Work functioning in cancer patients: looking beyond return to work
Dorland, H.F.

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General introduction
With the growing group of cancer patients and the more and more chronic nature of several common cancers, the management of symptoms related to cancer and cancer treatment has become an important part of survivorship care. Approximately 50% of the 3.45 million people diagnosed with cancer each year in Europe are part of the working population and an increasing number of cancer patients are likely to continue working or return to work after cancer diagnosis. Twelve months after diagnosis, approximately 60% of the working patients had returned to work or stayed at work; 24 months after diagnosis, this percentage increased to 89%.

Cancer patients may experience physical and psychosocial health problems such as fatigue, depressive symptoms and changes in cognitive function due to cancer diagnosis and treatment, which can persist for years after treatment. These health problems have serious consequences for working cancer patients. For example, (breast) cancer patients reported cognitive problems that negatively affected their work performance and described fatigue as disruptive for work outcomes even years after treatment.

To date, little attention has been paid to the problems that the expanding group of cancer patients experience in meeting the job demands, as most studies focus on return to work, work status or work disability. Insight into cancer patients' functioning at work and the factors that play a role herein is important to promote sustainable return to work. The absence of data on health-related work functioning and the need for measures to ensure sustainable return to work has prompted the establishment of a longitudinal cohort study on the work life after cancer (WO rk LIfe after CAncer; WOLICA). Investigating how cancer patients function at work after return to work is important for (occupational) physicians, employers and cancer patients. With this knowledge, cancer patients in need of additional guidance and support when back at work can be identified. The overall aim of this thesis is therefore to expand our knowledge of health-related work functioning among cancer patients during the first 18 months after return to work, with regard to health, psychosocial and work-related factors.
Cancer and work

In the Netherlands, more than 100,000 individuals are diagnosed with cancer each year and this number is still increasing\textsuperscript{13}. In 2016, approximately 40% of the newly diagnosed cancer patients were of working age\textsuperscript{13}. Because of earlier detection and continuing developments in treatment, individuals are more likely to survive a cancer diagnosis and an increasing part of the cancer patients is able to return to work, or to (partly) stay at work during treatment\textsuperscript{14-16}. Cancer patients resume work for several reasons. For most cancer patients, work is a financial necessity\textsuperscript{15}. Another reason for work resumption is to re-establish identity and the former structure of everyday life\textsuperscript{17,18}. An interview study on the meaning of work and working life after cancer showed that work contributes to social relations with others and helps to give meaning to life\textsuperscript{17}.

In 2010, Feuerstein et al. developed the Cancer & Work model (Figure 1)\textsuperscript{19}. They based their model on the cancer survivorship and work disability literature as well as on clinical experience. The Cancer & Work model considers cancer patients’ individual characteristics, health, functional status in relation to demands, work environment, policy, procedures, and financial factors. It provides a framework to conceptualize problems related to work. Most elements of the model were empirically supported by observed associations. In this thesis, the Cancer & Work model informed us to design the focus group study and the questionnaire for the subsequent longitudinal cohort study WOLICA.

For the purpose of this thesis, we have added variables to the model. Feuerstein et al. stated that the work outcome of interest should be determined as a function of the specific research question\textsuperscript{19}. As we are focusing on the difficulties that cancer patients experience in conducting their work (when back) after cancer diagnosis, work functioning was our main outcome of interest. Moreover, it is important to keep in mind that the model was not designed to be exhaustive\textsuperscript{19}. For example, other symptoms of cancer and its treatment may be important to consider, such as depressive symptoms. As previous literature showed that depressive symptoms affect cancer patients at work\textsuperscript{5,6,10}, we have added depressive symptoms to the model.
The findings in this thesis are based on data of working cancer patients in the Netherlands. To interpret the results, it is necessary to understand the specific context, i.e., the Dutch social security system. In the Netherlands, cancer patients report sick to their employer, who sends a sick-report to the occupational health service (OHS) to start medical guidance. An occupational physician (OP) consults with sick-listed cancer patients every 4 to 6 weeks and advises the patient and employer about work accommodations and other activities to facilitate return to work. One of the most important work accommodations is the reduction of working hours and tasks. In successive consultations, the OP advises to increase working hours and expand tasks resulting in a gradual return to work. For OPs, the Netherlands Society of Occupational Medicine (NVAB) has developed a practice guideline to advise cancer patients and their employers about return to work.
In the Netherlands, the employer financially compensates sickness absence for a maximum period of two years. Employers usually pay 100% of the employee’s income in the first year of sickness absence and 70% of the income in the second year. Most sick-listed cancer patients return to work to their own workplace. If this is not possible (e.g., due to the job characteristics), the employer is responsible for searching a job with characteristics that better fit the employee’s capacities, either within the company or in other companies. Cancer patients who have not fully returned to work (i.e., at equal income as before sickness absence) after two years of sickness absence can apply for a (partial) disability pension at the National Social Security Institute (UWV). When applying for disability pension, the UWV reviews if return to work activities of the employee and employer were sufficient.

Looking beyond return to work: work functioning in cancer patients

To date, most cancer and work research has focused on return to work, work status or work disability\(^\text{10}\) and little attention has been paid to how cancer patients function at work after return to work. As long-term physical or psychosocial problems may negatively influence cancer patients’ functioning at work\(^\text{10}\), it is important to move beyond the simple dichotomy of return to work yes/no as outcome and to use new work outcome measures reflecting functioning at work. During the conduct of our study, this was also stressed by Duijts et al. who stated that validated measures of work-related aspects should be used for a better understanding and assessment of work outcomes in cancer survivorship, measuring actual work activities\(^\text{21}\). To assess how employees perform their work tasks given their physical health or emotional problems, the concept of ‘health-related work functioning’ was developed in the late 90s, and recently updated to address the changes in work\(^\text{22-25}\). Health-related work functioning reflects the interplay between work and health and can be seen as a continuum\(^\text{22,23,26}\). On the one side of the continuum, a worker is able to meet all work demands without difficulties given his/her health status (experiencing difficulties 0% of the time) when performing work. On the other side of the continuum, a worker is no longer able to meet the work demands (experiencing difficulties 100% of the time) and does not work at all\(^\text{23}\).
Earlier, cross-sectional studies in the United States have investigated cancer patient’s work functioning\textsuperscript{27-29}. Brain cancer patients were less able to meet the work demands than a control group without a life threatening illness or chronic disease due to depressive symptoms, fatigue, cognitive limitations, insufficient sleep, and negative problem solving orientation\textsuperscript{27}. Breast cancer patients with fatigue or hot flashes reported work productivity below the healthy worker norm\textsuperscript{28} and were less productive than their peers who never had cancer\textsuperscript{29}. The cross-sectional design of these studies does not allow looking into the course of work functioning after return to work. Moreover, little is known about the influence of health and psychosocial factors such as cancer diagnosis, cancer treatment, fatigue, depressive symptoms, cognitive symptoms and work-related factors on work functioning over time.

With a better understanding of the influence of health, psychosocial and work-related factors on cancer patients’ work functioning, (occupational) health professionals and employers can be better equipped to provide the appropriate guidance and support at the workplace. More in-depth knowledge about the relationship between health, psychosocial and work-related factors with work functioning is important to develop supportive interventions for cancer patients at work and towards the prevention of work disability\textsuperscript{29}. The current longitudinal WOLICA study with repeated measures is an important step forwards because the study provides insight in the experienced difficulties and consequences for cancer patients’ work functioning after return to work.

**Work-specific cognitive symptoms**

The effects of cancer-related cognitive symptoms are identified by cancer patients as a primary problem affecting work ability and job performance\textsuperscript{21}. Cognitive symptoms, such as diminished memory, executive function, attention and information processing speed\textsuperscript{30}, are one of the most bothersome symptom clusters experienced by cancer patients\textsuperscript{31}. Even when cognitive symptoms are experienced as mild, they can have profound consequences upon quality of life, especially when they are persistent and left untreated\textsuperscript{32}. As cognitive symptoms can be experienced for more than 20 years following treatment\textsuperscript{8}, they are likely to affect cancer patient’s functioning at work\textsuperscript{5,6}. 
Cognitive symptoms experienced at work (i.e., work-specific cognitive symptoms) demand a better understanding of their impact on work outcomes, as well as develop effective interventions to reduce their impact. Furthermore, more detailed information about modifiable factors associated with the course of work-specific cognitive symptoms may offer directions for treatment of work-specific cognitive symptoms. Physicians, labour experts and employers can use this information to guide and support cancer patients back at work.

**Overall aim and specific research objectives**

The overall aim of this thesis is to expand our knowledge of health-related work functioning among cancer patients who returned to work after cancer diagnosis and treatment with curative intent. This overall aim has been translated into the following research objectives:

1. To identify barriers and facilitators of work functioning among cancer patients after return to work (Chapter 2).
2. To cross-culturally translate and adapt the Cognitive Symptom Checklist-Work into Dutch and to assess the reliability and validity of the CSC-W Dutch version (Chapter 3).
3. To identify work functioning trajectories in the year following return to work in cancer patients and to examine baseline socio-demographic, health-related and work-related variables associated with work functioning trajectories (Chapter 4).
4. To investigate the course of work functioning, health status and work-related factors among cancer patients during 18 months after return to work and to examine the associations between these variables and work functioning over time (Chapter 5).
5. To describe the course of work-specific cognitive symptoms in the first 18 months post return to work and to examine the associations with work characteristics, fatigue and depressive symptoms over time (Chapter 6).

Qualitative and quantitative methods were used to address the overall aim and specific research objects of this thesis.
Outline of this thesis

This first chapter is a general introduction providing detailed information about the background of the study and the major concepts - health-related work functioning and work-specific cognitive symptoms - examined in this thesis. Chapter 2 presents the focus group study, conducted to gain more insight into barriers and facilitators of work functioning among cancer patients after return to work. Chapter 3 describes the cross-cultural translation and adaptation of an existing American questionnaire to measure work-specific cognitive symptoms into Dutch and the validation of this new Dutch questionnaire in the Dutch work context. In chapter 4, trajectories of work functioning in the first year after return to work are examined. The course of health- and work-related factors and their association with work functioning is investigated in chapter 5. In chapter 6, the course of work-specific cognitive symptoms in the first 18 months after return to work is identified and associations of work characteristics, fatigue and depressive symptoms with work-specific cognitive symptoms over time are examined. Chapter 7 is a general discussion of the main findings of this thesis and their implications as well as the methodological considerations, and provides directions for research and practice.

Focus group study

To identify barriers and facilitators of cancer patients’ work functioning, a focus group study was conducted with cancer patients who had returned to work in the three years prior to the focus group meeting and with professionals from (occupational) health care. Four focus groups were conducted: three with cancer patients (n=6, n=8, and n=8) and one with (occupational) health care professionals (n=7; two labour experts, two insurance physicians, one nurse practitioner, one OP, and one occupational social worker). Findings from this qualitative study were combined with evidence from the literature to inform the development of the questionnaires for the longitudinal cohort study.
The WOrk Life after CAncer (WOLICA) cohort study

A longitudinal cohort study with repeated measurements was conducted to expand our knowledge of work functioning among cancer patients who had returned to work after cancer diagnosis, the ‘WOrk Life after CAncer’ (WOLICA) cohort study. Cancer patients were eligible for inclusion when they 1) were between 18 and 65 years old, and 2) had resumed work for at least 12 hours/week in the past 3 months, during or following cancer treatment. Exclusion criteria were 1) recurrent cancer, 2) treated with palliative intent, 3) no paid employment for at least 1 year prior to cancer diagnosis, and 4) not able to complete a questionnaire in Dutch. Cancer patients were recruited for the WOLICA study by OPs working at three national OHSs in the Netherlands. These three OHSs provide occupational health care services for approximately 3 million employees, i.e., one-third of the Dutch workforce. When patients were interested to participate in the WOLICA study, OPs forwarded the patient’s name and address to the research team. Cancer patients were then informed about the study by phone by the research team. Cancer patients who met the inclusion criteria received additional study information, an informed consent form and the baseline questionnaire. Patients who did not return the baseline questionnaire and the informed consent received a reminder after 3-4 weeks. Cancer patients received no incentive for participation. The WOLICA study was reviewed and approved by the Medical Ethical Committee of the University Medical Center Groningen (M12.125242).

The WOLICA study was designed as longitudinal cohort study with seven measurement points during 18 months follow-up. As shown in Figure 2, cancer patients received questionnaires every 3 months. A comprehensive questionnaire was developed, based on the Cancer & Work model (Figure 1)\(^\text{19}\) and the findings of the focus group study. Major concepts, i.e., work functioning, health and psychosocial factors and work-related factors, were assessed at baseline, 6, 12, and 18 months after return to work. To get a better understanding of the course of work functioning over time, work functioning was measured at three intermediate measurement points (i.e., at 3, 9 and 15 months after return to work) with a short questionnaire.
Cancer patients completed the questionnaires at home, on paper or online, based on their own preference. The final WOLICA cohort consisted of \( n = 384 \) cancer patients. Many cancer patients completed the baseline and follow-up questionnaires, resulting in a retention rate of 80% at the seventh measurement point. An overview of the measured concepts, the used instruments, the measurement points and chapters is presented in Table 1.
Table 1. Overview of the measured concepts, instruments, measurement points and chapters

<table>
<thead>
<tr>
<th>Concept</th>
<th>Measurement instrument</th>
<th>Measurement points (months)</th>
<th>Chapter</th>
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<tr>
<td>Work functioning</td>
<td>WRFQ 2.0</td>
<td>3, 4, 5, 6</td>
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<td></td>
<td>4, 6</td>
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<td></td>
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<tr>
<td>Treatment completion</td>
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<tr>
<td>Time between diagnosis and return to work</td>
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<td>4, 6</td>
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<tr>
<td>Health and psychosocial factors</td>
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<tr>
<td>Quality of life</td>
<td>EORTC-QLQ-30</td>
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<tr>
<td>Fatigue</td>
<td>CIS-8</td>
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<td>Job type</td>
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<td>4, 6</td>
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<td>4, 5</td>
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References
