### **EDITORIAL**

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# European cancer rehabilitation and survivorship, 2018: one of a kind

Susanne Oksbjerg Dalton<sup>a,b</sup> and Christoffer Johansen<sup>c,d</sup>

<sup>a</sup>Danish Cancer Society Research Center, Copenhagen, Denmark; <sup>b</sup>Department of Clinical Oncology and Palliative Care, Zealand University Hospital, Naestved, Denmark; <sup>c</sup>Department of Oncology, Copenhagen University Hospital, Copenhagen, Denmark; <sup>d</sup>Danish Cancer Society Research Center, Unit of Survivorship Research, Copenhagen, Denmark

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In a world of digital solutions to almost every problem and a change in communication from a hand-written letter traveling for weeks over long distances to short messages reaching you within milliseconds – no matter where in the world, the question of whether we should continue to organize scientific meetings to present, discuss and reflect upon science and practice arises. Why not just organize a videoconference and transmit presentations to the remote audiences? When we initiated the European Cancer Rehabilitation and Survivorship meetings almost 10 years ago, we could not foresee the success in terms of participation, eagerness to present and the bibliometric success of the publications emerging from these bi-annual symposia generously sponsored by Acta Oncologica.

In short, during these 10 years, we organized five ECRS symposia and produced 140 papers of which many are among the most downloaded and cited papers published in Acta Oncologica [1–4]. We have had attendees from all over the world, many returning enjoying the spirit and fellowship of the ECRS. This is a remarkable achievement as the field of survivorship in broad terms is quite new. Although the term cancer survivor was introduced back in the 1980s [5], it has not been many years since the term survivorship was launched by clinical societies like IOM and ASCO [6,7] on the background of a population of cancer survivors which today is growing almost exponentially.

Many of these cancer survivors are living complex everyday lives as about 50% of them have one or more additional chronic condition at the time of diagnosis and close to 30% use five or more prescribed medications on a daily basis data coming from a nationwide and population-based study in Denmark (unpublished data). Not only the cancer disease and the aftermath of treatment require attention and followup but also other health problems and conditions. Looking at the population of survivors, they have a higher risk of hospitalization for a broad range of incident somatic diseases after the cancer diagnosis than cancer-free people in comparison, most pronounced in the first years after the cancer diagnosis [8]. In combination, this information points to the need for an ampler model of follow-up considering all diseases affecting an individual, not only the cancer, and thereby moving the care from disease specific to a comprehensive personalized intervention in line with the general idea of personalized genotyped treatment of disease.

The course and risk of late effects in childhood cancer survivors are well described and risk factors identified are all closely related to the specific treatment provided for the cancer disease. In adults, we need more knowledge in order to prevent, detect early and treat late effects, which may have a more systemic character such as depression, fatigue, or pain. Some late effects and symptoms may be a result of surgery like lymphedema, ostomies, and speech problems or an effect of radiation therapy such as chronic diarrhea, cardiovascular effects, or pulmonary changes or chemotherapy like peripheral neuropathies [9]. Numerous late effects may be listed associated with the specific treatment. Probably, these symptoms and diseases require symptomatic treatment. This implies, that we in principle define the post-treatment symptoms as normal symptoms and not specific for cancer patients or cancer treatment. Cancer and its treatment cause other chronic diseases and these diseases must be addressed just as we treat these diseases when they occur in persons not characterized by being cancer patients.

This fifth ECRS symposium had a strong track of late effect researchers presenting data and perspectives in this field of research. The newly establishment of three Danish late effect research units covering separate research themes; general late effects as well as late effects after breast cancer and after pelvic cancer diseases. In a collaboration between these national units, research results may inform the development of guidelines for clinical practice in most common late effects (www.cancer.dk/bedrevidenomsenfoelger [In Danish]).

Likewise, the papers selected for publication from the symposium cover diverse aspects of survivorship research. Research on prehabilitation and optimization of patients to provide better foundations for better survivorship among patients is a fast growing area and is represented by papers on prehabilitation before surgery [10–12]. Also papers address Patient Reported Outcomes (PRO) use and readiness

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for e-health solutions during therapy and rehabilitation [13–15].

A number of papers describe ongoing efforts to develop and test interventions to improve follow-up care and to prevent development of severe late effects providing us with crucial information on feasibility and patient perspectives [16–19], adherence [20,21], and effects on quality of life [22].

Observational evidence describes physical activity levels and other lifestyle behaviors [23–25] while two papers illustrate the importance of cancer on the family addressing lifestyle in spouses to cancer survivors [26] and on dyadic associations of fear of recurrence among couples affected by cancer [27].

Severe late effects like cardiovascular disease or depression seem to a larger degree to affect prostate cancer patients with short education, even if lifestyle and pre-cancer morbidity is accounted for [28,29]. With social disparities in both referral and attendance to rehabilitation [30] these findings strongly indicate inequality in survivorship. Not all groups of cancer patients benefit equally from advantages in early diagnostics, treatment and follow-up and survivorship care [31].

New knowledge is presented on a number of late effects of cancer treatment, their associated factors, symptom patterns over time as well as consequences on quality of life and work life. Several papers address brain alterations and cognitive dysfunction among cancer survivors [32–34] while aspects of chronic fatigue [35], chronic pain [36], sexual dysfunction [37], diarrhea [38], trajectories of psychological distress [39], quality of life [40–42] and returning to [43], and staying at work [44] constitute the focus in original research and review papers.

In 2016, prehabilitation in cancer patients [45], organization of follow-up [46] but also PRO) were emerging topics [47]. The integration of quality-of-life measurements with PRO seem to address the need for both psychological and somatic subjective reporting from cancer survivors (i.e. 48,49]. Also in 2016, the aspect of being a relative to a cancer survivor became a subject on the research agenda [50]. Bit by bit, the ECRS papers contribute with covering the knowledge gaps enabling us to work towards establishing evidence-based clinical survivorship care.

We already decided that we will once again invite you to Copenhagen 28-29 September 2020, Bon Voyage.

#### **Disclosure statement**

No potential conflict of interest was reported by the authors.

## References

- Dalton SO, Bidstrup PE, Johansen C. Rehabilitation of cancer patients: needed, but how? Acta Oncol. 2011;50:163–166.
- [2] Dalton SO, Johansen C. New paradigms in planning cancer rehabilitation and survivorship. Acta Oncol. 2013;52:191–194.
- Johansen C, Dalton SO. Survivorship searching for new directions. Acta Oncol. 2015;54:569–573.
- [4] Johansen C, Dalton SO. Survivorship in new harbors. Acta Oncol. 2017;56:119–122.

- [5] Twombly R. What's in a name: who is a cancer survivor? J Natl Cancer Inst. 2004;96:1414–1415.
- [6] Institute of Medicine. 2005. From cancer patient to cancer survivor: lost in transition. Washington, DC: National Academies Press.
- [7] Shapiro CL, Jacobsen PB, Henderson T, et al. ReCAP: ASCO core curriculum for cancer survivorship education. Jop. 2016;145: e108–e117.
- [8] Kjaer TK, Andersen EAW, Winther JF, et al. Long-term somatic disease risk in adult Danish cancer survivors. JAMA Oncol. 2019. doi: 10.1001/jamaoncol.2018.7192 [e-pub ahead of print].
- [9] Rowland JH, Bellizzi KM. Cancer survivorship issues: life after treatment and implications for an aging population. J Clin Oncol. 2014;32:2662–2668.
- [10] Minnella EM, Liberman AS, Charlebois P, et al. The impact of improved functional capacity before surgery on postoperative complications: a study in colorectal cancer. Acta Oncol. 2019;58: 573–578.
- [11] Herrstedt A, Bay ML, Simonsen C, et al. Exercise-mediated improvement of depression in patients with gastro-esophageal junction cancer is linked to Kynurenine metabolism. Acta Oncol. 2019;58:579–587.
- [12] West MA, Astin R, Moyses HE, et al. Exercise prehabilitation may lead to augmented tumor regression following neoadjuvant chemoradiotherapy in locally advanced rectal cancer. Acta Oncol. 2019;58:588–595.
- [13] Nissen A, Bager L, Pappot H. The use of PRO in adverse event identification during cancer therapy – choosing the right questions to ask. Acta Oncol. 2019;58:596–602.
- [14] Holländer-Mieritz C, Johansen J, Johansen C, et al. Comparing the patients' subjective experiences of acute side effects during radiotherapy for head and neck cancer with four difference patient-reported outcomes questionnaires. Acta Oncol. 2019;58: 603–609.
- [15] Rossen S, Kayser L, Vibe-Petersen J, et al. Technology in exercisebased cancer rehabilitation: a cross-sectional study of receptiveness and readiness for e-Health utilization in Danish cancer rehabilitation. Acta Oncol. 2019;58:610–618.
- [16] Saltbaek L, Karlsen RV, Bidstrup PE, et al. MyHealth: specialist nurse-led follow-up in breast cancer. A randomized controlled trial – development and feasibility. Acta Oncol. 2019;58:619–626.
- [17] Hovdenak Jakobsen I, Juul T, Thaysen HV, On behalf of the FURCA project group, et al. Differences in baseline characteristics and 1-year psychological factors between participants and nonparticipants in the randomized, controlled trial regarding patientled Follow-Up after Rectal Cancer (FURCA). Acta Oncol. 2019;58: 627–633.
- [18] Høeg BL, Tjørnhøj-Thomsen T, Skaarup JA, et al. Whose perspective is it anyway? Dilemmas of patient involvement in the development of a randomized clinical trial – a qualitative study. Acta Oncol. 2019;58:634–641.
- [19] Dengsø KE, Tjørnhøj-Thomsen T, Dalton SO, et al. It's all about the CA-19-9. A longitudinal qualitative study of patients' experiences and perspectives on follow-up after curative surgery for cancer in the pancreas, duodenum or bile-duct. Acta Oncol. 2019; 58:642–649.
- [20] Lund LW, Ammitzbøll G, Hansen DG, et al. Adherence to a longterm progressive resistance training program, combining supervised and home-based exercise for breast cancer patients during adjuvant treatment. Acta Oncol. 2019;58:650–657.
- [21] Hajdú SF, Christensen MB, Kristensen MØ, et al. Adherence to preventive swallowing exercises for head and neck cancer patients undergoing (chemo)radiotherapy treatment. Acta Oncol. 2019;58:658–664.
- [22] Ammitzbøll G, Kjaer TK, Johansen C, et al. Effect of progressive resistance training on health-related quality of life in the first year after breast cancer surgery – results from a randomized controlled trial. Acta Oncol. 2019;58:665–672.
- [23] Gal R, Monninkhof EM, Peeters PHM, et al. Physical activity levels of women with breast cancer during and after treatment, a

comparison with the Dutch female population. Acta Oncol. 2019; 58:673-681.

- [24] Gjerset GM, Kiserud CE, Loge JH, et al. Changes in fatigue, health-related quality of life and physical activity after a oneweek educational program for cancer survivors. Acta Oncol. 2019; 58:682–689.
- [25] Bersvendsen HS, Haugnes HS, Fagerli U-M, et al. Lifestyle behavior among lymphoma survivors after high-dose therapy with autologous hematopoietic stem cell transplantation, assessed by patient-reported outcomes. Acta Oncol. 2019;58:690–699.
- [26] Ezendam NPM, Karlsen RV, Christensen J, et al. Do people improve health behavior after their partner is diagnosed with cancer? A prospective study in the Danish diet, Cancer and Health Cohort. Acta Oncol. 2019;58:700–707.
- [27] Wu LM, McGinty H, Amidi A, et al. Longitudinal dyadic associations of fear of cancer recurrence and the impact of treatment in prostate cancer patients and their spouses. Acta Oncol. 2019;58: 708–714.
- [28] Moustsen IR, Friberg AS, Larsen SB, et al. The association between education and risk of major cardiovascular events among prostate cancer patients: a study from the Diet, Cancer and Health study. Acta Oncol. 2019;58:715–721.
- [29] Friberg AS, Moustsen IR, Larsen SB, et al. Educational level and the risk of depression after prostate cancer. Acta Oncol. 2019;58: 722–729.
- [30] Dalton SO, Olsen MH, Moustsen IR, et al. Socioeconomic position, referral and attendance to rehabilitation after a cancer diagnosis.
  A population-based study in Copenhagen, Denmark, 2010-2015. Acta Oncol. 2019;58:730–736.
- [31] Dalton SO, Olsen MH, Johansen C, et al. Socioeconomic inequality in cancer survival – changes over time. A population-based study, Denmark, 1987–2013. Acta Oncol. 2019;58:737–744.
- [32] Amidi A, Wu LM. Structural brain alterations following adult non-CNS cancers: a systematic review of the neuroimaging literature. Acta Oncol. 2019;58:522–536.
- [33] Haldbo-Classen L, Amidi A, Wu LM, et al. Long-term cognitive dysfunction after radiation therapy for primary brain tumors. Acta Oncol. 2019;58:745–752.
- [34] Buskbjerg CDR, Amidi A, Demontis D, et al. Genetic risk factors for cancer-related cognitive impairments: a systematic review. Acta Oncol. 2019;58:537–547.
- [35] Bøhn S-K, Thorsen L, Kiserud CE, et al. Chronic fatigue and associated factors among long-term survivors of cancers in young adulthood. Acta Oncol. 2019;58:753–762.
- [36] Bovbjerg DH, Keefe FJ, Soo MS, et al. Persistent breast pain in post-surgery breast cancer survivors and women with no history of breast surgery or cancer: associations with pain catastrophizing, perceived breast cancer risk, breast cancer worry, and emotional distress. Acta Oncol. 2019;58:763–768.

- [37] Bond CB, Jensen PT, Groenvold M, et al. Prevalence and possible predictors of sexual dysfunction and selfreported needs related to the sexual life of advanced cancer patients. Acta Oncol. 2019; 58:769–775.
- [38] Larsen HM, Borre M, Christensen P, et al. Clinical evaluation and treatment of chronic bowel symptoms following cancer in the colon and pelvic organs. Acta Oncol. 2019;58:776–781.
- [39] Lotfi-Jam K, Gough K, Schofield P, et al. A longitudinal study of four unique trajectories of psychological distress in cancer survivors after completing potentially curative treatment. Acta Oncol. 2019;58:782–789.
- [40] Nathalie Zandbergen N, de Rooij BH, Vos MC, et al. Changes in health-related quality of life among gynecologic cancer survivors during the two years after initial treatment: a longitudinal analysis. Acta Oncol. 2019;58:790–800.
- [41] Kristensen HØ, ThyØ A, Christensen P. Systematic review of the impact of demographic and socioeconomic factors on quality of life in ostomized colorectal cancer survivors. Acta Oncol. 2019;58: 566–572.
- [42] Thong MSY, Koch-Gallenkamp L, Jansen L, et al. Age-specific health-related quality of life in longterm and very long-term colorectal cancer survivors versus population controls – a populationbased study. Acta Oncol. 2019;58:801–810.
- [43] Arndt V, Koch-Gallenkamp L, Bertram H, et al. Return to work after cancer. A multi-regional population-based study from Germany. Acta Oncol. 2019;58:811–818.
- [44] Stapelfeldt CM, Klaver KM, Rosbjerg RS, et al. A systematic review of interventions to retain chronically ill occupationally active employees in work: can findings be transferred to cancer survivors? Acta Oncol. 2019;58:548–565.
- [45] Carli F, Gillis C, Scheede-Bergdahl C. Promoting a culture of prehabilitation for the surgical cancer patient. Acta Oncol. 2017;56: 128–133.
- [46] van de Poll-Franse LV, Nicolaije KAH, Ezendam N. The impact of cancer survivorship care plans on patient and health care provider outcomes: a current perspective. Acta Oncol. 2017;56: 134–138.
- [47] Gordon B-B, Chen RC. Patient-reported outcomes in cancer survivorship. Acta Oncol. 2017;56:166–173.
- [48] Caruso R, Nanni MG, Riba M, et al. Depressive spectrum disorders in cancer: prevalence, risk factors and screening for depression: a critical review. Acta Oncol. 2017;56:146–155.
- [49] Arndt V, Koch-Gallenkamp L, Jansen L, et al. Quality of life in long-term and very long-term cancer survivors versus population controls in Germany. Acta Oncol. 2017;56:190–197.
- [50] Badr H. New frontiers in couple-based interventions in cancer care: refining the prescription for spousal communication. Acta Oncol. 2017;56:139–145.