical and technical developments, there is less focus placed on adequately addressing the plethora of challenges associated with cancer survivorship.

In spite of relative recent attention attributed to survivorship, the work that remains is colossal [4, 5]. It is urgent to address these challenges to ensure high quality long-term care and quality of life for cancer survivors.

*Correspondence:

Régine Kiasuwa Mbengi
regine.kiasuwambengi@sciensano.be

¹ Belgian Cancer Centre, Sciensano, Brussels, Belgium



© The Author(s) 2024. **Open Access** This article is licensed under a Creative Commons Attribution 4.0 International License, which permits use, sharing, adaptation, distribution and reproduction in any medium or format, as long as you give appropriate credit to the original author(s) and the source, provide a link to the Creative Commons licence, and indicate if changes were made. The images or other third party material in this article are included in the article's Creative Commons licence, unless indicated otherwise in a credit line to the material. If material is not included in the article's Creative Commons licence and your intended use is not permitted by statutory regulation or exceeds the permitted use, you will need to obtain permission directly from the copyright holder. To view a copy of this licence, visit <http://creativecommons.org/licenses/by/4.0/>. The Creative Commons Public Domain Dedication waiver (<http://creativecommons.org/publicdomain/zero/1.0/>) applies to the data made available in this article, unless otherwise stated in a credit line to the data.

Methodology

The issue overview, gaps, and recommendations were identified in a participative manner with Belgian Europe's Beating Cancer Plan (EBCP) Mirror Group on Survivorship. The group consists of more than 50 members, with representatives from patient organizations, NGOs, hospitals, professional organizations, registries and universities.

Building off evidence-based recommendations on survivorship from the Joint Action CanCon [6], the Belgian EBCP Mirror Group on Survivorship [7] developed concrete recommendations to improve survivorship care in Belgium. They did so by reviewing the 42 actions of the EBCP and assessing these actions for opportunities to address cancer survivorship issues. They then compared the actions in EBCP and the evidence based recommendations from CanCon with current open calls and/or ongoing projects at the EU-level in which cancer survivorship is addressed. Synergies with the Belgian context were then identified and the extent to which the EBCP projects could benefit to the Belgian Handbook for Supportive Care were assessed (Table 1). The main objective of this work was to identify the challenges hindering the rehabilitation and the quality of life of cancer survivors.

Issue overview

Survivorship has often taken a back seat to other elements in the patient pathway. Treatment toxicities, physiological and psychosocial (late) effects, overconsumption of drugs and drug interactions, management of comorbidities, etc., should be at the heart of survivorship initiatives in Belgium, but also at the EU level. Survivorship remains important for the entire Belgian and EU population; from youth, to people aged over 65 years. The latter remains particularly important as while Europe is an aging continent, most Member States do not consider survivorship care as a necessity in public health care systems.

In 2017, under the framework of the Joint Action CanCon, EU experts worked together to develop evidence-based recommendations to improve the integration of cancer survivorship and rehabilitation in national cancer control programs [8]. In addition to these recommendations, the Mirror Group's review of the EBCP actions, and discussions of opportunities for survivorship in Belgium, resulted in four priority proposals:

- I. Creation of a national cancer survivorship portal to improve the 'information and communication' among professionals and patients
- II. The development of a generic cancer survivorship care pathway (SCP) and the setup of a recovery

convention, ensuring equal and high-quality survivorship care for all cancer patients

- III. A pilot of the SCP and research efforts for its monitoring and evaluation
- IV. Development of local networks of oncological aftercare

The submission of these recommendations for action to the Ministry of Public Health and the underlying discussions led to the decision to start with the development of a Handbook for Cancer Supportive Care [9].

In the following parts of this policy brief we will (1) examine the extent to which the activities in Belgium and in the EBCP address the areas for development, and (2) present recommendations for persistent gaps that are not currently addressed.

Survivorship in the EBCP: results from a gap analysis

We screened the 42 actions of the EBCP on their opportunity and relevance to address cancer survivorship. Three out of the 42 actions of the EBCP directly address survivorship. Chapter 6 of the EBCP, 'Improving the Quality of Life for Cancer Patients, Survivors, and Carers', includes the most initiatives related to cancer survivorship. The first of these actions is the flagship 'Better life for cancer patients', which focuses on the development of the Cancer Survivor Smart-Card (34.1) and the creation of a framework for data storage and exchange (34.2). The second is action 35, which foresees the development of a code of conduct for access to financial services, which can be regarded as a step back compared to the Right to be forgotten. The third is action 36, which concerns the legal frameworks of the work conditions for cancer survivors and their social security status. It should also be noted that the terms 'survivors' and 'survivorship' also appear in chapters 5.1 on 'delivering higher-quality care' (for the creation of an EU network of expertise), 5.2 on 'ensuring a high-quality workforce' (for the training of the health workforce), and 8 on 'putting childhood cancer under the spotlight'.

Twelve other actions were identified that could potentially have an impact on cancer survivorship. This offers considerable room for manoeuvre, and to highlight the topic of survivorship in future projects and work programmes.

The following table presents the aforementioned actions, their potential impact for survivorship, the possible impact of the action on survivorship care, followed by a presentation of the existing infrastructure in Belgium, and the gaps between the objective of the action and the infrastructure in Belgium. This final column details the gaps and is the basis of the policy recommendations presented in the subsequent section.

Table 1 The selected list of EBCP actions and their potential impact for survivorship (care) and related infrastructure in Belgium, and the gaps between the two

| Action | The flagship, initiative or action ^a | Possible impact on survivorship care ^b | Planned or ongoing projects including survivorship ^c | Existing infrastructure/activities in BE ^d | Persistent Gaps in BE ^e |
|--------|--|---|--|---|---|
| 1 | 'Knowledge Centre on Cancer' | Indicators to monitor the QoL of survivors, the quality of survivorship care, access to rehabilitation, return-to-work | Currently no data related to cancer survival, survivorship or quality of life of survivors is included in the ECIPI ^f | No infrastructure | No information system in Belgium for survivorship |
| 13 | Occupational Safety and Health Strategic Framework 2021–2027 | Inclusion of binding legal basis for the protection of workers with cancer and job maintenance | The EU strategic framework on health and safety at work 2021–2027 ^g | The plan for the reintegration of patients in (long-term) sick leave (but is not cancer specific) | The BE plan for work reintegration is not adapted to cancer survivors and people report difficulties finding the right and updated information |
| 23.1 | National Comprehensive Cancer Centre(s) | Inclusion of prerogatives for CCCs in cancer survivorship care and rehabilitation | One task of the JA CraNE addresses survivorship/return-to-work pathway ^h | Minimal requirements to be recognized 'oncological care program' (OCP) Some OCPs recently decided to create 'survivorship clinics' in their institutions | No requirements related to (long-term) survivorship care in the legal basis of Oncological Care Programmes |
| 23.2 | New cancer Reference Networks | Share expertise on survivorship | One work package of the JA Network of Expertise is dedicated to survivorship | Some OCPs recently decided to create 'survivorship clinics' in their institutions. | |
| 25 | European Initiative to Understand Cancer (UNCAN.eu) | Ensure a place for survivorship care and quality of life of survivors on the national and EU research agendas | UNCAN.eu put survivorship on the EU strategic agenda for cancer research ⁱ | While the BSMO has a Survivorship Taskforce, there is no national or regional coordinated initiatives for cancer survivorship research in Belgium | Cancer survivorship research in Belgium needs to be put at the agenda of funders |
| 26 | Inter-specialty training program | Ensure the training of professionals in survivorship care and rehabilitation and facilitate expertise and knowledge sharing | Nothing started | No valorised training for cancer survivorship in BE | Specializations in oncology do not require work with oncological patients or a shift in late effect clinic, however theory is taught in classes |
| 31.1 | Partnership on Precision Medicine | Needed to anticipate the rehabilitation needs | Nothing started | Many personalized medicine initiatives in BE arose but none of them address cancer survivorship | The inclusion of survivorship in personalized pathways |
| 34.1 | Cancer Survivor Smart-Card | Improvement of survivorship needs and care registration | Ongoing | There is a pilot for the introduction of the survivorship passport | No electronic records are available to register and monitor survivor's physical or psychosocial information |
| 34.2 | European Cancer Patient Digital Centre | | | | |
| 35 | Fair access to financial services | Improve long-term reintegration and QoL | Ongoing | The right to be forgotten is implemented in Belgium since 2019 | The Royal Decree of 26th May 2019 implementing the right to be forgotten |
| 36.1 | Return to work | Practical solutions to support RTW | Ongoing | Several studies have been performed in BE to understand the issues related to RTW after cancer | More efforts should be dedicated to the development of interventions and cost-effectiveness studies |

Table 1 (continued)

| Action | The flagship, initiative or action ^a | Possible impact on survivorship care ^b | Planned or ongoing projects including survivorship ^c | Existing infrastructure/activities in BE ^d | Persistent Gaps in BE ^e |
|--------|---|---|---|---|---|
| 41 | EU Network of Youth Cancer Survivors | Improve transnational cooperation and efforts to improve QoL of CAYAs | Several calls are open Different projects of the PanCare society | A project for a convention to better support and organize psychosocial care for children is under development | An organized transition from childhood to adulthood post cancer care is still lacking, although some recent initiatives are supported |

^aThis column describes the flagship or action of the EBCP related to survivorship

^bThis column describes the possible impact the action has on survivorship care

^cThis column describes the any ongoing projects related to the action and survivorship

^dThis column details any existing projects related to the action taking place in Belgium

^eThis column details the gaps that still exist in Belgium related to the action, given the ongoing projects and current infrastructure in Belgium. These gaps form the basis of the below recommendations

^fEU Joint Research Center. European Cancer Inequalities Registry data tool: <https://cancer-inequalities.jrc.ec.europa.eu/data-tool-by-country?ind=ALLMORT&ft=TOTAL>

^gEuropean Commission. 28 June 2021. Communication from the Commission to the European Parliament, the Council, the European Economic and Social Committee and the Committee of the Region. COM(2021) 323 final. EU strategic framework on health and safety at work 2021–2027 Occupational safety and health in a changing world of work. <https://eur-lex.europa.eu/legal-content/EN/TXT/PDF/?uri=CELEX:52021DC0323&from=EN>

^hJoint Action on European Network of Comprehensive Cancer Centres. WP8 Equitable Access to high-quality care & research network in the context of CCCs. <https://crane4health.eu/wp8-equitable-access-to-high-quality-care-and-research-networks-in-the-context-of-cccs/>

ⁱSolary E. et al. UNCAN.eu, a European Initiative to Understand Cancer. Cancer Discovery November 2022. https://uncan.eu/wp-content/uploads/2023/01/UNCAN_eu-a-European-Initiative_Eric-Solary-et-al_IN-FOCUS-2022.pdf

Policy recommendations

The EBCP funded projects and programs are still ongoing and the overview provided in this policy brief is not comprehensive. Cancer survivors are not forgotten in the EBCP and several chapters include them in some extent. In Belgium, several initiatives related to survivorship have been identified. However, unmet needs among cancer survivors are still numerous [10]. In this section we detail our recommended actions to overcome the challenges associated with these unmet needs.

First, through our analysis, it is clear that high quality survivorship care and its organization are side-lined in chapter 5 (high standards in cancer care). This creates unnecessary partitioning between survivorship care and the diagnostic and treatment phases. Even information systems and monitoring between diagnostics and treatment, and survivorship seems to be the purpose of a distinct initiative (flagship 8). This does not lend to the integration of survivorship care in future care organization developments. This sends a wrong signal to health-care authorities and professionals. Given that more cancer patients will survive in the future, Belgium and EU countries should implement best practices, and include survivorship care in their clinical guidelines as well as in their care pathways.

Second, at both Belgium and EU levels, the scarce attention given to survivorship in the projects addressing the organization of cancer care, represents missed opportunities to integrate survivorship care in standardized care pathways. This is of tremendous importance as the criteria and indicators being developed, such as those for the certification of comprehensive centres, will exclude survivorship care and rehabilitation from their scope. Health authorities and administrations must pay attention to the provision of indicators related to cancer survivorship when planning and designing quality insurance schemes, including certification of centres.

Third, although recently cancer patients are benefitting from better treatments and care organization, the organization of supportive care is lacking, for various reasons [10]. There is a need to ensure that cancer patients and survivors also benefit from innovations, just as patients under treatment do. In that vein, support is required to foster more research and knowledge exchange, to confront the lack of evidence in many areas of survivorship.

In conclusion, cancer survivorship care remains an afterthought in care organisation, as if it were an add-on. Given the increase of cancer survivors, their unmet needs may put the sustainability of healthcare and social security systems at risk, and more importantly, their wellbeing and social inclusion. The underlying glaring inequity between survivorship and other cancer care domains is not acceptable and decision-makers should concentrate the efforts in

subsequent work programs to get back on track to guarantee quality of life and access to high-quality survivorship care for the 12 million European cancer survivors and their relatives.

Abbreviations

| | |
|-----------|--------------------------------|
| EU | European Union |
| EBCP | Europe's beating cancer plan |
| QoL | Quality of Life |
| SCP | Survivorship care pathway |
| JA CanCon | Joint action on cancer control |

Acknowledgements

We do thank all scientists from the Belgian Cancer Centre and the members of the BE EBCP- Mirror group for their contributions during the discussions of the working groups.

Prof. Elisabeth De Waele (UZ Brussel), Valérie Servais (UC Louvain), Anke Boone (KU Leuven), Hans Neefs (KomOpTegenKanker), Hugué Désiron (ACT-Désiron), Dr. Vincent Verschaeve (Grand Hopital de Charleroi), Nele Adriaenssens (UZ Brussel), Prof. Maëlle de Ville de Goyet (UC Louvain), Dr. Philip Debruyne (AZ Groeninge), Dr. Christine Langenaeken (AZ Klina), Hélène Antoine-Poiriel (Sciensano), Hanna Peacock (Belgian Cancer Registry), Isabelle Merckaert (Institut Jules Bordet, ULB), Christel Fontaine (UZ Brussel), Prof. Gwen Sys (UZ Gent), Kathi Apostolidis (ECPC), Stefan Gijsels (Patient Expert Centre).

About this supplement:

This article has been published as part of Archives of Public Health Volume 82 Supplement 1, 2024: Coming together to fight cancer: a series of policy briefs taking stock of the implementation of Europe's Beating Cancer Plan (EBCP) in Belgium. The full contents of the supplement are available online at <https://archpublichealth.biomedcentral.com/articles/supplements/volume-82-supplement-1>.

Authors' contributions

All authors contributed in writing the manuscript. All authors read and approved the final manuscript.

Funding

The work of the Belgian Cancer Centre of Sciensano is funded by the National Institute for Health and Disability Insurance (NIHDI) and the European Union. Views and opinions expressed are however those of the author(s) only and do not necessarily reflect those of the NIHDI or the European Union. Neither the European Union nor the granting authority can be held responsible for them. The NIHDI didn't play any role in the conceptualization, design, data collection, analysis, decision to publish, or preparation of the manuscript.

Availability of data and material

Not applicable.

Declarations

Ethics approval and consent to participate

Not applicable.

Consent for publication

Not applicable.

Competing interest

The authors declare that they have no competing interests.

Received: 5 September 2023 Accepted: 12 August 2024

Published online: 29 August 2024

References

1. European Commission. Europe's Beating Cancer Plan. Available at: https://health.ec.europa.eu/system/files/2022-02/eu_cancer-plan_en_0.pdf. Accessed 07 Jul 2024.
2. Fondation Belge Contre le Cancer. Le Baromètre belge du cancer. Edition 2021. Available at: https://cancer.be/wp-content/uploads/2024/01/fcc_barometre_du_cancer_2021.pdf. Accessed 07 Jul 2024.
3. Van Leeuwen M, Husson O, Alberti P, Arraras JI, Chinot OL, Costantini A, EORTC QLQ. Understanding the quality of life (QOL) issues in survivors of cancer: towards the development of an EORTC QOL cancer survivorship questionnaire. *Health Qual Life Outcomes*. 2018;16:1–15.
4. Pollack LA, Greer GE, Rowland JH, et al. Cancer Survivorship: A New Challenge in Comprehensive Cancer Control. *Cancer Causes Control*. 2005;16(Suppl 1):51–9. <https://doi.org/10.1007/s10552-005-0452>.
5. Aziz NM. Cancer survivorship research: State of knowledge, challenges and opportunities. *Acta Oncol*. 2007;46(4):417–32.
6. Cancer Control Joint Action. Official website: <https://cancercontrol.eu/archived/who-we-are/mission-statement.html>. Accessed 07 Jul 2024.
7. Europe Beating Cancer Plan. The Belgian Mirror Group. <https://www.sciensano.be/en/projects/belgian-europes-beating-cancer-plan-mirror-group>. Accessed 07 Jul 2024.
8. European guide on quality improvement in comprehensive cancer control [Electronic source] / [editors] Tit Albreht, Régine Kiasuwa & Marc Van den Bulcke. - El. book - Ljubljana : National Institute of Public Health ; Brussels : Scientific Institute of Public Health, 2017
9. BeONCOsup: Belgian Handbook for Oncological Supportive Care. <https://www.sciensano.be/fr/projets/belgian-handbook-hemato-oncological-supportive-care>. Accessed 07 Jul 2024.
10. Vaz-Luis I, et al. ESMO Expert Consensus Statements on Cancer Survivorship : promoting high-quality survivorship care and research in Europe. *Ann Oncol*. 2022;33(11):1119–33.

Publisher's Note

Springer Nature remains neutral with regard to jurisdictional claims in published maps and institutional affiliations.