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## Beyond treatment – Psychosocial and behavioural issues in cancer survivorship research and practice



Neil K. Aaronson <sup>a,\*</sup>, Vittorio Mattioli <sup>b</sup>, Ollie Minton <sup>c</sup>, Joachim Weis <sup>d</sup>,  
 Christoffer Johansen <sup>e</sup>, Susanne O. Dalton <sup>f</sup>, Irma M. Verdonck-de Leeuw <sup>g</sup>,  
 Kevin D. Stein <sup>h</sup>, Catherine M. Alfano <sup>i</sup>, Anja Mehnert <sup>j</sup>, Angela de Boer <sup>k</sup>,  
 Lonneke V. van de Poll-Franse <sup>l</sup>

<sup>a</sup> Division of Psychosocial Research and Epidemiology, The Netherlands Cancer Institute, Amsterdam, The Netherlands

<sup>b</sup> O.U. Anesthesiology, Intensive Care, Pain and Palliative Care, Experimental Unit of Psycho-Oncology, National Cancer Research Center 'Giovanni Paolo II', Bari, Italy

<sup>c</sup> Palliative Medicine, Division of Population Health Sciences and Education, St. George's University of London, London, United Kingdom

<sup>d</sup> Department of Psychosocial Oncology, Clinic for Tumor Biology, University of Freiburg, Freiburg, Germany

<sup>e</sup> Cancer Late Effects Research, Oncology, Finsencenteret, Rigshospitalet, University of Copenhagen & Danish Cancer Society Research Centre, Copenhagen, Denmark

<sup>f</sup> Unit of Survivorship Research, The Danish Cancer Society Research Centre, Copenhagen, Denmark

<sup>g</sup> Department of Otolaryngology, Head and Neck Surgery, VU University Medical Center and Department of Clinical Psychology, VU University, Amsterdam, The Netherlands

<sup>h</sup> Behavioral Research Center, Intramural Research Department, American Cancer Society, Atlanta, GA, USA

<sup>i</sup> Office of Cancer Survivorship, Division of Cancer Control and Population Sciences, National Cancer Institute, National Institutes of Health (NIH)/Department of Health and Human Services (DHHS), Bethesda, MD, USA

<sup>j</sup> Section of Psychosocial Oncology, Department of Medical Psychology and Medical Sociology, University Medical Center Leipzig, Leipzig, Germany

<sup>k</sup> Coronel Institute of Occupational Health, Academic Medical Center, Amsterdam, The Netherlands

<sup>l</sup> Centre of Research on Psychology in Somatic Diseases (CoRPS), Tilburg University, Comprehensive Cancer Centre of the Netherlands, Eindhoven, The Netherlands

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### ABSTRACT

The population of cancer survivors has grown steadily over the past several decades. Surviving cancer, however, is not synonymous with a life free of problems related to the disease and its treatment. In this paper we provide a brief overview of selected physical and psychosocial health problems prevalent among cancer survivors, namely pain, fatigue, psychological distress and work participation. We also address issues surrounding self-management and e-Health interventions for cancer survivors, and programmes to encourage survivors to adopt healthier lifestyles. Finally, we discuss approaches to assessing health-related quality of life in cancer survivors, and the use of cancer registries in conducting psychosocial survivorship research. We highlight research and practice priorities in each of these areas. While the priorities vary per topic, common themes that emerged included: (1) Symptoms should not be viewed in isolation, but rather as part of a cluster of interrelated symptoms. This has implications for both understanding the

\* Corresponding author: Address: Division of Psychosocial Research and Epidemiology, The Netherlands Cancer Institute, Plesmanlaan 121, 1066 CX Amsterdam, The Netherlands. Tel.: +31 20 512 2481; fax: +31 20 512 2322.

E-mail address: [n.aaronson@nki.nl](mailto:n.aaronson@nki.nl) (N.K. Aaronson).

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aetiology of symptoms and for their treatment; (2) Psychosocial interventions need to be evidence-based, and where possible should be tailored to the needs of the individual cancer survivor. Relatively low cost interventions with self-management and e-Health elements may be appropriate for the majority of survivors, with resource intensive interventions being reserved for those most in need; (3) More effort should be devoted to disseminating and implementing interventions in practice, and to evaluating their cost-effectiveness; and (4) Greater attention should be paid to the needs of vulnerable and high-risk populations of survivors, including the socioeconomically disadvantaged and the elderly.

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## 1. Introduction

More than half of European patients diagnosed with cancer survive 5 years or longer after their primary diagnosis [1]. A disease-free status, however, is not synonymous with a life free of physical and psychosocial health problems related to the cancer and its treatment. In this paper we provide a brief overview of selected psychosocial issues in cancer survivorship. Specifically, we focus on pain, fatigue, psychological distress and work participation. We also address issues surrounding self-management and e-Health interventions for cancer survivors, and programmes to encourage survivors to adopt healthier lifestyles. Finally, we examine approaches to assessing health-related quality of life in cancer survivors, and the use of cancer registries in conducting psychosocial survivorship research. Our intent is not to provide a comprehensive review of these topics, but rather to briefly summarise the current state of affairs and, more importantly, to highlight what we believe are some of the priorities for future research and clinical care development initiatives.

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## 2. Pain and pain management

Chronic pain is one of the most distressing and disabling symptoms experienced by cancer patients and survivors. Knowledge of pain and its effects on cancer survivors is still limited due to the small number of studies, and thus it is often left unrecognised and untreated [2].

Pain is not only caused by tissue damage produced by the cancer itself but can also be caused by treatment-related toxic or traumatic damage to peripheral and central neural structures, resulting in long-lasting or even late onset neuropathy. Pain may persist after treatment or may emerge several months or even years after treatment has been completed. This is described as post-cancer pain syndrome.

Pain rates of 30–50% have been reported in cancer survivors, varying as a function of diagnosis, stage, disease status, comorbid conditions, initial pain management, patient characteristics (e.g. sex, cultural background) and measures used to assess pain. Importantly, pain is also reported in disease-free cancer survivors. An analysis of the 2002 *National Health Interview Survey* in over 30,000 persons found that the prevalence of pain in cancer survivors was much higher (34%) than in controls without a history of cancer (18%) [3]. The highest

prevalence rates were observed in post-thoracotomy (up to 80%), post-amputation/phantom limb (50% to 80%), post-neck dissection (52%) and breast cancer (63%) patients [4].

Post-cancer pain syndromes should be viewed as part of a cluster of symptoms, including fatigue, anxiety, depression and sleep disturbance. All of these symptoms may be caused, at least in part, by a common, underlying biological mechanism. Combined, these symptoms have a negative impact on survivors' physical and psychosocial functioning [5].

Chronic pain is a persistent stressor that indirectly affects the feedback loop of the hypothalamic–pituitary–adrenal (HPA) axis through involvement of brain regions in the limbic system. The HPA axis is also activated in response to psychological stressors such as depression and anxiety [6]. Emotional distress, depression, anxiety and fear may contribute significantly to the resulting pain experience [7].

Even when the 3-step WHO pain ladder is employed, complete relief from chronic cancer pain may be an unrealistic expectation in some patients [8]. Opioid therapy is a useful tool, but in the survivorship setting its use is often discouraged due to long-term side effects, including the development of opiate-induced hyperalgesia, as well as the risk of abuse and addiction [9]. Non-opioid medication options include antidepressants, antiepileptic drugs and topical agents, in addition to non-steroidal anti-inflammatory agents and acetaminophen [10]. Intrathecal therapies with non-opioid alternatives, such as ziconotide or other drugs, should also be considered for the management of chronic pain, particularly if it is neuropathic [9]. Gene therapy represents a potentially useful, new approach. However, this requires careful selection of a therapeutic gene that properly modulates the nociceptive cascade without causing additional complications for the patient [11]. In selected patients, interventional modalities may be considered, including nerve blocks, trigger point injections, spinal cord stimulators or implanted intrathecal pumps [10].

An equally if not more useful approach may be to encourage survivors to actively participate in the plan of care for their pain management, with an emphasis on self-activation and non-pharmacologic therapies, and to help them focus on certain outcomes such as improved functional capacities, restorative sleep, social activities, mood and coping, which may help to reduce pain to a tolerable level [5,10].

Our knowledge and understanding of chronic pain in cancer survivors can be enhanced by: (1) investigations of symptom clusters and the total symptom burden experienced by

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