Enhancing return to work of cancer patients

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Chapter 1.

General introduction

The impact of a cancer diagnosis on a person's life

Cancer is a generic term that comprises many heterogeneous diseases, with different treatment modalities, survival rates, and variable impacts on the health and life of patients.[1] On the other hand, there are many similarities between cancer types, such as the receipt of a sudden and unexpected diagnosis, the fact that it is a life-threatening disease, the time consuming and disabling treatment, and the fear of recurrence.[1] For these reasons, cancer patients are often studied as an entity.

Thanks to excellent doctors and researchers, cancer is no longer a fatal disease for many patients. In the Netherlands, the five-year survival rate increased from approximately 46% in 1989-1993 to approximately 59% in 2003-2007.[2] The cancer survival rate has increased as a result of advanced treatment and as a result of screening and earlier and better diagnosis.[2] In addition, advanced treatment has most often led to a smaller impact on functioning than in the past, and in several cancer types, the quality of life of patients has improved considerably.[2]

Currently, the most common treatment modalities are surgery, chemotherapy, and radiotherapy, or a combination of these three, depending on the cancer diagnosis and the patient's characteristics.[1] The duration of cancer treatment ranges from days to more than a year after the initial diagnosis, depending on the type and number of treatment modalities.[1] In case of a tumour susceptible to hormones, treatment is usually prolonged by years with hormone therapy.[1]

Although the quality of life of cancer patients has improved in the past few decades, many patients still experience long-term physical and psychological complaints. These complaints include, for example, decreased physical function,[3] fatigue,[4] distress,[5] concentration problems, and depression.[6] These symptoms may last from months to years after the end of treatment[7] and may have a negative effect on all aspects of a cancer patient's quality of life.[8] Therefore, for many patients, cancer has become a chronic disease that leads to poorer overall health and lower quality of life in comparison with the general population.[9] [10] Furthermore, apart from long-term physical and psychological complaints, other factors such as having paid employment, the amount of social support, and the current income level are associated with the quality of life of cancer patients.[11] [12]

Receiving a cancer diagnosis is, for many patients a life-changing event[13] that often results in an evaluation of their various roles in life. As a consequence, some patients set new priorities while others want to return to 'normal' as soon as possible. In addition, some cancer patients are forced to make adjustments to their lives due to long-term physical or psychological complaints.

The importance of work for cancer patients

Cancer may result in a re-evaluation of the role of work in patients' lives.[14-18] As a result, some cancer patients decide to stop working and retire early while others decide to keep working. A decision to retire early is made, for instance, due to health problems[19] or economic self-sufficiency,[20] whereas a decision to keep working may include a goal of returning to 'normal'.[21] Unfortunately, some patients are forced to stop working as a consequence of a cancer diagnosis or due to the long-term side effects (e.g. concentration problems, fatigue) in combination with a patient's work demands.[22]

Various studies have noted that cancer patients attribute great meaning to work.[18,21] For example, cancer patients report positive outcomes of having paid work; work provides social inclusion,[17 23] reduces financial problems,[18 23] is associated with the quality of life of cancer patients, [12 24] and shapes life after treatment.[18] Furthermore, cancer patients report a positive attitude towards work; work offers a sense of control in insecure times,[21] a sense of self-worth,[25] gives meaning to life,[17] and it takes the patient's mind off of the illness.[15 17 23] As a result, a return to work should be made possible for those patients who are able and want to do so.

The scale of studying work in cancer patients

In 2009, the number of people diagnosed with cancer (i.e. the incidence) was approximately 91.000 in the Netherlands[26] and is expected to increase to approximately 123.000 in 2020.[2] This increase is caused by the ageing of the population because the incidence of cancer is strongly related to older age.[2] In 2009 the number of people living with cancer (i.e. the prevalence) was approximately 420.000 in the Netherlands,[26] and this number is expected to increase to 666.000 in 2020,[2] an increase of 57%.

In the Netherlands, approximately 40% of the cancer patients are in the working population.[26 27] The working population is defined as all people in the 15-64 age group

of which approximately 70% has paid employment for at least twelve hours per week.[28] In 2009, the incidence of cancer in the working population was approximately 38.000.[26] It is expected that this incidence will increase in the near future.[29] Reasons for this increase in incidence include: increased survival rates for (childhood) cancer,[2] the ageing of the working population,[28] and people having to work longer before retiring. The last factor is likely to contribute the most to an increase of the incidence of cancer in the working population. This is because the incidence in the 65-69 age group was 11.666 in 2009,[26] which would have meant a 34% increase of cancer in the working population. Consequently, employees diagnosed with cancer will become more common in the workplace.

The adverse work outcomes of cancer patients

Cancer patients have a 37% higher risk of unemployment in comparison to non-cancer patients.[30] Additionally, the rate of return to work of patients ranges between 30% and 93%.[31] The variation among cancer patients is large: some are never sick-listed, whereas others are never able to return to work. In addition to work loss, some patients are confronted with lower work functioning,[32 33] lower work ability,[34 35] difficulties with managing their work,[36 37] unreasonable treatment at the workplace,[36 38] or face a decrease in income.[39 40] It is not only cancer patients experiencing these adverse work outcomes who are affected; the employer and the society are affected as well due to associated costs related to absenteeism, lower work productivity, and disability pensions.[41]

Difficulties with the return to work of cancer patients are associated with factors from various areas and are described extensively in the literature.[42] For instance, factors that have been associated with these difficulties are as follows: socio-demographic characteristics (e.g. age),[43 44] clinical characteristics (e.g. diagnosis),[12 45] work-related characteristics (e.g. work accommodations),[36 46] personal-related characteristics (e.g. work ability),[47] and the social security system (e.g. level of compensation). Stakeholders from various contexts and with various motives are involved in the return to work of cancer patients, i.e. work (e.g. the supervisor),[48-50] health care (e.g. the physician),[51 52] social security (e.g. the occupational physician),[53] and the personal environment (e.g. the family).[52] Adverse work outcomes are often measured as work loss due to ill health.

Nevertheless, other, less apparent, aspects have a significant impact as well; for example, reduced work functioning, reduced work ability, loss of earnings, loss of promotion opportunities, lower job satisfaction, or the inability to change jobs. Therefore, it is not only work loss at follow-up that is a subject of study in this thesis but also work functioning and work ability. However, measuring work functioning may be difficult[54] and as a result, tools that measure work functioning adequately are necessary. Adverse work outcomes irrevocably lead to additional costs for the society, the employer, and for a work-disabled cancer patient. In consequence, it is not only the level of work disability that is measured in this thesis but also the associated costs from a societal perspective.

This thesis focuses on paid employment only, as unemployment and unpaid work both entail a different institutional context. This thesis focuses on cancer patients who are treated with curative intent and who have a reasonable life expectancy only.

Organisation of the social security system in the Netherlands

Both the institutional and the cultural contexts of a country have an effect on adverse work outcomes,[54 55] which differs greatly among developed countries. Therefore, to be able to understand how these outcomes evolve for sick-listed employees, it is necessary to know how the social security system protects employees who have adverse work outcomes, and to know about the cultural context in which this system is embedded.

In the Netherlands, personal health insurance is not linked to an employment contract, and it is not of interest if a sickness absence is work-related or not. The Improved Gatekeepers Act covers the insurance of sick-listed employees against wage loss and is in force during the first two years of sick leave. The Act states that a sick-listed employee cannot be fired due to health reasons. Additionally, sick-listed employees receive at least 70% of their wage, but often 100%, in the first year, which the employer is obligated to pay. Both the employer and the sick-listed employee are responsible for the return to work. Sick-listed employees usually have an occupational physician who makes a disability evaluation with regard to the employee's work and health situation, and who independently advises the employer and the employee on a return to work. In the Netherlands, employees with cancer should be guided according to the evidence-based guidelines of the Dutch Association of Occupational Physicians.[56]

After two years of sick leave, an insurance physician of the Dutch Institute for Employee Benefit Schemes (UWV) assesses whether the sick-listed employee qualifies for a disability pension. This government institution is obligated to pay the disability pension. The employer can then terminate the employment contract.

In conclusion, because work is important for cancer patients and because a substantial number of the patients are confronted with adverse work outcomes, it is essential to address this problem with appropriate interventions. The subsequent sections provide a brief description of the theoretical approach, possible appropriate interventions to address this problem, and discuss how these interventions should be evaluated. Hereafter, the objective of this thesis, the research questions, and the outline of this thesis are presented.

The theoretical approach to adverse work outcomes of cancer patients

Various models exist to describe adverse work outcomes originating from a health deficit, depending on the area of research and the objective.[57] Because a person's health is not directly related to the level of adverse work outcomes but is influenced by the personal (e.g. coping) and the environmental context (e.g. work demands) and involves various stakeholders,[42 57] most models address the complexity of adverse work outcomes. It is important to understand these factors and understand each stakeholder to comprehend the underlying mechanism of this problem. This is important for the development of interventions and the identification of patients at the highest risk of being confronted with adverse work outcomes.

In this thesis, two models have been used as theoretical approaches to address adverse work outcomes affecting cancer patients: the International Classification of Functioning (ICF) of the World Health Organization (WHO)[58] and the shared-care model for cancer survivor care.[59] First, the International Classification of Functioning (ICF) of the World Health Organization (WHO) is used as a theoretical approach of adverse work outcomes of cancer patients because this model elaborates on the clinical characteristics and addresses these outcomes from the patient perspective.[58] This is considered important, because clinical characteristics such as the cancer diagnosis, treatment, and long-term side effects are significant prognostic factors for adverse work

outcomes of patients.[42] [45] In addition to clinical characteristics, the ICF provides clarification for the finding that both personal factors (e.g. self-assessed work ability), and environmental factors (e.g. work demands) are important prognostic for whether patients return to work.

Second, because the adverse work outcomes are considered as one aspect of cancer survivor care, this problem should not be dealt with in isolation but should be integrated into cancer care and occupational health care. Therefore, the shared-care model for cancer survivor care is used as a theoretical approach for hospital-based integrated care.[59] This model is adapted to study adverse work outcomes, the occupational health care setting, and to addresses adverse work outcomes in an early phase while improving the communication between the hospital and the occupational physician. The studies described in this thesis verify whether this model of hospital-based integrated care can be adapted to adverse work outcomes and the occupational health care setting.

Interventions to reduce adverse work outcomes of cancer patients: hospital-based integrated care

As mentioned, the degree to which someone is confronted with adverse work outcomes is a complex phenomenon that is influenced by various factors and involves various stakeholders. For this reason, interventions aimed at reducing the occurrence of such event for cancer patients should intervene multiple factors, stakeholders, or a combination of these.

Health outcomes are related to the adverse work outcomes of cancer patients. For that reason, interventions aimed at improving cancer treatment or aimed at managing the adverse side-effects of cancer treatment may have the potential to reduce these outcomes. Furthermore, cancer care that is focused on work as well, may be beneficial. For example, physicians' advice about work is correlated with the return to work by patients.[51] Therefore, providing work advice as part of cancer care may be useful. On the other hand, a personal factor such as self-assessed work ability is an important prognostic factor for a return to work, irrespective of clinical characteristics.[47] For this reason, interventions addressing misconceptions about work ability may be beneficial.[60] The work environment is another important factor that significantly influences the

adverse work outcomes of cancer patients. Thus, interventions aimed at facilitating workplace accommodations and improving guidance by occupational physicians or the employer may be effective as well.[53]

Apart from designing interventions to reduce adverse work outcomes in cancer patients, studying both the effectiveness of such an intervention and the intervention implementation process itself, in a study with high methodological quality is also important. By studying the effectiveness of an intervention, one is able to decide whether it reduced adverse work outcomes. By studying the intervention implementation process, one is able to conclude if the intervention was implemented as intended, which is important when interpreting the findings of an intervention; should the intervention itself be optimised or its implementation?

Currently the 'gold standard' for determining the effectiveness of an intervention is a randomised controlled trial[61] in which patients are allocated randomly to an intervention group or to a control group. At the end of the study, the intervention group is compared to the control group on the basis of outcomes defined a priori. Effectiveness is established if the intervention group demonstrates a statistically significant improvement on one of these outcomes compared to the control group.

As mentioned previously, adverse work outcomes are often measured as work loss due to ill health. Therefore, the primary outcome of an intervention that aimed at reducing adverse work outcomes among cancer patients should measure the time from sick leave to return to work. However, a return to work cannot be at the expense of quality of life. Therefore, an intervention should be considered effective if patients assigned to the intervention group have a return to work significantly faster than patients assigned to the control group (usual care) and if, at the same time, their quality of life does not significantly deteriorate.

Less apparent aspects of adverse work outcomes have a significant impact as well; along with a return to work, work functioning and work ability should also be measured outcomes. One commonly used measurement tool of impaired work functioning due to ill health is the Work Limitation Questionnaire (WLQ).[62] However, two reviews on the measurement properties of questionnaires that measure work functioning due to ill health noted that the measurement error of the WLQ has not been determined.[63] [64] The measurement error is an important property of a

questionnaire when using it to quantify the outcome of an intervention. To be able to use the WLQ as an outcome measure, both the measurement error and the measurement properties of the Dutch translation of the WLQ should be determined in a population of cancer patients.

Objective of the thesis and research questions

In conclusion, since the survival rates of cancer have increased considerably in recent years, the majority of cancer patients face new challenges upon cancer survivorship. For patients of working age, one key factor of cancer survivorship is work, as work provides personal and economic value. Unfortunately, previous studies indicated that cancer patients are more often confronted with adverse work outcomes when compared with the general working population. For this reason, it is important to design comprehensive interventions to reduce adverse work outcomes among cancer patients. Such hospital-based work support intervention should be evaluated in studies with high methodological quality, including effectiveness analysis as well as a process evaluation. Furthermore, as the psychometric properties of the WLQ, a commonly used questionnaire that measures impaired work functioning, are currently unknown for Dutch cancer patients, this should be subject of study as well.

In line with this rationale, the main objective of this thesis is to gain more knowledge on how to reduce the adverse work outcomes of cancer patients. The following research questions are put forward:

1. What are important aspects in the design of a hospital-based work support intervention for cancer patients with the aim of enhancing the return to work and quality of life?
2. What are the measurement properties of the Dutch translation of the Work Limitation Questionnaire (WLQ) among cancer patients?
3. How is the process of a hospital-based work support intervention for cancer patients evaluated?
4. What is the effectiveness of a hospital-based work support intervention compared to usual care for cancer patients on return to work and quality of life?

Outline of the thesis

Chapter 2 presents a systematic review on the content of interventions focusing on the return to work of cancer patients as well as on the assessment of the efficacy of these interventions on the return to work. **Chapter 3**, a qualitative study, describes cancer patients' experiences with their return to work. In **Chapter 4**, a validation study of the Dutch translation of the Work Limitation Questionnaire (WLQ) among cancer patients is presented. **Chapter 5** provides a description of the development of a hospital-based work support intervention for cancer patients as well as a study design to evaluate the effectiveness of the intervention. **Chapter 6**, **7**, and **8** address the evaluation of a hospital-based work support intervention for cancer patients: **Chapter 6**, a case study, illustrates its application; **Chapter 7** provides a process evaluation; and **Chapter 8** presents the effectiveness on return to work and quality of life, work ability, work functioning, and costs (e.g. lost productivity costs). This thesis ends with a general discussion in **Chapter 9**, in which the main findings of the studies described in this thesis are summarised and interpreted. In addition, the context in which these studies were conducted is illustrated. This general discussion ends with recommendations for further research and practice.

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