

Commentary

Psychosocial cancer research – late career perspectives: the International Psycho-Oncology Society 2014 Sutherland Award lecture

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Abstract

This paper consists of reflections in relation to how follow-up is organized in the growing population of cancer survivors. It also includes focus on late effects in cancer patients. The paper also highlights research contributions in the area of depression in cancer patients and discusses these findings in relation to the daily clinical practice. Parts of this paper were a lecture given as a humble response to the Arthur M. Sutherland Award 2014.

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Background

In the preamble, presenting the Arthur M. Sutherland Award at the homepage of the International Psycho-Oncology Society [IPOS], it is stated that the award honors an IPOS or psycho-oncology community member with a lifetime achievement in the field of psycho-oncology. This is a late career award and recognizes sustained and distinguished output in psycho-oncology over their whole career. This is the society's most important award and reflects the international standing of the recipient.

In the succeeding texts find reflections coming from almost 30 years of psychosocial cancer research and practice, however, not observed as a late career contribution but as part of the ongoing discussion of how psychosocial aspects of cancer becomes recognized and integrated in clinical care of cancer patients.

The situation

There is a lack of thorough discussions of the current situation created by a rapid change in demography worldwide, the increase in our abilities to treat the majority of chronic illnesses and the change in the number of cancer survivors characterized by the change in demography and the existence of comorbidity, either at time of diagnosis or existing as a consequence of the cancer treatment. In fact, socioeconomic position and financial resources, social network and availability of social support as well as health literacy and psychological factors, are all factors, which influence and interact with the aforementioned situations.

There is no cure for our development; we only have to deal with it. And it is all about how we deal with the situation. From years of public administration and the health sector as such, no matter if we treat an insured population of wealthy cancer patients or a population receiving the services from a health sector paid by tax, we are experienced with a model of problem solving. This model is best described as, 'shooting at anything trespassing our territory', to close it down. Not too much preparation, not too much consideration and discussion – act and solve. It has some nice aspects as problems may disappear and seem resolved but also downsides including the creation of new problems, which arise from the solving of the initial problem.

However, this direct and active behavior sometimes is not enough, and the number of cancer survivors is a growing and increasingly complicated challenge in our societies no matter where on earth you walk in to the 'situation room' and amplify the pictures brought to you by the scientific drone humming around in the higher layers of the atmosphere. In the EU and in the USA, there are millions of citizens, who have experienced the consequences of a cancer treatment and who are looking for new ways of handling their changed life circumstances. Over the next decades, we expect 25 million incident cases worldwide [1]. We have not established late effect clinics on a large scale and across all cancer diseases but conducted follow-up as a service aiming at detecting recurrences and new primary cancers usually lasting for the first 5 years following diagnosis. The evidence is limited, to be nice, for organizing follow-up of cancer diseases following a calendar and setting up appointments on a regular basis with a decreasing frequency over the years. Most patients call the oncology department or their

GP when symptoms occur and are then enrolled in the treatment algorithms for recurrences, or they go into a program treating the new cancer disease, which is some 4–15% of the incident cancers.

One may say that the health sector is drowning in its own success. Following decades of very limited development in the survival of major cancers, we are now seeing survival rates for cancer patients, which in breast cancer patients living in some affluent, industrialized societies come closer to the life expectancy of the background population [2]. The problem is that we have only limited knowledge on the incidence, prevalence, in fact the entire trajectory and prognostic influence of later effects of the cancer treatment in the survivor population. We do have knowledge, for example, there is a higher risk for certain cardiovascular diseases in lymphoma cancer survivors or that there is a risk for lymphedema in breast cancer survivors but still not enough to establish algorithms for prevention actions, for early detection, or even for rapid treatment the moment these late effects are diagnosed.

When money is involved, we do know something – colostomy appliances in patients with a total rectal extirpation, lymphedema compression stockings in breast cancer patients and speech facilitating appliances following laryngectomy are examples of industrial involvement in facilitating life of cancer survivors. On the other hand, all the psychological problems arising in not only the patient but also in next-of-kin having a relation to the patient have been treated in a more almost reluctant way, probably because it is unclear who should take the responsibility – the oncologist, the GP, or other health professionals.

Follow-up I

Imagine that you have established a complete surveillance system, which keeps a track record of millions of cancer patients in order to identify recurrences and new primary cancers. It runs for decades, and almost nobody challenge the missing evidence for the effect of such follow-up programs. It was enforced that regular contacts with patients including a brief clinical examination and interview concerning general signs of recurrence such as random, unexplained episodes of fever, weight loss, vomiting, or pain would lead to more frequent and earlier detections of recurrences improving the prognosis for the patients. Also, the information obtained during regular contacts bounced back as information improving the clinical practice. It was a rewarding feeling to meet patients who fared well, and doctors also used patients with uncomplicated trajectories as examples of successful strategies for treating cancer. In the busy everyday life of an outpatient clinic, an uncomplicated survivor consultation established room for a more complicated patient and thereby a justification for the entire idea that one service fits all patients. No matter the overwhelming body of literature, which

for decades has documented how patients with a small number of years in school, a short or no education, higher number of unemployment periods, living alone, or having one or more comorbidities at time of diagnosis were patients in need. These patients are in particular need for any kind of support reaching from understanding what the disease actually was about, understanding one's own complicated biology, to the social consequences of both the cancer and other morbidities. How did the treatment of one disease interact with treatment of the other disease?, what can I do?, what will my body tolerate?, what is not possible anymore?, what is a late effect?, and what is a sign of recurrence and so on?

Care has been seen as a universal instrument for changing the conditions of all individuals diagnosed with cancer without, almost no, discussion of the fact that care takes place in a social setting determined by cultural values, social circumstances, and expectancies to life content. And we, who developed the principles of care, in all aspects, are coming from higher educated layers of society applying our own understanding of the 'good life' in all aspects of care from hygiene to values centered around physical activity, diet, alcohol consumption, and quit smoking policies. We apply policies around healthy living, as we believe that all patients will benefit from this intervention and have reported numerous observational studies and clinical randomized trials in which we have tested the effects of changes in lifestyle parameters leaving out the obvious problem that patients who denied participation actually were the group of patients we wanted to reach in our trials. We treat patients not in need.

Psychological effects of the cancer

As stated previously, the psychological consequences of cancer have been looked upon as a stepchild to cancer-specific care. Arthur Sutherland actually was one of the first clinicians who documented the existence of both existential and more psychological problems in cancer patients back in the 1950s [3,4]. We tried to document the original findings by Sutherland by taking a more epidemiological approach and apply this methodology to psychosocial cancer research. I would highlight three studies, which in my mind are substantial contributions to our documentation and understanding of depression as a serious event in cancer.

All these activities were only possible due to the amazing Scandinavian and especially Danish administrative registration of socioeconomic conditions, not only census data but annually updated information on each resident living in the small country, having 5.6 million inhabitants as of 2015, combined with access to health and disease registries established in a nationwide and population-based fashion-making large-scale, well-powered studies possible, which actually may give answers in an unbiased

way. Thereby, these studies may address a narrow, simple question but cannot give a detailed, multi dimensional insightful response to a clinical problem, which only may be solved in more clinical 'bedside' studies.

In the first study, we linked data on all 5,703,754 persons living in Denmark on January 1, 1973, or born thereafter, to the Danish Cancer Registry and identified 608,591 adults with a diagnosis of cancer. Follow-up for hospitalization for depression in the Danish Psychiatric Central Register from 1973 through 2003 yielded 121,227,396 person-years and 121,304 hospitalizations for depression.

The risk for depression in the first year after a cancer diagnosis was increased, with relative risks (RR's) ranging from 1.16 (95% CI, 0.90 to 1.51) in women with colorectal cancer to 3.08 (95% CI, 1.88 to 5.02) in men with brain cancer. Decreasing but still significant excess risks during subsequent years were observed for most specific cancers. The risk remained increased throughout the study period for both men and women surviving hormone-related cancers, for women surviving smoking-related cancers and for men surviving virus-related and immune-related cancers [5]. We all know that hospitalization is a serious event, meaning that the findings from this study only addressed or concerned patients who experienced this event leaving out the population, which would be at risk for prescription of antidepressive medication. Years later, it became possible to obtain access to a nationwide prescription database in which we addressed this question.

We used Danish national registries to identify 1,997,669 women with no diagnosis of cancer or a major psychiatric disorder. This cohort was followed from 1998 to 2011 for a diagnosis of breast cancer and for the two outcomes, hospital contact for depression and redeemed prescriptions for antidepressants. We identified 44,494 women with breast cancer. In the first year after diagnosis, the rate ratio for a hospital contact for depression was 1.70 (95% CI 1.41 to 2.05) and that for use of antidepressants was 3.09 (95% CI 2.95 to 3.22); these rate ratios were significantly increased after 3 and 8 years, respectively. Comorbidity, node-positive disease, older age, basic and vocational educational levels, and living alone were associated with use of antidepressants. Women with breast cancer are at long-term increased risk for first depression, including both severe episodes leading to hospital contact and use of antidepressants. Clinicians should be aware that the risk is highest in women with comorbid conditions, node-positive disease, and age of 70 years or more. We found no clear association between type of surgery or adjuvant treatment and risk for depression [6]. An amazing finding, which both illustrates the need for psychological intervention and the potential arena for actually preventing depression to occur. The paper also illustrate the power of findings based on such data covering the entire population of a relatively homogeneous population.

On the other hand, I want to highlight a study, which also illustrates how cancer has to be seen in a social context, a research track we are following up in a program focusing on 'next-of-kin' reactions to the cancer diagnosis in the family. In this study, we looked at men cohabiting with women diagnosed with breast cancer. Cohabiting is highlighted, as it is a way of living as a couple without being formally married and thereby the data captures a real life situation. In addition, it shows one of the strengths of the information available from Statistics Denmark, a major source for our research.

A few small studies published to date have suggested that major psychosocial problems develop in the partners of cancer patients; however, no studies have addressed their risk for severe depression. In a retrospective cohort study, the risk for hospitalization with an affective disorder of the male partners of women with breast cancer was investigated, using unbiased, nationwide, population-based information. Followed were 1,162,596 men born between 1925 and 1973 who were aged ≥ 30 years at study entry, resided in Denmark between 1994 and 2006, had no history of hospitalization for an affective disorder, and had lived continuously with the same partner for at least 5 years. During the 13 years of follow-up, breast cancer was diagnosed in the partners of 20,538 men. On multivariable analysis, men whose partner was diagnosed with breast cancer were found to be at an increased risk of being hospitalized with an affective disorder (hazards ratio, 1.39; 95% confidence interval, 1.20–1.61), with a dose-response pattern for the severity of breast cancer. Furthermore, men whose partner died after breast cancer had a significant, 3.6-fold increase in risk for an affective disorder when compared with men whose partner survived breast cancer. The results of this study supported the hypothesis that men whose partner had breast cancer were at an increased risk for hospitalization with an affective disorder [7].

The results show the social infectious character of a cancer disease and point to the limitations in the entire intervention policy in cancer care. To the best of my knowledge, we do not have protocols neither for patient intervention nor for more broad interventions using a more social structure/system approach. And if such protocols exist, they have not been tested in large scale randomized controlled trial's.

Follow-up II

Whereas the follow-up programs and survivorship care are widely disseminated and have been reviewed and discussed for years, there is only limited discussion of how much of the somatic and psychological surveillance for which patients themselves may take responsibility. In almost all health systems, it is expected that the population at risk reacts to symptoms and makes contact with

professionals in order to have the symptoms investigated. What is interesting to focus on is how we silently change the relationship between the individual and the health sector when the diagnosis has been established. It is as if the health system and the patient collectively decide that the patient no longer has the capacity to react to symptoms but now has to be more closely surveyed.

Both in terms of patient self-management and in terms of how we define the role of patients in relation to cancer care, I envisage that we will have to change the paradigm of care. Concurrent with the increase in the number of cancer survivors, the need for more out-hospital treatments and thereby a serious decrease in meetings between the patient and the 'system', in broad terms, we will have to rely on patient observations combined with observations from 'next-of-kin' – a spouse, a child, or another relative. Of course, there is also a development in the surveillance made possible by digital technology, which will play a major role in developing sources of information, which will support both patients and the health system. Still, we need to face the fact that patients to a large extent will become symptom observers and we will have to educate coming generations to be much more willing to enter this role both in relation to cancer but also in relation to other major chronic disease. Naturally, there are cancer diseases, which only can be surveyed by blood tests and/or imaging technologies

Health literacy, ability to self-manage aspects of diseases, and patient-reported outcomes that doctors actually react on and use as instruments in the clinical decision-making are new outcomes or aspects of cancer care, which will change the paradigm for cancer treatment. eHealth platforms and an increasing demand for transparency, facilitating patient access to all individual information filed

in the health system, will become the new way of communication between patient and 'system'. In the way, this individual transparency also goes the other way as illustrated by increasing surveillance conducted by governments of the activity of each citizen.

Still, there is a need for studies, which aim at reducing psychological and social effects of the cancer diagnosis, treatment, and the 'existential plight' as Avery Weisman named the first 100 days as a cancer patient [8]. Sutherland documented the existence of depression and anxiety, which also has been documented by his scientific ancestors, including myself. However, we still lack instruments, which in a reliable way are able to detect patients in need for depression preventive actions. Also, there is a need for studies, which combine this intervention with lifestyle interventions as a response to the psychosomatic character of the problems that cancer survivors face.

Looking forward to this development, I hope to continue my late career activities and continue to design, fund, and conduct scientific studies, which can respond to the burning research questions with the use of the most sophisticated methods and thereby impact clinical practice.

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