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Rehabilitation of cancer patients – research perspectives

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Abstract

Rehabilitation of cancer patients include a broad range of activities aimed at information, counselling, advices on possible change of lifestyle and behaviour, psychological support, social welfare questions, ways of coping with side-effects of the anti-carcinogenic treatment given and additional treatment of numerous clinical problems. The change in the age distribution combined with the growing number of cancer survivors and the scarce economic resources allocated to 'after-treatment' clinical follow-up of cancer patients, even in the Scandinavian countries characterised by their public tax financed health system, emphasize the need for screening of rehabilitation needs among cancer patients. There is a need to identify patients in need for psychological and social intervention.

However, this intervention among cancer patients in need has to be based on results achieved in clinical studies. This paper gives a brief introduction to the field of rehabilitation research and indicates a number of areas in which research would be of benefit for the clinical organisation of rehabilitation activities. These areas include the implication of social inequality, a characterisation of cancer patients who rehabilitate successfully, the gender perspective in rehabilitation, the age perspective, how to establish cancer disease specific rehabilitation modules, family and community aspects of rehabilitation, the dilemma between individual responsibility for lifestyle changes and feelings of guilt and the need for models which can determine the best timing of the intervention among cancer patients.

This paper is organised in the following way: First some basic aspects in relation the cancer disease will be discussed and subsequently some specific research points will be stressed.

The burden of cancer is growing in terms of new cases diagnosed worldwide and in terms of number of survivors. According to the World Health Organisation a total of some 14 million new cases will be diagnosed in 2010. Some 60% of these cases will occur in the less developed parts of the world. Almost 7 million people now die each year from cancer but currently more than 25 million people are alive after treatment of their first cancer. (www.who.int). From a public health point of view, other chronic disorders such as cardiovascular disease and diabetes mellitus are of equal interest because people affected require the same life-long surveillance as cancer patients and likewise varying degrees of both clinical and psychosocial intervention are needed in order to facilitate full recovery and rehabilitation. The modern industrialised society may expect an exponential growth of elderly citizens alive and diagnosed with at least one chronic disease. Cancer is a major player in this scenario.

Rehabilitation of cancer patients include a broad range of activities aimed at information, counselling, advices on possible change of lifestyle and behaviour, psychological support, social welfare questions, ways of coping with side-effects of the anti-carcinogenic treatment given and additional treatment of numerous clinical problems. The change in the age distribution combined with the growing number of cancer survivors and the scarce economic resources allocated to 'after-treatment' clinical follow-up of cancer patients, even in the Scandinavian countries characterised by their public tax financed health system, emphasize the need for rehabilitation screening. Which patients are in need for psychological and social intervention or rehabilitation 'follow-up'? One may even discuss the need for guidelines for prescription of these follow-up activities.

Research into rehabilitation of cancer patients has to take into account some basic aspects of society, culture, psychological factors and social resources.

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Social inequality

Cancer is not a disease hitting at random. The causes of close to 35% of all cancers have been identified during the last 50 years of research [1]. However, to identify the causes does not imply that every citizen is able to act preventive and avoid the most obvious risk factors. We are still living in societies characterised by social inequality. In addition there are different cultures of behaviour, different values and norms. The social inequality may take various disguise such as race, ethnicity, education, employment, income, fortune and aspects of living and ownership to products of the affluent society. No matter how this factor is expressed it has a serious impact on the agenda of the rehabilitation research. In a Danish study of the association between socioeconomic position and stage of breast cancer at the time of diagnosis including a nationwide cohort of 28 765 women with a primary invasive breast cancer diagnosed between 1983 through 1999, the adjusted odds ratio for high-risk breast cancer was significantly reduced with longer education and higher disposable income for postmenopausal women, indicating an effect of social inequality of the aggressiveness of the cancer at the time of diagnosis [2]. This result is in line with a bulk of research indicating that social factors plays a major role both in the aetiology of cancer but probably more notorious in the prognosis of cancer [3]. In a prospective population based cohort study of more than 4400 colorectal cancer patients living in South West England the most deprived group of patients (indicated by unemployment, car ownership, overcrowded housing and not owner occupiers) had consistently worse survival than the most affluent. In addition the most deprived significantly more often received treatment for two or more serious comorbidities at presentation compared to most affluent [4]. The same tendency in the effect of various measures of socioeconomic status has been reported for most cancers i.e., bladder cancer [5], rectal and anal cancer [6], prostate cancer [7] and breast cancer [8]. Most of these studies adjust for biological prognostic factors such as age, stage at diagnosis and initial treatment. The interesting part of this effect of social inequality is that there seem to be a widening social deprivation gap in survival. For patients in England and Wales diagnosed in the late 1990s the deprivation gap in survival between rich and poor was wider compared to patients diagnosed in the late 1980s leading to the conclusion that the increased survival from cancer observed in England and Wales is significantly associated with a widening deprivation gap in survival. This nationwide and population based study included 2.2 million cancer patients who were diagnosed with the 20 most common cancers between 1986 and 1999. The social deprivation gap was a significant prognostic factor for 11 cancers in men and nine cancers in women [3]. Further aspects of inequality in the cancer care were recently illustrated by the uneven possibilities for developing countries to offer novel expensive prognostic assessments and new expensive cancer therapies [9].

The need for psychosocial support

In addition cancer patients are not uniform in their requirement for psychosocial support and rehabilitation efforts. Despite the fact that not many psychosocial screening instruments exists, which may identify cancer patients in need for support [10], most cancer patients in general are able to recover and cope with their disease by the help of family and friends. This majority of patients are not demanding specific psychosocial support from the public or private health system. The prevalence of depression ranges from 5% to 50% depending on the way this phenomenon is measured, the patient population under study and the design of the study [11].

However, there are some factors related to the psychological constitution of the individual which may influence survival. In a large prospective cohort study of Danish women diagnosed with early-stage ($n = 10\,382$) and late-stage ($n = 10\,211$) breast cancer the authors found that breast cancer patients who had been hospitalized for a depression before the cancer diagnosis had a modestly but significantly higher risk of mortality depending on stage of breast cancer and time of depression when adjusting for well-documented somatic prognostic variables. The results were not influenced by censoring unnatural causes of death such as accident, suicide, or homicide [12]. Likewise a small Danish cohort study observed that personality traits among cancer patients may influence mortality [13].

Distress experienced shortly after diagnosis is expectable but some patients are at risk for suffering from severe persistent distress and preliminary data seem to indicate that some patients are at increased risk for hospitalisation with depression for up to ten years after diagnosis (Dalton, personal communication). In order to identify these patients it is necessary to test and develop screening instruments, which may predict persistent distress defined as elevated distress for, say more than 6 months after diagnosis of cancer. If it is proven feasible to administer a short screening instrument, this may be integrated in the standard treatment of cancer patients in order to ensure referral of patients in risk for developing persistent severe distress. This

screening activity may also include screening for rehabilitation needs. In the long-term follow up of cancer patients it would be important to have access to rehabilitation screening instruments, which would enable the clinician to identify the needs and requirements of any patient at any time of follow-up.

People who may be characterised as more vulnerable due to prior depression, personality traits or a high prevalence of co-morbidity may be more prone to the effects of all aspects of the diagnosis of a cancer and thus in higher need for support. This possibility may partly be explained by an excess exposure to tobacco smoking and alcohol consumption as well as the general lifestyle. The majority of psychosocial intervention programs does not take into account that this is a fact but offer the same program components to all cancer patients. The current practise of cancer treatment implies that we treat equally but it seems wrong doing so – since the effect of the cancer does not strike all of us equally. Just as the emerging theory within chemotherapy utilising a targeted individual therapy, emphasized by the availability of new drugs such as the aromatase-inhibitors, angiogenesis-inhibitors and tyrokinase-inhibitors, we need to develop targeted psychosocial and rehabilitating therapies/interventions. These therapeutic considerations need to take into account the existing social inequality, cultural differences as well as psychological factors. Finally I cannot leave this question without mentioning that very few of the rehabilitation interventions carried out are based on a theoretical paradigm that has been developed with this specific purpose.

Rehabilitation research

Besides the social inequality and the psychosocial 'background' parameters, a cancer survivor faces a diversity of physical and emotional sequelae, which all may be concerted in the concept of side-effects indicating their unwanted character. These side effects have emerged as increasingly important and it has become more common to address and hopefully relieve them through physical and psychosocial rehabilitation. More than 50% of cancer patients may, during their life after their first cancer diagnosis, have impairments or limitations which could potentially be improved by rehabilitative interventions. However, based on the above mentioned aspects it is difficult to estimate the extent to which cancer patients require rehabilitation as there are large national and international differences in rehabilitation need thresholds as well as the type of rehabilitation offered. Apart from the obvious gains for the patient, cancer rehabilitation can also be important in socio-economic terms by reducing pressure on health system resources and increasing the working population. In the past, rehabilitation was mainly targeted at cancer patients with visible disability. However, continuous research since the early 1970s has shown that even patients without physiological effects remain preoccupied about their disease and future health, often leading to psychological disturbances. It is now recognised that there are many aspects of rehabilitation ranging from psychosocial interventions to the more physical aspects such as life style changes. Ideally all of these should be combined or targeted to specific patient needs in order to achieve the major goal: not only to survive but to survive to a life.

Behaviour and lifestyle

For cancer survivors in particular, a common problem is to identify behavioral risk factors, which may influence survival, and after identifying these factors, finding some way to modify these behaviors. In a recent study by Holmes and colleagues [14] it was shown that physical activity after a breast cancer diagnosis may reduce the risk of death from this disease. The greatest benefit occurred in women who performed the equivalent of walking 3 to 5 hours per week at an average pace, with little evidence of a correlation between increased benefit and greater energy expenditure. Women with breast cancer who are physically active may improve their survival. This prospective observational study was based on responses from 2987 female registered nurses in the Nurses' Health Study who were diagnosed with stage I, II, or III breast cancer between 1984 and 1998 and who were followed up until 2002 for breast cancer mortality. An interesting finding was that the RR of breast cancer death for women with hormone-responsive tumours, who were moderately physical active compared with women with hormone-responsive tumours, who were less active, was 0.50 (95% CI, 0.34–0.74) [11]. In another prospective, observational study of 573 women with stage I to III colorectal cancer, increasing levels of exercise after diagnosis of non-metastatic colorectal cancer reduced cancer-specific mortality (P for trend = 0.008) and overall mortality (P for trend = 0.003). Women who increased their activity (when comparing pre-diagnosis to post-diagnosis values) had a hazard ratio of 0.48 (95% CI, 0.24 to 0.97) for colorectal cancer deaths and a hazard ratio of 0.51 (95% CI, 0.30 to 0.85) for any-cause death, compared with those with no change in activity. In conclusion, the authors stated that recreational physical activity after the diagnosis of stages I to III

colorectal cancer may reduce the risk of colorectal cancer-specific and overall mortality [15]. These findings of this study were supported by a review of 26 published studies, which demonstrated physiological and psychological benefits of physical activity. However, most of these studies suffer limitations because they are not randomized controlled trials and/or use small sample sizes [16]. This review concludes that cancer patients may have positive physiological and psychological benefits from exercise when undertaken during or after traditional cancer treatment. As such, other cancer groups, in addition to those with breast cancer, should also be included in clinical trials to address more specifically dose-response training for this population. In addition, contemporary resistance training designs that provide strong anabolic effects for muscle and bone may have an impact on counteracting some of the side effects of cancer management assisting patients to improve physical function and quality of life [16]. Despite the fact that we still do not know whether the physical activity in itself decreases mortality or less physically active women for some reason have a poorer prognosis, the above mentioned psychological and physiological benefits of physical activity are sufficient, to advice cancer patients to become physical active as a part of their own healing efforts.

As a cancer patient you may become an active component in your own treatment and this will be a dramatic change compared to cancer patients who in earlier times were left with no advice how to contribute to ones own health and survival. The effects of the physical activity in combination with other initiatives in other lifestyle areas will be of interest to explore further. In addition the effect of handing over responsibility for treatment effects to cancer patients also needs careful investigation to address guilt feelings and self accusation problems.

Research agenda

My point, which I hope is well taken, is that in the decades to come more and more patients diagnosed with the high incidence cancers belong to lower socioeconomic classes, deprived or underserved subpopulations in the society, no matter how this status is defined. Today almost the entire effort in rehabilitation practise and research is based on intellectual literacy, middle class values, middle class ambitions of life and its' metaphor: the individual responsibility for health.

The future research in rehabilitation has to take the above mentioned aspects or basic conditions into account. There is no need to highlight how research in rehabilitation has to be conducted. The methodological principles guiding psychosocial oncologists are not different from the principles guiding the researcher who decides to initialise the classic clinical trial, the prospective observational study or the establishment of retrospective data. The challenge of the future research agenda is how data is established, which have 'adjusted for' or acknowledged the cocktail consisting of social inequality, cultural differences and the individual range of psychological impact of the cancer disease and social life. In addition this cocktail also contain information of personal characteristics, i.e., personal resources necessary for changing behaviour and lifestyle, family dynamics, community resources available for the patient, and in some countries, the entire question of economic resources and health insurance. Furthermore this data is only of interest if they are closely linked to clinical data, which embed the rehabilitation research into the clinical reality.

Below I have given a non-prioritised list of future areas of cancer specific rehabilitation research, which may increase the quality of the rehabilitation programs offered to cancer patients and their families

1. There is a need for studies of how lower SES groups anticipate health, anticipate cancer, how life is valued, values associated with choice of diet, alcohol consumption, tobacco smoking and regular physical activity. Unfold the experiences with the health system, reasons for various degrees of compliance with the treatment prescribed or recommended behavioural changes. Also we need more knowledge about compliance with e.g., prophylactic programs such as vaccinations, cervical screening and dental care. Studies that dive into all aspects of what it means to belong to the poor part of society – and diagnosed with cancer.
2. One project may search to identify cancer patients who successfully rehabilitated quickly after the diagnosis and treatment of the cancer. What characterise such patients? This study may combine epidemiological methods and qualitative in depth interviews as well as focus groups and observational field studies. It can also include questionnaire data or be conducted using register-based data. The study requires one or more definitions of successful rehabilitation.
3. There is a gender perspective in cancer care, which is present in the different ways men and women comply with the intentions of the care given. There is a need to elucidate in which aspects the two gender differs in terms of affinity to the supportive cancer care offered.

Rehabilitation programs dedicated to cancer patients needs more seriously to take into account that the needs for successful rehabilitation differ between the two sexes. However, currently almost no specific and valid data exist on this issue.

4. Age plays a major role in life orientation. Not much is known about the rehabilitation requirements of different age-groups. Especially in childhood cancer it would be of interest and importance to further develop rehabilitation models, which also addressed the former mentioned aspects of rehabilitation research.
5. Rehabilitation intervention needs to be cancer disease specific. The research in rehabilitation has to address this issue based on the fact that gender, age, treatment, side-effects as well as physiologic, psychological and social consequences of a cancer disease will depend on the type of cancer diagnosed. It is astonishing how little knowledge has been published concerning the best rehabilitation to offer many of the cancers with a relatively high prevalence of survivors.
6. Rehabilitation research into family aspects and community questions is important because much of the rehabilitation prescribed will require fundamental changes in family life and thereby involve other family members. Likewise the community aspect would be of interest as long as the rehabilitation of cancer patients would benefit from more visibility in the society.
7. Assuming that the individual cancer patient increasingly will be responsible for some lifestyle changes based on recommendations from health professionals, one may fear that this responsibility, if not fulfilled, may result in guilt feelings and self accusations. To the best of my knowledge, no studies have investigated how patients and professionals may be able to handle the dilemma between various degrees of empowerment (the patient is an acting subject in his own life circumstances) and various degrees of passive dependence (the patient has experience a strong external locus of control and only follow doctors prescriptions).
8. There is a need for research, which address the problem of timing. We do not know so much about when rehabilitation is of importance in the life after a cancer diagnosis and treatment.

Many other projects or areas of research are of importance but the above mentioned problems seem to be very crucial and tied to the reality of our affluent, industrialised societies, which are composed of social, cultural and psychological diversities. The research agenda in cancer rehabilitation needs to include this diversity and face the new social aspects of cancer incidence and prevalence.

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