Chapter 9.

General discussion
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?

Main findings

Design of a hospital-based work support intervention for cancer patients

We developed an intervention for cancer patients with the primary aim of enhancing the return to work and quality of life (Chapter 5). Important aspects of the design of this type of intervention include the following: 1) an early hospital-based intervention that is integrated into the usual psycho-oncological care (Chapter 2), 2) addressing misconceptions about cancer and work (Chapter 2), 3) involvement of the occupational physician and the supervisor (Chapter 3), and 4) informing the patient’s occupational physician about patient’s diagnosis and cancer treatment (Chapter 5).

Psychometric properties of the Work Limitation Questionnaire (WLQ) among cancer survivors

To understand the full impact of a cancer diagnosis on adverse work outcomes, it is also important to understand the work functioning of cancer survivors. A commonly used measure of the impairment of work functioning due to ill health is the Work Limitation Questionnaire (WLQ), which has been translated into Dutch. However, the measurement properties of the Dutch translation of the WLQ for use in cancer survivors are currently unknown. To determine the measurement properties of the WLQ for use with cancer patients, we conducted a cohort study with three
WLQ for use with cancer patients, we conducted a cohort study with three measurement points (Chapter 4). We found sufficient reproducibility at the group level but not at the individual level as the minimal important change (4.0) exceeded the smallest detectable change at the group level (3.1) but not at the individual level (18.0). There was no indication of systematic bias or proportional bias. The internal consistency and construct validity for the WLQ and its subscales were sufficient or slightly less than sufficient. There was a floor effect for one subscale but there were no ceiling effects. Responsiveness was sufficient with an area under the curve of a Receiver Operating Characteristic (ROC) of 0.68. The WLQ is reproducible, valid, and responsive for the use at group level, but it is not sufficiently reproducible for clinical use among cancer survivors.

Process evaluation of a hospital-based work support intervention for cancer patients

How is the process of a hospital-based work support intervention evaluated? To answer this question, we conducted a case study (Chapter 6) and a process evaluation (Chapter 7). We conducted a case study to describe how the return-to-work process progressed in a cancer patient and how a hospital-based work support intervention supported this process (Chapter 6). Furthermore, we performed a process evaluation at the level of the hospital department, nurse, and patient (Chapter 7). The following process evaluation outcomes were assessed: recruitment, context, reach, intensity of the intervention delivered, intensity of the intervention received, and fidelity.

The results of the case study revealed that the support delivered by the nurse helped the patient to resume work gradually and the sending of information from the treating physician and the nurse improved communication with the occupational physician. This resulted in the patient being able to achieve lasting return to work (Chapter 6). The results of the process evaluation showed that 47% of all eligible patients participated in the study. Nurses’ meetings with the patients were conducted according to the protocol in 85% of the cases. In 100% of the cases, at least one letter was sent to the occupational physician, and in 10% of the cases a meeting took place between the patient, the occupational physician, and the supervisor. Our method, which involved asking occupational physicians to organise a meeting between the patient, the supervisor, and themselves to draw up a return to work plan, proved
difficult. Patients and nurses found the intervention in general very useful (Chapter 7). Nurses made the following suggestions to optimise the intervention: 1) meetings must be planned at the right time and should be allotted sufficient time, 2) meetings should be conducted face-to-face, and 3) to be able to deliver all meetings face-to-face it may mean that the intervention should be handed over to another health care professional who has longer follow-up consultations in usual cancer care.

Based on the case study and the process evaluation, we conclude that the intervention yields high acceptability to implement in usual psycho-oncological care but that it proved difficult to involve the occupational physician. Patients were highly satisfied and nurses found the intervention useful and feasible.

Effectiveness of an innovative hospital-based work support intervention for cancer patients

We studied the effectiveness of an innovative hospital-based work support intervention in a multi-centre randomised controlled trial with a follow-up of 12 months (Chapter 8). Cancer patients who were treated with curative intent and who had paid work participated. Patients were randomly assigned to the intervention group (N=65) or to the control group (N=68). Outcomes were the rate of and time to return to work, quality of life, work ability, work functioning, and costs (i.e. costs to deliver the intervention and lost productivity costs). The relative risk of the intervention versus usual care of the return to work rate was calculated at follow-up. The time until return to work was analysed with a Kaplan Meijer survival analysis and Cox regression analysis. Secondary outcomes were analysed with multi-level analysis.

The rate of return to full or partial work at the 12 month follow-up was 79% in the intervention group versus 79% in the control group; and 86% and 83% respectively when excluding patients who died within the follow-up period and with a life expectancy of months. The relative risk of returning to work (full or partial) in the intervention group versus the control group was 1.03 (95% confidence interval 0.84 – 1.2). The median time from initial sick leave to partial return to work was 194 days (range 14-435) in the intervention group and 192 days (range 82-465) in the control group (p = 0.90). The hazard ratio of partial return to work was 1.03 (95% confidence interval of 0.64 – 1.6) of the intervention group versus the control group. Quality of life
improved statistically significant over time (p ranged from 0.014 to ≤ 0.001) but did not differ statistically significant between groups (p ranged from 0.15 to 0.99). Work ability and work functioning improved over time but did not differ statistically between groups. The cost of delivering the intervention was €119. Lost productivity costs did not differ between groups (€41.792 versus €40.147).

Return-to-work rates were generally high. We found non-statistically significant differences between groups, but there is still considerable uncertainty about possible effects of the intervention. Further research is needed to determine which aspects of the intervention are useful and which elements need improvement.

The context: cancer survivorship care, occupational health care, and the social security system

The approach of addressing adverse work outcomes of cancer patients by means of an early hospital-based work support intervention integrated into usual psycho-oncological care is innovative. Especially at the start of this thesis in January 2008, when few initiatives were focused primarily on ameliorating the adverse work outcomes experienced by cancer patients (Chapter 2).

From a historical perspective, this intervention was timely and innovative. It is only recently that improved cancer survival rates created a need for a focus on cancer patients’ return to work. Moreover, in the past few decades, the social security system in the Netherlands has focused more on workers’ disability than their ability; thus it was relatively easy to obtain a disability pension, especially in the case of a life-threatening disease such as cancer.12 For this reason, cancer patients were generally less encouraged to consider returning to work. Finally, curative care and occupational health care are formally separated in the Netherlands;2 thus treating physicians are not accustomed to addressing the return-to-work concerns of their patients. All these reasons contributed to a perspective of cancer care that was more focused on supporting patients in getting a disability pension than on helping them to return to work. The return to work of cancer patients was usually not addressed in the workplace either, because the perspective extended to the workplace where some supervisors and/or occupational physicians considered it inappropriate even to address the possibility of a return to work. Furthermore, the preceding Dutch disability Act discouraged employers
from addressing cancer patients’ return to work, as a sick-listed employee could be fired after one year of sick-leave.²

The concept that work is important for cancer patients has gained more recognition in the time between the development of the intervention and the end of this study. For instance, the Dutch Federation of Cancer patient organisation (NFK) has made efforts to help cancer patients with their work concerns.³⁵ Their focus on work broadened from supporting patients with an adequate assessment of a cancer patient’s disability pension to empowering cancer patients to return to work.⁶⁷ This shift in focus can also be observed in the recently published guideline for occupational physicians on cancer and work⁸ and in the inclusion of work issues in a recently published guideline for cancer rehabilitation.⁹

It is interesting to consider the origins of this change. The main cause is the shift in the focus of the Dutch government from disability assessment to getting workers with disabilities back to work. Numerous legislations have been made and implemented to create incentives for employers and employees to bring employees on sick-leave back to work.² For instance, the requirements for getting a disability benefit have become stricter. Furthermore, the support of workers on sick-leave have become mandatory, and employers are now legally required to compensate wage loss during the first two years of sick-leave.² In combination with the increased rates of cancer survival, this change led to an increased interest in the work-related concerns of cancer patients. Changes in the societal and medical perceptions of what constitutes fitness for work can be observed; it is now often accepted that one can resume work gradually before full recovery is achieved,¹⁰ that returning to work may contribute to recovery,¹¹⁰ and that work is a relevant factor during treatment. In other words, the benefits of work for persons with a chronic illness are more often recognised.¹⁰ Furthermore, persons with a chronic illness who remain at or return to work will become more valuable in an ageing society.

In the occupational health context, it can be observed that the labour market in European countries is shifting from permanent employment contracts to temporary employment contracts and to more precarious work in general.¹¹¹² In addition, the proportion of self-employed persons, who not always have access to occupational health care, is also increasing.¹¹ These changes are important, as these workers may be at
higher risk of experiencing adverse work outcomes. Because of the global economic recession, many companies face financial difficulties and will cut costs, leading to termination of employment contracts. These cuts will most likely affect workers with cancer-related sick-leave more adversely than in better economic times.

In summary, the studies conducted in this thesis were performed during a time period in which the perspective of the importance of cancer patients’ return to work rapidly changed. The subsequent sections will elaborate the extent to which this changing perspective may have influenced the findings of the studies in this thesis.

Methodological considerations

One adverse consequence of the intervention being innovative was that some hospital departments were not (yet) ready for this approach and chose not to participate in the intervention study (Chapter 7). For this reason, we were not able to include as many patients in our study as would have been required according to the pre-determined power analysis (Chapter 5). It was therefore not possible to test our findings with sufficient power leading to more uncertainty in the results. Return-to-work rates were generally high. We found similar return to work outcomes for both groups, but there is still considerable uncertainty about possible effects (Chapter 8). There are several possible explanations for the lack of statistically significance in these findings, which can be found in the content of the intervention and in the study design.

Intervention content

The basic assumption behind the intervention was that return to work would increase as patients’ self-assessed work ability improved. This change would be effected by patient education and support addressing misconceptions about cancer and work. We found that self-assessed work ability increased significantly over time but did not differ significantly between groups. It could be that a more intense intervention is required to address misconceptions. This mechanism is supported by the experience of some nurses who did not feel convinced of their competence to deliver the return-to-work advices (Chapter 7). It may be that our half-day training course was too short to enable nurses to gain the knowledge that is required to adequately address patients’ misconceptions about the return to work. On the other hand, we do not know precisely which
misconceptions impede the return to work and which should be addressed. For instance, we found that the understanding that it is useful to resume work gradually, even before one is fully recovered, was common in the usual care group as well. The prevalence of this belief might have resulted from more general changes in the perception of the importance of work for cancer patients, as noted earlier. In contrast, we also found that misconceptions about cancer and work still persist. Nurses described that one unexpected element of the patient education involved creating awareness that the social security safety net in the Netherlands has cut back in recent years and that companies may not be as loyal as anticipated. In sum, some misconceptions about cancer and work may have persisted and may have resulted in the absence of an intervention effect.

We experienced difficulties in involving the occupational physician and the employer in the intervention (Chapter 7). The involvement of the occupational physician and the supervisor appeared to be important in our qualitative study (Chapter 3). Therefore, the absence of an intervention effect may have been caused by the lack of involvement of the occupational physician and the supervisor.

**Study design**

Another possible explanation for the non-statistically significant findings may be found in the study design. Several forms of bias may have influenced the findings of the intervention study (Chapter 8).

The contrast between the intervention group and the control group may have been reduced in several ways. The quality of usual care regarding work advice was most likely higher in hospital departments that were willing and able to participate at the start of the study compared to hospital departments that were not willing and able to participate because nurses who worked in hospital departments that participated already recognised the importance of work for cancer patients. Next, the study design in which patients were randomised within one hospital department led to contamination between the intervention group and the control group. We tried to reduce this form of contamination between groups by separating nurses who delivered the intervention from nurses who delivered usual care, but contamination proved more persistent than had been estimated at the start of the study. Furthermore, the contrast between groups
may have been reduced due to the fact that all cancer patients were informed about the general aim of the study (i.e. information bias) and because of the increased recognition of the importance of work for cancer patients. Both aspects may have led to an increased awareness in the usual care group that the return to work should receive more attention and may have led to the use of co-interventions, such as (vocational) rehabilitation. Finally, the contrast between groups may have been reduced due to a patient selection bias; patients participating in this study may already be of the opinion that work is an important subject that should receive attention. In summary, the contrast between the groups may have been reduced in several ways and this shift likely caused an underestimation of the effect of the intervention versus usual care.

A bias might also have resulted from the measurement of the primary and secondary outcomes, such as the choice of questionnaires and the measurement points. The questionnaires we used to measure primary and secondary outcome, were reported to be valid\textsuperscript{15, 16} except that the validity and reliability of the Dutch translation of the Work Limitation Questionnaire (WLQ) had not previously been tested in a population of cancer patients. Therefore, we conducted a validation study of the Dutch translation of the WLQ in a population of cancer patients (Chapter 4). The results showed that the WLQ is valid to use at a group level. Furthermore, recall bias may have been introduced when we assessed the outcomes at a time interval of six months. We choose this long time interval to ease the burden on patients filling in questionnaires. However, this interval may have been too long to reliably assess return to work. The recall bias is expected to be the same between the intervention group and the control group, and would therefore not likely have affected our findings on effectiveness significantly. However, it may, fail to reliably represent the time until return to work.

Finally, the follow-up period of one year may be too short to study the primary outcome of a sustainable return to work, as the median time until full return to work was 269 and as 45% achieved full return to work at one-year follow-up. Therefore, it is possible that the findings of the study would have been different at 18 and 24 months follow-up but this is not likely as time progresses, the probability of a patient returning to work decreases and as we studied an early intervention. Therefore, we assumed that the effect would have been within the 1-year follow-up, rather than at the end of a very long-term follow-up period.
External validity: generalisability of findings and intervention implementation

As most studies conducted in this thesis were performed with female cancer patients, our findings cannot be generalised to male cancer patients because male cancer patients may face other problems upon their return to work or may attribute a different meaning to work.

The studies described in this thesis were all performed in the Netherlands, which has a unique culture in terms of occupational health care, the social security system, and cultural characteristics. It is generally acknowledged that the disability legalisation of a country especially influences the adverse work outcomes of employees on sick-leave and that disability legalisations varies widely among countries. For that reason, the effect of interventions on adverse work outcomes may also vary from one country to another. However, the early hospital-based work support intervention integrated into usual psycho-oncological care can be generalised to other countries because cancer patients in other countries experiencing a lack of support about their return to work from the hospital as often as patients in the Netherlands. Furthermore, as the intervention implementation appeared to be successful regarding patient education and support at the hospital and as the intervention implementation could be adapted to different local psycho-oncological care settings, we assume that it could also be adapted to the psycho-oncological care of other countries.

Implications for further research

As most of the studies in this thesis and in the literature (Chapter 2) have been conducted among breast cancer patients only, one recommendation for further research is to broaden the scope to all cancer types to verify that the findings described in this thesis apply to all cancer types. This work is especially important, because different prognostic factors influence the return to work by patients with different cancer types and because cancer diagnosis and cancer treatment are prognostic factors for return to work.

Along similar lines, most of the studies in this thesis and in the literature have been conducted among cancer patients with relatively good survival chances, which may be considered adequate, because the return to work may be more a cause for concern for them. However, cancer patients with less good survival chances will have
work concerns other than returning to work, such as whether they are able to or want to remain in paid work. Therefore, they may also benefit from patient education and support about these specific work concerns delivered by a nurse. Thus, another recommendation for further research is to broaden its scope to include cancer patients with less good survival chances and to elucidate their work concerns and their needs.

Most importantly, because patients and nurses appreciated the intervention, because it appeared that the intervention could be implemented in usual psycho-oncological care (Chapter 7), and because we found similar work outcomes for both groups, further research is needed to study which aspects of the intervention are useful and which elements need improvement.

**Intervention content**

We learned from the intervention study that it was difficult to engage the occupational physicians (Chapter 7), while the involvement of the occupational physician and the supervisor appeared to be important in our qualitative study (Chapter 3). For that reason, the intervention should be adapted such that the workplace is more involved. One possibility is to develop a web-based system or to send coded emails instead of letters to lower the barrier between the hospital and the occupational physician. However, one drawback of these systems is that patient privacy must be guaranteed at all times. Another option is to give the patient the information. For instance, patients could be given an informational leaflet about cancer and work, and they can use the leaflet as a starting point to discuss their return to work with their supervisor and/or occupational physician. In addition, an informational leaflet may provide the supervisor with general information regarding the consequences of a cancer diagnosis for work outcomes. These informational leaflets were recently developed by the Dutch Federation of Cancer patient organisations (NFK). Finally, occupational physicians could be given more training on the specific needs of this population.

It might be more difficult than estimated to address misconceptions about cancer and work. We do not know precisely which misconceptions impede the return to work and which should be addressed and the training that we gave to the nurses may have been insufficient. Both aspects should receive more attention in further research. Furthermore, the intervention ought to be tailored to employees with a temporary
employment contract, as patients who did not have an employer anymore stated that they could not comply with all advices (Chapter 7).

It is generally acknowledged that the variation in time until return to work is large; some patients are never on sick-leave and work through treatment, whereas others are never able to return to work. This assumption was supported by the studies included in this thesis (Chapter 8). From the intervention study (Chapter 8), it could be derived that some patients had already fully returned to work before the intervention started, while other patients would have preferred to receive much more and much longer support, as they were not able to work at follow-up. Therefore, it may be important to identify patients who have a higher risk of getting adverse work outcomes based on a clinical prediction rule. Such a clinical prediction rule for work outcomes should be developed and evaluated for accuracy in identifying patients with a higher risk of adverse work outcomes. Thereafter, health care professionals should receive training in applying the clinical prediction rule in practice.

Apart from identifying patients at a higher risk, it is also important to tailor the level of the intervention to meet the needs of the patients in a process called ‘stepped care’22. A very rough estimation based on our intervention study can be made. To start with, very few patients need no support, as they encountered insignificant problems upon their return to work. At the next step, the majority of patients may benefit from receiving patient education and support about work. Finally, a minority of the patients need a more intensive intervention. It is not feasible for a nurse alone to deliver a much more intensive intervention as part of the nurse’s normal psycho-oncological care because of the burden on the health care, which will even become more pressing in the near future as the number of cancer patients who will survive will increase.23 The intervention for the second and third category of patients should be modelled after self-management, as self-management is a promising solution to the burden on the health care. Self-management could be more efficiently delivered through e-health, which is, for instance, the partial delivery of an intervention over the Internet. It has been suggested that e-health in combination with support from a health care professional is most effective.24 25 Another advantage of an e-health intervention is that it can be easier tailored to the needs of the patient, as it is less structured. Such an intervention might prove the key to ending our difficulties with involving the occupational physician and
the supervisor in the intervention. Finally, the content of an e-health intervention may also be tailored to the variation in the seriousness of the cancer. The patients facing the most difficulties upon returning to work may benefit from a referral to an extra intense intervention such as an occupational physician specialised in the work concerns of cancer patients or a vocational rehabilitation coach specialised in cancer.26

The intervention was not specifically developed for a certain cancer type, but it was difficult to include cancer types other than breast and gynaecological cancers, frequently because of the limited psycho-oncological care of hospital departments that treated other cancer types. At these departments, there was for instance no nurse who could assist the treating physician in assessing the inclusion and exclusion criteria and informing cancer patients about the intervention study. Nurses were most often involved in breast cancer care only, as cancer care was most developed in the field of breast cancer care.27 However, it is assumed that cancer survivorship care will improve in the near future for other cancer types,27 which might make it easier to include other cancer types in future studies.

Intervention study design

We found that contamination took place between the intervention group and the control group. The disadvantages of a cluster randomised controlled trial (i.e. differences in baseline values) may now balance out the disadvantages of a randomised controlled trial in one department (i.e. contamination). In addition, in a cluster randomised controlled trial, it is in general easier to maintain contrast between groups, as it is not always required to inform individual patients, to which intervention arm they are assigned and what the general aim of the intervention arm is, which is likely to lead to less information bias and use of co-interventions.28 This type of study design has been considered ethical and feasible in practice.28

When we developed the study design, we made the decision to assess the economic costs from a societal perspective as the society incurs costs when a cancer patient is not able to return to work. However, in addition to the societal perspective, the economic costs calculated from the perspective of a health insurance company perspective are important for this type of intervention because the hospital department bears the cost of the intervention, while the cancer patient and the employer may
receive the primary benefit (earlier and sustainable return to work). Health insurance companies are primarily interested in whether interventions are effective in reducing the medical consumption as they bear the costs for the medical consumption. For that reason, if a hospital-based work support intervention appears effective, it is important to consider whether the intervention also reduces the patient medical consumption. In that case, health insurance companies might pay for the intervention, which may result in hospital departments being more likely to implement the intervention, as they will be compensated for the intervention costs.

**Recommendations for practice**

An important general recommendation for practice is that an individualised approach is required, as the differences between cancer patients are large in terms of both the problems experienced on return to work and the differences in the importance of work (Chapter 3 and 8). This finding holds especially for cancer patients with less good survival chances (Chapter 3). Therefore, it is important that healthcare professionals be made aware of these individual differences, verify the work concerns and importance of work of an individual patient, and fine-tune their support and advice to the individual patient.

*Cancer survivorship care*

A specific recommendation for cancer survivorship care is to be aware of the work concerns of cancer patients and to address the adverse work outcomes of cancer patients early in treatment phase, as well as at follow-up, as the intervention is appreciated by patients and perceived to be useful and feasible by nurses. Furthermore, the recent published guideline ‘cancer rehabilitation’ states that work should be a permanent subject of cancer rehabilitation, both during active treatment as well as at follow-up. We found similar return to work outcomes for both groups but there is still considerable uncertainty about possible effects, so further research is needed to study which aspects are useful and which aspects need improvement.

Oncological rehabilitation is considered reimbursable care by the Dutch health insurance companies, which should, according to the recent published rehabilitation guideline, also include interventions that address adverse work outcomes. Therefore, it
would be helpful to further recognise that support for work resumption is a need of cancer patients that should be addressed by the health care system, which hospital departments should be able to reimburse by the health insurance companies if an intervention is (cost-)effective.

**Occupational health care, supervisor, employer**

Occupational health care professionals and the employer should be attentive to the long-term consequences of cancer treatment on work outcomes to prevent a wear-off effect on attention and support (Chapter 3). The transition from cancer patient to survivor may have all types of complications, suggesting that it is important to follow someone for some time after sustainable return to work. Most patients mentioned that a gradual return to work facilitated their return to work process (Chapter 3). Therefore, another recommendation is to offer modified work duties as much as possible.

In addition to the employee with cancer being confronted with cancer, the supervisor and colleagues are confronted with cancer as well, which might make them unsure how to address their sick colleague (Chapter 3). The supervisor and colleagues may feel unsure how to address a colleague with cancer, which may be partly caused by the historical perspective on work of cancer patients as noted earlier. For those reasons, some cancer patients still experience a stigma related to cancer and work. Examples include the stigma that their work was not important for them during or after treatment, the stigma that they were not able to return to work, and/or the stigma that their work productivity was lower in comparison to healthy subjects (Chapter 3). The above concerns suggest that support of the employer/occupational health services should not be limited to the employee with cancer but should be broadened to the colleagues as well.

**Cancer patients**

Cancer patients are recommended to make themselves aware of the rules of the Dutch social security system, which are not fine-tuned to a specific diagnosis but similar for all persons on sick-leave regardless of the cause. Moreover, it may be beneficial for cancer patients to understand the barriers for return to work such as low self-assessed work ability or misconceptions about return to work. It will most likely be helpful to discuss
how to overcome these barriers early in the treatment process with a health care professional.

In sum, in this thesis, adverse work outcomes of cancer patients were addressed by developing a hospital-based work support intervention and by studying its effects on return to work and quality of life in a multi-centre randomised controlled trial. The importance of work for cancer patients is confirmed by the studies in this thesis. The intervention was easily accepted in usual care and patients were highly satisfied. We found high return to work rates and improved quality of life scores in both the intervention and the control groups, possible effects of the intervention need more attention. Therefore, interventions should be further developed to support cancer patients with their return to work.
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