ACTA ONCOLOGICA, 2017
VOL. 56, NO. 2, 119–122
http://dx.doi.org/10.1080/0284186X.2016.1277262

Taylor & Francis
Taylor & Francis Group

EDITORIAL

Survivorship in new harbors

Christoffer Johansen[a,b] and Susanne Oksbjerg Dalton[b]

[a]Department of Oncology, Copenhagen University Hospital, Copenhagen, Denmark; [b]Survivorship, Danish Cancer Society Research Center, Copenhagen, Denmark

Acta Oncologica was once again main sponsor for the European Cancer Rehabilitation and Survivorship Symposium (ECRS) in Copenhagen September 2016. The three preceding symposia were held in 2010, 2012 and 2014 [see 1–11]. In 2016, some 350 clinicians, scientists and people working in the area provided knowledge about the growing field of cancer survivorship. We also organized workshops with more than 100 participants and used this forum for exchange of clinical practice and development of the scientific methods we apply when studying cancer survivors.

Developments in demography and medical advancement challenge our health care models.

Health care systems are constantly challenged by patient demands, budget restrictions, implementation of new equipment and overall demographic changes with an aging population. This contributes to a continuous integrative maneuver to establish a well-functioning everyday work place and not the least – institutions that address the needs of the patients with high-quality care. In the horizon, we realize the changing demographic landscape with more patients having more than one disease over a life span. The number of diseases on the death certificate will probably increase by one or two per generation, expecting a person born in this decade to die with 4–6 chronic disorders. Chronicity becomes an everyday phenomenon, which disputes the whole concept of cancer as a single disease.

Cancer patients are no longer only cancer patients; they have become diseased citizens and cancer is only one out of several biological realities, which affect the physiology, the social life, and psychology. Cardiovascular diseases, endocrine disorders, musculoskeletal or neurodegenerative diseases become concurrent conditions competing between each other when deciding, which therapy the patient has to comply with. This calls for development of new algorithms, with personalized medicine targeting the cancer as well as the concurrent diseases.

Do we expect cancer patients to be in gene-specific treatment for their cancer and do we then imagine that these patients also are in gene-specific treatment for their specific genetic variant of, e.g., hypertension? This situation is close, but yet far away, and points to the need for integrated treatment plans and integration of specialties that the medical profession has used decades to establish as independent entities. Now it is time to reunite the medical specialties for the sake of integrated treatment. We have reached a point where our old ideas about division of knowledge between specialties simply does not work. Our current model applies to cancer as a single disease. The new model has to apply to the citizens taking into account the entire list of diseases and drugs or other modalities used for the treatment of these diseases.

Our sequential model of cancer care is also challenged. We have developed and refined a diagnostic system including decision on treatment options followed by a treatment period and later rehabilitation. Often the treatment results in late effects, which in time also require treatment. It is a model, which assigns responsibility between authorities and balances between public or private institutions depending on the organization of the health care system in each country. Still, everywhere we look, the model is sequential.

This approach needs rethinking. Why not prevent acute symptoms and perhaps even the late effects or at least reduce their severity? Why not initiate rehabilitation at date of diagnosis as this, in principle may relieve the total symptom burden in the patients with cancer? Small, however, extremely interesting and promising randomized trials have shown that the cancer patients undergoing surgery may benefit in terms of their postoperative physiological and psychological outcome if a certain time period is spend to prepare and optimize the health of the patient. If the physical condition is optimized it may facilitate that the surgery is not followed by unwanted physical side effects related to the surgery. Alongside, it may also have a psychological effect, which the patient may benefit from in coping with the cancer diagnosis and its treatment. The psychological effect may go through the potential empowerment of the patient. Instead of sitting at home, ruminating over the diagnosis and the changed perspectives of life, waiting for the surgery, we actually hand back some options for patients to influence the cancer trajectory. In popular terms, we are promoting that the patient may become ‘an editor of his own life’. The loss of control, the distress, anxiety and depression, which often follows a cancer diagnosis, may then be tackled. Not completely, but partly by assigning some tasks to the patient in the time between diagnosis and first treatment. We may even argue that this time-period should be prolonged, at least for some cancers, such as breast cancers, prostate and colorectal cancers. By rethinking the model, we may take on

CONTACT Christoffer Johansen christof@cancer.dk Department of Oncology, Copenhagen University Hospital, Copenhagen, Denmark

a new perspective that adds meaningful activities for patients and their families. Increasing physical activity, quitting smoking, improving the diet, and reducing the alcohol intake in order to have a better outcome of the treatment [12,13]. The optimization may not only be relevant for improving outcomes after surgery, but also after chemotherapy or radiation – or whatever treatment modalities we suggest the patient to undergo.

One of the main areas of research presented and discussed at our fourth ECRS symposium was indeed pre-habilitation in cancer patients. We present both a review and reanalysis of prior studies suggesting that a short and intense training and protein substitution program in preparation for surgery for colorectal cancer may improve recovery and patient functional capacity [14,15] in a patient group where there is clear potential for addressing modifiable risk factors before undergoing major surgery [16]. Developing and testing interventions for patients before and during treatment can be difficult as patients are undergoing intensive diagnostic work-up, may experience distress due to uncertainty and anxiety for the outcome, and if in treatment, also dealing with acute side effects of this. This can make the decision to take part in new research seem overwhelming and thus careful piloting of interventions, evaluation of acceptance and adherence are of paramount importance. Several interesting studies are underway of pre-habilitation prior to and during adjuvant treatment, i.e., a pilot study of a progressive resistance training program to prevent development of lymphedema among breast cancer patients [17] and a feasibility evaluation of a swallowing intervention among head and neck cancer patients [18].

Several papers address organization of follow-up care. A review of survivorship care plans (SCPs) concludes that there is not enough evidence to implement these on a large scale or to abandon them [19]. Most patients would prefer to have their SCP explained in detail at the end of the treatment, indicating substantial cost in implementing SCPs for patients and thus a need for sound evidence of benefit from SCPs [20]. The organization of programs of follow-up care of cancer patients, have been challenged in later years. So who should be in charge of the follow-up care, i.e., detection of recurrence or late effects – the cancer specialist, the general practitioner or the patient? Prostate and melanoma cancer survivors had different preferences regarding cancer specialist or general practitioner for follow-up care based on age, education level, gender and satisfaction with the general practitioner [21]. A retrospective cohort of early-stage endometrial cancer survivors indicated that symptom-based and thus patient-initiated follow-up would be superior to regular follow-up visits as most recurrences are symptomatic, but also point to a challenge because there is social inequality in ability to perceive and react to symptoms without preplanned visits [22]. Along the same lines, a randomized controlled trial (RCT) testing if patient education and subsequent patient-led follow-up care of rectal cancer patients may improve well-being of survivors is under development [23]. The concept of patient empowerment in cancer follow-up may be conceptualized as mastery, skills and knowledge, and to be able to have one's concerns and issues addressed by the health care system [24]. It is, however, important to – when developing interventions based on patient involvement that the interventions are not only efficient, but also feasible for all patients – not just the resourceful, well-educated survivors with strong social networks. In handing back the responsibility of individualized care to the patient and his family, the health system must make sure that it supports all patients to enable them to be in charge of their own care. One possible way to support vulnerable patients through care trajectories is patient navigation – with promising results shown for both health staff and peer navigator [25]. However, in a pilot study of navigator support among newly diagnosed lung cancer patients, the patient, staff and organizational barriers were present [26].

Patient reported outcomes (PROs) are increasingly seen as important in the development of ongoing patient cancer care; as a tool useful during interventions but also in the development of patient initiated follow-up. Commonly used, validated PRO instruments to assess quality of life, symptoms, and unmet needs during survivorship are reviewed [27] and further, a systematic review of relevant scales and questionnaires that measure patient empowerment points to the need for development of questionnaires based on theory, developed for a specific target group to ensure sensitivity and relevance [28].

We present a number of studies on late effects and QoL. A review of reviews and meta-analyses summarizes the high prevalence of depression among cancer survivors, its risk factors but also the evidence of suboptimal detection and management of depression despite of the knowledge [29]. In line with this, a German study showed that, compared to population norms, detriments in HRQoL among long-term cancer survivors persist over more than a decade and affect predominantly younger patients [30]. Studies of specific factors associated with QoL among cancer survivors document that both patient related factors as comorbidity and social factors and late effects like fatigue among adolescent and young adult survivors of lymphoma were associated with HRQoL [31]; that any level of dysphagia were associated with clinically relevant decreases in HRQoL and functioning among head and neck cancer survivors [32]; that pain was associated with poorer self-reported health and QoL in CRC survivors [33]; while conversely low education was associated with lower physical functioning and increased pain among a mixed group of survivors [34]. Studies of rare cancers underline the issue of small samples, but also descriptively illustrate important HRQoL issues in both patients with cholangiocarcinoma [35] and sarcoma [36].

Specific interventions addressing important symptoms and late effects after cancer treatment may improve the consequences that patients perceive and examples of this include that specific reconstructions in breast cancer patients lead to higher esthetic satisfaction and higher QoL [37]. Further, patients with chronic fatigue express need for more complex rehabilitation encompassing several components [38] and similarly patients who suffer clinical levels of fear of recurrence experience unmet needs years after end of treatment [39]. Return to work is an important measure of rehabilitation but is also complex; a Dutch study shows that even after

return to work, survivors with low self-perceived work ability have an increased risk to discontinue their work [40]. Secondary results from an intervention in irradiated prostate cancer survivors show that more appropriate coping styles can be supported [41] whereas explorative analyses of a mindfulness trial in breast cancer survivors show that attachment avoidance, and potentially radiotherapy, may be clinically relevant factors for identifying the patients who may benefit most from mindfulness as a pain management strategy [42].

Most people do not experience cancer alone and partners or significant others provide emotional support and care while cancer takes a heavy toll on them and their relationship with the patient [43]. In order to help couples through the experience, we need to develop a more nuanced view of communication in couples – and to acknowledge that preexisting communication patterns exist that may influence efficacy of any couples intervention. In a cohort of couples dealing with breast cancer, it was evident that satisfaction with sex life in sexually active couples needs to be addressed as a couple (not individual) issue [44]. An intervention study that indeed includes the couple as the unit for intervention among prostate cancer patients to reduce sexual and urological dysfunction showed that both couple counseling and pelvic floor muscle training were well accepted and achievable for participants [45]. Another intervention targets families of childhood cancer survivors in order to promote healthy coping strategies show a high recruitment and retention rates and high acceptance indicating relevance to the families [46].

We continue to discuss how to provide the evidence needed for preventing, early detecting and treating the late effects that cancer survivors experience [47–49]. New initiatives are underway covered by the ideas for the establishment of clinics directed at creating services for patients having the most severe late effect problems and concurrently establish scientific data which can support the evidence needed to move forward. Research and clinic hand in hand is probably the best way to move forward. We look forward to the next ECRS symposium in September 2018 in Copenhagen.

Disclosure statement

The authors report no conflicts of interest. The authors alone are responsible for the content and writing of this article.

ORCID

Christoffer Johansen http://orcid.org/0000-0002-4384-206X
Susanne Oksbjerg Dalton http://orcid.org/0000-0002-5485-2730

References

[1] Ewertz M, Qourtrup C, Eckhoff L. Chemotherapy-induced peripheral neuropathy in patients treated with taxanes and platinum derivatives. Acta Oncol. 2015;54:587–591.
[2] Kurita G, Sjøgren P. Pain management in cancer survivorship. Acta Oncol. 2015;54:629–634.
[3] Christensen JF, Bandak M, Campbell A, et al. Treatment-related cardiovascular late-EFFECTS and exercise training countermeasures in testicular germ cell cancer survivorship. Acta Oncol. 2015;54:592–599.
[4] Minton O, Foster J, Maher J. The role of behavioral modification and exercise in the management of cancer related fatigue to reduce its impact during and after cancer treatment. Acta Oncol. 2015;54:581–586.
[5] Lahart IA, Metsios GS, Nevill AM, et al. Physical activity and risk of death and recurrence in breast cancer survivors; a systematic review and meta-analysis of epidemiological studies. Acta Oncol. 2015;54:635–654.
[6] Midtgaard J, Hammer NM, Andersen C, et al. Cancer survivors' experience of exercise-based cancer rehabilitation – a meta-synthesis of qualitative research. Acta Oncol. 2015;54:609–617.
[7] Salakari MRJ, Surakka T, Nurminen R, et al. Effects of rehabilitation among patients with advances cancer: a systematic review. Acta Oncol. 2015;54:618–628.
[8] Warrington L, Absolom K, Velikova G. Integrated care pathways for cancer survivors – a role for Patient-Reported Outcome Measures and health informatics. Acta Oncol. 2015;54:600–608.
[9] Kazak AE, Schneider S, DiDonato S, et al. Family psychosocial risk screening guided by the Pediatric Preventative Psychosocial Health Model (PPPHM) using the Psychosocial Assessment Tool (PAT). Acta Oncol. 2015;54:574–580.
[10] Schofield P, Chambers S. Effective, clinically feasible and sustainable: Key design features of psycho-educational and supportive care interventions to promote individualised self-management in cancer care. Acta Oncol. 2015;54:805–812.
[11] Winther JF, Kenborg L, Byrne J, et al. Childhood cancer survivor cohorts in Europe. Acta Oncol. 2015;54:655–668.
[12] Silver JK, Baima J. Cancer prehabilitation: an opportunity to decrease treatment-related morbidity, increase cancer treatment options, and improve physical and psychological health outcomes. Am J Phys Med Rehabil. 2013;92:715–727.
[13] Carli F, Silver JK, Felman LS, et al. Surgical prehabilitation in patients with cancer: state-of-the-science and recommendations for future research from a panel of subject matter experts. Phys Med Rehabil Clin N Am. 2017;28:49–64.
[14] Carli F, Gillis C, Scheede-Bergdhal C. Promoting a culture of prehabilitation for the surgical cancer patient. Acta Oncol. 2017;56:128–133.
[15] Minnella EM, Bousquet-Dion G, Awasthi R, et al. Multimodal prehabilitation improves functional capacity before and after colorectal surgery for cancer: a five-year research experience. Acta Oncol. 2017;56:298–300.
[16] van Rooijen SJ, Carli F, Dalton SO, et al. Preoperative modifiable risk factors in colorectal surgery: an observational cohort study identifying the possible value of prehabilitation. Acta Oncol. 2017;56:329–334.
[17] Ammitzbøll G, Lanng C, Kroman N, et al. Progressive strength training to prevent LYmphoedema in the first year after breast CAncer – the LYCA Feasibility Study. Acta Oncol. 2017;56:360–366.
[18] Hajdú SF, Wessel I, Johansen, et al. Swallowing therapy and progressive resistance training in head and neck cancer patients undergoing radiotherapy treatment: RCT protocol and preliminary data. Acta Oncol. 2017;56:354–359.
[19] van de Poll-Franse LV, Nicolaije KAH, Ezendam NPM. The impact of cancer survivorship care plans on patient and health care provider outcomes: a current perspective. Acta Oncol. 2017;56:134–138.
[20] Kinnane NA, Piper AJ, Jefford M. How will cancer survivors use survivorship care plans? Acta Oncol. 2017;56:183–189.
[21] Huibertse LJ, van Eenbergen M, de Rooij BH, et al. Cancer survivors' preference for follow-up care providers: a cross-sectional study from the population-based PROFILES-registry. Acta Oncol. 2017;56:278–287.

[22] Jeppesen MM, Mogensen O, Hansen DG, et al. Detection of recurrence in early stage endometrial cancer – the role of symptoms and routine follow-up. Acta Oncol. 2017;56:262–269.
[23] Jakobsen IH, Juul T, Bernstein I, et al. Follow-up after rectal cancer: developing and testing a novel patient-led follow-up programme. Study protocol. Acta Oncol. 2017;56:307–313.
[24] Johnsen AT, Eskildsen NB, Thomsen TG, et al. Conceptualising patient empowerment in cancer follow-up by combining theory and qualitative data. Acta Oncol. 2017;56:232–238.
[25] Freund K. Implementation of evidence-based patient navigation programs. Acta Oncol. 2017;56:123–127.
[26] Kjær TK, Mellemgaard A, Oksen MS, et al. Recruiting newly referred lung cancer patients to a patient navigator intervention (PACO): lessons learnt from a pilot study. Acta Oncol. 2017;56:335–341.
[27] Gordon B-B, Chen RC. Patient-reported outcomes in cancer survivorship. Acta Oncol. 2017;56:166–173.
[28] Eskildsen NB, Joergensen CR, Thomsen TG, et al. Patient empowerment: a systematic review of questionnaires measuring empowerment in cancer patients. Acta Oncol. 2017;56:156–165.
[29] 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.
[30] 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.
[31] Husson O, Prins JB, Kaal SEJ, et al. Adolescent and young adult (AYA) lymphoma survivors report lower health-related quality of life compared to a normative population: results from the PROFILES registry. Acta Oncol. 2017;56:288–294.
[32] Daugaard R, Kjær TK, Johansen C, et al. Association between late effects assessed by physicians and quality of life reported by head-and-neck cancer survivors. Acta Oncol. 2017;56:342–347.
[33] Drury A, Payne S, Brady A-M. The cost of survival: an exploration of colorectal cancer survivors' experiences of pain. Acta Oncol. 2017;56:205–211.
[34] Winther D, Nygaard TK, Horsbøl TA, et al. Associations between education and physical functioning and pain in adult Danish cancer survivors. Acta Oncol. 2017;56:348–353.
[35] Dengsø KE, Hillingsø J, Marcussen AM, et al. Health-related quality of life and anxiety and depression in patients diagnosed with cholangiocarcinoma: a prospective cohort study. Acta Oncol. 2017;56:198–204.
[36] Saebye C, Fugloe HM, Nymark T, et al. Factors associated with reduced functional outcome and quality of life in patients having limb-sparing surgery for soft-tissue sarcomas – a national multicenter study of 128 patients. Acta Oncol. 2017;56:239–244.
[37] Juhl AA, Christensen S, Zachariae R, et al. Unilateral breast reconstruction after mastectomy – patient satisfaction, aesthetic outcome and quality of life. Acta Oncol. 2017;56:225–231.
[38] Gjerset GM, Loge JM, Kiserud CE, et al. Perceived needs for different components in a rehabilitation program among cancer survivors with chronic fatigue compared to survivors without chronic fatigue. Acta Oncol. 2017;56:245–253.
[39] Ellegaard MB, Grau C, Zachariae R, et al. Fear of cancer recurrence and unmet needs among breast cancer survivors in the first five years. A cross-sectional study. Acta Oncol. 2017;56:314–320.
[40] Duijts SFA, Kieffer JM, van Muijen P, et al. Sustained employability and health-related quality of life in cancer survivors up to four years after diagnosis. Acta Oncol. 2017;56:174–182.
[41] Dieperink KB, Johansen C, Hansen S, et al. Male coping through a long-term cancer trajectory. Secondary outcomes from a RTC examining the effect of a multidisciplinary rehabilitation program (RePCa) among radiated men with prostate cancer. Acta Oncol. 2017;56:254–261.
[42] Johannsen M, O'Toole MS, O'Connor M, et al. Clinical and psychological moderators of the effect of mindfulness-based cognitive therapy on persistent pain in women treated for primary breast cancer – explorative analyses from a randomized controlled trial. Acta Oncol. 2017;56:321–328.
[43] Badr H. New frontiers in couple-based interventions in cancer care: refining the prescription for spousal communication. Acta Oncol. 2017;56:139–145.
[44] Rottmann N, Hansen DG, Christensen R, et al. Satisfaction with sex life in sexually active heterosexual couples dealing with breast cancer: a nationwide longitudinal study. Acta Oncol. 2017;56:212–219.
[45] Karlsen RV, Bidstrup PE, Hvarness H, et al. Feasibility and acceptability of couple counselling and pelvic floor muscle training after operation for prostate cancer. Acta Oncol. 2017;56:270–277.
[46] Salem H, Johansen C, Schmiegelow K, et al. FAMily-Oriented Support (FAMOS): development and feasibility of a psychosocial intervention for families of childhood cancer survivors. Acta Oncol. 2017;56:366–374.
[47] Dalton SO, Bidstrup PE, Johansen C. Rehabilitation of cancer patients: needed, but how? Acta Oncol. 2011;50:163–166.
[48] Dalton SO, Johansen C. New paradigms in planning cancer rehabilitation and survivorship. Acta Oncol. 2013;52:191–194.
[49] Johansen C, Dalton SO. Survivorship – searching for new directions. Acta Oncol. 2015;54:569–573.