Return to work in cancer survivors with job loss
Maartje Plonia van Egmond

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Return to work in cancer survivors with job loss

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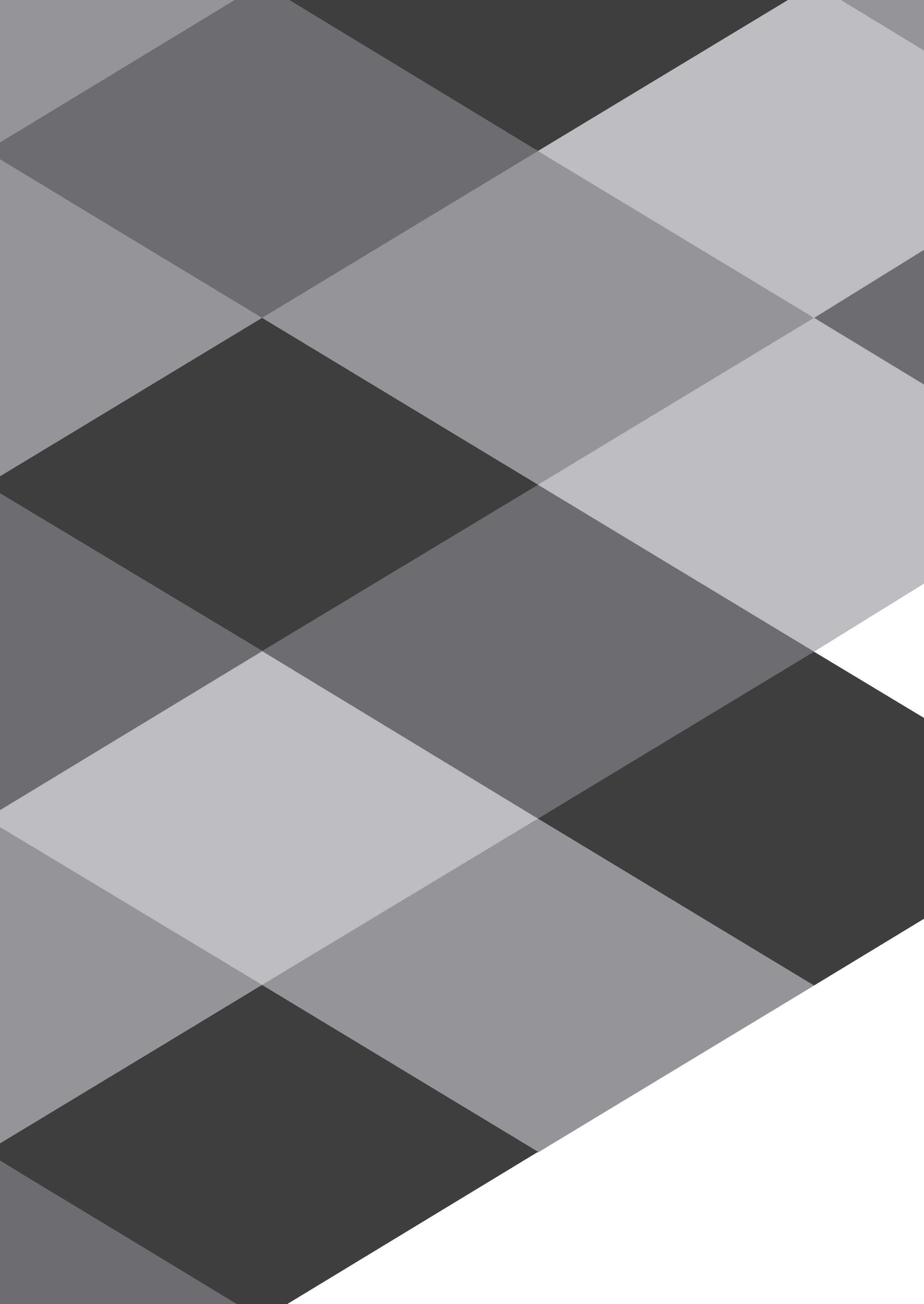

Ik weet nog hoe je ongeduldig op de bank zat te hupsen
Mag ik al weer aan het werk?
Kan ik het wel aan?
Wat doet mijn werkgever na twee jaar?
Ook al verloor jij uiteindelijk de strijd
Die paar maanden dat je weer naar de ambulancedienst kon
De sirenes kon laten loeien om anderen te helpen
Die waren onbetaalbaar, net als de grijns op je gezicht
Als je telkens doodmoe maar voldaan thuiskwam
Bij het schrijven denk ik aan jou en alle anderen die strijden om het leven
en hun werk te behouden.

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De Naam des HEEREN zij geprezen, van nu aan tot in der eeuwigheid
Psalm 113:2

Contents

1.

General introduction

'There are cancer patients and survivors who are currently not working, while they would like to return to work. It is my ambition to break the taboo of working with cancer, and to increase awareness among employers and workers, in order to improve cancer survivors' participation in work. (...) Specifically, there is room for improvement with regard to the social security system. It is worrisome that, in the absence of an employer, cancer survivors in the social security system lack support and opportunities to gradually and sustainably return to work.'

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This quote is part of a letter written by L.F. Asscher, the Dutch Minister of Social Affairs and Employment, addressed to the Chair of the House of Representatives of the Netherlands, on July 10th 2015 [1]. The full letter summarizes the conclusions of an advisory committee that evaluated the current situation in the Netherlands with regard to cancer patients' and survivors' participation in the labour market. The main conclusions were that cancer survivors are challenged in their return to work, that especially unemployed cancer survivors within the social security system are at a disadvantage in return to work, and that more research is needed to understand the return to work process of cancer survivors. This thesis is dedicated specifically to the return to work process of cancer survivors within the Dutch social security system, who have experienced job loss.

In order to fully understand the challenges and chances for return to work in cancer survivors with job loss, it is important to develop methods for return to work support for these cancer survivors. Also, the context of the social security system should be explored, in order to understand the road of return to work for cancer survivors with job loss, from receiving benefits to participation in work.

Cancer survivorship and the importance of work

In 2012, globally, 14.1 million persons were diagnosed with cancer, of whom 3.45 million in Europe [2].
Fortunately, many cancer patients make the transition to cancer survivorship nowadays, as a result of early detection and successful treatments [3-5]. To illustrate, in the US, the number of persons living with a history of cancer was 1.5% of the population in 1971, compared to 4.5% in 2014 [6,7]. Currently, 40-50% of all persons diagnosed with cancer in Europe and the US is of working age, i.e., 16-65 years [4,8]. Although cancer patients may need to take up long periods of sick leave from work to receive anti-cancer treatment, i.e., several months or even years, most cancer survivors are motivated to return to work during or after treatment [9-11]. In fact, previous studies have demonstrated that 84-94% of cancer survivors returns to work within 24 months after diagnosis [12,13]. However, when looking at return to work over a period of six years beyond diagnosis, the overall average percentage of cancer survivors that has returned to work is only about 64% [10]. This indicates that there are various factors, perhaps related to the workplace or related to survivors' health status, that contribute to adverse work outcomes for cancer survivors in the long term.

Overall, cancer survivors are 1.4 times more likely to be unemployed, compared to healthy controls [14].
Although it has been documented that a cancer diagnosis may lead to a shift in life priorities, e.g., work becomes less important and family becomes more important, studies show that many cancer survivors consider work meaningful and they attribute positive effects to work [3,15]. For example, work enables cancer survivors to obtain a sense of social inclusion, normalty and control [11,16]. Furthermore, work provides a distraction from the illness, it increases self-worth and helps to reduce avoidable work disability and financial loss [17, 18]. It is evident that many cancer survivors attempt return to work, but a relatively large proportion fails to do so in a sustainable way [10].

Previous studies have identified several socio-demographic, cancer-related, psychosocial and work-related factors that influence return to work in cancer survivors [19-21]. For example, older age, being female and having a worse prognosis are negatively associated with return to work in cancer survivors [22]. Furthermore, long after the treatments have been completed, many cancer survivors suffer from long-term or even permanent health problems that may impair their work ability [9,23,24]. That is, cancer survivors may experience physical limitations, such as fatigue, reduced range of motion in the limbs, pain and sleep problems [25-30]. Also, psychosocial problems are prevalent among cancer survivors, such as cognitive limitations, including memory problems and organizational problems, reduced ability to cope in public situations, problems with social relations, anxiety, stress, and depression [9,25,28,31-33]. Moreover, work-related factors play an important role in the success or failure of cancer survivors' return to work. That is, a non-supportive work environment decreases the chance of return to work, while perceived employer accommodation, gradual return to work, counselling and rehabilitation services, among other factors, increase the likelihood of return to work after cancer [10,22]. For an increasing group of cancer survivors in Western societies, the majority of the return to work facilitators identified in the literature are not applicable, as they require involvement and support from an employer and workplace. That is, between 26-53% of cancer survivors becomes unemployed in the first six years after diagnosis [10]. In the absence of an employer and workplace, these cancer survivors may experience even more obstacles in return to work, compared to cancer survivors who still have an employer. Although most European countries have a social security system in place that takes over the responsibility for cancer survivors in the absence of an employer, there is room for improvement in these systems if they are to support unemployed cancer survivors in return to work [1].

Cancer survivors in the social security system

In the absence of an employer, cancer survivors in several European countries rely on financial support and return to work support from the social security system. Specifically with regard to the Netherlands, cancer survivors can apply for sickness or disability benefits, which are provided by the Dutch social security agency, to substitute loss of income [34]. For years, the Dutch social security agency has reported an increase in the number of cancer survivors with job loss. To illustrate, from 2006 to 2013, there was a 90% increase in the number of cancer survivors with job loss who applied for work disability benefits [35]. In 2014, 37% of all temporary work disability benefits that were granted to cancer survivors, were granted to cancer survivors with job loss [36]. The significant number of cancer survivors with job joss in the Netherlands is worrisome, as the Dutch social security agency has signalled that they currently do not have the expertise to provide tailored return to work support to cancer survivors within the social security system [1]. This is partly a matter of scarce resources, but it is also explained by a lack of cancer-related expertise in professionals employed at the social security agency. That is, the fact that the impact of cancer varies greatly between cancer survivors [37,38] makes it difficult for professionals at the social security agency to determine work ability after cancer, and to provide suitable tools to enhance labour market participation [39]. It is particularly relevant to identify barriers and facilitators for return to work in cancer survivors within the social security system, as the number of cancer survivors with job loss is expected to further increase in the future. Specifically, the rise in cancer incidence and prevalence [40,41], the increasing retirement age [42] and changes in the labour market, such as the increasing proportion of flexible employment contracts [43], are likely to contribute to the growing number of cancer survivors with job loss.

Flexible employment and vulnerability for job loss

In Western economies, there has been a developing trend towards flexible employment [43]. Temporary employment contracts have become a popular form of employment, gaining ground from the more traditional permanent employment contracts [44]. To illustrate, in 2015, circa 1.9 million persons were in flexible employment in the Netherlands, which is a 20% increase compared to 2008 [45]. In general, workers with temporary employment contracts are quite vulnerable for job loss. That is, employers have fewer financial and legal obligations to those workers, compared to their obligations towards workers in permanent employment [34,46,47]. For example, an employer can opt not to extend a temporary employment contract of a sick-listed worker, to avoid financial loss [48]. In the Netherlands, it has been demonstrated that cancer patients are indeed vulnerable for job loss in case of flexible employment, and that they struggle with return to work [49]. That is, after job loss, return to work involves going through job applications, which is a different experience compared to cancer survivors with permanent employment contracts, who may return to a former workplace. For cancer survivors who experience job loss, the key to return to work could be to develop a new type of intervention program, tailored to the personal needs for support, and tailored to the context of the social security system [50].

Interventions to support return to work

In the past, several return to work interventions have been developed for cancer survivors. A recently updated Cochrane review identified fifteen randomized controlled trials that offered intervention programs and studied return to work as a primary or secondary outcome measure [51]. Most of these studies included cancer patients and survivors with a specific diagnosis, such as breast cancer or prostate cancer. While no vocational interventions were found to be developed so far [51], there were five studies in this review that offered multidisciplinary interventions, which included a combination of vocational counselling, patient education, biofeedback-assisted behavioural training and/or physical exercise [52-56]. Overall, these studies provided moderate quality evidence that combined intervention programs may increase return to work rates in cancer survivors. However, the overall sample of the studies that offered multidisciplinary interventions was relatively small, i.e., 450 patients. Also, the combined effect of these multidisciplinary interventions on return to work was limited, i.e., the review reported an overall hazard ratio of 1.11 with a corresponding 95% confidence interval of 1.03-1.16 [51]. In a previous version of this Cochrane review, published in 2011, the authors concluded that there was some affirmative evidence with regard to the effectiveness of multidisciplinary return to work programs for cancer survivors, but that the overall quality of intervention studies needed to be improved [57]. In the updated review, it seems that there is an increase in evidence to support the theory that multidisciplinary interventions may benefit cancer survivors' return to work [51]. Still, four out of five studies offering multidisciplinary interventions were aimed mostly at female cancer survivors with breast or gynaecological cancer [52,54-56], and the remaining study only included prostate cancer patients [53]. Therefore, the generalizability of these effects across cancer survivors remains unclear.

Even if the evidence regarding the effectiveness of multidisciplinary return to work interventions for cancer survivors currently is more convincing, an important problem of return to work interventions remains, namely that these programs are not designed for cancer survivors with job loss [50]. Specifically, previous intervention programs often include activities such as re-integration consultation, vocational rehabilitation and workplace accommodations [51], which cannot be delivered in the absence of an employer or workplace, and are therefore unsuitable to support cancer survivors with job loss in their return to work [10,50].

Objective of this thesis and research questions

Considering the increase in the number of cancer survivors with job loss, and the lack of appropriate interventions to support their return to work, there is a need to investigate the barriers and facilitators for return to work in cancer survivors with job loss. Further, a tailored return to work intervention program should be developed for these survivors and its effectiveness should be evaluated. Also, the return to work process in cancer survivors should be studied in a broader context, by exploring the potential of gradual return to work such as therapeutic work, and problems after return to work in cancer survivors. Therefore, the main objectives of this thesis are:

1. To explore barriers and facilitators for return to work for cancer survivors with job loss, to translate this knowledge into a tailored return to work intervention program for these survivors, and to evaluate process outcomes and the effectiveness of this program on sustainable return to work in cancer survivors with job loss;

2. To obtain a broader perspective on sustainable return to work in cancer survivors with job loss, by exploring therapeutic work as a potential facilitator for return to work;

3. To present an overview of physical and/or psychosocial health problems that cancer survivors may experience beyond their return to work.

Thesis outline

In **Chapter two**, a focus group study on barriers and facilitators for return to work of sick-listed cancer survivors with job loss, as perceived by these cancer survivors and by insurance physicians from the Dutch Social Security Agency, is presented. In **Chapter three**, the study protocol of a randomized controlled trial is described, including the design of a tailored return to work intervention program for cancer survivors with job loss. A longitudinal study on the role of therapeutic work as a potential facilitator for return to work of cancer survivors is presented in **Chapter four**. It is also explored whether there are potential differences in access to therapeutic work between cancer survivors with job loss, and those who still have an employment contract. In **Chapter five**, a cross-sectional study is described, in which factors and motives associated with (non-)participation of cancer survivors with job loss in the tailored return to work program were examined. In **Chapter six**, a process evaluation of the randomized controlled trial procedures and the program procedures of the tailored return to work program is reported. The main study of this thesis is described in **Chapter seven**. This study presents the results of the randomized controlled trial, in which the effectiveness of the tailored return to work program on duration until sustainable return to work for cancer survivors with job loss, was evaluated. In **Chapter eight**, a systematic review is presented, which reports on physical and/or psychosocial problems that cancer survivors experience beyond their return to work. The main findings of this thesis are described and discussed in the context of cancer survivorship and the changing labour market in **Chapter nine**. Further, the applications of these findings in other sick-listed workers, particularly in workers with job loss due to health conditions other than cancer, are explored. This thesis is concluded with recommendations for future research and practice.

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Barriers and facilitators for return to work in cancer survivors with job loss experience: a focus group study

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Barriers and facilitators for return to work in cancer survivors with job loss experience: a focus group study

Abstract

Over 50% of cancer survivors lose their job or quit working. Cancer survivors who experience job loss may face different challenges regarding return to work, compared to cancer survivors with employers. This qualitative study aimed to explore barriers and facilitators for return to work in cancer survivors with job loss, and in insurance physicians who assist cancer survivors in their return to work.

We conducted five focus groups and one interview (cancer survivors, N = 17; insurance physicians, N = 23). Topics included, amongst others, experience of job loss and barriers and facilitators for return to work. Data were audio recorded and analysed using thematic analysis. Our main finding was that cancer survivors experienced a double loss: loss of job on top of loss of health. As a result, cancer survivors feared for job applications, lacked opportunities to gradually increase work ability, and faced reluctance from employers in hiring them. Insurance physicians expressed a need for more frequent and longer consultations with cancer survivors with job loss. We conclude that cancer survivors who experience double loss encounter specific barriers in the return to work process. This calls for a tailored approach regarding return to work support.

Introduction

Work ability and employment are negatively affected by long-term effects of cancer diagnosis and treatment [1,2]. As a result, it can be challenging for cancer survivors to meet job demands [3,4]. Studies have shown that, overall, cancer survivors have a 1.4 times higher risk of unemployment compared to healthy controls [1]. Furthermore, across studies, between 26-53% of cancer survivors loses their job or quits working during or after treatment [5]. Also, a large previous study in the United States found that cancer survivors are significantly more likely to file job loss claims, compared to employees with other impairments [6]. Once cancer survivors experience job loss, in many developed countries they may be (temporarily) supported by the national security system.

For example, in the Netherlands, in the absence of an employer, cancer survivors may be eligible for sickness or work disability benefits, which are provided by the national social security agency, to substitute loss of income [7]. The social security agency essentially takes over the role of an employer. Within the agency, insurance physicians are key figures who essentially take over the role that, in case the cancer survivor would still have an employer, would be fulfilled by an occupational physician. Cancer survivors who apply for sickness or disability benefits, are guided by these insurance physicians, who provide vocational rehabilitation support, assess work ability and evaluate opportunities for return to work [7]. Currently, 37% of all temporary work disability benefits granted to cancer survivors in the Netherlands are being granted to cancer survivors who lose their job [8]. We will further refer to these cancer survivors as ‘cancer survivors with job loss experience’. Overall, there is a 90% increase in the number of cancer survivors with job loss experience who apply for work disability benefits, from 2006 to 2013 [9]. It is expected that the number of cancer survivors with job loss experience, who are receiving sickness or work disability benefits, will keep increasing in the future. To illustrate, there was a 7.8% increase in temporary work disability benefits that were granted to cancer survivors from 2012 to 2013 [10]. The increase of the number of cancer survivors with job loss experience in the Netherlands and worldwide can, for a large part, be explained by a rise in cancer incidence and prevalence [11,12], a rise in retirement age [13,14], and a changing labour market [15]. In Western economies, temporary contracts have started to become a common form of employment arrangement, gaining ground from the more traditional permanent employment contracts. For example, in 2012, 1,120,000 persons were working on a temporary employment contract in the Netherlands, which is a 30% increase compared to 2005 [16]. Workers in developed countries with temporary employment contracts are relatively vulnerable for job loss when they are diagnosed with cancer (or other diseases), because employers in these countries have fewer financial and legal obligations compared to the obligations they have towards workers with permanent employment contracts [17]. That is, an employer may decide not to extend a temporary employment contract after a worker has been diagnosed with cancer, thereby handing his responsibilities for the employees’ case over to a national social security system.

The negative effects on health and psychological wellbeing of a temporary employment contract and consequently, an insecure working status and an increased risk of job loss have been demonstrated by previous studies in the general population. For example, persons with temporary employment contracts and an insecure working status generally experience worse health, elevated levels of stress and they have an increased risk for long-term (work) disability compared to employees with permanent employment contracts [18-21]. It is plausible that the negative effects of a relatively high risk for job loss that are found in the general population, also hold true for cancer survivors with job loss experience. In addition, after job loss, return to work involves going through job applications, which may be a different experience compared to employees with permanent employment contracts, who return to a former workplace. Therefore, cancer survivors with job loss experience may be at a disadvantage regarding return to work compared to cancer survivors with permanent employment contracts. Until now, no studies have been conducted specifically in cancer survivors with job loss experience regarding their return to work process. Therefore, the aim of this study was to explore experiences of job loss and to explore barriers and facilitators for return to work in a broad sample of cancer survivors, who have experienced job loss before or during cancer diagnosis and treatment. We will also include perspectives from insurance physicians, as, in the absence of an employer, they are involved in the return to work process of cancer survivors with job loss experience in the Netherlands.

Methods

This study employs a qualitative approach to explore return to work in cancer survivors with job loss experience. We conducted focus groups with cancer survivors and insurance physicians separately. Data were analysed using a thematic analysis approach [22]. We used the COREQ checklist for reporting qualitative studies [23]. This study was approved by the Medical Ethical committee of the VU University Medical Center, Amsterdam, The Netherlands.

Recruitment of cancer survivors with job loss experience

To recruit cancer survivors, we requested a search in the national database of the Dutch social security agency. The search was executed by a social security agency researcher to comply with privacy policies under the Dutch law. Survivors were eligible for participation if (1) they had received sickness or work disability benefits due to any type of cancer in the past 15-30 months; (2) they were able to understand and speak the Dutch language sufficiently; (3) they lived in three provinces of the Netherlands that were adjacent to the province of the VU University Medical Center (to reduce travel time); and (4) they were over 18 years old. We used a convenience sampling procedure to select potential participants from the search. We expected a response rate between 5% and 10%, given that this target group is reported by practitioners at the social security agency as hard to reach and possibly underregistered. We sent out invitational letters and informed consent forms to the sample of potential participants. When potential participants returned the informed consent form, we contacted them by telephone to inform them about the study and to check their availability. The focus groups were hosted at the VU University Medical Center in Amsterdam, The Netherlands. Participants were compensated for travel expenses.

Recruitment of insurance physicians

Focus groups with insurance physicians were scheduled during regular meetings of local insurance physician peer review groups. These are established groups of insurance physicians in the Netherlands, who regularly meet as a continuing medical education activity. We used the network of the Dutch Research Center for Insurance Medicine to identify local peer review groups that were willing to participate in this study. Groups were conveniently selected on availability and geographical distribution. Insurance physicians received no compensation for participation in this study.

Focus group procedures and content

The focus groups were held in the period of August 2012 until February 2013. The focus groups were held in private interview rooms and were facilitated by two moderators and 2 min secretaries. Each of the moderators were chosen on the basis of their experience with interviewing either cancer survivors or insurance physicians. The focus groups with cancer survivors were moderated by SD (senior researcher/epidemiologist; specialized in the field of cancer and work) and those with insurance physicians were moderated by SV (senior researcher/insurance physician; specialized in the field of insurance medicine). There were no established relationships between moderators and participants prior to the study.

The average duration of the focus groups was scheduled to be 2 h. The focus groups started with an introduction of the moderators, participants, and the topics to be discussed. Participants received a hand-out on which the topics were outlined. Topics were alike for cancer survivors and insurance physicians, but were phrased differently for each group to match their perspectives. An overview of the topics is provided in Table 1.

Table 1. Overview of interview topics

Topics for cancer survivors with job loss experiences	Topics for insurance physicians
Job loss experiences	Guidance of cancer survivors with job loss experiences
Guidance by insurance physicians	Perceived motivation for work in, and meaning of work for, cancer survivors with job loss experiences
Motivation for work and meaning of work	Perceived barriers and facilitators for return to work in cancer survivors with job loss experiences
Barriers and facilitators for return to work	
Experiences with return to work	

Data were recorded with an audio recording device. Participants had a card with a number in front of them. Individual quotes were anonymously recorded by minute secretaries, who wrote down the quote and the number of the participants' card. Participants were also asked to complete a short questionnaire regarding demographics and employment situation over time (for cancer survivors) or years of work experience (for insurance physicians).

Analysis

All data were recorded in Dutch and transcribed intelligent verbatim. Given the nature of the focus groups (i.e., group discussions), we decided not to send the transcripts back to the participants for individual correction or commenting. After analysis, selected quotes were translated to English by a native English speaker. MvE and AL conducted separate and independent analyses with the use of ATLAS.ti 5.2 software [24]. The initial coding tree existed of themes that were outlined in the topic list that was used during the focus groups (see Table 1). The final coding tree corresponded to the themes that are discussed in this paper. We performed standard procedures of thematic analysis, which consists of six phases [22]. In phase 5 and 6, MvE and AL discussed the results until consensus was reached. An overview of the phases is provided in Table 2. Furthermore, we systematically studied the level of data saturation. We explored the frequency of the quotes within each theme and their distribution across the focus groups, based on a data saturation approach as described by Guest et al. [25]. In addition, the themes were informally evaluated by the researchers and moderators to discuss if new results had been reported in the final focus groups.

Table 2. Phases of thematic analysis

Phase	Task	Performed by MvE and AL
1	Familiarize with data: reading transcripts, noting first impressions and ideas for themes	Independently
2	Analysis of data, assign detailed codes that are closely coded to the data	Independently
3	Review the list of codes and merge codes to create codes of higher and less detailed order; identify (sub)themes and merge themes that display overlap	Independently
4	Review if the result of phase three is satisfactory and plausible	Independently
5	Discuss results of analysis	In cooperation
6	Report results	In cooperation

Results

Recruitment

The initial search at the social security agency identified 2465 eligible cancer survivors, from which we selected 230 eligible participants. For 13 persons, the address was not found in the municipal population register or they were deceased. We sent out invitational letters and informed consent forms to 217 persons, of whom 21 (9.6%) responded positively. Responding cancer survivors were contacted by telephone to inform them about the study and to check their availability. Seven and eight persons participated in the two focus groups, respectively. Additionally, we conducted one interview with two cancer survivors. Originally, this session was scheduled as a focus group with six participants, but on the day of the focus group, four cancer survivors had to cancel due to illness or personal matters. With only two participants, we will refer to this session as an interview and not as a focus group. In total, 17 cancer survivors participated in the focus groups and the interview.

For insurance physicians, we identified five peer review groups that were interested to participate in the study. However, after three focus groups we decided a satisfactory level of data saturation was reached. In total, 23 insurance physicians in three groups participated in this study; the average number of participants in each group was eight (range 5-10).

The average duration of all focus groups and the interview was 2 h with a range of 1.5-2.5 h. The short questionnaire that aimed to collect demographic data were handed in by all participants except for one insurance physician. As the participants remained anonymous, we could not collect this insurance physician's information afterwards.

Participants

In total, 40 persons participated, i.e., 17 cancer survivors and 23 insurance physicians. The median age of cancer survivors was 51 years (range 31-58) and sixteen were female. The median age of insurance physicians was 52 years (range 28-63) and eight were female. An overview of participant demographics is provided in Table 3. Results are described per theme. For each theme, examples of quotes are inserted in the text to illustrate the findings. Further, additional quotes per theme are provided in the Appendix.

Table 3. Characteristics of focus group participants (N=39*)

Cancer survivors (N=17)		Insurance physicians (N=22*)	
Variable		Variable	
Age (years); median (range)	51 (31-58)	Age (years); median (range)	52 (28-63)
Gender; female N	16	Gender; female N	8
Year of cancer diagnosis; N		Years of experience as insurance physician; median (range)	14.5 (0.5-33)
2007	1		
2008	4		
2009	3		
2010	8		
2011	1		
Type of employment (contract) when diagnosed; N		Specialty in insurance medicine; N	
Temporary contract	7	Sickness benefits	8
Fixed contract	3	Combination of specialties	6
Temporary agency worker	3	Disability benefits	3
Other type of employment	3	Other tasks (e.g., judicial, education)	3
Unemployment benefits	1	Young disabled persons benefits	2
Employment status at time interview; N			
Unemployed	6		
Voluntary job	5		
Fixed contract	4		
Temporary contract	2		
Type of work after return to work; N			
Unemployed	6		
Volunteer (shop/church)	2		
Volunteer/entrepreneur	1		
Volunteer elderly care	1		
Volunteer (other)	1		
Secretary	1		
Assistant teacher	1		
Management assistant	1		
Nurse	1		
Nurse assistant	1		
Office employee	1		

* The short questionnaire was not handed in by one insurance physician.

Focus group themes

Job loss experiences

Cancer survivors who were working at the time of the cancer diagnosis said they initially intended to keep working. Most cancer survivors worried about their ability to stay at work, and some cancer survivors re-scheduled working hours and reduced their workload after diagnosis. Cancer survivors reported that the main causes for loss of employment at the time were that their temporary employment contracts were not extended, that they had suffered from side-effects of treatments, which disabled them for work, and/or that they had failed to combine work with treatment plans. Some cancer survivors felt that their former employers did not arrange for necessary adjustments to be made to the workplace or to their workload after they were diagnosed. Most cancer survivors felt forced to stop working by their employer or by the circumstances. Cancer survivors who voluntarily stopped working, often did so following advice from their medical specialist, insurance physician and/or their social environment.

Work was described by many cancer survivors as a reliable factor that still gave them something to hold on to, while dealing with a life-threatening disease. Consequently, job loss was generally described by cancer survivors as an unexpected and radical event. Some cancer survivors had strongly requested their employer to let them stay at work. A few cancer survivors could imagine why it would be undesirable for the company to keep them employed; others perceived the employer as being ungrateful for letting them go after years of faithful service to the company.

After job loss or initially going on sick leave, some cancer survivors still received attention (e.g., phone calls, flowers) from the workplace. A couple of cancer survivors who were on sick leave, were beforehand ensured that they could return to their job after recovery. When their temporary employment contract was not renewed during sick leave, this turned out to be an empty promise. Some cancer survivors were very disappointed about that, while others were more understanding about the decision their former employer had made.

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Cancer survivor (woman, age 46): "In the end, they did not renew my contract, which made me bitter. After all, despite your illness, in the beginning you do all you can to keep your standards up and to succeed despite your problems, but then it turns out not to be."

Guidance by insurance physician

Insurance physicians reported that cancer survivors, when they first visit the insurance physician, often seem to have wrongful expectations of the social security system, e.g., that cancer survivors will receive ongoing benefits because of their diagnosis. In insurance physicians' opinion, medical specialists contribute to this by giving false advice such as: 'Do not worry about work. You will receive sickness benefits anyway'.

Some insurance physicians mentioned that they approach cancer survivors with job loss experience differently than cancer survivors with permanent employment contracts, as they perceive cancer survivors with job loss experience as (1) more vulnerable in psychological and social aspects; (2) as having more problems in coping with the disease and loss of job; and (3) as generally lower educated, compared to cancer survivors with permanent employment contracts.

Because of these differences, insurance physicians expressed a need for additional consultation time in order to provide proper guidance to cancer survivors with job loss experience. Consultations should last longer and should be planned more frequently to establish a good relationship. Nevertheless, insurance physicians did not think it to be sensible to ask the cancer survivors in detail about experienced barriers and facilitators for return to work during consultations.

That is, many insurance physicians felt that, within the boundaries of the social security system, they did not have the means to offer proper support to these cancer survivors, such as scheduling consultations more frequently or the possibility to refer cancer survivors with job loss experience to a suitable return to work intervention program.

The majority of cancer survivors experienced their insurance physician to be indifferent if the insurance physician did not ask about their history of cancer. Consequently, during consultations, some cancer survivors felt the need to explain their situation and defend themselves for not being able to work. Most cancer survivors were confused, uncertain or disappointed about the low frequency of guidance and level of support by the insurance physician. However, some cancer survivors experienced a low frequency of contact as very pleasant, as this gave them time to rest and focus on their recovery. A couple of cancer survivors were unwilling to go to appointments with the insurance physician, while others thought of it as comparable to the obligations that employees have to consult occupational physicians. Cancer survivors who visited the same insurance physician every time, seemed more satisfied compared to those who had to visit different insurance physicians. They experienced the insurance physician to be supportive, committed and flexible in discussing their return to work planning.

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Cancer survivor (woman, age 53): "At a certain point, you hear nothing more from the social security agency. That's great, and it is convenient to be left alone but, on the other hand, it also made me restless."

Insurance physician (man, age 54): "I think that insurance physicians allocate the same amount of time to cancer patients as they do to, say, those with a simpler physical problem, such as a broken leg."

Motivation for return to work and meaning of work

Most cancer survivors said they did not actively start planning return to work until their treatment had been completed. They did report to be motivated to keep the option of return to work in the back of their minds, throughout the process of diagnosis and treatment. The main motivators for returning to work according to these cancer survivors were (in random order): (1) dealing with their illness and emotions (e.g., not feeling like a patient); (2) getting out of the house and undertaking things (again); (3) getting back into a daily rhythm; (4) feeling healthier, appreciated and useful; (5) financial reasons; and (6) participating in society. According to insurance physicians, in their experience the main motivators for cancer survivors to return to work were: (1) proving work ability; (2) participating in society; (3) distraction from cancer; and (4) staying in touch with (former) colleagues.

A few cancer survivors felt there was too much emotional distance between them and the workplace after cancer. For example, they had no contact with former colleagues or employers anymore, or they felt hurt because they had to leave work due to the cancer diagnosis or treatment. As a result of the emotional distance between them and the workplace, some cancer survivors said they completely gave up thinking about work or return to work.

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Cancer survivor (woman, age 51): "Working again is such a distraction and delight, because you are, once again, no longer a patient but a person."

Cancer survivor (woman, age 43): "I really longed to get back into society, staying at home made me sick, literally."

Psychosocial and cancer-related barriers and facilitators for return to work

After treatment, most cancer survivors struggled to actively put their minds to return to work. These cancer survivors said that, at the time, they struggled to cope with having faced a life-threatening disease, and also a lack of confidence in their chances of successfully returning to work, due to their job loss experiences.

Insurance physicians reported that they often perceive that there is a psychosocial barrier for return to work in these cancer survivors, as cancer (temporarily) seems to cause a shift in life priorities, i.e., family and private life become more important and work becomes less important. In addition, some cancer survivors mentioned that, after treatment, they needed help to shift from negative to positive cognitions, i.e., stop thinking of what they had lost and start thinking of what they can still do. Most cancer survivors experienced finding closure after cancer to be a long and difficult process, which could pose as a barrier for return to work. Cancer survivors who were receiving support and guidance from their environment, e.g., spouse or from professionals, such as their insurance physician or general physician, on how to recover and to cope, seemed more confident about (trying to) return to work.

With regard to their cancer history, several cancer survivors mentioned that their attempts to return to work were hindered by health problems as a result from treatment and diagnosis. In addition, most cancer survivors felt uncertain about their work ability after cancer, which made it hard for them to decide when and how to attempt to return to work. Some cancer survivors said they did not have enough energy to take up both housekeeping and trying to return to work simultaneously. Their return to work was sometimes facilitated by relatives taking over the cancer survivor's tasks at home, so that the cancer survivor would have enough energy to go to work.

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Insurance physician (woman, age 53): "If the weather is nice, they might think: ' Well, I have only three months left, I'd rather go to the beach than (go to work and) pack biscuits all day'."

Cancer survivor (woman, age 51): "That's what makes applying for jobs so hard; you don't know what your capabilities are. You have to be sure [and think] 'this is a job that I can do'; but how do you know?"

Work-related barriers and facilitators for return to work

Regarding return to work, most cancer survivors expressed a need to start slowly and gradually increase the number of working hours, e.g., in a subsidised job. This way, they could try working again and avoid burdening an employer with potential sickness absence. However, insurance physicians report that subsidized jobs nowadays are rare, as funding for them has been cut back over the years, which creates a barrier for cancer survivors to return to work.

Cancer survivors and insurance physicians reported that return to work is further hindered by employers' doubts about whether cancer survivors are able to meet job demands. Also, to them, employers seem to be prejudiced about the risk of recurrent cancer, i.e., employers overestimate the risk of recurrent cancer and are therefore reluctant to hire cancer survivors. Furthermore, cancer survivors must compete with a large group of 'healthy' persons for a job. During job interviews, most cancer survivors felt the need to be honest about their cancer history, but this often led to rejection by employers.

In general, several insurance physicians made a comparison between employed cancer survivors and cancer survivors with job loss experience, and concluded that there is a difference in their return to work situation. Insurance physicians reported that, due to doubts about work ability, reluctance from employers to hire cancer survivors, as well as a large emotional and sometimes also practical distance to the labour market, cancer survivors with job loss experience are at a disadvantage. To these insurance physicians, the most important return to work barriers for these cancer survivors, e.g. struggling to cope with cancer and job loss simultaneously, seemed related to, or the result of, the job loss experience. Furthermore, due to job loss, cancer survivors lack the support from an employer and colleagues. Instead, they enter the social security system, which was recognized by some of the insurance physicians as a factor that complicated the return to work process. These insurance physicians thought that social security systems in general have a certain 'tone of assessment' to them, which contributes to a more distant and impersonal approach to return to work guidance, compared to guidance in a workplace environment. Finally, insurance physicians mentioned that their own reluctance to discuss return to work with these cancer survivors may also create barriers for return to work. Some insurance physicians felt that it was not always morally justified to bring up return to work in conversations with cancer survivors, because of empathy and uncertainty of prognosis.

A couple of cancer survivors mentioned that, although they were motivated to return to work, their insurance physician advised them not to return to work (yet). Most insurance physicians agreed that this risk-averse attitude from insurance physicians can demotivate cancer survivors in their attempt to return to work. According to insurance physicians, high levels of motivation to return to work and satisfaction with a former job are the main facilitators for return to work. Also, a personal network of a cancer survivor can be a facilitating factor, as former employers may have a sense of good will towards the cancer survivors.

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Cancer survivor (woman, age 48): "I have a lot of acquaintances whom are entrepreneurs and they say: 'Well, if I could choose between you or a healthy person, I'd rather hire the healthy person'."

Insurance physician (woman, age 49): "A main issue with these cancer survivors is that they get laid off because they have cancer. And that bluntness from an employer hits them hard."

Insurance physician (man, age 61): "When an employee gets ill, there is a work environment that reacts to that by home visits, sending flowers and personal re-integration. While if you are unemployed, you have to conform to the rules of the social security agency, which has a tone of assessment to it."

Insurance physician (man, age 52): "Despite the good treatment outlooks, and the fact that these better prognoses are well known, I feel that society morally accepts that if one has cancer then this is a major problem and that one should not have to worry about work and other problems."

Experiences with return to work

Most cancer survivors started in voluntary jobs, which allowed them to expand their mental and physical capacities. A few cancer survivors found paid employment, sometimes with a possibility to gradually increase working hours.

Most cancer survivors enjoyed return to work, although they often felt fatigued and some were suffering from cognitive limitations. Also, the time pressure and interactions with colleagues were experienced by some as exhausting. The employers sometimes anticipated on these problems by adjusting job demands, e.g., allowing cancer survivors to work flexible hours. Some cancer survivors had thought of starting their own business, so that they could determine their own workload.

Financially, getting cancer was a setback for almost all cancer survivors. They were not able to do the same job or perform at the same level as before, which decreased their earnings. Some cancer survivors thought they could probably do a job on a higher level, but they felt they would have to sacrifice too much of their personal time and energy, in order to achieve that. Most cancer survivors were happy with the job they ended up with, although some of them felt that they would never have a completely satisfactory working life again. Cancer had taken that away from them.

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Cancer survivor (woman, age 43): "The moment I started working, I felt so much better. It was as if everything had changed."

Cancer survivor (woman, age 48): "I do not dislike my job. But sometimes when I have been filing the whole day, or doing other administrative work, I do think to myself: 'Why did this all happen to me?'"

Data saturation assessment

In order to evaluate the level of data saturation, we studied the distribution of the quotes per theme in the conducted focus groups. The results of this analysis are presented as cumulative percentages per theme in Table 4.

Table 4 shows that, for the majority of the themes, a high level of saturation was reached after the fifth focus group, e.g., 93% for the theme 'Guidance by insurance physician' and 80-90% of the combined themes 'Psychosocial, cancer-related and work-related barriers and facilitators for return to work'. Consequently, the contribution of the final focus groups and interview to the overall results was less extensive compared to the contributions by the focus groups, indicating a high level of data saturation for most themes. In addition, the conclusion from the informal assessment with the researchers and moderators after the final focus group was that relatively few new results had come forward in that session. Therefore, we concluded that data saturation in this study has reached a satisfactory level.

Table 4. Data saturation assessment

	Job loss experiences	Guidance by insurance physician	Motivation for return to work and meaning of work	Psychosocial and cancer-related barriers and facilitators for return to work	Work-related barriers and facilitators for return to work	Experiences with return to work
1st focus group (insurance physicians)	NA	15%	3%	15%	5%	NA
2nd focus group (insurance physicians)	NA	38%	6%	31%	13%	NA
3rd focus group (insurance physicians)	NA	49%	6%	48%	23%	NA
4th focus group (cancer survivors)	30%	66%	36%	74%	55%	36%
5th focus group (cancer survivors)	87%	93%	69%	90%	80%	69%
6th interview (cancer survivors)	100%	100%	100%	100%	100%	100%
Total N	31	66	30	62	40	42

Discussion

General findings

This study explores barriers and facilitators for return to work in cancer survivors with a job loss experience, both from the perspective of cancer survivors and from the perspective of insurance physicians, who provide guidance to cancer survivors with job loss experience in the absence of an employer. Our main findings are that the return to work process of cancer survivors who experienced job loss is complicated and that their return to work is influenced by several psychosocial, cancer-related and work-related barriers and facilitators, e.g., doubts about work ability and perceived reluctance from employers to hire cancer survivors.

Interpretation of findings

In this study, intention to return to work, flexibility of a (future) work environment, the amount and quality of guidance by professionals, and the presence of mental and physical health problems after cancer were mentioned as important determinants for the return to work process of unemployed cancer survivors. Previous studies have also found these factors to be of influence on the return to work process of cancer survivors, although not specifically taking loss of employment into account [5,26]. This may indicate that these factors are, to a certain extent, comparable between cancer survivors, regardless of their employment status. Also, the meaning of work for cancer survivors in this study, i.e., (return to) work is related to cancer survivors' identity, recovery process and financial situation, is largely comparable to findings in the literature on cancer survivors in general [27,28].

Further, when cancer survivors in this study did return to work, they reported to experience fatigue, cognitive limitations, decrease in wages and difficulty coping with the work environment. These findings are comparable to return to work experiences in other studies with cancer survivors, who experience decreased productivity and work ability due to cognitive limitations, coping issues and fatigue as well [4,29,30]. Finally, in order to stay at work, cancer survivors in this study, but also in other studies, make or undergo changes in their tasks, wages and/or working hours [5].

Interestingly, in this study we observed that insurance physicians distinguished cancer survivors with job loss experience from cancer survivors with permanent employment contracts. Specifically, insurance physicians reported that cancer survivors with job loss experience are in a different situation regarding return to work. Cancer survivors in this study felt that their return to work situation might have been different if they still had been employed after their diagnosis. Losing their job due to cancer was a shocking life-event for most participants, which happened around the same time of the cancer diagnosis. As a cancer diagnosis is already a life-changing event in itself [31,32], cancer survivors may go through various stages of loss and grief, e.g., stages of denial, anger and acceptance [33], to deal with the diagnosis and loss of health [34,35]. In cancer survivors with job loss experience, the process of loss and grief after a cancer diagnosis may be further complicated as a result of the additional emotional impact of job loss. Essentially, cancer survivors in this study were dealing with a situation of double loss: loss of job on top of loss of health, both due to cancer, which created emotional and practical barriers for their return to work. Consequently, cancer survivors with job loss experience may need a tailored approach regarding support for return to work.

Strengths and limitations

The main strength of this study is that it combines the perspectives from cancer survivors with job loss experience and insurance physicians on barriers and facilitators for return to work. Exploring both perspectives provides new insights into the complexity of the important theme 'work' for those who have lost their job at approximately the same time, or shortly after, they received a cancer diagnosis. Other strengths of this study are the relatively high level of data saturation for the most important themes, e.g., 'job loss experience' and the combined themes 'psychosocial, cancer-related and work-related barriers and facilitators for return to work', and certain aspects of the methodological design, e.g., the use of experienced moderators, independent analysis by two researchers and systematic analysis of the level of data saturation.

An important limitation of this study is that we were unable to conduct purposeful sampling for participants, given the fact that this target group is relatively hard to reach and possibly underregistered at the social security agency. Other studies have previously argued that in underregistered groups, the use of a probabilistic or purposeful sampling procedure may be virtually impossible [25]. As a result of the sampling procedure, we failed to include a fair distribution of men and women in this study. Another important limitation with regard to our sample, is that we did not obtain any information on cancer diagnosis, or type and duration of treatment. Consequently, some uncertainty with regard to the interpretation of our findings and the generalizability of our results to other cancer survivors remains. Further, a few cancer survivors seemed to imply that they had left work in mutual agreement with the employer, possibly because of treatment plans or severity of the diagnosis. For these cancer survivors, the experience of loss of employment may be different than the experience of those whose employment contract was expired and not renewed. With regard to the level of data saturation, it should be noticed that the final focus groups and interview did provide a reasonable amount of new results for the themes 'experiences with return to work' and 'motivation for return to work and meaning of work'. This may indicate that a satisfactory level of data saturation was not fully reached for these themes. Furthermore, due to recruitment via open invitation, it is possible that our sample is based on cancer survivors with relatively intense positive or negative job loss and/or return to work experiences. That is, they may have an increased need to share their experiences compared to persons who do not have such intense experiences. Consequently, their perception, either negative or positive, of the impact of barriers and facilitators for return to work may be biased compared to the total population of cancer survivors with job loss. Another limitation is that we included only insurance physicians to obtain professionals' perspectives on the topic of job loss and return to work for cancer survivors. The study may have benefited from including perspectives from, e.g., labour experts. Finally, our results give insight into experiences of job loss and return to work for cancer survivors in a Northern-European social security system. Therefore, translation to countries with different social security systems should be done cautiously.

Implications for practice and research

The results of this study allow us to conclude, with caution, that a situation of double loss, i.e., job loss on top of loss of health, creates significant barriers for cancer survivors to participate in the labour market. As a result, cancer survivors with job loss experience may be in need of a tailored approach regarding support for return to work. Future studies should aim to find ways for tailor-made re-integration and return to work support for cancer survivors with job loss experience, for example by developing and testing tailored return to work intervention programs that can be implemented in the daily practice of occupational professionals.

Furthermore, our findings provide insight into the return to work considerations and perceptions that cancer survivors may have. This information is particularly useful for professionals who provide return to work guidance and vocational support, such as insurance physicians or occupational physicians. Insurance physicians have a particular role in the Dutch social security system that is not generally found in other social security systems. However, their interests are similar to those of other occupational professionals, i.e., supporting return to work and reducing the chance of avoidable work loss. Therefore, our results may be used to create awareness among occupational professionals, regarding cancer survivors' considerations for return to work. These professionals can be either insurance physicians in the Netherlands, or similar professionals, e.g., occupational physicians in the Netherlands and abroad. If occupational professionals are more aware of these return to work considerations in cancer survivors, it may improve the overall quality of their consultation.

In future practice, return to work intervention programs should ideally be part of integrated cancer care [36]. Furthermore, return to work intervention programs should be carried out by a multidisciplinary team of practitioners, as a multidisciplinary approach is more effective in supporting return to work compared to monodisciplinary programs [37]. This is complementary to our findings, which indicate that a tailored return to work program should contain elements of coaching and empowerment in re-entering the labour market, elements of support in re-discovering work ability in a new job, and in getting accustomed to a new work environment and colleagues. Ideally, a gradual build-up of workload and opportunities to start in subsidised jobs, would be part of such a program, in order to reduce the risk of overburdening and absenteeism at the new work place. Currently, it is not part of usual practice to tailor a return to work program to the specific characteristics, such as age, background or having experienced job loss, of cancer survivors. This study may enhance awareness in practitioners regarding the content and elements of their return to work guidance.

Awareness may also be enhanced in financial parties, such as employers and social security agencies, who are generally responsible for supporting cancer survivors' participation in return to work programs. Our findings provide a convincing argument that there is a need for a tailored approach in return to work among cancer survivors. Practitioners and financial parties may realise that investing in such programs, with time and financial resources, may be profitable in terms of better perceived health and earlier return to work.

Additionally, investing in tailored return to work intervention programs may not only benefit cancer survivors with job loss experience, it may also relieve some of the pressure that is currently being put on the social security systems in Western developed countries, as these systems have to provide for an increasing number of sickness and work disability benefits for persons with job loss experience [7,38]. Finally, we recommend that, based on this exploratory study, future research should study potential differences in return to work processes between employed cancer survivors and cancer survivors with job loss experience, using a quantitative approach.

Conclusion

The experience of double loss (loss of job and loss of health), as well as the presence of psychosocial, cancer-related and work-related barriers for return to work can complicate the return to work process of cancer survivors, and calls for a tailored approach regarding support for return to work. Furthermore, the results of this study implicate that there are unique return to work challenges for cancer survivor with job loss experience, which contribute to a different return to work process compared to cancer survivors with permanent employment contracts. Consequently, we should investigate whether these differences are quantifiable and identify possibilities for a new approach in supporting return to work for cancer survivors, that is, an approach in which return to work support for cancer survivors is tailored to their employment status.

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Appendix

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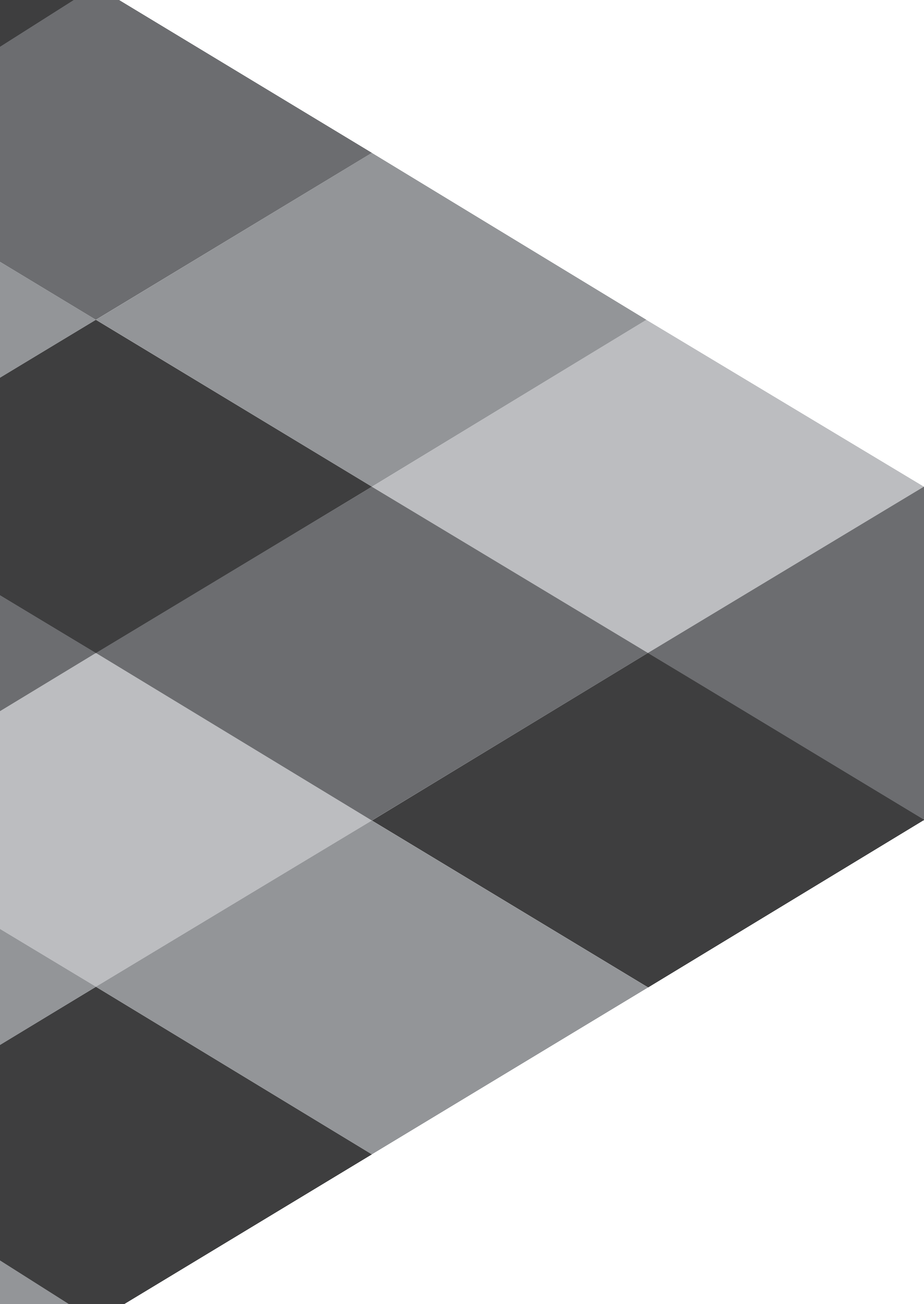
Summary of main focus group themes and illustrative quotes.

Focus group themes and subthemes	Quotes from participants
Job loss experiences	
Intention to keep working after diagnosis	Cancer survivor (woman, age 46): "I even sent an e-mail to my employer, I still have the letter, begging them to let me keep my job." Cancer survivor (woman, age 51): "My intention was to keep working. Work was my main distraction. People around me, especially my children and my husband, thought: 'get real', but I really did not want to stay at home."
Emotions and thoughts regarding job loss	Cancer survivor (woman, age 46): "When they didn't prolong my contract, I became very disheartened and depressed. I just could not face starting to search for another job. What if they ask me again whether or not I have been ill?" Cancer survivor (woman, age 58): "I thought to myself: 'That contract of mine is not going to be renewed. Actually, the company is not doing so well either, so, if I was in their shoes, I would not prolong it either."
Guidance by insurance physician	
Perceived characteristics of cancer survivors	Insurance physician (woman, age 49): "A major issue with cancer survivors is that they get laid off because they have cancer. And that bluntness from an employer hits them hard." Insurance physician (man, age 61): "When an employee becomes seriously ill, while working under a normal contract, the work environment might react by home visits, sending flowers and, possibly later, with a personnel re-integration program. However, if you are unemployed, you will have to conform to the rules of the social security agency, which has the air of assessment to it." Insurance physician (man, age 61): "We see that cancer survivors generally have a lower level of education than the average population."
Experience of guidance	Insurance physician (woman, age 30): "In a number of examples, it was very noticeable that the survivors had been written off [by insurance physicians]." Cancer survivor (woman, age 31): "They [insurance physicians] always ask the wrong questions. You are telling your story and they interrupt you asking: 'Can you do this, can you do that', and then I think to myself: 'They haven't listened to a thing I said'." Cancer survivor (woman, age 51): "In the two years that I was receiving sickness benefits, I was sent to seven different insurance physicians. And they all had their own different story – so there I am, describing my history over and over again." Cancer survivor (woman, age 53): "When I started working again, they said they would let my sickness benefit run on for another month, so that I could always fall back on it if I thought it was all too much." Cancer survivor (woman, age 51): "I must say I have never had any complaints about the social security agency. The help I received from everyone there was excellent."

Suggestions for improvement of guidance	Insurance physician (woman, age 49): "Time, I need time [...] There is no time for proper guidance." Insurance physician (man, age 58): "There is a lack of perspective. Even proper guidance, without a proper perspective, will get you no-where. If the insurance physicians have nothing to offer, they are simply not going to ask (the patient) certain questions." Insurance physician (man, age 63): "Psychosocial factors play a major role here and so I would plead that the consulting hours be increased to allow for proper and deeper questioning." Insurance physician (woman, age 52): "People/patients like them need to be seen a number of times so that a relationship can be established which goes past simple inventarisation and allows everyone to see where they are."
Motivation for return to work and meaning of work	
Motivation for work and meaning of work	Cancer survivor (woman, age 51): "For just a moment, you are not a patient. And that mattered a great deal to me." Cancer survivor (woman, age 53): "I wanted to experience that I could do things again, that you can heal over time and gradually take on more tasks." Cancer survivor (woman, age 51): "[it gave me] Energy. It's just nice to have people, colleagues, around you."
Psychosocial and cancer-related barriers and facilitators for return to work	
Changed cognitions and life preferences	Insurance physician (woman, age 49): "They think: 'I've just started feeling better and already I have to start thinking about work.'" Insurance physician (woman, age 49): "As soon as the diagnosis 'cancer' arrives, they just drop everything and think: 'Now I will start doing the things I like.'" Insurance physician (woman, age 49): "You need to break through a barrier. The barrier is that you feel it is time to return to work, but the cancer survivor is not yet ready."
Health problems and illness	Cancer survivor (woman, age 54): "I really want to [work], but my body just does not allow me." Cancer survivor (woman, age 53): "I refuse to give up, but actually, I just can't [work]."
Role of the social environment	Cancer survivor (woman, age 53): "In the beginning, those around are sympathetic saying…'take it easy'. But, when they see that you are able to do things (again), but are still not able to return to work, they appear not to understand and then to disapprove." Cancer survivor (woman, age 48): "They did support me, because I really wanted to [work]. It's not as if they said: 'Shouldn't you go back to work?'"
Doubts about work ability and starting return to work	Cancer survivor (woman, age 52): "I think the most important thing when applying for a new job is that you are able to pick up your life. The illness had a place in your life, but you are now over it and must not be obsessed that it will follow you whenever you apply for a job." Cancer survivor (woman, age 48): "I missed that you cannot start by just coming in for a therapeutic cup of coffee." Cancer survivor (woman, age 53): "It is hardly a good start, when applying for a job, to have to start the process with 'Actually, I need to build up my hours really slowly.'"

Work-related barriers and facilitators for return to work	
Labour market characteristics	Insurance physician (Man, age 58): “In the current labour market, who would hire these people?” Insurance physician (woman, age 53): “We are presently in a terrible labour market and that naturally counts for a great deal.”
Employers’ prejudice	Cancer survivor (woman, age 48): “Even voluntary work or whatever else I apply for, there is just no one that will have me.” Insurance physician (man, age 58): “They often get rejected. They also have to defend themselves a lot.”
Advice from insurance physicians	Insurance physician (man, age 61): “It is also a disease with a high level of sympathy. Does an insurance physician dare to say, just as loud as politicians do: ‘If your condition does not worsen within a year, you have to go to work’?” Insurance physician (woman, age 53): “It also depends on your own point of view. If you see how miserable the patient is, and you see that there is also a poor prognosis, how far should I go in trying to motivate that person to go back to work? I am probably thinking to myself ‘enjoy spending time with your grandchildren for as long as you can.’”
Experiences with return to work	
Mental and physical challenges	Cancer survivor (woman, age 48): “I am doing fine now [with the lymphedema], but that is because I do things the way I do. If I would increase my physical workload, then I would probably suffer a lot more.” Cancer survivor (woman, age 51): “I used to be a real Salvation Army type diehard. But, now I find it difficult to cope with the slightest of problems. I feel very vulnerable.” Cancer survivor (woman, age 46): “It’s still hard to find a balance. Sometimes you cross your own boundaries - for instance by doing too much in one afternoon - which you then you pay for on other days.”
Dealing with work environment and changes in type of job and wages	Cancer survivor (woman, age 48): “I am definitely doing work that is below my abilities. That is a major disadvantage of becoming ill. [..] But, at a certain point, you accept that, in times like these, you should be pleased to have a job no matter what. But, I am capable of much more.” Cancer survivor (woman, age 53): “I do not go there [to my occupational physician]. I am hired on a temporary contract and I do not want to jeopardize that.”



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Return to work in sick-listed cancer survivors with job loss:

Design of a randomised controlled trial

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Return to work in sick-listed cancer survivors with job loss: Design of a randomised controlled trial

Abstract

Background: Despite long-term or permanent health problems, cancer survivors are often motivated to return to work. For cancer survivors who have lost their job, return to work can be more challenging compared to employed survivors, as they generally find themselves in a more vulnerable social and financial position. Cancer survivors with job loss may therefore be in need of tailored return to work support. However, there is a lack of return to work intervention programs specifically targeting these cancer survivors. The number of cancer survivors with job loss in developed countries is rising due to, amongst others, increases in the incidence and survivor rate of cancer, the retirement age and the proportion of flexible employment contracts. Hence, we consider it important to develop a tailored return to work intervention program for cancer survivors with job loss, and to evaluate its effectiveness compared to usual care.

Methods/Design: This study employs a two-armed randomised controlled trial with a follow-up period of 12 months. The study population (n=164) will be recruited from a national sample of cancer survivors (18-60 years), who have been sick-listed for 12-36 months. Participants will be randomised by using computerized blocked randomisation (blocks of four). All participants will receive usual care as provided by the Dutch Social Security Agency. Additionally, participants in the intervention group will receive a tailored return to work intervention program, which includes vocational rehabilitation and supportive psychosocial components, as well as (therapeutic) placement at work. The primary outcome measure is duration until sustainable return to work; the secondary outcome measure is rate of return to work. Other parameters include, amongst others, fatigue, coping strategy and quality of life. We will perform Cox regression analyses to estimate hazard ratios for time to sustainable return to work.

Discussion: The hypothesis of this study is that a tailored approach for cancer survivors with job loss is more effective, regarding return to work, compared to usual care. The results of this study will provide insight into the ways in which return to work can be facilitated for cancer survivors with job loss.

Background

Cancer is increasingly perceived as a chronic disease with long-term or permanent health problems [1-3]. Multiple studies report cancer survivors (CSs) to experience, for example, fatigue, depression or functional impairments long after treatment has been completed [4-6]. As a result, CSs' quality of life, daily functioning and labour participation may be affected [7,8]. With regard to labour market participation, studies have shown that CSs are often motivated to return to work (RTW) and that they attribute positive effects to work. That is, CSs have reported that work enables them to regain a sense of normalty and control [9]. Also, RTW reduces avoidable work disability, thereby decreasing the risk of financial loss for both CSs and society [10].

A recent review found that circa 62% of CSs return to work within 12 months of sick leave. Although the majority of CSs eventually returns to work, still a considerable group of CSs does not resume work. Multiple reasons have been reported for CSs not returning to work, most of which can be categorized as cancer-related, psychosocial-related or work-related [11]. Specifically, work-related factors, such as absence of an employment contract, may create barriers for RTW of CSs. For persons with an insecure employment status, in general, the literature clearly shows that they experience a larger (emotional and practical) distance to the labour market, are lower educated and have an increased risk for prolonged sick leave compared to employees [12,13]. Also, in their RTW, CSs with job loss may face unique barriers, such as having to go through job application processes and compete with "healthy" workers for a job. As a result, after cancer, the RTW process for persons with job loss may be different from the RTW process in employed persons.

In the absence of an employer, CSs who have lost their job in the Netherlands may receive sickness or disability benefits from the Dutch Social Security Agency (SSA). If so, they will be supported by a SSA team, which consists of an insurance physician, a reintegration expert and a labour expert. The number of CSs that receive benefits, either temporary or permanent, has increased over the years. For instance, in 2013, 10.2% more CSs were receiving temporary disability benefits and 17.7% more CSs were receiving permanent disability benefits, compared to 2012 [14]. It is expected that the number of CSs with job loss in the occupational age will keep rising, not only in the Netherlands, but also in other Western economy countries, as a result of the increases in the incidence and survival rate of cancer [15], the retirement age [16], and the proportion of flexible employment contracts [17]. The Dutch SSA has specifically expressed a need for a tailored RTW intervention program for this target group. Current RTW programs are usually aimed at adjusting the current workplace of the CS and negotiating with the CS's own employer. For CSs with job loss, these programs are not suitable, as they have no workplace or employer (anymore). In addition, it is important to consider that, for CSs with job loss, RTW includes job application processes and starting in a new job that comes with an unfamiliar working environment. Consequently, CSs with job loss are in need of tailored support that targets these specific barriers to RTW.

Therefore, the aim of this study is to develop a tailored RTW intervention program for CSs with job loss, and to study its effectiveness on duration until sustainable RTW in a randomised controlled trial with a follow-up period of 12 months, compared to usual care, as currently provided by the SSA.

Methods/Design

Design/setting

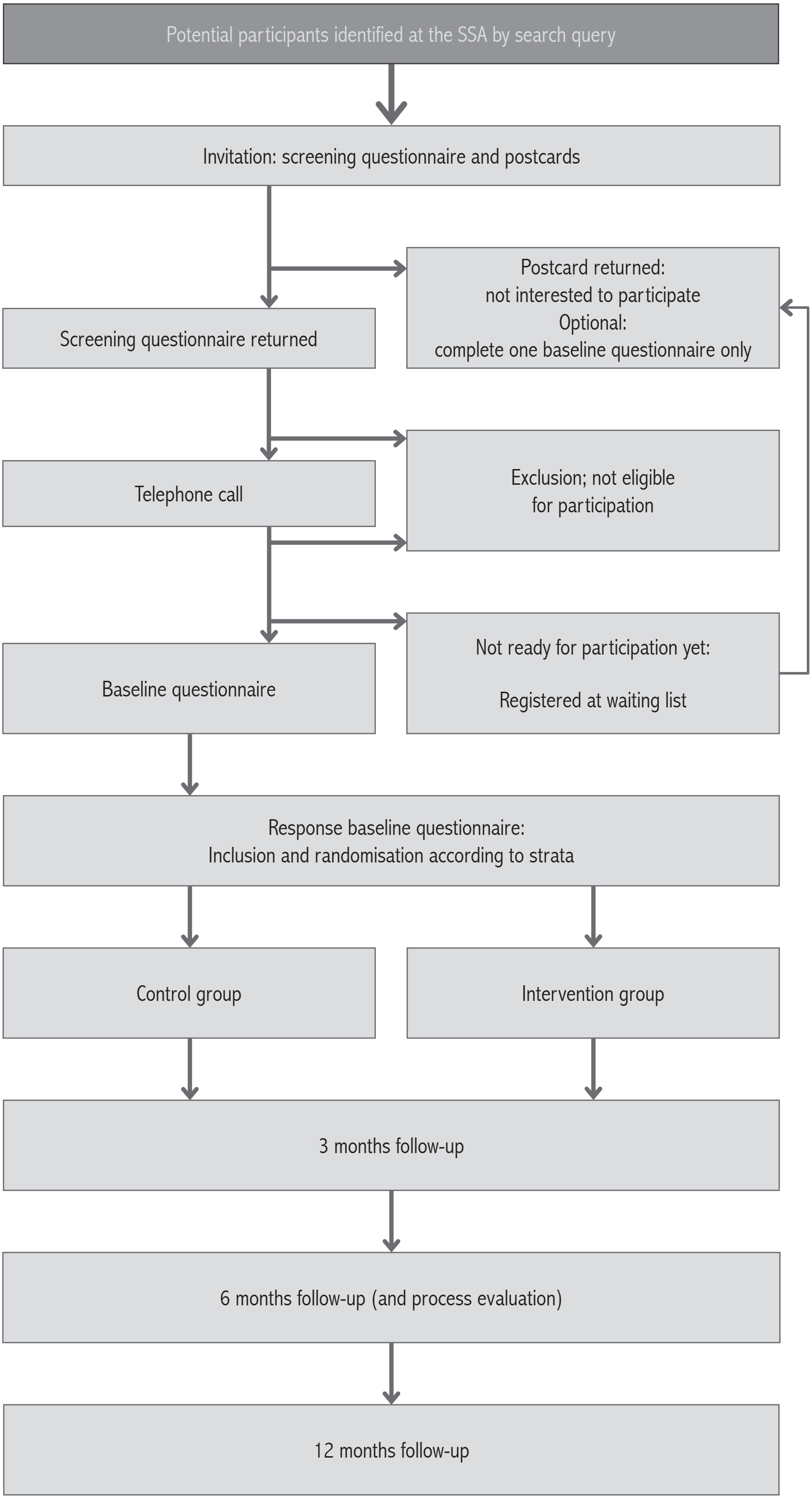
This study employs a two-armed non-blinded randomised controlled trial (RCT) with a follow-up period of 12 months. Data will be gathered using questionnaires at baseline, 3, 6 and 12 months post-study entry. Prior to the start of this study, a focus group study with CSs with job loss and/or unemployment experience was conducted, in order to explore barriers and facilitators they experienced with regard to RTW. We used the results from this focus group study to develop the intervention program that is being evaluated in this study. Design and results of the focus group study will be published separately. The CONSORT statement was used to report the design of this study [18]. The study was approved by the Medical Ethical Committee of the VU University Medical Center (VUmc) and the Scientific Committee of the EMGO+ Institute / VUmc.

Study population

The study population consists of CSs with job loss, aged 18 to 60 years, who are registered at the SSA and who have been sick-listed and receiving sickness or disability benefits in the last 12-36 months. Within the group of CSs with job loss, registered at the SSA, three subtypes of workers can be distinguished: (1) workers whose temporary employment contract ended before or during sick leave; (2) temporary agency workers, and (3) unemployed workers, i.e., these workers had lost their job prior to their cancer diagnosis, and consequently, they received unemployment benefits. After being diagnosed with cancer, their benefits changed from unemployment benefits to sickness or disability benefits.

CSs who have lost their job will be included in this study if they have completed intensive cancer treatment (at least) six weeks prior to the start of this study (based on self-report by the CS), if their health status allows them to participate in the study (based on self-report by the CS) and if they have no comorbidities (e.g., severe psychological or physical conditions, apart from a potential cancer diagnosis) that would interfere with participating in this study (based on report from the CSs' general practitioner (GP)). In case a CS is invited to participate, but is still receiving, or scheduled to receive, intensive (cancer) treatment (e.g., chemotherapy, radiotherapy, surgery or another type of intensive curative treatment), he/she will be wait-listed for inclusion until (at least) six weeks after completing such treatment(s). Furthermore, CSs will be excluded in case of pregnancy, lack of knowledge of the Dutch language and/or an ongoing conflict with the SSA regarding a sickness or disability benefit claim. Additionally, CSs will be excluded if they are participating, or signed up to be a participant, in a concurrent scientific study and/or re-integration or rehabilitation program aimed at RTW.

Figure 1: Participant recruitment flow diagram



Recruitment of participants

The process of recruitment is described below and illustrated in the participant recruitment flow diagram (Figure 1). Potentially eligible participants will be recruited using the national database of the SSA, in which persons applying for sickness or disability benefits are registered. The database contains data regarding demographics, employment status, type of sickness or disability benefit and medical cause, due to which the benefits are granted. A search query will be developed to identify CSs with granted benefits due to a cancer diagnosis. An in-house SSA researcher will use the query to identify potential participants, because of privacy concerns. This SSA researcher will only be involved in this particular part of the recruitment process and in no other parts of the study. Retrospectively, the search query will be used only once to identify CSs who have been sick-listed from 12 to 36 months. Prospectively, with a frequency of twice per month, the search query will be used to identify CSs who have been sick-listed for 12 months. Prospective recruitment will continue for an estimated duration of one and a half years, until the sample size will be reached.

Potential participants will receive an information package from the SSA, which will contain an invitational letter from the chief medical officer from the SSA, a brochure with more detailed information on the study, an informed consent form in which respondents can give their consent to be contacted for information regarding the study, and a short questionnaire. The information package will also include a postcard, by which persons can respond to the researcher whether they are interested in the study or they can provide a reason for declining participation, in case they wish not to participate. Also, on the postcard they can select the option of receiving only the baseline questionnaire, which aims to collect data for comparison between responders and non-responders. Finally, if a person is willing to participate, but only after a few weeks or months, they can select 'contact me later' on the postcard. Potential participants who do not return either the short questionnaire, including informed consent form, or the postcard, will receive a reminder letter after two weeks.

The short questionnaire in the information package aims to indicate whether or not the respondent is eligible for participation. Only when a respondent is clearly not eligible for participation in the study, based on this short questionnaire, the researchers will send an informational letter to thank them for their interest in the study. All other respondents will be contacted by telephone to provide additional information about the study procedures and to check if they meet the criteria for participation in the study. After the telephone call, respondents who meet the criteria will receive the baseline questionnaire and a second informed consent form, in which respondents give their consent to participate in the study. Respondents will be offered a choice between receiving the baseline and follow-up questionnaires on paper or via e-mail. If they do not return the baseline questionnaire and/or the informed consent form, then a reminder letter or e-mail will be send after two weeks. When the respondent returns the baseline questionnaire and the informed consent form, he/she will be included in the study and randomly allocated to either the intervention group or the control group. The participant's GP and the team at the SSA will be notified of the inclusion of the participant in this study and they will receive information about the study. The participant's file at the SSA will be labelled as 'research participant' to facilitate easy recognition by the SSA experts. The GP will be asked to report if the participant has any comorbidities that would interfere with participation (in the intervention program) in this study. In case the participant's GP feels that a participant's medical case may be unsuitable for participation in the study, the GP can contact the researchers to deliberate. If necessary, the researchers will organize a joint meeting with the GP and the research team to discuss the CS's case and achieve consensus about participation.

All participants will be guided by their SSA team according to usual care. Additionally, participants in the intervention group will receive the tailored RTW intervention program. All participants will be asked to complete all questionnaires prior to randomisation (T0), at 3 months (T1), at 6 months (T2) and at 12 months (T3) post-study entry. If a person does not return a follow-up questionnaire, then a reminder letter or e-mail will be sent after two weeks.

Tailored RTW intervention program

The intervention program was developed as a tailored RTW program in which participants, together with a RTW coach, will decide which needs should be addressed for the participant to RTW. The program was developed by the researchers in cooperation with the Dutch SSA and a national re-integration agency. In the developmental process of the program, we took results from previous studies on RTW for CSs into account [19-21]. For example, this tailored RTW intervention program contains a multidisciplinary approach towards RTW, as the literature showed that multidisciplinary RTW interventions for CSs may be more effective compared to monodisciplinary interventions or usual care [20,21].

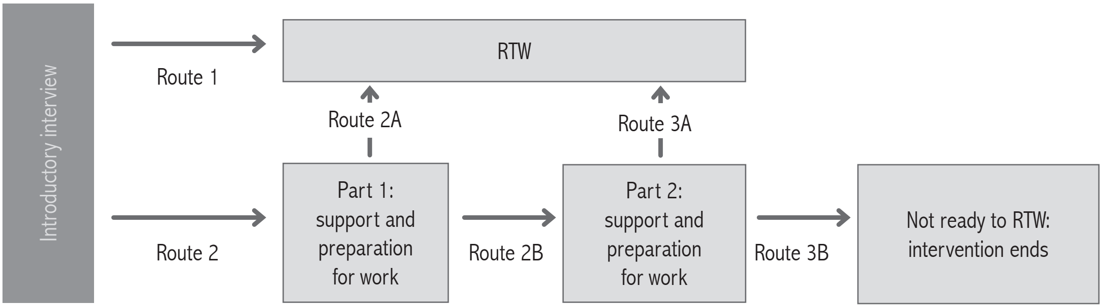
Furthermore, we obtained advice from important stakeholders in the field of 'cancer and work' in the Netherlands, i.e., medical specialists in oncology, medical social workers, re-integration and vocational rehabilitation agencies, and the Dutch Cancer Patient Movement (Leven met Kanker Beweging) [22]. Finally, we conducted a focus group study with CSs with job loss and with insurance physicians, to identify barriers and facilitators for RTW specifically in CSs with job loss. For example, we discussed which barriers and facilitators CSs with job loss experience in their RTW after cancer. Also, we explored what a suitable duration and intensity level, in terms of frequency of appointments, would be for the intervention program, and in what way the intervention program and the study procedures could be implemented at the SSA. We used the results of the focus group study in the developmental process of the intervention program.

The intervention is consistent with the 'Dutch Guideline of Oncologic Revalidation (Richtlijn Oncologische Revalidatie)' [23] and includes elements of a participatory approach, in which the participant will be actively involved in the development, content and execution of his/her RTW plan. Specifically, the participant will be encouraged to actively participate in (1) developing his/her consensus-based tailored RTW plan, (2) coaching on identifying obstacles and creating possibilities for RTW, and (3) exploring possibilities for (therapeutic) return to an actual workplace. The first two steps (developing a RTW plan and coaching) will take place in the participant's home or at a location nearby, and will be carried out by a re-integration agency, specialized in coaching and support of CSs regarding RTW. The third step (actual placement in a workplace) will be carried out by two job hunting agencies and the participants will travel to the nearest local office(s) of the agencies. The content of the tailored RTW intervention program is, to a certain extent, related to the attitudes-social influences-efficacy model [24]. That is, the first part of the intervention program, i.e., preparation for RTW, relates to behavioral determinants such as attitude and (self-) efficacy. The latter part of the program, e.g., removing barriers for RTW, relates to social influence by involvement of facilitating professionals in the RTW process.

Content of the intervention program

The tailored RTW intervention program will start with an introductory interview between the participant and an assigned coach from the re-integration agency. Prior to the introductory interview, the participant will be asked to fill out an additional introductory questionnaire. This questionnaire is specifically designed for the coach to obtain insight in the participant's motivation regarding RTW, needs for additional therapy (e.g., physical and/or psycho-educational), and the skills and knowledge of the participant regarding work and job application processes (e.g., the skill to write letters of application). The results of this questionnaire will be used as input for an introductory interview and to construct a work profile for the participant. During the interview, obstacles and possibilities for RTW and other forms of activities will be identified. Also, the coach and participant will work together during the interview to tailor the participant's intervention program. There will be several options (or 'routes') to tailor the intervention. The possible routes are displayed in Figure 2.

Figure 2: Routes in the tailored RTW intervention program



Routes in the intervention program

First, the coach will decide, together with the participant, whether or not the participant is ready to RTW, or needs additional support and preparation in order to RTW.

Route 1: The participant is ready to RTW at the time of the introductory interview. The coach will contact the researchers to independently assign a job hunting agency to this participant. The job hunter will invite the participant for a meeting to explore job opportunities, thereby taking the participant's work profile into account. Job hunters will always explicitly ask for a participant's permission to inform future employers of the participants' history of cancer. Based on the work profile, the job hunter will start a search for at least two jobs, fitting the profile. These jobs should be for at least three months and may include (1) working in paid employment, or (2) working in temporary employment, i.e., this type of work can be arranged with therapeutic conditions and ongoing benefits. The job hunter will have to find jobs within four weeks after the meeting with the participant. If the job hunter is unable to find these jobs, then the second job hunting agency involved in this study will also be invited to search for jobs for the participant. This involvement includes transfer of confidential information about the participant. The participant will be informed thoroughly about this procedure. Also, the participant can use the established work profile to look for jobs independently, alongside the job search with the job hunter. The total search time for a job will be three months. If both job hunting agencies do not find a suitable job for the participant by then, or if the participant is not able to RTW, then the intervention program will end. The participant will still receive usual care by the SSA during the entire follow-up period. If the job hunter finds a suitable job, the job hunter will stay in touch with the participant during the remaining period (up to three months) of the intervention program, to monitor whether the participant's RTW is successful and satisfactory. If applicable, the participant can continue to work in the new job after the intervention program has been completed.

Route 2: The participant needs support and preparation to RTW. The coach and participant can explore several topics for coaching. After the introductory interview, the participant will receive four sessions of coaching on chosen themes, e.g., how to deal with fatigue or changed life priorities, how to combine work and family, et cetera. As the intervention program continues, the coach and participant will gradually develop a work profile, which will incorporate the participant's capabilities, needs and preferences for a workplace. After completing the work profile, the coach and participant will decide whether or not the participant is ready to RTW (Route 2A or Route 2B).

Route 2A: The participant is ready to RTW. The participant will continue as described in Route 1. If the participant needs support at the workplace, the participant may receive five additional sessions of coaching while being in the process of RTW.

Route 2B: The participant needs more preparation to RTW. The participant will receive five additional sessions of coaching on chosen themes. After this, the coach and participant will again decide whether or not the participant is ready to RTW (Route 3A or Route 3B).

Route 3A: If the participant is ready to RTW, the participant will continue as described in Route 1.

Route 3B: If the participant is not ready to RTW, the intervention program will be terminated.

In Route 2, both 2A and 2B, the coach can also opt for additional support, for example support from a physical therapist and/or psychologist, in case specific physical and/or mental problems are present. If this is the case, the coach will discuss this with the participant's expert team at the SSA and/or the participant's GP.

Completion of the intervention program

The total duration of the program in the most extensive route (2B followed by 3A) will be six to seven months. Here, the participants will receive preparation to RTW for a maximum of four months, including ten sessions of coaching, job application preparation and possibly recovery support, such as physical therapy, and placement in a workplace for a minimum of three months. In general, we anticipate that duration of the program will vary between participants. Some participants will need the most extensive route, and others may need less support in order to facilitate their RTW. Also, in case of extraordinary circumstances, participants can put their tailored RTW intervention program on hold for a period of one month maximum. The limit of one month was chosen to allow for the program to be tailored to each participant's needs, while maintaining a relatively similar duration of most participants' programs. We will monitor the chosen route(s) for each participant. During the program, members of the SSA team, as well as the GP, will be notified of the program's start, progress and finish. They will receive a copy of the intervention plan and the evaluation report.

Outcome measures & prognostic factors

Data regarding primary and secondary outcome measures, as well as prognostic factors such as socio-demographic factors (i.e., age, gender, level of education), disease-related and work-related factors will be collected using questionnaires. If possible, additional data regarding usual care will be collected from the participant's file at the SSA. The primary outcome measure of this study is duration until sustainable RTW after sick leave, calculated as the number of days between the day of randomisation and the first day of sustainable RTW. Sustainable RTW is defined as a period of minimum 28 calendar days, during which the CS is working according to schedule. Work can be either paid work or work resumption with ongoing benefits, e.g., work with therapeutic conditions. Recurrences of sick leave within four weeks of RTW will be considered as belonging to the initial period of sick leave, in accordance with the requirements of the Dutch Sickness Benefits legislation. The secondary outcome measure of this study is rate of RTW, i.e., the proportion of participants in each group that sustainably returns to work. Rate of RTW will be not only obtained from questionnaire data, but also, if possible, from participants' files at the SSA. We will collect data on a number of prognostic factors:

- Intention to RTW will be measured using the 'Attitudes-Social influence-self-Efficacy' questionnaire (ASE) [25]. This questionnaire was designed to assess intention to RTW in a study of unemployed persons with common mental disorders. The questionnaire has not been validated. Therefore, its results will be used as an indicator for intention to RTW;
- Readiness to RTW will be measured using the Readiness to RTW Scale (RRTW) [26]. The items on the scale are related to the five stages of change described in the Transtheoretical model by Prochaska and DiClemente [27]. We will adjust the Scale to the Dutch situation as there is no validated translation available, and use the results of this scale as an indicator of readiness to RTW, instead of a validated outcome measure;
- Fatigue will be assessed with the 13-item self-reported FACT-Fatigue Scale (Version 4) [28]. Fatigue is measured in this questionnaire on a four-point scale (range 0-52). It has a high internal validity with a Cronbach's alpha of 0.96 and high test-retest reliability (ICC = 0.95) [29]];
- Psychological distress will be assessed with the Centre for Epidemiological Studies Depression Scale (CES-D) [30-32]. The CES-D is a 20-items questionnaire, measured on a four-point scale. It is designed to measure depressive symptomatology in the general population and has a high reliability with a Cronbach's alpha of 0.79-0.92 and a test-retest score of 0.90;
- General participation in society will be measured using the Utrecht Scale for Evaluation of Revalidation and Participation (User-P) [33]. The User-P scale aims to rate objective and subjective participation in persons with physical disabilities and consists of 31 items in three scales: Frequency, Restrictions, and Satisfaction. Internal consistency of the USER-Participation scales is moderate to good, with Cronbach's alpha ranging between 0.70 and 0.91. Spearman correlations between these scales range between 0.36 and 0.52. Test-retest reliability of the User-P scales was measured using the intraclass correlation coefficient (ICC). The ICC of the USER-P was 0.65 for the Frequency scale, 0.85 for the Restrictions scale, and 0.84 for the Satisfaction scale;
- Coping will be measured using the Utrecht Coping List (UCL) [34]. The UCL has 47 statements covering seven coping strategies, such as active problem solving, seeking social support and depressive reaction, and is scored on a four-point scale. Its reliability varies between 0.43 and 0.89, depending on the subscale used. The test-retest score ranges from 0.45 to 0.85, depending on the subscale used;
- General health and quality of life will be assessed with the European Organisation for Research and Treatment of Cancer Quality of Life Questionnaire (EORTC QLQ C-30 version 3.0) [35]. This 30-item list incorporates nine multi-item scales: five functional scales (physical, role, cognitive, emotional and social); three symptom scales (fatigue, pain, nausea and vomiting); and a global health and quality of life scale. The test-retest score has shown to be high for all functional scales with a range of 0.82 to 0.91, and a reliability score over 0.80 for four out of five scales, with cognitive functioning scoring 0.68 [36];
- Health-related quality of life will be measured using the EuroQol 5D scale, developed by the EuroQol group (EQ-5D) [37]. The EQ-5D consists of 5 scales: Mobility, Self-care, Usual activity, Pain/Discomfort, and Anxiety/Depression, with a scale of three levels per item (i.e., no problem, some problems, and extreme problems). The EQ-5D is a generic instrument and has been used in cancer research in numerous studies. Furthermore, a visual analogue scale is provided (range 0-100) to assess overall health state;
- Limitations experienced at work will be measured in participants who have returned to work during the follow-up period, using the Work Limitations Questionnaire (WLQ) [38]. The WLQ consists of 25 items, which describe four dimensions of limitations: limitations in handling time, physical, mental and interpersonal limitations. The questionnaire was tested in two field trials, and the four scales achieved Cronbach's alphas of > 0.90.

- Occupational impact of sleep will be measured in participants who have returned to work during the follow-up period, using the Dutch Occupational Impact of Sleep Questionnaire (OISQ) [39]. The OISQ consists of 24 items, which aim to assess the effect of sleep quality on work performance. The OISQ has been validated in the Dutch population, correlating highly with other validated sleep questionnaires (coefficients range 0.28 to 0.43, $P<0.0001$) and has a high reliability score (Cronbach's alpha of 0.96). This measure was added as studies have demonstrated that sleep disturbances are common in CSs and that they are related to poorer physical and emotional health, concentration problems (for example at work), and difficulty coping with stress [40].

Process evaluation

A process evaluation will be conducted to examine the tailored RTW intervention program regarding feasibility, satisfaction, and barriers and facilitators for implementation. The process evaluation will be designed according to the RE-AIM (Reach, Effectiveness, Adoption, Implementation, and Maintenance) framework [41]. The measurements of the process evaluation will be based on: (1) data regarding study procedures and adherence to study protocol, and (2) data collected using additional process evaluation questionnaires, which will be designed separately for participants, team members from the SSA, the re-integration agency and the job hunting agencies.

Sample size

As a starting point for calculating the sample size, we chose a Hazard Ratio of 2, indicating that the participants in the intervention group RTW twice as quickly compared to the participants in the control group. This Hazard Ratio is based on comparable studies on RTW of workers who are sick-listed and who are receiving sickness benefits [42,43]. Assuming that half of the workers will achieve sustainable RTW during the first 12 months of the follow-up period, and based on a power of (1-b=) 0.80 and a two-sided significance level of 0.05 (a), a sample size of 130 participants ($n = 2 \times 65$) is needed. Based on comparable research, loss to follow-up of 20% is taken into account. This results in 164 participants ($n = 2 \times 82$) to be included in the study. This number of participants seems feasible as samples from the registration database at the SSA indicate that approximately 3000 persons could be invited for participation over a time period of one and a half year.

Randomisation

Prior to randomisation, we will apply pre-stratification in our inclusion procedure to ensure equal representation of the three subtypes amongst CSs with job loss in our sample; (1) workers whose temporary employment contract ended before or during sick leave; (2) temporary agency workers; and (3) unemployed workers. Randomisation to either the intervention group or control group will be performed on the individual level and will be performed separately for each stratum. Randomisation will be performed by the coordinating researchers (with the exception of the executive researcher), using computerized blocked randomisation by means of the Randomisation Plan Generator [44]. The number of participants in each block will be four, with an allocation ratio of 1:1.

Blinding to the randomisation outcome in this study is not possible due to the nature of the intervention program, in which various stakeholders will need to cooperate to support and guide participants in the intervention group. Furthermore, for practical reasons with regard to usual care, the researchers will have to inform the SSA team and the GP of participants about the inclusion of the participant and the group to which the participant was randomised.

Co-interventions and compliance

For participants in the control group, we cannot prevent co-interventions, e.g., recovery therapy or support from job hunters, being offered to them, as these interventions can be part of the SSA's usual care. For participants in the intervention group, we will ask the SSA team not to offer any additional interventions during the period in which the CS participates in our intervention program. During the follow-up period, after the intervention program in this study has been completed, the SSA team may still offer interventions that are available through usual care. We will monitor any co-interventions offered in both groups by asking questions about this in the questionnaires and, if possible, by data from the participants' files at the SSA.

Statistical analysis

All statistical analyses will be performed according to the intension-to-treat principle. If necessary, the per-protocol principle will also be applied [45]. Descriptive analyses will be performed to check whether there are relevant differences in the baseline characteristics of the intervention and the control group at baseline. Analyses will be performed on an individual level. All analyses will be performed both crude and adjusted for potential confounders, e.g., gender, age, stratum of participants, or type of cancer. Also, these variables will be checked for effect modification. Scores on the included outcomes measures and parameters in the study will be calculated according to published scoring algorithms. The results of the questionnaires will be compared between both groups at baseline and at 3, 6 and 12 months follow-up. Correction for baseline values will be applied. The primary outcome measure, duration until sustainable RTW in both groups, will be described using the Kaplan-Meier method. We will use the Cox proportional hazard model to estimate hazard ratios and corresponding 95% confidence intervals for sustainable RTW. Finally, we will also perform multiple regression analysis to determine associations between the primary outcome measure and predictor variables, such as fatigue and coping strategy, in order to identify prognostic factors for RTW in this population. A two-tailed significance level of <0.05 is considered statistically significant in all analyses. All analyses will be performed using SPSS 20.0 [46].

Discussion

In light of an increasing incidence of cancer and an improving survival rate [47], a rising retirement age [16,48] and a growing number of temporary employment contracts within Western labour markets [17], it is expected that the number of CSs who have lost their job in the working age will increase. CSs with job loss may experience unique challenges in their RTW process, compared to employed CSs, e.g., competition with “healthy” individuals for a job, lack of a workplace to return to and lack of social support from colleagues or an employer. Therefore, they may be in need for a tailored approach for RTW. This study aims to evaluate the effectiveness of a tailored RTW intervention program on duration until sustainable RTW of CSs with job loss, compared to usual care.

Methodological considerations regarding the study design

There are several methodological aspects of this study that can be considered. One of the main strengths of this study is that, in the developmental process of the tailored RTW intervention program, we have incorporated (1) ideas and perspectives of a large variety of stakeholders in the fields of cancer, work and insurance medicine in the Netherlands, (2) results from previous international studies on RTW for CSs, and (3) results from a qualitative focus group study on barriers and facilitators for RTW in CSs with job loss. Another strength of this study is that we will evaluate the effectiveness of the tailored RTW intervention program with a RCT design, and that we will conduct a process evaluation alongside the RCT. Furthermore, the procedures for this study were developed in accordance with the Dutch SSA. This will facilitate implementation of the study protocol, particularly the recruitment protocol, at the SSA. There are also several limitations to be considered with regard to the study design. First of all, this is the first study to be conducted that incorporates a RTW intervention for CSs with job loss. Therefore, in developing the tailored RTW intervention program, we had to rely on indirect evidence from studies on RTW for employed CSs, and adjust this information, taking into account our knowledge of the situation of CSs with job loss, which is a subjective process. We did not take other intervention studies on RTW in persons with chronic diseases (other than cancer) into account in developing the tailored RTW intervention program. Still, the tailored RTW intervention program is based on elements of the attitudes-social influences-efficacy model [24], which indicates that there is, to some extent, a scientific basis for the content of the program. Ideally, this study design would have incorporated a pilot phase, in which we could evaluate whether the intervention program would be acceptable and sufficiently tailored to the needs of CSs with job loss. In addition, a pilot study would have enabled us to discover potential implementation problems for the intervention program beforehand and to evaluate whether or not the chosen recruitment strategy for the RCT would be feasible and successful. Unfortunately, we were not able to carry out a pilot phase in this study.

With regard to the sample size, we chose a Hazard Ratio of 2, which is not uncommon for studies in (moderately) comparable populations. Still, this number might be optimistic in terms of the anticipated results. Another limitation is that this study does not use blinding, i.e., we have to disclose to the participant's RTW team at the SSA whether the participant is in the intervention group or the control group. This could potentially lead to awareness in the SSA teams about their care being evaluated, which could result in a different type of usual care provided to the intervention group compared to the control group. Finally, blinding could prevent contamination of the control group, but as this study recruits 82 participants for the intervention group on a national level, the researchers estimate the risk of contamination of the control group marginal. Potentially, increased awareness of RTW could lead to participants in the control group employing RTW activities on their own, which they might not have done if they were not participating in the study. Enhanced RTW activities in the control group could distort a potential effect of the tailored RTW intervention program and lead to an underestimation of any effect that will be measured between the intervention group and the control group. Finally, it is not unlikely that CSs with job loss feel disappointed in the labour market (due to job loss) or the social security system (due to a lack of appropriate RTW interventions), which may influence their willingness to participate in an experimental study that offers a RTW intervention program. This could potentially lead to selection bias in our sample of participants.

Implications of study findings for research

The results of this study will contribute to the literature by providing insight into the RTW process of CSs with job loss and the ways in which RTW can be facilitated for them. In a broader perspective, the results of this study may change the way the RTW process of CSs is generally studied. To this day, the literature on RTW does not distinguish CSs based on work-related factors, such as working status or type of employment contract, but rather distinguishes CSs on medical factors, such as type of diagnosis. If the results of this study demonstrate a positive effect in favor of a tailored approach for CSs with job loss, then opportunities may be created to develop future RTW interventions tailored to work-related factors, e.g., employment status, present in CSs. Possibly, this approach may also be applied to persons with job loss with other (chronic) conditions, in order to facilitate their RTW.

Implications of study findings for practice

This study may demonstrate that it is effective to tailor RTW support for CSs to work-related factors, such as employment status, at least in Western economy countries. If so, policymakers should find ways to implement tailored RTW intervention programs for CSs with job loss. This study may also have a positive impact on the increasing burden of sickness and disability benefits. As more CSs may return to work as a result of a tailored RTW intervention program, the number of CSs receiving benefits will decrease. As benefits are indirectly provided by the tax payers in Western economy countries, society as a whole could potentially profit from a higher number of CSs returning to work.

Conclusion

There is a gap in the literature regarding the RTW process of CSs who have lost their job. We hypothesize that CSs with job loss benefit from a tailored approach regarding RTW support, as a result of unique challenges, e.g., lack of a current job, going through job application processes, competing with "healthy" individuals for a job and having a large emotional and practical distance to the labour market. This study aims to facilitate sustainable RTW for CSs with job loss, by offering a tailored RTW intervention program and evaluate its effectiveness compared to usual care. Results of this study will be available in 2016.

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Therapeutic work as a facilitator for return to paid work in cancer survivors

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Therapeutic work as a facilitator for return to paid work in cancer survivors

Abstract

Purpose: The increase of flexible employment in European labour markets has contributed to workers' risk of job loss. For sick-listed workers with chronic illnesses, such as cancer, and especially those without an employment contract, participation in therapeutic work may be an important step towards paid employment. The purpose of this study was to determine the role of therapeutic employment as facilitator for return to paid work, in a cohort of sick-listed cancer survivors (CSs) with and without an employment contract.

Methods: In this longitudinal study, data were used from a cohort of Dutch CSs ($N=192$), who applied for disability benefits after 2 years of sick leave. The primary outcome measure was return to paid work after 1 year. Logistic regression analysis was applied.

Results: Of the participating CSs (mean age 50.7 years, 33% male), 69% had an employment contract at baseline. CSs without an employment contract participated significantly less in therapeutic work ($p < 0.001$) and were less likely to return to paid work after 1 year ($p = 0.001$), than those with a contract. Participation in therapeutic work significantly increased the chance of return to paid work after 1 year (OR 6.97; 95% CI 2.94-16.51), adjusted for age, gender, level of work disability and having an employment contract.

Conclusions: Participation in therapeutic work could be an important facilitator for return to paid work in sick-listed CSs. The effectiveness of therapeutic work as a means to return to paid employment for sick-listed workers should be studied in an experimental setting.

Introduction

Over the past decades, new employment arrangements have emerged in the European labour market [1-3]. That is, across countries, there has been a shift from permanent employment to flexible employment, e.g., fixed-term employment contracts or temporary agency work [2]. Currently, between 8-33% of workers in European countries have a flexible employment contract. To illustrate, 1,120,000 workers in the Netherlands worked in flexible employment in 2012, which is an increase of 30% compared to 2005 [4].

Several studies have demonstrated the negative impact that flexible employment may have on workers' health and job security [5-8]. Specifically, workers with a flexible employment contract may have poorer self-rated health, and experience higher levels of stress, fatigue and an inferior degree of mental health, compared to workers with a permanent employment contract [6,9,10]. Further, workers with a flexible employment contract, by definition, have no long-term job security and receive less commitment from the employer, compared to workers with a permanent employment contract [9,11]. Especially in case of chronic illnesses, e.g., cardiovascular or respiratory diseases, diabetes or cancer, workers in flexible employment are vulnerable for job loss [12,13].

Sick-listed workers with job loss experience more obstacles with regard to return to work (RTW) compared to sick-listed workers who still have an employment contract [14,15]. In a recent qualitative study, workers without an employment contract, who were diagnosed with cancer, were interviewed on perceived barriers and facilitators for RTW [16]. Cancer survivors (CSs) in this study reported that participation in sheltered forms of employment, such as therapeutic work, was desirable as preparation for return to paid work. Therapeutic work involves, e.g., a gradual buildup of workload and working hours, a consistent level of RTW support, and flexibility in job demands and working hours [17]. Moreover, in therapeutic work, an employer is actively involved in the workers' buildup process. However, opportunities for therapeutic work have diminished over the years, which may have a negative impact on the RTW of workers with cancer or another chronic condition [16]. This may be particularly true for sick-listed workers without an employment contract, as they have fewer means of RTW support than workers who still have an employment contract [18,19]

So far, the role of therapeutic work as a step in preparation for return to paid work, has not been studied in workers with chronic illnesses, such as cancer. It is important to study if participation in therapeutic work increases the chance of return to paid work in sick-listed CSs, especially given the expected increase in CSs of working age 20. Further, considering the increase in flexible employment, it is relevant to explore potential differences in participation in therapeutic work, between workers with and without an employment contract. Therefore, in this study, data from a national cohort of CSs in the Netherlands were used to explore the role of therapeutic employment as a facilitator for return to paid work, in workers with and without an employment contract.

Methods

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Design

For this longitudinal study, baseline (T0) and 1-year follow-up data (T1) were used from a prospective cohort of CSs, who had been on sick leave for two years, and who applied for a disability benefit at the Social Security Agency (SSA) in the Netherlands [21]. In the cohort study, data were obtained from participants through questionnaires and the SSA registries. Given the fact that CSs in the cohort were assessed for work disability shortly after baseline, the outcome of CSs' work disability assessment at the SSA was included in our analyses as a potential confounding factor. A detailed description of the study procedures of the cohort study has been published previously [21]. The cohort study was approved by the Medical Ethics Committee of the VU University Medical Center, Amsterdam, The Netherlands.

Study population and procedures

All CSs who applied for a disability benefit after 2 years of sick leave, who were between 18 and 64 years old, and who had a confirmed diagnosis of cancer, were invited to participate. CSs were excluded in case of: receiving active chemotherapy and/or radiotherapy treatment, application for work disability benefits due to a somatic or psychiatric disorder other than cancer, application of a revision of a previous work disability assessment, history of self-employment and history of working in a sheltered workplace. From July 2011 to February 2012, potentially eligible CSs were identified weekly, using a search query in the registries at the SSA headquarters. Potential participants received an information package that included an information flyer, a baseline questionnaire, and an informed consent form. CSs who returned the questionnaire and informed consent form, received a gift voucher. CSs who participated at baseline, received a follow-up questionnaire after 1 year. For the current study, a subset of CSs who participated in the cohort was selected. To be included in this subset, CSs were selected if they were not working in paid employment at baseline, and if they were not permanently and fully disabled for work (based on the outcome of the SSA's work disability assessment).

Measurements

The primary outcome measure of the current study was RTW (yes; no), which was defined as return to any type of paid employment after 1 year follow-up. The independent variable in this study was participation in therapeutic work (yes; no) at baseline. The following variables were taken into account as potential confounders in the analyses: age (in years), gender (male; female), level of education (no education/primary school/lower vocational education; secondary school; vocational education/upper secondary school; upper vocational education/university), marital status (single; married; living together with partner, children and/or others; divorced/widowed), ethnicity (Dutch; non-Dutch), outcome of the work disability assessment (0-35%; 35-80%; 80-100% temporary disabled, calculated as a percentage of wage loss, and categorized in accordance with the Dutch social security legislation), unemployment before start of sick leave, and employment contract during sick leave (having an employment contract; not having an employment contract).

Statistical analyses

T-tests and chi-square tests were used to describe and evaluate differences in characteristics, and proportions of participation in therapeutic work and return to paid work 1 year later, between CSs with an employment contract and CSs without an employment contract. The crude association between the independent variable, i.e., participation in therapeutic work at baseline, and the dependent variable, i.e., return to paid work after 1 year, was studied using logistic regression analysis. A backward entry strategy was then used to evaluate the possibility of joint confounding, i.e., confounding by factors that individually do not lead to confounding, but when combined do lead to confounding. Using this specific strategy, all potential confounders were entered into the model, after which potential confounders were randomly removed from the model. If the removal of a variable caused a change in the regression coefficient of the independent variable of >10%, the change was considered meaningful and the variable remained in the model. The crude association was adjusted for age and gender regardless of any relevant confounding, as this allows for comparison between previous studies.
SPSS 22.0 was applied to conduct the analyses [22].

Results

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Study population

Of the 484 participants in the original national cohort, 192 CSs were eligible for the current study. Of these, 39% participated in therapeutic work at baseline. The mean age was 50.7 years, 33% was male, and 70% was married. Over 96% of the study population had the Dutch nationality, more than two-third (69%) had an employment contract, and 31% did not have an employment contract at baseline. The average total of working years prior to sick leave was 25.5 years.
The characteristics of the study population are presented in Table 1.

Table 1 Characteristics of CSs with and without an employment at baseline

Variable	Categories	Total group (N=192)	CSs (contract); N=132)	CSs (no contract; N=60)	P-value*
		Mean (SD)	Mean (SD)	Mean (SD)	
Age in years		50.7 (8.0)	50.4 (7.6)	51.4 (9.0)	0.444
Years working before sick leave		25.5 (11.2)	24.7 (10.8)	27.2 (11.8)	0.162
		N (%) †	N (%) †	N (%) †	
Gender	Male	63 (32.8)	38 (28.8)	25 (41.7)	0.078
	Female	129 (67.2)	94 (71.2)	35 (58.3)	
Level of education	None/ primary / lower vocational education	56 (29.2)	38 (28.8)	18 (30.0)	0.432
	Secondary school	35 (18.2)	24 (18.2)	24 (18.2)	
	Vocational education/ upper secondary school	56 (29.2)	35 (26.5)	35 (26.5)	
	Upper vocational education/ university	45 (23.4)	36 (26.5)	35 (26.5)	
Principal wage earner	No	87 (45.5)	62 (47.3)	25 (41.7)	0.466
	Yes	104 (54.5)	69 (52.7)	35 (58.3)	
Marital status	Unmarried	17 (8.9)	8 (6.1)	9 (15)	0.211
	Married	135 (70.3)	95 (72.0)	40 (66.7)	
	Living together	14 (7.3)	11 (8.3)	3 (5.0)	
	Divorced/widowed	26 (13.5)	18 (13.6)	8 (13.3)	
Having children	No	50 (26.0)	33 (25)	17 (28.3)	0.626
	Yes	142 (74.0)	99 (75)	43 (71.7)	
Ethnicity	Dutch	185 (96.4)	127 (96.2)	58 (96.7)	0.876
	Non-Dutch	7 (3.6)	5 (3.8)	2 (3.3)	
Tumor type	Breast	86 (44.8)	57 (43.2)	29 (48.3)	0.464
	Urinary tract	14 (7.3)	10 (7.6)	4 (6.7)	
	Urogenital male	6 (3.1)	4 (3.0)	2 (3.3)	
	Urogenital female	7 (3.6)	4 (3.0)	3 (5.0)	
	Respiratory tract	8 (4.2)	8 (6.1)	0 (0.0)	
	Digestive system	25 (13.0)	15 (11.4)	10 (16.7)	
	Head and neck	10 (5.2)	9 (6.8)	1 (1.7)	
	Hematological	29 (15.1)	19 (14.4)	10 (16.7)	
	Central nervous system	2 (1.0)	2 (1.5)	0 (0.0)	
	Other type of cancer	5 (2.6)	4 (3.0)	1 (1.7)	

Metastasized cancer	No	109 (57.7)	73 (56.6)	36 (60.0)	0.907
	Yes, lymph nodes	70 (37.0)	49 (38.0)	21 (35.0)	
	Yes, distant	10 (5.3)	7 (5.4)	3 (5.0)	
Treatment modalities	Surgery	147 (76.6)	97 (73.5)	50 (83.3)	0.135
	Radiotherapy	114 (59.4)	79 (59.8)	35 (58.3)	0.843
	Chemotherapy	143 (74.5)	100 (75.8)	43 (71.7)	0.547
	Hormone therapy	56 (29.2)	38 (28.8)	18 (30.0)	0.864
	Immunotherapy	15 (7.8)	11 (8.3)	4 (6.7)	0.690
	No treatment	1 (0.5)	1 (0.8)	0 (0.0)	0.499
Declared free of disease by physician	No	48 (25.8)	27 (20.8)	21 (37.5)	0.057
	Yes	84 (45.2)	63 (48.5)	21 (37.5)	
	Do not know	54 (29.0)	40 (30.8)	14 (25.0)	
Comorbidity	No	108 (56.3)	77 (58.3)	31 (51.7)	0.388
	Yes	84 (43.8)	55 (41.7)	29 (48.3)	
Work disability assessment (temporary disabled)	<35%	41 (21.4)	22 (16.7)	19 (31.7)	0.062
	35-80%	57 (29.7)	41 (31.1)	16 (26.7)	
	80-100%	94 (49.0)	69 (52.3)	25 (41.7)	
Participation in therapeutic work	No	117 (60.9)	64 (48.5)	53 (88.3)	<0.001
	Yes	75 (39.1)	68 (51.5)	7 (11.7)	
Return to paid work after 1 year	No	139 (72)	86 (65)	53 (88)	0.001
	Yes	53 (28)	46 (35)	7 (12)	
Type of sector previous job	Blue collar	73 (43.5)	56 (42.4)	17 (47.2)	0.006
	White collar	45 (26.8)	29 (22.0)	16 (44.4)	
	Civil servant	14 (8.3)	13 (9.8)	1 (2.8)	
	Health care worker	36 (21.4)	34 (25.8)	2 (5.6)	
Shift work previous job	No	103 (53.6)	80 (60.6)	23 (38.3)	<0.001
	Yes	65 (33.9)	52 (39.4)	13 (21.7)	
	Not applicable (unemployed before sick leave)	24 (12.5)	0 (0)	24 (40.0)	
Managerial tasks previous job	No	137 (71.4)	106 (81.5)	31 (51.7)	<0.001
	Yes	29 (15.1)	24 (18.5)	5 (8.3)	
	Not applicable (unemployed before sick leave)	24 (12.5)	0 (0.0)	24 (40.0)	
Previous job demands	Psychological and physical	82 (42.9)	68 (51.9)	14 (23.3)	<0.001
	Mainly psychological	44 (23.0)	29 (22.1)	15 (25.0)	
	Mainly physical	41 (21.5)	34 (26.0)	7 (11.7)	
	Not applicable (unemployed before sick leave)	24 (12.6)	0 (0.0)	24 (40.0)	

* P-values are the result of T-tests and Chi-square tests for differences in characteristics between CSs with and without an employment contract; † The calculated totals of numbers and percentages per variable may approach or exceed 100% because of missing values, the option to provide multiple answers, or rounding differences.

Therapeutic work, return to paid work and having an employment contract

A significant crude association between participation in therapeutic work and RTW 1 year later was found. In these unadjusted analyses, CSs who participated in therapeutic work, had a significantly higher odds of RTW 1 year later, compared to CSs who did not participate in therapeutic work (Odds Ratio (OR) 12.26; 95% Confidence Interval (CI) 5.68-26.50). Of the potential confounders, the outcome of the work disability assessment and having an employment contract, had a significant influence on the association between therapeutic work and RTW. That is, CSs in the lower categories of work disability (i.e., 0-35%; 35-80% temporary disabled) had a significantly higher chance of RTW ($p < 0.001$) than CSs in the highest category of work disability (i.e., 80-100% temporary disabled. Further, CSs without an employment contract participated significantly less often in therapeutic work ($p < 0.001$), and were less likely to RTW after 1 year ($p = 0.001$), than those with an employment contract. The association between therapeutic work and return to paid work 1 year later, was thus adjusted for age, gender, outcome of the work disability assessment and having an employment contract (OR 6.97; 95% CI 2.94-16.51). The results of the logistic regression analyses are presented in Table 2.

Table 2. Association between participation in therapeutic work at baseline and RTW 1 year later

	Crude model			Adjusted model 1			Final model		
	OR*	95% CI	P †	OR*	95% CI	P †	OR*	95% CI	P †
Therapeutic work ‡	12.26	5.68-26.50	< 0.001	9.70	4.33-21.70	< 0.001	6.97	2.94-16.51	< 0.001
Age				0.98	0.93-1.03	0.368	0.97	0.92-1.03	0.311
Gender				1.48	0.60-3.66	0.392	1.42	0.57-3.55	0.457
0-35% disabled**				5.16	1.85-14.42	0.002	6.50	2.19-19.32	0.001
35-80% disabled**				3.92	1.48-10.39	0.006	4.33	1.63-11.52	0.003
No employment contract ††							0.38	0.13-1.12	0.078

*Odds Ratio; † P-value; ‡ Compared to the reference category "not participating in therapeutic work"; ** compared to the reference group "80-100% work disabled"; †† compared to the reference group "having an employment contract"

Discussion

Main findings

The main finding of this study is that CS who participated in therapeutic work at baseline had a highly increased chance of return to paid work 1 year later, compared to those who did not perform therapeutic work. Furthermore, CSs without an employment contract participated significantly less in therapeutic work, and were less likely to return to paid employment after 1 year, compared to CSs with an employment contract.

Interpretation of findings

In this study, CSs who participated in therapeutic work at baseline, were far more likely to return to paid employment within 1 year follow-up. So far, no studies have particularly reported on the role of therapeutic work as a facilitator for RTW. Still, there are other studies that also describe RTW facilitators, somewhat comparable to therapeutic work [23,24]. That is, therapeutic work is characterized as sheltered work, with fewer obligations, fewer stress-inducing activities, and more room for accommodation to the workers' needs, than regular employment [17]. Several of these characteristics of therapeutic employment have been identified as individual RTW facilitators by other studies in workers with cancer and other chronic illnesses [23,24]. For example, two large reviews by Mehnert et al. [25] and Spelten et al. [26] found that, amongst other factors, perceived employer accommodation, counseling, and miscellaneous training services at work, were important facilitators for RTW in CSs. Further, from a chronic illnesses perspective, Boot et al. conducted a large mixed-methods study on RTW in older workers with chronic illnesses. Although no quantitative association between work-related factors and RTW were found, qualitatively, workers reported that psychosocial resources at work, e.g., support from colleagues and the employer, were important facilitators for RTW [27]. In a related study, psychosocial resources at work were found to be predictive of RTW in older workers with chronic disease, although not in workers without chronic disease [28]. Further, studies in CSs and workers with chronic illnesses have also reported on the crucial role that employers have with regard to RTW, i.e., providing support and a sense of value, taking care of practical arrangements and communication to colleagues on behalf of the worker [29-31]. As therapeutic work combines several of these RTW facilitators, i.e., psychosocial resources at work, gradual buildup of workload and support from an employer, into a single working arrangement, this may explain why CSs in our study, who participated in therapeutic work at baseline, were more successful in returning to paid employment within 1 year, than workers who did not participate in therapeutic work.

Further, in this study, the association between therapeutic work and return to paid work was significantly influenced by the outcome of CSs' work disability assessment short after baseline. This seems plausible, as multiple studies across workers have demonstrated that higher levels of work disability decrease the chance of RTW [32,33]. It should be mentioned that both impaired health, as well as corresponding financial incentives in the form of disability benefits in Western social security systems, may contribute to the negative association between higher levels of work disability and decreased chance of RTW [11].

This study also revealed that CSs with an employment contract participated significantly more often in therapeutic work at baseline, and logically, were significantly more often at work in paid employment after 1 year, compared to CSs without an employment contract. The difference in participation in therapeutic work between CSs with and without an employment contract may be explained by access to therapeutic work, as well as motivation for (therapeutic) RTW. First, it should be considered that opportunities to participate in therapeutic work during sick leave are often provided by an employer, either because the employer is obliged to do so by law, or because of an employer's commitment to the worker. Two previous studies in employers of workers with breast cancer and chronic musculoskeletal pain demonstrated that employers can be committed and willing to invest in their employee [34,35]. For CSs without an employment contract, logically, there is no employer who is legally obliged, or intrinsically motivated, to provide RTW support in the form of therapeutic work. As a result, CSs who have an employment contract are, at least in the Netherlands, by definition more likely to have access to therapeutic work, compared to CSs who are no longer employed. For the latter group, it is theoretically still possible that a previous employer would offer them therapeutic employment, but this is rarely the case. After all, the previous employer did not renew the employment contract in the first place. It is therefore plausible that both the legal context of employment arrangements, as well as the personal attitude of employers, influences CSs' access to therapeutic employment.

Finally, motivation may play a role in the decision to participate in therapeutic work, as therapeutic work is often a form of preparation for return to paid work [36]. Potentially, CSs who participated in therapeutic work in this study, were more motivated to RTW, or were physically or mentally better prepared for RTW, than those who were not participating in therapeutic work. Previous studies in CSs, as well as studies in workers with other chronic illnesses, have shown that a better health status, and corresponding higher levels of work ability, may reduce the duration of sick leave and increases the likelihood of RTW [33,37-39]. Further, it has been widely documented that chronic illnesses, including cancer, may have a significant impact on the meaning that is attributed to work [40,41]. That is, after facing a life-threatening disease (return to) work may become less important, while family or hobbies may become more important [42,43]. Possibly, a change in the meaning of work, combined with the experience of job loss, has an impact on the extent to which CSs in this study were motivated to participate in therapeutic work and to RTW 16. However, such conclusions should be drawn cautiously, as other studies have also reported that work may remain important for CSs during and after treatment [36,42].

Strengths and limitations

The main strength of this study is that data were used from a national cohort of CSs in the Netherlands. There are also several limitations that should be mentioned. First, the sample of CSs in this study was relatively small. Also, because of substantial differences between the groups in this study, there is a possibility of residual confounding. Both these factors limit the generalizability of our results. Further, we know from previous studies that between 84-94% CSs returned to work within 24 months of sick leave [25]. As this study included CSs who did not yet return to paid work within 24 months, it is plausible that our results apply to CSs who, compared to (the majority of) CSs as described in other studies, struggle with RTW more, or in different ways. Also, as this was a longitudinal cohort study, no conclusive evidence with regard to causality can be drawn from our results. Finally, our results should be interpreted in the context of a national social security system, and translation of these results to non-Western countries should be done cautiously.

Implications for future research and practice

The findings of this study indicate that there may be a beneficial relationship between therapeutic work and return to paid work in workers with cancer. Further, we recommend that researchers investigate if RTW in CSs may be facilitated by providing access to therapeutic work or comparable forms of sheltered employment in a randomized controlled trial. Further, the extent to which our results can be extrapolated to larger populations of CSs and workers with other chronic illnesses, should be studied. Moreover, as flexible employment keeps increasing in Western countries [44], it is vital that practitioners and policymakers explore opportunities for access to therapeutic work and psychosocial resources, compatible with these new employment arrangements. The key to enhancing labour market participation of workers with chronic illnesses, could be for governments and institutions to offer or subsidize therapeutic employment arrangements, a responsibility which presently lies almost exclusively in the hands of employers.

Conclusion

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Participation in therapeutic work could be an important facilitator for return to paid work in sick-listed CSs. The effectiveness of therapeutic work as a means to return to paid employment should be studied in experimental settings. If effective, policymakers may pave the way to therapeutic work or similar constructs of sheltered work for CSs, particularly for those without an employment contract, in order to prepare for RTW in paid employment.

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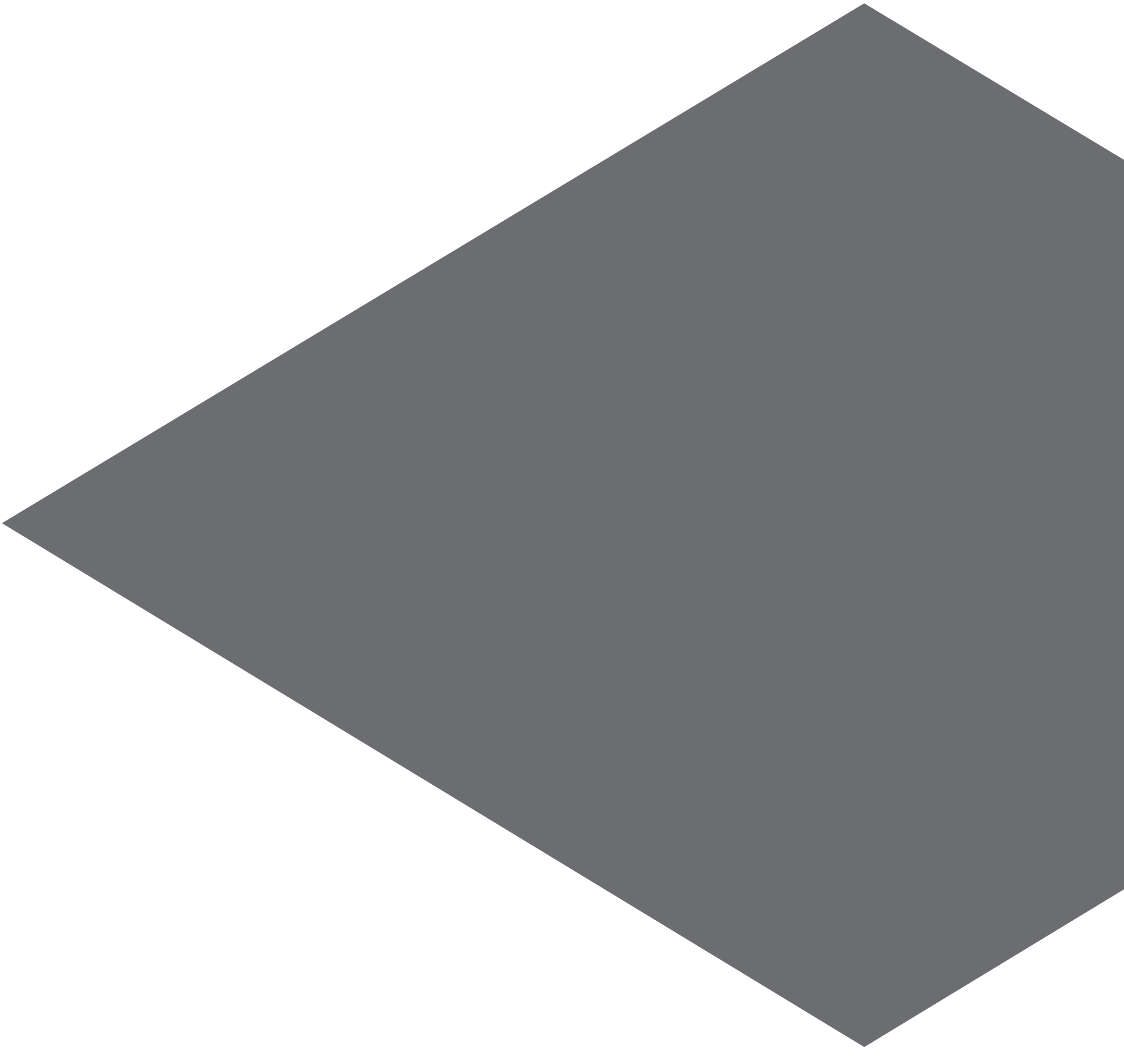

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Factors associated with (non-)participation of cancer survivors with job loss in a supportive return to work program

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Factors associated with (non-)participation of cancer survivors with job loss in a supportive return to work program

Abstract

Purpose: To evaluate and implement supportive programs, it is important to understand which CSs are participating in these programs, and which motives exist for declining participation. Recently, a supportive return to work (RTW) program was offered to CSs with job loss. The purpose of this study was to identify factors and motives associated with (non-)participation of CSs with job loss in the RTW program.
Methods: In this cross-sectional study (N=286), information on socio-demographics, health-related, psychosocial, and work-related characteristics of CSs in the RTW program was collected. Similar data were collected from those who declined participation. Multivariable logistic regression analyses were conducted ($p<0.05$) to identify factors associated with (non-)participation. Motives for declining participation were identified using descriptive analysis.
Results: Being married (odds ratio (OR) 0.23; 95% confidence interval (CI) 0.08-0.69) or living together (OR 0.25; 95% CI 0.07-0.96) decreased the likelihood of participation in the RTW program. Having a temporary employment contract prior to unemployment (OR 2.60; 95% CI 1.20-5.63), a clear intention to RTW (OR 2.65; 95% CI 1.20-5.82), and higher scores on a readiness to RTW instrument, i.e., contemplation scale (OR 2.00; 95% CI 1.65-2.40) and prepared for action-self-evaluative scale (OR 1.27; 95% CI 1.04-1.54), increased the likelihood of participation. Physical (50%) and mental problems (36%) were leading motives for declining participation.
Conclusions: The results from this study help to distinguish CSs that may not need RTW support, from those who are most in need of RTW support. Practitioners and researchers should tailor RTW support to CSs' socio-demographic, health-related and work-related characteristics.

Introduction

Annually, 1.7 million persons at working age (15-65 years) are diagnosed with cancer in the European Union, of which 40,000 in the Netherlands [1,2]. For most cancer survivors (CSs), motivation for work participation remains during and/or after treatment [3,4]. Eventually, 64% of CSs returns to work (RTW) [5]. However, a considerable part of CSs does not RTW. That is, CSs' work ability may be affected by long-term or permanent health problems, such as fatigue or cognitive impairments [6-8]. Further, other cancer-related, psychosocial and work-related factors, e.g., an unfavorable cancer prognosis and lack of support from employer and colleagues, may reduce the chance of RTW [9].

RTW can be especially challenging for CSs who become unemployed [10]. Between 26 and 53% of CSs lose their job or quit working during or after treatment [5]. In Western countries, these percentages have been increasing [11], which is partly explained by the increasing popularity of temporary employment contracts among employers [12] and the rising retirement age [13]. In the Netherlands, CSs who become unemployed during sick leave can apply for financial support, i.e., sickness benefits, at the Social Security Agency (SSA). These benefits partly cover the former salary, with a maximum of two years. During sick leave, RTW options are limited for CSs with job loss, as they lack support from an employer and colleagues, as well as opportunities for gradual RTW [14,15]. In contrast, CSs with a fixed employment contract benefit from employment security during the first 2 years of sick leave, i.e., a certain level of financial stability, RTW support, and options for workplace accommodations. Given this contrast, the RTW process of CSs with job loss may be more complicated than the RTW process of employed CSs [10]. To support Dutch CSs with job loss, a supportive RTW program was recently developed and offered in an experimental setting [16].

When offering supportive programs to CSs, it is important to consider the role of (non-)participation, as generally only a selection of the invited CSs participates in these programs [17]. For example, with regard to supportive RTW interventions for CSs in the Netherlands, in a previous hospital-based supportive RTW program for female CSs, 74% signed up to participate [18]. Further, in a study evaluating the effects of a high-intensity physical rehabilitation program on RTW for CSs who had received chemotherapy, 85% was interested to partake [19]. So far, factors and motives associated with (non-)participation of CSs have mainly been studied within the context of clinical trials, i.e., trials in which new cancer treatments are evaluated [20,21]. However, the circumstances for participation in clinical studies differ from those for participation in studies offering supportive programs. That is, clinical studies take place in a different setting, i.e., laboratory or hospital, and may appeal to a different kind of motivation for participation, e.g., receiving experimental treatment or financial incentives.

Evaluating (non-)participation in supportive programs for CSs may provide information to optimize recruitment procedures, and facilitate proper interpretation of the effects of these programs. Therefore, the aim of the current study is to identify factors and motives associated with (non-)participation of CSs with job loss in a supportive RTW program.

Methods

Design

In this cross-sectional study, we used data from CSs with job loss, invited to participate in a supportive RTW program within a randomized controlled trial (RCT). Questionnaire data of CSs interested to participate in the RTW program were collected, as well as data from CSs who declined participation, who were willing to complete a one-time questionnaire. The SSA provided additional data from all invited CSs, for comparison between participants and non-participants. The study procedures of the RCT have been published previously [16].

Study population

CSs with job loss were eligible for participation in the RTW program if they were registered at the SSA as recipients of sickness or disability benefits for a period of 12-36 months after first day of sick leave. Furthermore, eligible CSs were 18 to 60 years old; had completed intensive cancer treatment at least 6 weeks prior to the start of the RTW program; were free of comorbidities that interfered with participation (based on report by CSs' general physician). Also, their health had to be sufficient to participate (based on self-report). CSs were excluded from participation in case of the following: a lack of knowledge of the Dutch language; a conflict with the SSA regarding a (previous) benefits claim; and (registration for) participation in a concurrent scientific study and/or supportive program.

Study procedure

CSs with job loss were recruited through the SSA registries. Invitations were sent by mail to potentially eligible CSs, throughout the Netherlands, from April 2013 to January 2015. The invitation included an information flyer, a screening questionnaire, an informed consent form, and a postcard. CSs who were interested in participation in the RTW program could respond by returning the screening questionnaire and informed consent form. The researchers checked the in- and exclusion criteria during a telephone conversation, after which eligible CSs received a baseline questionnaire and a second informed consent form. After returning the baseline questionnaire and informed consent form, CSs were included in the study. After returning the baseline questionnaire and informed consent form, CSs were included in the study. At this point, an information letter was sent to CSs' general physician, to inform them about the study and ask them to notify the researchers of any comorbidities that could interfere with participation in the program. If so, the researchers would deliberate with the physician whether or not the program was appropriate. CSs could also decline by returning a postcard, on which they could indicate personal or predetermined motives for declining, e.g., "I am experiencing physical health problems" or "I have already found a new job". Further, CSs could disclose on the postcard whether they were interested in completing a one-time questionnaire. CSs who were interested received this questionnaire, including an informed consent form, shortly after their decline. The one-time questionnaire for non-participants in the supportive program was identical to the baseline questionnaire for participants.

The supportive RTW program

The supportive RTW program was developed as a tailored program, i.e., the more support CSs needed, the further they proceeded in the program. Participating CSs were supported by reintegration professionals to develop a consensus-based RTW plan, which included coaching on various themes, e.g., RTW planning or coping with cancer, and actual job placement. A detailed description of the supportive RTW program has been published previously [16].

Measurements

The dependent variable of the current study is participation (yes; no) in the supportive RTW program.
Independent variables potentially associated with the dependent variable were as follows:

- Socio-demographics: age (in years), gender (male; female), level of education (no education/primary school/lower vocational education; secondary school; vocational education/upper secondary school; upper vocational education/university), principal wage earner (yes; no), marital status (single; married; living together with partner, children and/or others; divorced/widowed), having children (yes; no), and ethnicity (Dutch; non-Dutch).
- Health-related and psychosocial variables: tumor type, treatment modalities (no treatment; surgery; radiotherapy; chemotherapy; hormone therapy; immunotherapy; other treatment (yes; no); being declared free of disease by physician/specialist (yes; no), comorbidity (yes; no), levels of depressive symptoms (assessed using Centre for Epidemiological Studies Depression Scale (CES-D), of which the scores were dichotomized, using the predetermined cut-off point of >16 points to indicate risk of clinical depression [22-24]), fatigue (assessed using the Functional Assessment of Chronic Illness Therapy Fatigue Scale (FACIT-Fatigue)) [25], coping preferences (assessed using the Utrecht Coping List (UCL)) [26], and general health and quality of life (levels of functioning), i.e., physical, emotional, social, cognitive and role functioning; sleeping problems and financial problems due to illness (assessed using the European Organization for Research and Treatment of Cancer Quality of Life Questionnaire (EORTC QLQ C-30)) [27].
- Work-related variables: characteristics of previous job, i.e., type of sector (blue collar; white collar; civil servant; health care worker), working hours (hours/week), shift work (yes; no), managerial tasks (yes; no), type of job demands (psychological; physical; both), type of employment contract (fixed; temporary; temporary agency work; other). Further, total number of years working, level of perceived work ability compared to lifetime best (assessed using the Work Ability Index (WAI)) [28], participation in society, e.g., participation in voluntary work, studies, and daily activities (assessed using the Utrecht Scale for Evaluation of Revalidation and Participation (USER-P), containing three scales: frequency of participation, restrictions in participation and satisfaction with participation [29]), and readiness to RTW (assessed using the Readiness to RTW instrument (RRTW)) [30], related to the five stages of change that are described in the transtheoretical model by Prochaska and DiClemente) [31], and intention to RTW (uncertain or no intention to RTW; clear intention to RTW) (assessed using the Attitudes-Social influence-self-Efficacy questionnaire (ASE)) [32].

Statistical analyses

Descriptive analyses, t-tests and chi-square tests were used to describe differences in self-reported socio-demographic, health-related and psychosocial, and work-related characteristics of participants (interested in the RTW program) and non-participants who completed the one-time questionnaire. Further, the SSA provided data regarding age, gender and cancer diagnosis for all invited CSs. T-tests and chi-square tests were used to study potential differences in characteristics among CSs in four groups, i.e., (1) participants (CSs interested to participate in the RTW program), (2) non-participants who completed the one-time questionnaire, (3) non-participants who only returned the postcard, and (4) CSs who did not respond to the invitation at all.

To construct a multivariable hierarchical model for participants and non-participants (one-time questionnaire), first, univariate analyses between the independent variables and the dependent variable, i.e., (non-)participation in the RTW program, were conducted. All variables with p-value < 0.2 were considered for the model and tested for multicollinearity before continuing analysis. Variables with correlation coefficients of <-0.8 or >0.8 were removed from the analyses [33].

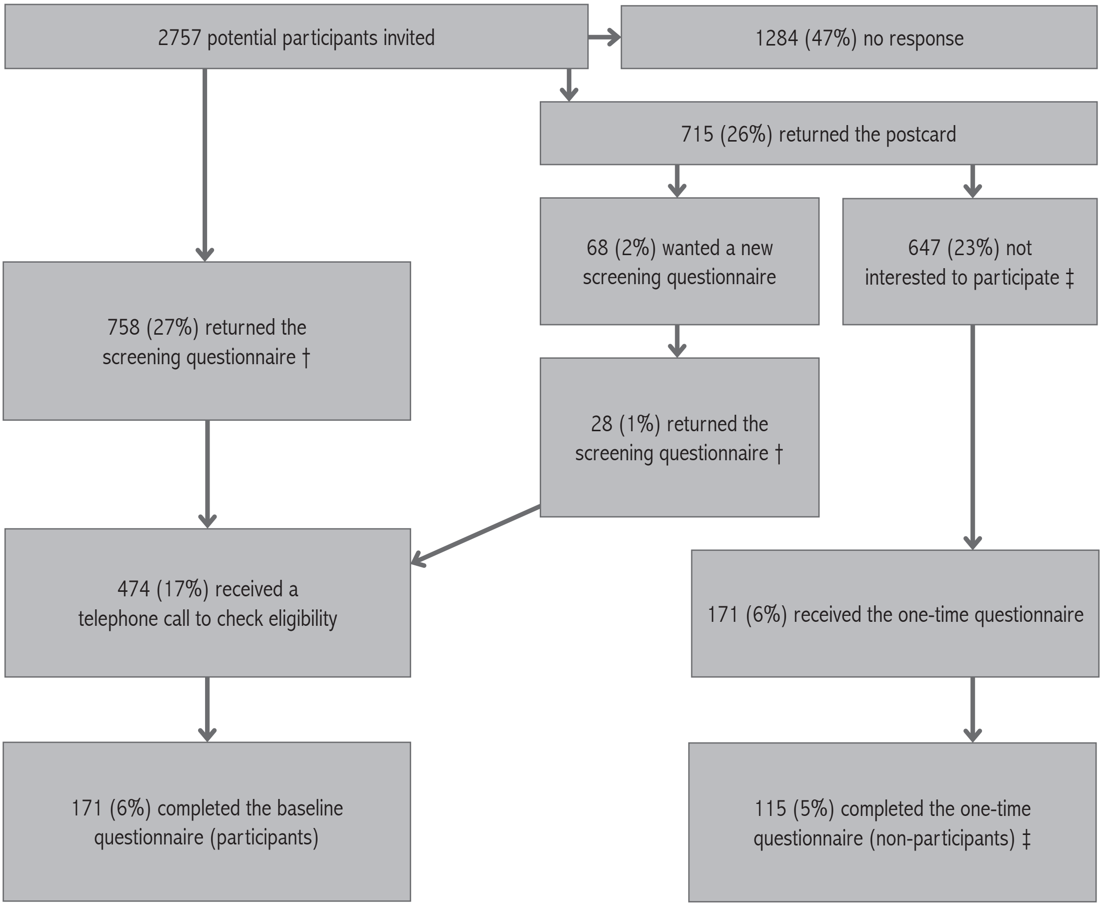
Using multiple logistic regression analysis, variables were entered into one of three cluster models, i.e., socio-demographic, health-related and psychosocial, or work-related model. All variables with a p-value < 0.1 in the cluster models were considered eligible for the multivariable model. The final multivariable model had a cut-off point of p-value < 0.05. Goodness of fit of the model was described using Nagelkerke R-squared. Using descriptive statistics, motives for declining to participate in the supportive RTW program were analyzed. SPSS version 20.0 was applied to conduct the analyses [34].

Characteristics of (non-)participants

Of the 2757 invited CSs with job loss, 786 (29%) were interested to participate in the supportive RTW program, of whom 171 met the inclusion criteria. Six hundred forty-seven CSs (23%) declined participation by returning the postcard. Of these, 115 (18%) completed the one-time questionnaire. One thousand two hundred eighty-four CSs (47%) did not respond to the invitation at all (Figure 1).

The mean age of participants in the RTW program was 48.4 years (SD 8.6), 69% was female, 57% was the principal wage earner, and 48% was married. In the group of non-participants (one-time questionnaire), the mean age was 50.9 (SD 8.9), 66% was female, 45% was the principal wage earner and 65% was married. In both groups, over 90% had the Dutch nationality, and the majority (39-40%) had suffered from breast cancer (Table 1).

Figure 1: Recruitment flow diagram*



* Percentages were calculated from the number of potential participants invited (N=2757). Combined percentages mentioned in the text may differ by 1% because of rounding differences; † 786 CSs were interested to participate in the program, calculated as the sum of 758 and 28 returned screening questionnaires; ‡ 532 CSs only returned the postcard (calculated as the difference between 647 CSs who returned the postcard and the 115 CSs who returned the postcard and the one-time questionnaire).

Table 1 Characteristics of (non-)participating CSs with job loss in a supportive RTW program.

Group	Variable	Categories	Participants (N=171)	Non-participants (N=115)	P-value*
			Mean (SD)	Mean (SD)	
Socio-demographics	Age (years)		48.4 (8.6)	50.9 (8.9)	0.015
			N (%) †	N (%) †	
	Gender	Male	53 (31)	39 (34)	0.569
		Female	118 (69)	75 (66)	
	Level of education	None/primary/lower vocational education	30 (18)	31 (27)	0.106
		Secondary school	28 (16)	24 (21)	
		Vocational education/upper secondary school	60 (35)	31 (27)	
		Upper vocational education/university	53 (31)	28 (25)	
	Principal wage earner	No	74 (44)	61 (55)	0.061
		Yes	96 (57)	50 (45)	
	Marital status	Living alone	36 (21)	13 (11)	0.031
		Married	81 (48)	74 (65)	
		Living together	28 (17)	16 (14)	
		Divorced/widowed	24 (14)	11 (10)	
	Having children	No	59 (35)	29 (25)	0.095
		Yes	112 (66)	86 (75)	
	Ethnicity	Dutch	163 (95)	105 (91)	0.170
		Non-Dutch	8 (5)	10 (9)	
Health-related and psychosocial factors	Tumor type	Breast	68 (40)	45 (39)	0.914
		Lung	3 (2)	11 (10)	0.003
		Gynecological	7 (4)	2 (2)	0.263
		Colon	13 (8)	9 (8)	0.944
		Gastro-intestinal	10 (6)	5 (4)	0.577
		Head and neck	8 (5)	4 (4)	0.620
		Skin/melanoma	0 (0)	4 (4)	0.014
		Prostate	3 (2)	5 (4)	0.192
		Hematological	23 (14)	7 (6)	0.046
		Brain	8 (5)	7 (6)	0.600
		Other type of cancer	24 (14)	9 (8)	0.107
		Cancer recurrence	4 (2)	7 (6)	0.106

	Treatment modalities	No treatment	2 (1)	0 (0)	0.247
		Surgery	124 (73)	93 (82)	0.079
		Radiotherapy	84 (49)	51 (45)	0.468
		Chemotherapy	109 (64)	70 (61)	0.689
		Hormone therapy	47 (28)	25 (22)	0.290
		Immunotherapy	13 (8)	7 (6)	0.636
		Other type of treatment	13 (8)	5 (4)	0.274
	Declared free of disease	No	56 (33)	49 (44)	0.063
		Yes	113 (67)	62 (56)	
	Comorbidity	No	87 (51)	46 (40)	0.081
		Yes	84 (49)	68 (60)	
	Depression	No depressive symptoms	101 (59)	68 (60)	0.968
		At risk of depression	69 (41)	46 (40)	
			Mean (SD)	Mean (SD)	
	Fatigue	(0-52)	33.0 (9.8)	30.0 (11.2)	0.018
	Coping	Active tackling (7-28)	18.6 (3.9)	17.0 (3.6)	0.001
		Seeking social support (6-24)	13.3 (4.0)	13.2 (3.4)	0.705
		Palliative reacting (8-32)	18.7 (3.4)	17.9 (3.3)	0.050
		Avoiding (8-32)	16.4 (3.5)	16.6 (3.2)	0.631
		Passive reacting (7-28)	12.7 (3.3)	12.3 (3.3)	0.320
		Reassuring thoughts (5-20)	12.5 (2.6)	12.4 (2.4)	0.779
		Expression of emotions (3-12)	6.0 (1.7)	5.8 (1.7)	0.290
	Health-related quality of life (levels of functioning)	Quality of life (0-100)	63.7 (17.3)	53.5 (21.1)	0.000
		Physical functioning (0-100)	78.8 (14.8)	68.4 (20.7)	0.000
		Emotional functioning (0-100)	64.1 (25.0)	64.2 (26.3)	0.947
		Social functioning (0-100)	69.0 (26.0)	60.2 (26.6)	0.006
		Cognitive functioning (0-100)	66.5 (26.9)	64.7 (25.5)	0.590
		Role functioning (0-100)	63.1 (26.4)	54.5 (28.7)	0.010
		Sleeping problems (0-100)	37.8 (33.8)	44.1 (33.4)	0.126
		Financial problems (0-100)	40.6 (35.6)	37.8 (32.1)	0.495

* P-values are the result of T-tests and chi-square tests for univariate associations between participants and non-participants; † N and calculated percentages may approach or exceed the total N and 100% because of missing values or rounding differences.

Table 1 Characteristics of (non-)participating CSs with job loss in a supportive RTW program (continued)

Group	Variable	Categories	Participants (N=171)	Non-participants (N=115)	P-value*
Work-related factors			N (%)†	N (%)†	
	Type of sector previous job	Blue collar	12 (7)	11 (10)	0.616
		White collar	58 (35)	43 (39)	
		Civil servant	56 (33)	35 (32)	
		Health care worker	42 (25)	22 (20)	
	Type of previous employment contract	Fixed employment	49 (23)	55 (50)	0.001
		Temporary employment	95 (57)	41 (37)	
		Temporary agency work	21 (13)	10 (9)	
		Other type of contract	2 (1)	5 (5)	
	Shift work previous job	No	51 (30)	36 (32)	0.727
		Yes	118 (70)	77 (68)	
	Managerial tasks previous job	No	134 (79)	90 (80)	0.942
		Yes	35 (21)	23 (20)	
	Previous job demands	Psychological and physical	51 (30)	46 (42)	0.030
		Mainly psychological	73 (44)	31 (28)	
		Mainly physical	44 (26)	33 (30)	
	Intention to RTW	Uncertain or no intention to RTW	49 (29)	72 (64)	0.000
		Clear intention to RTW	122 (71)	40 (36)	
			Mean (SD)	Mean (SD)	
	Total number of years working		24.1 (10.1)	26.7 (10.5)	0.038
	Working hours a week previous job		28.9 (11.5)	27.3 (11.9)	0.246
	Work ability	(0-10)	4.6 (2.0)	3.3 (2.5)	0.000
	Participation in daily activities	Frequency of participation (0-100)	32.1 (8.2)	28.9 (10.9)	0.006
		Restrictions in participation (0-100)	81.8 (13.8)	75.4 (18.5)	0.001
		Satisfaction with participation (0-100)	63.5 (15.2)	62.3 (16.1)	0.542
	Readiness to RTW stages	Precontemplation (1-15)	4.9 (2.1)	6.9 (3.4)	0.000
		Contemplation (1-15)	12.1 (1.9)	8.7 (2.9)	0.000
		Prepared for action - self evaluative (1-10)	6.8 (1.8)	5.3 (2.5)	0.000
		Prepared for action - behavioral (1-15)	9.8 (2.2)	9.4 (3.2)	0.302

* P-values are the result of T-tests and chi-square tests for univariate associations between participants and non-participants; † N and calculated percentages may approach or exceed the total N and 100% because of missing values or rounding differences.

Using the SSA data, we found no significant differences in gender between participating CSs and any of the non-participating CSs. Participating CSs were significantly younger than non-participants who completed the one-time questionnaire (mean difference (MD) 2.6 years; p=0.015) and non-participants who only returned the postcard (MD 1.9 years; p=0.012). CSs who did not respond to the invitation at all were significantly younger compared to the other CSs, i.e., participants (MD 2.6 years; p < 0.001), non-participants (one-time questionnaire) (MD 4.8 years; p < 0.001), and non-participants (postcard only) (MD 4.6 years; p < 0.001). Also, the proportion of breast cancer survivors was significantly lower in CSs that did not respond to the invitation at all than participants (p < 0.001), non-participants (one-time questionnaire) (p=0.014) and non-participants (postcard only) (p=0.015). The proportions of other cancer diagnoses were too small for analysis.

Factors associated with (non-)participation in the RTW program

Questionnaire data from participants (N=171) and non-participants (one-time questionnaire) (N=115) were merged into a sample of 286. The univariate analysis identified 31 factors associated with (non-)participation in the RTW program (Table 1). These factors were considered for multiple regression analysis within their cluster, i.e., socio-demographic, health-related and psychosocial, or work-related cluster. The factors "diagnosis: skin cancer/melanoma" and "treatment modalities: no treatment" were removed due to the low number of cases.

In the cluster models, 11 factors were associated with a lower chance of participation in the RTW program, i.e., higher age, marital status (married or living with someone), having had lung cancer and/or surgery, having no/an unclear intention to RTW, having had a fixed employment contract, having had both physically and psychologically high demands in a previous job, and lower scores on various scales, i.e., physical functioning, coping preference - active tackling, readiness to RTW - contemplation phase, readiness to RTW - prepared for action-self-evaluative phase. These factors were entered into a multivariable model (Table 2).

The multivariable model showed that CSs with job loss who were married (OR 0.23; 95% CI 0.08-0.69) or living together (OR 0.25; 95% CI 0.07-0.96) were significantly less likely to participate than CSs living alone. CSs who had a temporary employment contract prior to job loss, were significantly more likely to participate than CSs who had had a fixed employment contract prior to loss of employment (OR 2.60; 95% CI 1.20-5.63). Also, CSs with a clear intention to RTW were significantly more likely to participate than CSs with no or an unclear intention to RTW (OR 2.65; 95% CI 1.20-5.82). Finally, higher scores on the contemplation scale (OR 2.00; 95% CI 1.65-2.40) and the prepared for action - self-evaluative scale (OR 1.27; 95% CI 1.04-1.54) of the Readiness to RTW scale, meaning that a person is contemplating RTW or starting to prepare for RTW, were significantly associated with participation in the program. The Nagelkerke R-squared demonstrated that the model is of reasonable quality (p-value 0.580).

Table 2 Multivariable model of factors associated with (non-)participation of cancer survivors with job loss in the supportive RTW program*

Group	Factor	Categories	Odds ratio (95% CI)	P-value
Socio-demographics	Marital status	Living alone	Ref.	
		Married	0.23 (0.08-0.69)	0.009
		Living together	0.25 (0.07-0.96)	0.044
		Divorced/widowed	0.82 (0.18-3.67)	0.790
Work-related factors	Type of employment contract prior to loss of employment	Fixed employment contract	Ref.	
		Temporary employment contract	2.60 (1.20-5.63)	0.016
		Temporary agency work contract	2.41 (0.71-8.17)	0.157
		Other type of contract	0.24 (0.25-2.38)	0.224
	Intention to RTW	Uncertain or no intention to RTW;	Ref.	
		Clear intention to RTW	2.65 (1.20-5.82)	0.015
	Readiness to RTW stage 2: Contemplation †		2.00 (1.65-2.40)	0.000
	Readiness to RTW stage 3: Prepared for action- self evaluative †		1.27 (1.04-1.54)	0.017

* The model is based on 261 CSs, because of missing values; † Higher score in this stage is associated with a higher chance of participation in the RTW program.

Motives for declining participation in the supportive RTW program

The most frequently reported motives for declining participation were physical motives (50.4%), e.g., experiencing physical limitations or still undergoing cancer treatment, and mental motives (36.3%), e.g., experiencing anxiety or depression (Table 3). On over 40% of the postcards, more than one motive for declining participation was listed.

Table 3 Motives for declining participation in the supportive RTW program*

Motives	Non-participants N (% of 647)	Non-participants postcard N (% of 532) †	Non-participants questionnaire N (% of 115) ‡	P-value**
Physical reasons	326 (50.4%)	282 (53.0)	44 (38.3)	0.004
Mental reasons	235 (36.3%)	210 (39.5)	25 (21.7)	0.000
Negative associations with RTW	87 (13.4%)	78 (14.7)	9 (7.8)	0.051
Not willing to participate in a RCT	34 (5.3%)	30 (5.6)	4 (3.5)	0.346
Personal reasons	27 (4.2%)	23 (4.3)	4 (3.5)	0.681

* CSs could indicate multiple motives for declining participation; † Non-participants who returned the postcard, indicating reasons for declining participation; ‡ Non-participants who completed the one-time questionnaire; ** P-values are the result of chi-square tests between the two groups of non-participants.

Discussion

Main findings

The results of this study demonstrate that CSs who were unmarried and/or lived alone, and who had a temporary employment contract prior to job loss, a clear intention to RTW, and higher scores on the contemplation scale and the prepared for action-self-evaluative scale of the Readiness to RTW scale were more likely to participate. Physical and mental problems were the main reasons for declining participation.

Interpretation of the findings

Non-participants (one-time questionnaire and postcard only) and participants in this study were significantly older than CSs who did not respond to the invitation at all. Previous studies have shown that younger CSs are more likely to RTW [16,35-37]. In the general population, younger persons are less challenged in finding new employment, and may need less support, compared to older persons [38]. This might be true for CSs as well. That is, facing fewer RTW challenges than older CSs could explain why younger CSs were less interested to participate in a supportive RTW program. This could imply that supportive RTW interventions should be directed more towards the needs of older sick-listed workers [39].

Further, groups of non-participants (one-time questionnaire and postcard only) and participants included significant higher proportions of breast CSs, compared to non-participants who did not respond to the invitation at all. This seems in line with previous studies, which also found that breast CSs participate frequently in supportive interventions [40,41]. The relatively high number of breast CSs in our supportive RTW program may be partly explained by the generally favorable prognosis of breast cancer, and relatively low impact on work ability, compared to other types of cancer in the occupational age [7].

CSs with job loss who were married or living together were less likely to participate in the RTW program than CSs who lived alone. In line with our findings, an earlier study reported that married CSs are at risk for non-participation in supportive programs, compared to unmarried CSs [42]. Another study found that married CSs were more likely to leave the workforce compared to unmarried CSs, although this effect was only found for women [43]. Possibly, married CSs are discouraged to RTW by their spouse for protective reasons. Further, married CSs may not have financial motive for RTW, as their spouse may provide an additional source of income [43]. In these studies, job loss was not taken into account. Potentially, in our study, a lack of financial motive, or a protective attitude from a spouse, prevented married CSs from participation in the supportive RTW program. Conclusively, the factors determining participation of CSs who are married or living together may be more complex compared to factors influencing participation of CSs who are living alone.

CSs with a temporary employment contract prior to job loss were more likely to participate in the RTW program, compared to those with a fixed employment contract prior to job loss. It should be taken into account that, in the Netherlands, CSs with a temporary employment contract may experience job loss earlier in the cancer trajectory, as employers frequently do not renew an expiring temporary contract during sick leave [10,15]. Consequently, CSs with a temporary employment contract may have had more urgent financial needs, less RTW support and more time to consider and prepare for RTW, compared to CSs with a fixed employment contract [10]. This may make CSs with a temporary employment contract more inclined to participate.

A clear intention to RTW was associated with a higher chance of participation in the supportive RTW program. Another recent study indicated that intention to RTW is a strong predictor for actual RTW [9], although not specifically for CSs with job loss. Further, CSs with higher scores on the contemplation scale and the prepared for action - self-evaluative scale of the Readiness to RTW instrument were more likely to participate in the RTW program. As the scales reflect contemplation of RTW and preparation for RTW [30], we hypothesize that, for CSs with job loss with higher scores on these scales, the invitation to participate in the RTW program arrived at a suitable moment.

Interestingly, there was a discrepancy between the multivariable model, which included factors from the socio-demographic and work-related clusters, and the self-reported motives for declining participation, which were more health-related. Possibly, there are undetected differences with regard to health status between the non-participants (one-time questionnaire), and the non-participants who only returned the postcard. In this perspective, the multivariable model may represent CSs with job loss who have a relatively good health status.

Strengths and limitations

The strengths of this study are that data were used from CSs who were recruited on a national level, and that a clustered hierarchical analysis approach was applied. The limitations of this study should be recognized as well. First, there is a risk of selection bias in our sample, which might affect generalizability, particularly with regard to CSs experiencing a worse health condition. That is, participants in the RTW program were screened on health-related criteria to determine eligibility for the RCT, while no screening was applied to non-participants, as there was little to no contact with those survivors. If the one-time questionnaire had also been completed by CSs who did not meet the inclusion criteria, this would have improved the generalizability of our results. Further, CSs who do not master the Dutch language may be underrepresented in this study, due to the exclusion criteria of the RCT. Finally, the results of this study should be interpreted in the context of the Dutch social security system. Translating our results to other social security systems should be done cautiously.

Implications for future research and practice

Researchers and practitioners offering RTW support to CSs with job loss should take the presence of (financial) support from a spouse into account, as this may play an important role in the decision of CSs to receive RTW support [42,43]. Further, in CSs who had a temporary employment contract, the need for RTW support should be monitored from the start of sick leave, in order to adequately intervene [44]. Practitioners should also inquire about the intention and perceived readiness to RTW [5]. This may facilitate the planning and execution of RTW, e.g., determining the time to RTW or gradual buildup of the workload [10.] Researchers recruiting CSs with job loss for supportive RTW programs should be aware of the role of physical and mental health problems as barriers for participation [17].

Conclusion

Marital status, type of employment contract and motivational factors may influence CSs' participation in a supportive RTW program. Considering these factors may aid the identification of CSs who do not need RTW support, and those who are in need of RTW support the most. Practitioners and researchers should take CSs' socio-demographic, health-related and work-related characteristics into account, when offering RTW support. We recommend that future studies in CSs, or other patients with long-term or chronic conditions, collect data regarding (non-)participation. This information can be used to optimize recruitment strategies for supportive RTW programs, in order to provide sick-listed workers with the RTW support that they may need.

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6

Offering a tailored return to work program to cancer survivors with job loss:

a process evaluation

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Offering a tailored return to work program to cancer survivors with job loss: a process evaluation

Abstract

Background: In Europe, 1.7 million persons of working age are diagnosed with cancer each year. During or after treatment, cancer survivors (CSs) are vulnerable for job loss, and many CSs struggle with return to work (RTW). When offering RTW interventions to CSs, it is important to conduct a process evaluation to assess such factors as the population reached and implementation problems. Recently, we developed an innovative RTW program, tailored specifically to the needs of CSs with job loss in the Netherlands. The aim of this study was to evaluate the likelihood of theory and implementation failure, as well as to evaluate procedures for recruitment, execution and implementation of the tailored RTW program for CSs with job loss.

Methods: Six components were evaluated in the RTW program: Recruitment, Reach, Dosage, Implementation, Satisfaction, and Experienced Barriers. Data were provided by logbooks and questionnaires from participating CSs, occupational health care (OHC) professionals, and re-integration coaches and job hunting officers who delivered the RTW program. SPSS and Excel were used to conduct the analyses.

Results: 85 CSs received the tailored RTW program. Their mean age was 47.9 years (SD 8.5). The majority were female (72%), married (52%), and of Dutch nationality (91%). The program reached 88.2% of the target population and 52% of participants who started the program received the adequate dosage. The program implementation score was 45.9%. Participants' mean overall program duration remained within the protocol boundaries. Re-integration coaches were more satisfied with the program than job hunting officers or OHC professionals. Likewise, participants were more satisfied with the program delivery by the re-integration coaches than with the delivery by the job hunting officers. Reported barriers within the RTW program were a lack of communication, high program intensity and short program duration, and, with regard to the job hunting officers, a lack of experience with cancer-related RTW problems.

Conclusions: Participants, OHC professionals, re-integration coaches and job hunting officers generally had positive experiences with the innovative tailored RTW program. Facilitating communication between the delivering parties, and engaging usual care during program delivery, could be key elements to improved program implementation.

Background

Each year, 3.45 million people are diagnosed with cancer in the European Union [1]. Of these, around half are persons of working age (aged between 15 and 64 years) [2]. The marked impact of cancer on workers has been documented by multiple studies [3-5]: in the first 6 years after diagnosis, between one quarter and half of cancer survivors (CSs) become unemployed [6, 7]. Across studies, CSs are 1.4 times more likely to become unemployed than healthy controls [8], and many CSs struggle with return to work (RTW) [6, 9]. A limited number of RTW interventions have been developed specifically for CSs [10, 11]. A review found 18 studies that offered re-integration interventions for CSs, of which three programs focused specifically on RTW [12]. From these studies, no definitive conclusions could be drawn with regard to the effectiveness of RTW programs for CSs. Also, the quality assessment of these studies revealed that the overall quality was low, and that study procedures should be improved in the future [12].

The first step to improving study procedures and program delivery is to evaluate the procedures of ongoing studies and programs, by conducting a process evaluation [13]. Process evaluations can be conducted alongside the delivery of intervention programs, and are aimed at assessing several process outcomes, such as the extent to which the target population was reached and the intervention was delivered according to protocol [14, 15]. Process evaluations allow researchers to better understand the individual intervention components, including their relation to each other, potential barriers to their implementation, and their impact on the intervention aims evaluation [13, 16, 17]. Further, process evaluations enable researchers to evaluate the likelihood of theory or implementation failure by linking the outcomes of the process evaluation to the effects of the program [15]. They also provide insight into the perceptions of the participants and stakeholders involved, and can contribute to the quality of future intervention studies. Moreover, the feasibility of, and incentives for, future implementation of an intervention program in daily practice can be identified through a process evaluation.

Recently, a tailored RTW program was delivered to sick-listed CSs with job loss in the Netherlands [18]. Previous studies have demonstrated that, for these CSs, RTW may be particularly challenging because of limited access to the labour market, the absence of opportunities for gradual RTW and workplace accommodations, and lack of support from an employer and colleagues. A tailored RTW intervention program could be an important step towards paid employment for these CSs [19]. Three organizations were contracted to deliver the program to the participants, and the program was implemented in cooperation with the Dutch Social Security Agency (SSA), as it is the agency with the primary legislative responsibility to support workers who lose their employment contract [20]. Given the multi-component character of the program, and the number of professionals involved [13], it was considered especially desirable to conduct a process evaluation alongside the tailored RTW program. Consequently, alongside the delivery of this program, data regarding process outcomes were collected.

This is one of the first studies in which an intervention for workers with job loss was developed, in cooperation with multiple organizations, and the occupational health services from the SSA. No previous studies of this kind were aimed at sick-listed workers due to cancer [21-23]. Therefore, the aim of this study was to gain insight into the feasibility of delivering the tailored RTW program to CSs with job loss in the Netherlands. Specifically, this study evaluated the procedures regarding recruitment, execution and implementation of the tailored RTW program, and evaluated the likelihood of theory and implementation failure. As the results with regard to the effectiveness of the program were not available at the time, this process evaluation will not link the program's process outcomes to the effectiveness outcomes.

Methods

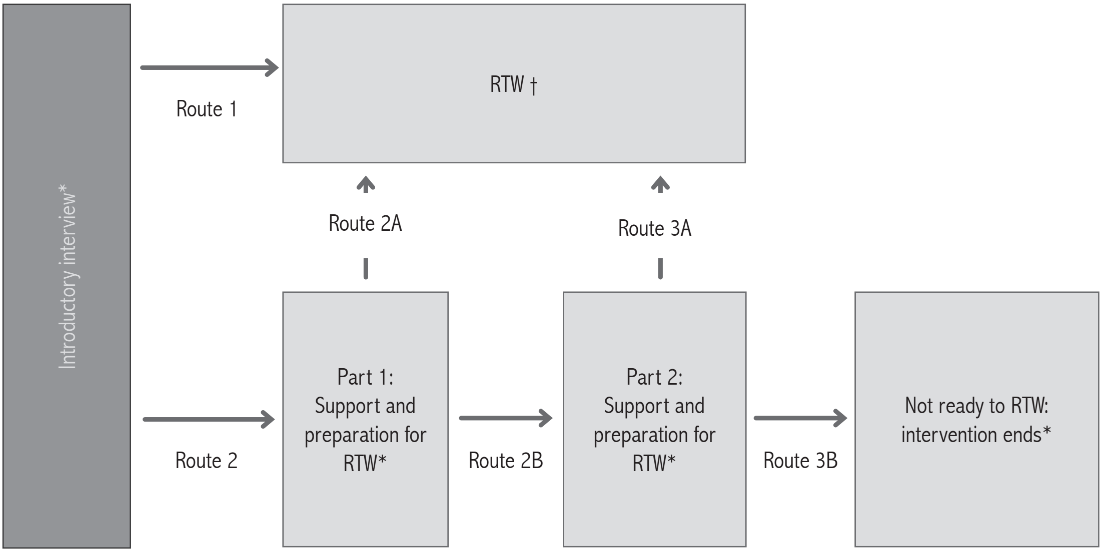
Design and procedures

This study concerns a process evaluation of the recruitment procedures, execution and implementation of a tailored RTW program for CSs with job loss in the Netherlands, which was offered within an experimental setting. The full study procedures and design of the RTW program have been published previously [18]. In summary, potentially eligible CSs with job loss were recruited for the RTW program from April 2013 to January 2015, by an invitation from the SSA. CSs who were interested in participating completed a screening questionnaire, after which the researchers contacted them by telephone to discuss participation. Those who were eligible to participate received a baseline questionnaire and informed consent form, and were included in the study after the completion and return of both. An information letter was sent to each participant's general physician (GP) to inform them of their patient's participation in the study, and to ask if there were any medical contra-indications for participation. If so, the researchers would deliberate with the GP whether participation in the program was appropriate. After enrolment in the study, CSs were randomly allocated to the intervention or control group. Participants in the intervention group received the tailored RTW program, as well as usual care provided by OHC professionals from the SSA.

Tailored RTW program

The tailored RTW program consisted of three parts: an introductory interview, a "Preparation for RTW" part, and a "RTW" part. The tailored RTW program encouraged participants to engage in developing a consensus-based RTW plan, to actively participate in coaching sessions to prepare for RTW, and to explore opportunities for RTW in therapeutic work or paid employment. The tailored aspect of the program was embedded in participants' ability to select various routes in the program, which matched the individually required level of RTW support. The program is presented in Figure 1.

Figure 1. Design of the tailored RTW program



*Carried out by the re-integration coaches; † carried out by the job hunting officers

For all participants, the tailored RTW program started with an introductory interview with a re-integration coach. In this interview, the coach and participant identified obstacles and possibilities for RTW. Drawing on this assessment, they chose a suitable route through the intervention program, by discussing if the participant was ready to "RTW" or if "Preparation for RTW" was needed. In addition, the participant's expectations and present RTW activities were discussed. Participants who were already actively applying for jobs started with the "RTW" part of the program (Figure 1: Route 1 in the program). In this part of the program, the coach would end the introductory interview by drawing up a short work profile, which included the participant's wishes and capabilities for work. The work profile was used in the communication between the participant and one or two job hunting agencies. The job hunting agencies then attempted to place the participant in therapeutic or paid work that matched the participant's wishes and capabilities. The staff at the two job hunting agencies that delivered the "RTW" part consisted mainly of vocational therapists or human resource experts. It should be mentioned that the job hunting agency staff had no specific expertise with regard to cancer. As the job hunting agencies had several locations across the Netherlands, participants travelled to the local office nearest to them for meetings with the agency.

For participants who concluded in their introductory interview that they were not involved in RTW activities (e.g., applying for jobs), the coach and participant decided that the participant would start with the "Preparation for RTW" part (Route 2 in the program). A re-integration agency, specialized in RTW coaching for CSs, delivered this part of the program (developing a RTW plan, coaching, and constructing a work profile). The coaches from this re-integration agency also conducted the introductory interviews at the start of the program. In general, these coaches were mostly former cancer patients who had experience with cancer survivorship and job loss. They had participated in training and education to become a RTW coach for cancer survivors. The meetings for the "Preparation for RTW" part of the program were held at the participant's home or at a nearby office of the re-integration agency.

All program meetings between participants and re-integration coaches or job hunting agency personnel were face-to-face meetings. The program did not employ any peer-group activities. Alongside the "Preparation for RTW" part of the program, it was possible for participants to be referred to specialist physical or psychological care. This could happen if the participant and coaches concluded that the participant needed specialist care for such problems as extreme fatigue, psychological stress or trauma. Within the intervention program, the re-integration coaches registered when they referred participants to specialist care, but the content and duration of this care was not monitored as this was part of regular usual care within the Dutch healthcare system. The specific content of the program routes are described extensively below. The full content of the tailored RTW program was previously published as part of the study protocol [18].

Route 1: The coach and participant decided that the participant was ready to RTW. The coach contacted the researchers, who randomly assigned the participant to one of the two job hunting agencies (by using randomisation software). The participant and the selected agency held a meeting to explore job opportunities. According to the study protocol, the agency was expected to find at least two suitable jobs that matched the participants' work profile, and their wishes for RTW. Further, these jobs could be either therapeutic or paid work, and had to be offered for at least three months. The protocol further dictated that the job hunting agencies should arrange for two job options within four weeks after the first meeting with the participant. If the agency was unable to meet these requirements, the second job hunting agency involved in this study joined the search for jobs.

Route 2: The coach and participant decided that the participant was not yet ready to RTW yet, and that (s)he needed preparation for RTW. In the following weeks, the participant and coach created a work profile, based on the participant's wishes and needs for return to work. Also, the participant's working experience and capabilities were taken into account. Alongside the development of the work profile, the re-integration coach held four to five individual coaching sessions with the participant. These sessions were scheduled to last for 1-1.5 hours and were aimed at themes that the participant and the coach selected together. Within the protocol, eight predetermined themes were available, with the additional option to deviate from these themes if necessary. Examples of predetermined coaching themes were: "fatigue and managing energy levels and RTW", "communication about cancer at work" and "stress, fluctuations in work ability and managing work, private life and recovery". When the work profile and coaching sessions were completed, the participant and coach re-evaluated whether the participant was ready to RTW (Route 2A or Route 2B).

Route 2A: The coach and participant decided that it was time to RTW. The coach contacted the researchers, after which a job hunting officer was randomly assigned to the case of the participant. This route is similar to Route 1 (described above).

Route 2B: The coach and participant decided that the participant needed more preparation for RTW. The coach and participant held four to five additional coaching sessions focused on preferred themes. This process is similar to the process described in Route 2, with the exception that the work profile was completed at this stage. After participating in additional coaching sessions, the coach and participant re-evaluated if the participant was ready to RTW (Route 3A or Route 3B).

Route 3A: The coach and participant decided that the participant was ready to RTW. The coach contacted the researchers, after which a job hunting agency was randomly assigned to the participant's case. This route is similar to Route 1 (described above).

Route 3B: It could be that the coach and the participant concluded that the participant was not ready to RTW after receiving the full "Preparation for RTW" part of the program. In that case, the intervention program was terminated and the participant's case was referred to usual care for follow-up.

The maximum duration of the tailored RTW program was 7 months. The maximum duration of the "Preparation for RTW" part was 3 months; the maximum duration of the "RTW" part was also 3 months, and 1 month delay was calculated to allow for unforeseen events, such as illnesses or holidays. After participants completed the tailored RTW program, the researchers sent process evaluation questionnaires to the teams of OHC professionals, the coaches and the job hunting agencies. For participants, process evaluation questionnaires were sent 6 months after the start of their RTW program. Additionally, the researchers, as well as the re-integration coaches and job hunting officers who delivered the RTW program, kept logbooks on their activities and progress during program delivery.

Target population

The target group for the tailored RTW program were CSs who were 18-60 years of age, had completed intensive cancer treatment, and were registered at the SSA as recipients of sickness or disability benefits due to cancer. CSs had to be sick-listed for a period of minimum 12 months and maximum 36 months. The 12-month cut-off value was chosen in accordance with the Dutch social security legislation, in which eligibility for benefits has to be re-evaluated after 12 months of sick leave. The limit of 36 months was chosen because data past 36 months of sick leave were not accessible at the SSA. The complete inclusion and exclusion criteria for participation in the RCT were previously published as part of the study protocol [18].

Measures and data analysis

This process evaluation consisted of assessing six components within the tailored RTW program: Recruitment, Reach, Dosage, Implementation, Satisfaction, and Experienced Barriers. Relevant literature from Steckler and Linnan [15], as well as previously published frameworks, such as the RE-AIM (Reach, Effectiveness, Adoption, Implementation, and Maintenance) framework [24, 25], were taken into account in the design of this process evaluation. All reported results were based on available data: no measures of imputation were used to replace missing data. An overview of the process evaluation components is presented in Table 1. To analyze the data, we calculated descriptive statistics using Excel 2010 and SPSS 22.0 [26].

Table 1. Components of the process evaluation and data sources for evaluation

Components	Definition of the component	Data sources for component evaluation
Recruitment	Result of the recruitment procedures for participants	Research logbooks
Reach	Proportion of eligible participants who started participation in the tailored RTW program.	Research logbooks
Dosage	Flow diagram of proportion of chosen routes in the RTW program, and calculated adequate dosage of the program for participants. Frequency of chosen themes during coaching and additional referral to physical or psychological rehabilitation care.	Research and intervention logbooks
Implementation	Composite score of reach and dosage	Scores on reach and dosage
Satisfaction	Participants' satisfaction with the content, intensity, and duration of the tailored RTW program, OHC professionals' satisfaction of the use of the program along usual care; coaches' and job hunting officers' satisfaction in working with the program.	Questionnaires for participants, OHC professionals, coaches and job hunting officers
Experienced Barriers within the tailored RTW program	Summary of barriers in following or executing the RTW program as experienced by participants, coaches and job hunting officers. Reasons for not being referred to RTW.	Research and intervention logbooks, questionnaires, minutes from meetings

Recruitment

'Recruitment' was defined as the result of all procedures to recruit eligible CSs for participation in the tailored RTW program. At the level of the participants, data regarding response were obtained from the research logbooks and displayed in a participant recruitment diagram. Recruitment was not evaluated at the organizational level (i.e., level of the OHC professionals, coaches and job hunting agencies), as the involvement of these organizations depended on the participant's route through the intervention program.

Reach

'Reach' was defined as the proportion of the target group that participated in the tailored RTW program. Participation in the program was defined as participating at least in the introductory interview, because this step was crucial as a starting point for each participant's program. These data were provided by the research and intervention logbooks from the researchers and re-integration coaches.

Dosage

'Dosage' was defined as the proportion of participants who started the program, who received an adequate dose of the tailored RTW program. Adequate dose was defined as having received a job offer through the services of the job hunting agency during the program. Participants who did not meet with the job hunting agency, because they had already found a job or decided to found their own company during the "preparation for RTW" part of the program, were also considered to have received an adequate dose.

Further, the number of times each step in the RTW program was delivered, was described. Also, the mean overall duration of the RTW program, and range of duration between participants, was calculated. Additionally, it was reported if, and which, themes were discussed in the coaching sessions of the RTW program, and if the coaches referred participants to specialist physical or psychological rehabilitation care, alongside the RTW program. These data were provided by the intervention logbooks from the re-integration coaches and job hunting officers.

Implementation

‘Implementation’ was defined as a composite score of the results of the components ‘reach’ and ‘dosage’, and was calculated by multiplying these proportions.

Satisfaction

‘Satisfaction’ was defined as the extent to which the content, intensity, duration and delivery of the tailored RTW program was satisfactory according to the participants, OHC professionals, coaches and job hunting officers. Overall satisfaction and experience scores were calculated for each group. These data were captured by the process evaluation questionnaires. The OHC professionals, coaches and job hunting officers received one process evaluation questionnaire for each participant that was under their care.

Experienced Barriers within the program

This component summarized the experienced barriers with regard to participation in, or execution of, the tailored RTW program, as experienced by participants, OHC professionals, coaches and job hunting officers. These data were provided by the logbooks, process evaluation questionnaires, and by minutes from meetings between the researchers, the SSA, re-integration coaches and job hunting officers.

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Target population

The characteristics of participants in the tailored RTW program are described in Table 2. The recruitment of these participants was described as a component of the process evaluation (see below). The mean age of the participants was 47.9 years (SD 8.5). The majority were female (72%), married (52%), had children (65%) and were of Dutch nationality (91%). More than half of the participants were the principal wage earner of their household (54%). Breast cancer was the most prevalent cancer among all participants (35%).

Table 2. Baseline characteristics of CSs with job loss who participated in the intervention group of the RCT

Variable	Categories	Participants (N=85)
		Mean (SD)
Age in years		47.9 (8.5)
		N (%)*
Gender	Male	24 (28)
	Female	61 (72)
Level of education	None/primary / lower vocational education	12 (14)
	Secondary school	18 (21)
	Vocational education/upper secondary school	32 (38)
	Upper vocational education/ university	23 (27)
Marital status	Living alone	17 (21)
	Married	43 (52)
	Living together	12 (15)
	Divorced/widowed	11 (13)
Having children	No	30 (35)
	Yes	55 (65)
(non-)Dutch nationality	Dutch	77 (91)
	Non-Dutch	8 (9)
Principal wage earner	No	39 (46)
	Yes	46 (54)
Type of sector previous job	Blue collar	7 (8)
	White collar	27 (33)
	Civil servant	26 (31)
	Health care worker	23 (28)

Type of employment contract prior to loss of employment	Fixed employment contract	25 (30)
	Temporary employment	47 (57)
	Temporary agency work contract	10 (12)
	Other type of contract	1 (1)
Previous job demands	Psychological and physical	27 (33)
	Mainly psychological	36 (43)
	Mainly physical	20 (24)
Tumor type	Breast	30 (35)
	Lung	1 (1)
	Gynecological	4 (5)
	Colon	10 (12)
	Gastro-intestinal	6 (7)
	Head and neck	2 (2)
	Skin/ melanoma	0 (0)
	Prostate	2 (2)
	Hematological	12 (14)
	Brain	1 (1)
	Other type of cancer	14 (17)
	Cancer recurrence	3 (4)
Treatment modalities	No treatment	2 (2)
	Surgery	64 (75)
	Radiotherapy	32 (38)
	Chemotherapy	52 (61)
	Hormone therapy	19 (25)
	Immunotherapy	8 (9)
	Other type of treatment	5 (6)
Declared free of disease	No	28 (33)
	Yes	57 (67)
Comorbidity	No	44 (52)
	Yes	41 (48)
		Mean (SD)
Work ability	(0-10)	4.7 (2.1)

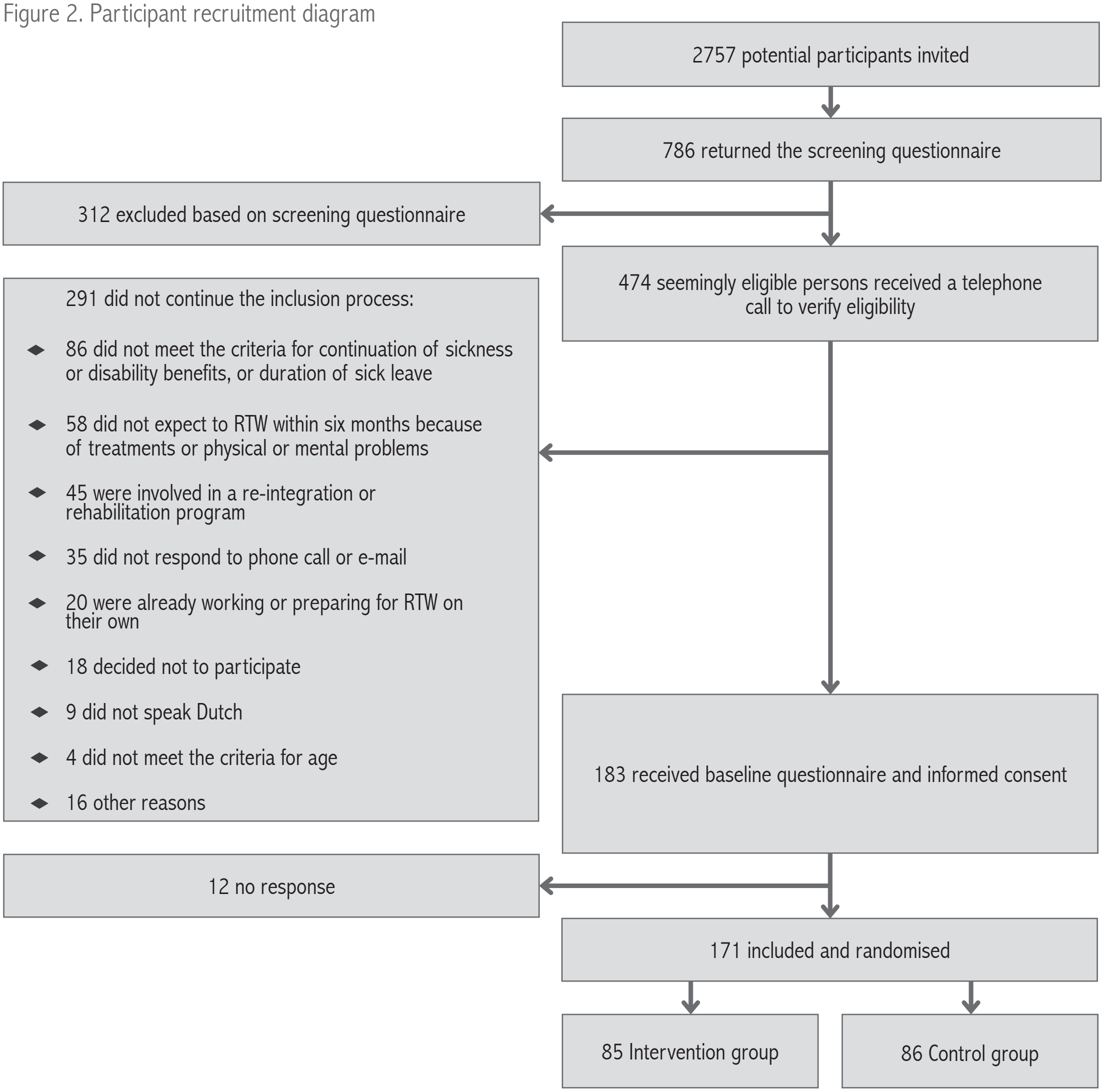
* N and calculated percentages may approach or exceed the total N and 100% because of missing values or rounding differences.

Components of the process evaluation

Recruitment

In total, 2757 potential participants were invited to participate in the study, of whom 786 were interested in participating and returned the screening questionnaire. Among these, 312 did not meet the study inclusion criteria. The researchers contacted the remaining 474 potential participants by telephone. Of those, 291 did not continue the inclusion process due to various reasons: for example, 86 CSs did not meet the inclusion criteria for sickness or disability benefits and duration of sick leave, 58 CSs did not expect to be ready to RTW within six months, and 45 CSs were already involved or signed up for another re-integration or rehabilitation program. Also, 20 CSs had already returned to work or were in the process of RTW, and 35 CSs could not be reached. Of the 183 CSs who fulfilled the inclusion criteria and received a baseline questionnaire, 171 returned the questionnaire and were included in the study. After inclusion, none of the participants' GPs reported a medical contra-indication for participation in the program. Of the 171 CSs in the study, 85 participants were randomly assigned to the tailored RTW program (Figure 2).

Figure 2. Participant recruitment diagram



Reach

Of the 85 CSs who were assigned to the tailored RTW program, 75 started the program by participating in the introductory interview. The other ten CSs did not start the program because of health problems and misinformation during recruitment regarding their eligibility for sickness or disability benefits. Therefore, the reach of the target group that participated in the tailored RTW program was 75 out of 85 CSs in the target group, i.e., 88.2%.

Dosage

In Table 3, the six steps of the tailored RTW program are displayed, together with the proportion of participants who participated in each step. Of the 85 participants, 75 started the program, and 42 participants were referred to the job hunting agencies. In total, 33 participants were not referred to the job hunting agencies, for reasons that were reported as being work-related (14 participants), cancer-related (13 participants), personal (four participants), program-related (one participant) and unknown (one participant).

Specifically, regarding work-related reasons, nine persons had already found employment by themselves, or decided to found their own company. During the "Preparation for RTW" part of the program, three persons were not ready to return to work in their own perception, and two persons wanted to find a job without the assistance of the job hunting officers. Regarding cancer-related reasons, three persons were re-assessed at the SSA and found to be fully work disabled; seven persons suffered from medical complications and/or an increase in the level of physical and mental problems; two persons had recurrent cancer; and one person passed away during the program. Also, four participants had personal problems that, according to the re-integration coaches, prevented them from participating (fully) in the program, such as social, financial or psychological problems. Additionally, one person reportedly quit the program because (s)he did not agree with the approach taken by the re-integration coach. Afterwards, the coach reported that, in her perception, the participant had some personal problems which interfered with the participant's ability to follow the program according to schedule. Attempts of the coach to stimulate the participant could have backfired, resulting in the fact that this particular participant quit the program.

To calculate the dosage, we assessed if jobs were offered to the participants by one or both of the job hunting agencies, which was the case for 30 participants, and if participants had already found employment, or decided to become an entrepreneur, before being transferred to a job hunting officer, which was true for nine participants. Ultimately 39 participants received the adequate dosage of the tailored RTW program (52% of the 75 participants who started the program).

Table 3. Steps in the tailored RTW program

RTW program steps	Proportion of participants who received this step. N (% of total 85 participants)
Step 1: Introductory interview	75 (88.2)
Step 2 (optional): Preparation for RTW (part 1)	54 (72.0)
Step 3 (optional): Preparation for RTW (part 2)	26 (34.7)
Step 4: Referral to job hunting agency for RTW	42 (49.4)
Step 5: Job hunting agency intake	41 (48.2)
Step 6: Job hunting agencies offered two suitable jobs	30 (35.3)

Themes during coaching sessions

For all 54 participants who participated in the program steps “Preparation for RTW (part 1 and optionally part 2)”, one or more themes were selected for the coaching sessions. Eight predefined themes were available during these steps in the program. The frequency of the chosen themes is presented in Table 4. The most popular themes were “Stress, fluctuations in work ability and managing work, private life and recovery” and “self-control, self-influence and resilience at work”. Both themes were chosen by 43 participants. The range of chosen themes between participants was zero to seven themes. Participants could choose different themes for each coaching session (with a maximum of eight themes). The median number of themes chosen per participant was five. Five participants did not choose any of the predefined themes, as it was also possible to deviate from the themes and discuss other personal challenges with regard to RTW.

Table 4. Chosen themes during the coaching sessions in steps “Preparation for RTW (part 1 and 2)”

Theme	N (% of 54 participants)
Introduction and planning of RTW program and coaching	2 (3.7)
Fatigue and managing energy levels and RTW	38 (70.4)
Cognitive and concentration problems and RTW	24 (44.4)
Stress, fluctuations in work ability and managing work, private life and recovery	43 (79.6)
Communication about cancer at work	28 (51.9)
Self-control, self-influence and resilience at work	43 (79.6)
Increasing work ability and endurance in work and recovery	38 (70.4)
Legislation, rights, duties, and opportunities regarding work and illness	29 (53.7)

Referral to physical or psychological rehabilitation care alongside the program

Of the 54 participants in the program steps “Preparation for RTW (part 1 and optionally part 2)”, 27 participants were referred to rehabilitation care alongside the RTW program. Among these, nine were referred to physical care, nine to psychological care, and another nine participants were referred to both physical and psychological care. Participants receiving professional physical care were generally referred to (oncology) physical therapy (13 participants). Participants receiving psychological help were generally referred to a psychologist (12 participants).

Duration of the program

The protocol of the tailored RTW program allowed for a maximum program duration of 7 months, or 210 days. That is, 90 days were available for “Preparation for RTW (part 1 and optionally part 2)”, another 90 days were available for “RTW”, and 30 days were calculated for potential delays during the program. In practice, the mean duration of the tailored RTW program across participants was 156 days (SD 90), which was within time according to protocol. It should be noted that the overall duration also included participants who did not continue to the “RTW” part of the program. For participants who participated in both “Preparation for RTW (part 1 and optionally part 2)”, and “RTW”, i.e., the most extensive route in the program, the overall duration was 199 days (SD 84), which was still within protocol time.

Looking at the separate parts of the program, the mean duration of “Preparation for RTW (part 1 and optionally part 2)” was within the protocol deadline including delay, i.e., 117 days (SD 80). However, there was a large range in duration between the participants (7 - 373 days). The mean duration of “RTW” was 123 days (SD 59), which was longer than the protocol allowed, even with delay. Again, the range in duration of the RTW part was large (29 - 302 days).

Implementation

The implementation score was calculated by multiplying the percentage of the target group that was reached for the tailored RTW program, i.e., 88.2%, with the percentage of participants who started the program, who received an adequate dosage of the program, i.e., 52%. Therefore, the implementation score of the tailored RTW program was 45.9%.

Satisfaction

Satisfaction was based on the process evaluation questionnaires. Of the 85 participants assigned to the RTW program, 68 participants returned the process evaluation questionnaire. Of those, five did not start participation in the RTW program. Their answers were therefore removed from the analysis.

For participants, satisfaction and experiences with the RTW program are presented in Table 5. In general, participants were more satisfied and reported more positive experiences with the “Preparation for RTW (part 1 and optionally part 2)” part of the program, than with the “RTW” part. The combined experience scores for “RTW” were actually slightly negative, i.e., 2.7 on a Likert scale of 1 to 5, with 1 being very dissatisfied and 5 being very satisfied. Participants thought the “Preparation for RTW (part 1 and optionally part 2)” part was more useful to their RTW and that the time trade-off (invested time versus returned benefits of the program) was better, compared to the “RTW” part of the program. Also, participants reported more confidence in the program delivery by the re-integration coaches, than that of the job hunting officers. Finally, the majority of participants who were offered employment through the job hunting officers reported feeling neutral to very dissatisfied in relation to the jobs they were placed in. Despite these ambiguity in experiences, over 70% of participants would probably to certainly recommend the tailored RTW program to other CSs with job loss.

Table 5. Participants' satisfaction with the tailored RTW program

Topics regarding the "Preparation for RTW 1 and 2" parts of the program	Participants (N=63)*
Satisfaction (score range 1-5)†	Mean (SD)
To what extent are you satisfied with:	
-Working with the re-integration coach	4.4 (0.8)
-Drawing up the RTW plan	4.2 (0.8)
-Program delivered by the re-integration coach (including themes)	4.2 (0.9)
-Drawing up a work profile in preparation for RTW	4.0 (1.0)
-Referral to a professional for physical rehabilitation care	4.2 (0.8)
-Referral to a professional for psychological rehabilitation care	3.9 (0.9)
Overall satisfaction score "Preparation for RTW part 1 and 2"	4.2 (0.2)
Experience statements "Preparation for RTW part 1 and 2" (score range 1-5)‡	Mean (SD)
-The RTW plan fit well with my wishes and needs for support	3.8 (1.0)
-The physical intensity of the program was all right	3.9 (1.0)
-The psychological intensity of the program was all right	3.8 (1.0)
-The duration of this part of the program was all right	3.3 (1.3)
Overall experience score "Preparation for RTW part 1 and 2"	3.7 (0.3)
Additional questions regarding steps "Preparation for RTW part 1 and 2"	N (%)
To what extent did you have confidence in the re-integration coach?	
-I had full confidence	27 (60.0)
-I had reasonable confidence	16 (35.6)
-I had little confidence	1 (2.2)
-I had no confidence	1 (2.2)
What did you think of the amount of time spent in this part of the program?	
-It was the right amount of time	27 (61.4)
-It took up a lot of time	5 (11.4)
-It didn't take up a lot of time	12 (27.3)
What do you think of the amount of time invested and the returned benefits of participating in this part of the program?	
-It cost me little time and gained me a lot	21 (46.7)
-It cost me much time and gained me a lot	6 (13.3)
-It cost me little time and gained me little	13 (28.9)
-It cost me much time and gained me little	5 (11.1)
To what extent was it useful for you to participate in this part of the program?	
-Very useful	32 (71.1)
-Reasonably useful	9 (20.0)
-Neutral	1 (2.2)
-Not so useful	2 (4.4)
-Not at all useful	1 (2.2)

Topics regarding the “RTW” part of the program	
Experience statements (score range 1-5)‡	Mean (SD)
-The offered jobs fit well with my wishes and needs for RTW	2.9 (1.1)
-By working in the job that was offered, I feel that I can make it in the labour market	2.5 (1.1)
Combined experience score “RTW”	2.7 (0.3)
Additional questions regarding the RTW part of the program	N (%)
To what extent did you have confidence in the job hunting officers?	
-I had full confidence	6 (30.0)
-I had reasonable confidence	10 (50.0)
-I had little confidence	3 (15.0)
-I had no confidence	1 (5.0)
To what extent are you satisfied with working in the jobs offered:	
-Very satisfied	0 (0.0)
-Satisfied	2 (10.0)
-Neutral	12 (60.0)
-Dissatisfied	2 (10.0)
-Very dissatisfied	4 (20.0)
To what extent was the work easy to combine with other activities in your life?	
-It was easily combined	14 (70.0)
-It was not easily combined	6 (30.0)
What do you think of the amount of time invested and the returned benefits of participating in this part of the program?	
-It cost me little time and gained me a lot	1 (5.0)
-It cost me much time and gained me a lot	3 (15.0)
-It cost me little time and gained me little	8 (40.0)
-It cost me much time and gained me little	8 (40.0)
To what extent was it useful for you to participate in these steps of the program?	
-Very useful	4(20.0)
-Reasonably useful	4 (20.0)
-Neutral	8 (40.0)
-Not so useful	3 (15.0)
-Not at all useful	1 (5.0)
Overall, if you reflect on the <u>complete RTW program</u>, would you recommend this program to someone else in your situation?	
-Certainly	29 (49.2)
-Probably	14 (23.7)
-Maybe	10 (16.9)
-Unlikely	2 (3.4)
-Certainly not	4 (6.8)

* Total N may vary per question, as some parts of the program were optional, and some participants didn’t continue the program or did not return the questionnaire. Percentages for each question were calculated based on the number of participants that completed the question; † A higher score reflects a higher level of satisfaction; ‡ A higher score reflects a higher level of agreement with the statement.

Overall, the re-integration coaches reported the highest levels of satisfaction (3.8 on a Likert scale of 1-5), and the highest overall experience score regarding the execution of the tailored RTW program (4.4 on a Likert scale of 1-5) (Table 6). On the same scales, the OHC professionals reported the lowest levels of satisfaction (3.4) and experience (3.6) regarding the execution of the program. Further, 78.8% of the re-integration coaches and 93.8% of the job hunting officers thought that, in general, delivering the program increased their work load, but that they were not bothered by this.

Table 6. OHC professionals', re-integration coaches' and job hunting officers' satisfaction with the tailored RTW program

Topics	OHC professionals (N=68)*	Re-integration coaches (N=52)*	Job hunting officers (N=48)*
Satisfaction (score range 1-5)†	Mean (SD)	Mean (SD)	Mean (SD)
To what extent are you satisfied with:			
-Protocol for delivering the program	N/A	3.8 (0.4)	3.7 (0.8)
-Instructions from my own organization	N/A	4.4 (0.5)	4.0 (0.5)
-Options to deviate within the program protocol	N/A	3.9 (0.6)	3.7 (1.0)
-Options for tailoring the program to participants' needs	N/A	3.5 (0.7)	N/A
-Communication with a contact person within your organization	N/A	4.0 (0.6)	3.7 (0.6)
-Communication with the researchers	N/A	3.6 (0.5)	3.6 (0.7)
-Communication with the OHC professionals during the program	N/A	3.0 (0.8)	3.1 (0.8)
-Transfer from the re-integration coach to the job hunting officers	N/A	3.7 (1.1)	3.8 (0.6)
-Communication with the job hunting officers	N/A	3.3 (1.3)	N/A
-Communication with the re-integration coach	N/A	N/A	3.8 (0.5)
- Program completion and final contact with the participant	N/A	4.3 (0.6)	3.6 (0.8)
-General information about the program through the SSA	3.7 (1.0)	N/A	N/A
-Information about your patient participating in the program	3.6 (0.9)	N/A	N/A
-Opportunities to deliberate with the researchers	3.4 (0.8)	N/A	N/A
-Information regarding the content of your patients' program	3.5 (0.9)	N/A	N/A
-Opportunities to deliberate with the re-integration coach	3.2 (1.0)	N/A	N/A
-Final report from the re-integration coach	3.5 (1.1)	N/A	N/A
-Information about your patients' transfer to job hunting agencies	3.3 (1.0)	N/A	N/A
-Opportunities to deliberate with the job hunting officers	3.2 (1.0)	N/A	N/A
-Final report from the job hunting officers	3.4 (1.0)	N/A	N/A
Overall satisfaction score	3.4 (0.2)	3.8 (0.4)	3.7 (0.2)

Experience statements (score range 1-5)‡	Mean (SD)	Mean (SD)	Mean (SD)
-The program fit well into my organization	3.7 (0.8)	4.5 (0.6)	4.4 (0.7)
-Before the program started, the program objective was clear to me	3.3 (1.0)	4.6 (0.5)	4.4 (0.6)
-Delivering the program was similar to my usual job demands	N/A	4.5 (0.6)	4.1 (1.0)
-Cooperating with the program agreed with my usual work tasks	3.7 (0.7)	N/A	N/A
-Before the program started, I was excited about it	N/A	4.7 (0.5)	4.6 (0.5)
-It was easy to follow the program protocol	N/A	3.9 (0.7)	3.5 (1.1)
-In hindsight, it was useful for me to participate in the program	N/A	4.2 (0.8)	4.2 (0.6)
-I was able to deliver my usual care alongside the program	3.6 (0.8)	N/A	N/A
-In the future, I would work with such a program again	3.8 (0.8)	4.6 (0.6)	4.5 (0.7)
Overall experience score	3.6 (0.2)	4.4 (0.3)	4.2 (0.4)
Time consumption of the program	N (%)	N (%)	N (%)
Delivering, or cooperating with, the program took up extra work time:			
-Yes and I did mind that	7 (10.3)	3 (5.8)	1 (2.1)
-Yes but I did not mind that	12 (17.6)	41 (78.8)	45 (93.8)
-Neutral	17 (25.0)	9 (15.4)	1 (2.1)
-No	29 (42.6)	0 (0.0)	1 (2.1)

* One process evaluation questionnaire was completed per participant, therefore, the N per group of professionals reflects the number of times a questionnaire was completed by a professional from that group. Also, due to missing values or rounding differences, N and percentages may approach or exceed the total N or 100%; † A higher score reflects a higher level of satisfaction; ‡ A higher score reflects a higher level of agreement with the statement.

Experienced barriers within the program

Participants, re-integration coaches and job hunting officers reported that one of the main barriers within the RTW program was that the perceived duration of the program was too short, and that the perceived program intensity was too high. Specifically, some participants felt they needed more time to prepare for RTW, and they thought the “Preparation for RTW” part should be extended. Another important obstacle in the delivery of the program was the lack of clear communication between OHC professionals, re-integration coaches and job hunting officers. Specific barriers for communication among these parties were the large number of professionals involved and the fact that most communication went through digital channels (for feasibility reasons, as the program was offered on a national level). Also, the high workload of OHC professionals, and that a lot of participants’ files were frequently re-distributed within the SSA, e.g., when a new OHC team was assigned, or when the participant moved to a different district, contributed to these problems. As a result, some of the OHC professionals were not informed about the RTW program in an accurately or timely manner, and did not deliver the necessary documents to the re-integration coach. This delayed the start and progress of the RTW program for most of the participants.

Another obstacle was that, in the experience of participants and re-integration coaches, the job hunting officers had little experience with the health problems and the RTW process of CSs. As a result, the job hunting officers were not always able to intervene adequately in case of cancer-related problems. Further, participants and re-integration coaches reported specific problems in the delivery of the program by the job hunting officers, i.e., a lack of initiative and a lack of interest in the participants’ situation. To illustrate, it was reported during two meetings with the research team that the job hunting officers sometimes did not respond in time or at all to transfer requests by the re-integration coaches. Also, necessary documents from the job hunting officers were generally delivered late or not at all, and the documents provided to them by the re-integration coaches were often not used. The researchers requested that the job hunting officers use the documents from the re-integration agencies and to deliver their documents in time. However, there seemed to be a lack of motivation in the job hunting officers to do so. This led to delays in the delivery of the program. Further, at least two participants reported they had actually quit the program because they felt discouraged by the job hunting officers. For example, one participant mentioned that a job hunting officer had said that it would be very hard to find a job for him/her. A number of participants mentioned that they felt that the job hunting officers were only operating from a commercial perspective. As a result of these actions and the lack of clear communication, the re-integration coaches mentioned during the meetings that they had lost confidence in the “RTW” part of the program.

In contrast, many participants were very enthusiastic about program delivery by the re-integration coaches, and several participants gave them praise, such as that they felt they owed their new job to them. In two cases however, participants reported that the coach was not able to answer their questions, and that the program delivery was not person-oriented enough.

Discussion

Main results

The main results of this study are that the tailored RTW program reached 88.2% of the target population, that more than half of the participants who started the program (52%) received the adequate dosage, and that the implementation score was 45.9%. The overall mean duration of the RTW program stayed within protocol boundaries; however, there was large variation between the participants in the program duration. Re-integration coaches reported the highest levels of satisfaction and positive experience with the program, compared to the job hunting officers or OHC professionals. Likewise, participants were more satisfied with the program delivery by the re-integration coaches than with the delivery by the job hunting officers. High program intensity and short program duration, as well as communication and cooperation problems, hindered the delivery of the RTW program.

Interpretation of results

This was the first study to offer an innovative RTW program tailored to the needs of a specific subgroup of CSs, that is, CSs with job loss. In the Netherlands, previous studies were conducted that are, to some extent, comparable to the present study. For example, several RTW programs have been offered to sick-listed Dutch workers with distress, low back pain and musculoskeletal disorders [22, 27-29]. Generally, these studies proved that the implementation and execution of a RTW program for sick-listed workers is feasible. However, Lammerts et al. recently found that the implementation and execution of a participatory RTW intervention for workers with common mental disorders was less successful [30]. That study particularly reported obstacles in the implementation phase, as 28% of the participants received a medical contra-indication for the program. In contrast, in the present study, no contra-indications for CSs' participation in the program were reported. This may be explained by the strict and stepwise recruitment procedures of the present study, through which CSs with severe medical problems were eliminated from the inclusion process [18]. However, still thirteen participants in our study were unable to complete the RTW program because of physical and mental problems. Also, about one-third of the participants received additional physical or psychological rehabilitation care alongside the program. It could be that the participants took part in the additional rehabilitation care simply because it was offered to them, but it is also possible that for these participants, a contra-indication from the GP might have been appropriate. An explanation for the lack of reported contra-indications could then be that GPs lose contact with CSs during the cancer trajectory. That is, cancer trajectories can easily take up several months, during which the patient receives specialized medical care [31]. A previous study by Guassora et al. demonstrated that the transition between specialized care and primary care presents problems, and argued that GPs may need to be prepared to receive CSs in their daily practice [32]. It is also possible that the program information did not reach or fully inform some GPs, thereby limiting their assessment of the appropriateness of the program.

In the present study, the implementation score (45.9%), as well as the number of participants who received the adequate dosage (52%), was only moderately good. This was mainly the result of the fact that only 49.4% of the participants was referred to the job hunting agencies. It should be mentioned that we did not set a specific goal for the program implementation score or the dosage, but it was implicitly expected that a higher implementation score and better dosage would be reached. Theory and/or implementation failure may explain these results. With regard to theory failure, it could be that the RTW program was only suited for a particular subgroup of the target group. That is, it could be that mainly relatively healthy CSs with job loss successfully participated in the RTW program [33]. The fact that several participants mentioned that the program was too intense and too short, and that some CSs with health problems could not continue the program, support this theory. In comparison, past RTW interventions for CSs had a longer duration than the program in the present study [12]. To illustrate, Stapelfeldt et al. offered a municipality-based RTW intervention for CSs in Denmark with a maximum duration of 1 year [34], and Tamminga et al. offered a hospital-based RTW intervention in the Netherlands with a maximum duration of 14 months [35]. It is worth considering that the duration or intensity of our program should be revisited. However, this would raise new questions with regard to the feasibility and financial aspects of the program [36]. In summary, we can hypothesize that there was indeed a mismatch between the target group and the RTW program, as not all CSs with job loss successfully participated in the program.

Further, we should consider that the present study may have suffered from implementation failure. For example, the duration of the RTW program varied greatly between participants, and several barriers for program delivery and participation were reported. An important barrier was the lack of clear communication between OHC professional, re-integration coaches and job hunting officers. A previous study by Anema et al. reported that cooperation and sharing information between OHC professionals and GPs can be problematic [37]. Perhaps this is also true for communication between OHC professionals, re-integration coaches and job hunting officers. Further, the program delay can be partly attributed to the recent economic recession in the Dutch labour market, which made it difficult for the job hunting officers to find employment for participants in this study [38]. Previous studies conducted in the past years reported similar delays in finding work opportunities for participants [22, 30].

Furthermore, there were specific indicators that the RTW program was not well implemented with the job hunting officers, i.e., their program delivery was delayed, there had been cooperation problems, and reportedly they had little specific knowledge with regard to cancer-related health problems. Specifically job hunting officers' lack of sensitivity or experience with regard to cancer-related problems could explain the lower levels of satisfaction with their program delivery.
In comparison, in the study by Tamminga et al., a RTW program was delivered by nurses with cancer expertise. In that study, participants reported high satisfaction scores [35]. It could be that the lack of knowledge and experience regarding cancer-related problems hindered the job hunting officers in delivering the program. It should also be considered that re-integration coaches who had unsatisfactory cooperation experiences with the job hunting officers, with whom they worked earlier in the intervention, willingly or unwillingly may have given a negative impression of the job hunting officers to participants who started the RTW program later on. As a result, participants may have decided against participating in the "RTW" part of the program, contributing to the moderate dosage and implementation scores.
An alternative explanation for the lack of transfers to the "RTW" part of the program could be that the "Preparation for RTW" part was quite successful. That is, the "Preparation for RTW" part was generally so well received by participants and professionals that some participants had already found employment and did not need the assistance of the job hunting officers anymore. This indicates that the "RTW" part of the program was in fact redundant for some participants.

Strengths and limitations

The key strength of this study is that data were obtained through various sources (such as questionnaires and logbooks from all parties involved, and also minutes of meetings) in order to gain a full perspective on the process of delivering the RTW program. There are however several limitations to this study that should be mentioned. First of all only 63 out of 85 participants completed the process evaluation questionnaires. Further, in a few cases, data were missing on certain questions or dates, and the datasets for calculating satisfaction and experience scores were relatively small, especially for the job hunting officers, in which case the scores were based on 48 questionnaires. Additionally, we did not measure fidelity as a measure of the intervention program's quality in this study. Because of the nature of the program, i.e., participants could choose their own route through the program, it was quite impossible to compare participants' overall routes throughout the program. Therefore, we offered a comparison and evaluation of the program elements only, i.e., "Preparation for RTW" part and "RTW" part, instead of offering an overall interpretation on the program's fidelity.
These factors limit the generalizability of our results. Also, the intervention logbooks from the job hunting officers were generally delivered past schedule, which could have introduced recall bias in the data. The qualitative results with regard to experienced program barriers should be interpreted cautiously, as they were based on individual comments. In order to gain a more comprehensive perspective of the participants' experiences, a qualitative study inquiring about specific barriers in the program, could be conducted in the future. Also, the tailored RTW program was offered in cooperation with the Dutch SSA. Therefore, our results should be interpreted in the context of the Dutch social security system: the fact that the program delivery and implementation relied heavily on the social security context, could mean that efforts to replicate this study in another social or political context may be only partly successful.

Implications for practice and research

This study demonstrated that, despite delays and several barriers in the program, CSs with job loss were generally satisfied with a RTW program tailored to their needs. The "Preparation for RTW" part of the program was the most appreciated element in the program. In order to prevent similar obstacles for program delivery in future studies, we would recommend that researchers introduce a pilot-phase in their studies, during which potential implementation problems can be identified and resolved [39]. As there seemed to be specific problems with the implementation of the program in the daily practice of the job hunting agencies, we would recommend that researchers specifically investigate the motives and capabilities of commercial parties when involving them in research projects, in order to ensure commitment and sustainable program delivery. Further, considering that long-term or permanent health problems are highly prevalent among CSs [40], we would recommend that experts delivering RTW programs to CSs receive training with regard to potential medical problems in the target group. For example, job hunting officers or other practitioners could participate in a seminar on cancer and work. Another aim of such training could be to enhance the quality and level of cooperation between these professionals. Previous studies in Denmark have demonstrated that satisfactory cooperation between groups of professionals can be difficult to achieve in a RTW context, not only for those working with CSs, but also for those working with patients with mental illness, for instance [41, 42]. Finally, we encourage clinical practitioners, OHC professionals and GPs to engage in future programs for sick-listed workers, for example by offering their expertise during recruitment [41, 43]. This may facilitate a more accurate and efficient reach of the target population, and provides a guarantee for usual care to continue alongside intervention programs.

Conclusions

In general, the participants, re-integration coaches, job hunting officers and OHC professionals had positive experiences with the innovative tailored RTW program. This program can be considered a first promising step towards tailored RTW support for CSs with job loss, and potentially for other sick-listed workers, with a significant challenge to labour market participation. Facilitating communication between the delivering parties, and engaging usual care during program delivery, could be key elements to improved program implementation.

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Effectiveness of a tailored return to work program for cancer survivors with job loss: results of a randomized controlled trial

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Effectiveness of a tailored return to work program for cancer survivors with job loss: results of a randomized controlled trial

Abstract

Background: Up to 53% of cancer survivors (CSs) experiences job loss during or after treatment. To support CSs with job loss in the Netherlands, a tailored return to work (RTW) program was developed. The objective of this study was to assess the effectiveness of the program on duration until sustainable RTW in CSs with job loss.

Material and Methods: This study employed a two-armed (intervention/control) randomized controlled design with one year follow-up. The primary outcome measure was duration until sustainable RTW. The secondary outcome measures were: rate of RTW, fatigue, quality of life, and participation in society. Descriptive analyses, Kaplan-Meier estimators and Cox regression analyses were conducted.

Results: Participants (N=171) had a mean age of 48.4 years (SD=8.6). The majority was female (69%) and breast cancer survivor (40%). The crude Hazard Ratio (HR) for duration until sustainable RTW was 0.86 (95% CI 0.46-1.62, p=0.642). In the adjusted model, the intervention group had a slight, but statistically non-significant, improvement in duration until sustainable RTW compared to the control group (HR 1.16; 95% CI 0.59-2.31; p=0.663). The program did not have any significant effects on secondary outcome measures.

Conclusion: Since the tailored RTW program did not demonstrate a statistically significant effect on duration until sustainable RTW in CSs with job loss, implementation of the program in its current form is not recommended.

Introduction

Among the many challenges in cancer survivorship are long-term or permanent physical and mental health problems, which often occur as a result of diagnosis and treatment [1,2]. For example, cancer survivors (CSs) may experience fatigue, pain and cognitive problems, long after treatment has been completed [3]. Studies have shown that these health problems may greatly affect CSs' daily functioning and quality of life [4]. Moreover, for CSs in the working age, impairments in physical and mental health may reduce chances of participation in work [5]. For example, up to 53% of CSs becomes unemployed, either by job loss or quitting work, in the first six years after diagnosis [6]. Moreover, across studies, CSs are 1.4 times more likely to be unemployed than healthy persons [7]. Although 64% of CSs return to work (RTW) eventually, studies show that many CSs struggle with RTW [6].

Furthermore, due to the increase in flexible employment in Western economies, more workers on long-term sick leave, including CSs, are vulnerable to job loss [8]. To illustrate the increase of flexible employment in the Netherlands, there was an increase of 20% in the number of persons working with a temporary contract in 2015, compared to 2008 [9]. A recent Dutch report showed that workers in temporary employment may experience job loss after being diagnosed with cancer, as Dutch employers are generally not inclined to prolong the temporary employment contracts of these workers [10].
For CSs who experience job loss, the process of RTW can be more complicated, compared to CSs who still have an employment contract, facing a large distance to the labor market, potential employer stigmatization during job interviews and no access to support from employer and colleagues [11]. Therefore, CSs who have experienced job loss may be in need for tailored RTW support.

The importance of RTW support for CSs with job loss is further stressed by insurance physicians, working at the Dutch Social Security Agency (SSA), where they provide medical consultation and assess work ability. In the Netherlands, the SSA is responsible for persons who become unemployed before or during sick leave, for example due to cancer [12]. The SSA takes over the role of the former employer in case of job loss, by providing substituted income in the form of sickness or disability benefits. The SSA also provides RTW guidance through the services of re-integration experts, labour experts and insurance physicians [12]. Both insurance physicians and CSs with job loss have previously reported that the SSA's usual care, including RTW guidance, is not suited to the specific RTW needs of CSs with job loss [11].

In order to meet the need for adequate RTW support in CSs with job loss, from 2011 onward, the SSA cooperated with the VU University Medical Center to develop and evaluate a tailored RTW program. From 2013 to 2015, the RTW program was offered to CSs with job loss in the Netherlands, on a national level [13]. We hypothesized that offering a tailored return to work program to CSs with job loss would lead to a significant improvement in duration until RTW in these cancer survivors, compared to the usual care that is currently provided by the SSA. The purpose of this study was to test this hypothesis and assess the effectiveness of the tailored RTW program on duration until sustainable RTW for CSs with job loss.

Material and methods

Design

In this randomized controlled trial (RCT), the effectiveness of a tailored RTW program on duration until sustainable RTW was assessed in a population of sick-listed CSs with job loss. The RTW program was offered in a two-armed (intervention and control), non-blinded RCT, with a follow-up period of twelve months. The intervention group received the program, as well as usual care by professionals from the SSA. The control group only received the usual care from the SSA. The SSA's usual care generally consisted of a few meetings per year with an insurance physician, and potentially also a labour market or reintegration expert. The aim of these meetings was to discuss or evaluate work ability and opportunities for RTW. In that way, these meetings were somewhat comparable to meetings between a sick-listed employee and an occupational physician of his/her company. In general, usual care from the SSA does not involve any type of re-integration or supportive intervention program. As the study protocol of the RCT has been published previously, a summary of the study procedures is provided here [13]. This study has been approved by the Medical Ethical Committee of the VU University Medical Center, Amsterdam, The Netherlands. The RCT is registered in the Dutch Trial Register, registration number NTR3652.

Study population and sample size

The population of this study consisted of CSs who had experienced job loss. Most CSs in this population experienced job loss after diagnosis, because their temporary employment contract expired during/after treatment, and was not renewed. Additionally, some CSs experienced job loss before diagnosis, and were receiving unemployment benefits at time of diagnosis. After diagnosis, their unemployment benefits were changed to sickness benefits, and they became part of the population of CSs with job loss, registered at the SSA. In order to participate in this study, CSs with job loss had to be registered at the SSA as: sick-listed, receiving sickness or disability benefits due to cancer, without employment, and of working age, i.e. 18 to 60 years. Specifically, CSs were selected who were on sick leave for at least 12 months and maximum 36 months. The 12-month cut-off was chosen in accordance with the Dutch social security system, in which CSs' eligibility for sickness benefits is re-evaluated at twelve months. The 36-month cut-off was chosen because of limited availability of reliable data in the SSA registries, past three years of sick leave. Further, CSs had to have completed intensive cancer treatment at least six weeks before inclusion, and had to feel healthy enough to potentially participate in the RTW program (based on CSs' self-report). Additionally, the CS's general physician was contacted after inclusion in the study, to verify that the CS had no comorbidities that would interfere with participation. CSs were excluded if they, among other factors, were diagnosed with metastasized cancer, were pregnant, did not speak fluent Dutch, or if they had signed up to participate in a concurrent program or study. After trial commencement, an amendment was approved by the Medical Ethical Committee of the VU University Medical Center to also include CSs with metastasized cancer in the study. This amendment was motivated by comments from CSs with metastasized cancer in the inclusion process, who were motivated and able to participate, and by advice obtained from the Dutch cancer patient movement.

Recruitment

Recruitment was organized both retrospectively and prospectively from April 2013 to January 2015. Retrospectively, all CSs who met the inclusion criteria were identified in the SSA-registries, and invited to participate. Prospectively, CSs who reached the 12-month threshold were identified every other week, and invited to participate. Eligible CSs received an invitational package via postal mail. The package included an information letter, an information leaflet, a screening questionnaire with an informed consent form, a postcard, and a letter from the chief medical officer of the SSA, explaining and supporting the study, and stating that CSs were under no obligation to participate.

CSs who were not interested to participate could use the postcard to inform the researchers of their decision. On the postcard, they could provide motives for declining participation, e.g., 'I have already found a new job' or 'Due to physical problems, I am not ready to RTW yet'. Also, CSs could use the postcard to postpone the invitation to participate, i.e. they could list a new date on which they would like to be re-invited for the study. CSs who were interested to participate could complete the screening questionnaire and informed consent form, and return these to the researchers.

If the CS was eligible to participate, based on the screening questionnaire, (s)he was contacted by telephone to verify if the inclusion criteria for the study were met. Also, additional information regarding the RCT was provided by phone. The CS then received the baseline questionnaire and a second informed consent form for participation in the RCT. After these forms were returned, the CS was included in the study and randomization was performed.

Randomization

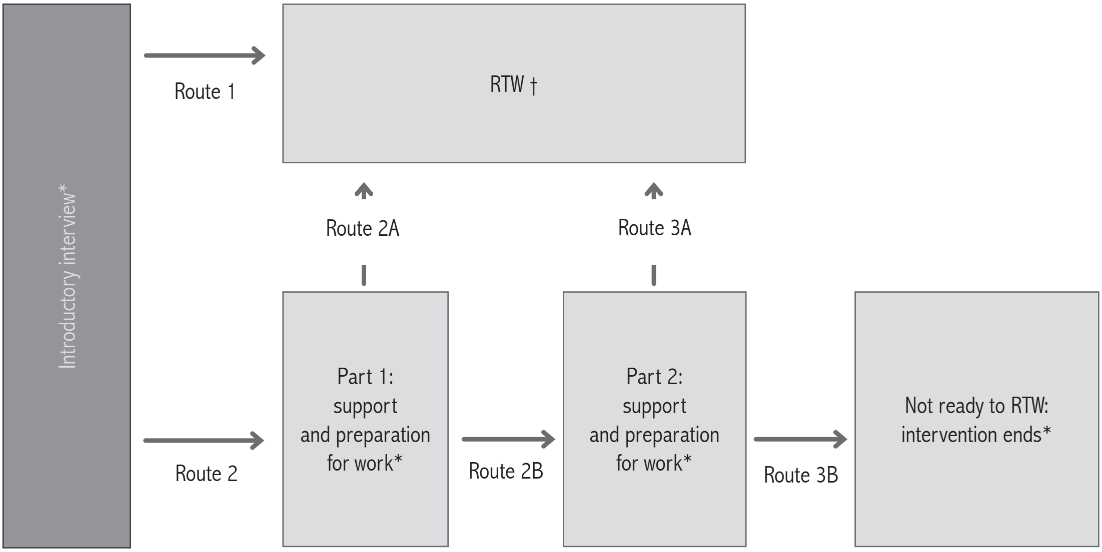
After inclusion in the study, participants were randomly allocated to the intervention or the control group, using randomization software. The first step in the randomization procedure was to identify the participant's stratum, based on the employment situation prior to the participant's sick leave, as indicated in the screening questionnaire and retrieved from the SSA registry. Since professionals at the SSA indicated that there could be substantial differences between participants, because of their previous employment situation, three different strata were distinguished, i.e. (1) workers whose temporary employment contract ended during sick leave, (2) temporary agency workers, and (3) unemployed workers, i.e. workers who were in-between jobs and, when diagnosed with cancer, were transferred within the SSA-system from unemployment benefits to sickness benefits. Within each stratum, participants were randomly allocated (block size: 4; ratio 1:1) to either the intervention or the control group. A researcher (KB) who wasn't involved in the inclusion process of participants performed the identification of the appropriate stratum and conducted the randomization procedure. The outcomes of the randomization procedure were double-checked by SD.

Tailored RTW program

The tailored RTW program consisted of an introductory interview, a "Preparation for RTW" part, and a "RTW" part. Throughout the entire program, participants were encouraged to actively participate in the development of a consensus-based RTW plan, as well as to participate in coaching sessions to prepare for RTW, and to explore possibilities for (therapeutic) RTW. The whole RTW program was tailored in the sense that participants could select various routes through the different parts of the program, to match the required level of RTW support. The program is presented in Figure 1.

All participants in the intervention group started the tailored RTW program with an introductory interview with a re-integration coach. In this interview, potential obstacles and possibilities for RTW were identified, and a route through the intervention program was chosen. Specifically, it was evaluated if the participant was ready to "RTW", or if "Preparation for RTW" was needed. Also, participant's expectations and present activities with regard to RTW were discussed. If participants were already actively looking for jobs, they would start with the "RTW" part (Figure 1: Route 1 in the program). In this part of the program, participants were placed in therapeutic or paid work with the support of two job hunting agencies. The two job hunting agencies who delivered the "RTW" part employed mostly vocational therapists or personnel with a background in human resource management. They had no specific expertise with regard to cancer. The job hunting agencies had multiple locations across the Netherlands. Participants traveled to the local office nearest to them.
If the conclusion of the introductory interview was that the participant was not actively involved in RTW activities, e.g. looking for work, the participant would start with the "Preparation for RTW" part (Route 2 in the program). This part (developing a RTW plan and coaching) was carried out by a re-integration agency, specialized in RTW coaching for CSs. The coaches from this re-integration agency also conducted the introductory interviews. These coaches were generally ex-cancer patients who had experience with cancer survivorship and job loss, and who had received training to become a specialized coach in the area of cancer and RTW. The "Preparation for RTW" part of the program took place in the participant's home or at an office of the re-integration agency nearby. All meetings with the re-integration coaches and job hunting agency personnel were individual face-to-face meetings. All the available routes in the intervention program are shortly described below. The full content of the tailored RTW program was previously published as part of the study protocol [13].

Figure 1 The tailored RTW program



*Carried out by the re-integration coaches; † carried out by the job hunters.

Route 1: The coach and participant decided that the participant was ready to RTW. The coach then contacted the researchers to randomly assign the participant to one of the two job hunting agencies. The selected job hunting agency invited the participant for a meeting to explore job opportunities. The job hunting agency was required to find at least two suitable jobs that matched with participants work profile or wishes for RTW. Further, employment had to be offered for at least three months, and should have been either paid employment, or work with therapeutic conditions and on-going benefits. According to protocol, the job hunting agencies should have found these jobs within four weeks after the first meeting with the participant. When the job hunting agency was unable to meet these requirements, the second job hunting agency involved in this study joined the search for jobs.

Route 2: The coach and participant decided that the participant was not yet ready to start looking for a job, but that (s)he first needed preparation for RTW. In the following weeks, the participant and coach created a work profile. The work profile was based on an extensive inventory of the participants' wishes and needs for return to work, and on the participants' working experience and capabilities. Alongside this process, the participant received coaching on themes that the participant and the coach selected together. There were twelve predetermined themes available, and there was also an option to deviate from these themes if necessary. Examples of themes that were used in the coaching were: "Fatigue and managing energy levels and RTW", "Communication about cancer at work" and "Stress, fluctuations in work ability and managing work, private life and recovery". After completing the work profile and participating in four sessions of coaching, the participant and coach reevaluated whether the participant was ready to RTW (Route 2A or Route 2B).

Route 2A: The participant was ready to RTW. In this case, the coach would contact the researchers, after which a job hunter was assigned to organize a meeting with the participant and to start looking for workplaces that would fit the work profile that was created. This route is similar to route 1 and is therefore described in more detail in the aforementioned paragraph "Route 1".

Route 2B: It was decided that the participant needed more preparation for RTW. Therefore, the participant received additional sessions of coaching on chosen themes. This process is essentially the same as the process described in route 2, with the exception that the work profile was already completed at this stage. After participating in additional sessions of coaching, the coach and participant reevaluated if the participant was ready to RTW (Route 3A or Route 3B).

Route 3A: The participant was ready to RTW. In this case, the coach would contact the researchers, after which a job hunter was assigned to organize a meeting with the participant and to start looking for workplaces that would fit the work profile that was created. This route is similar to route 1 and is therefore described in more detail in the aforementioned paragraph "Route 1".

Route 3B: If the participant was not ready to RTW after receiving the full "Preparation for RTW" part of the program, the intervention program was terminated and the participant's case was referred to usual care for follow-up.

The maximum duration of the "Preparation for RTW" part was three months. The maximum duration of the "RTW" part was also three months. Further, one-month delay was allowed within the whole program to allow for unforeseen events, such as illnesses or holidays. Therefore, the maximum duration of the RTW program was seven months.

Outcome measures and prognostic factors

The primary outcome measure of this study was duration until sustainable RTW. This was calculated as the number of days between the day of inclusion and the first day of sustainable RTW. Sustainable RTW was defined as a period of at least 28 calendar days, during which the participant was working. Work could be paid employment, but also work resumption with on-going benefits was considered, i.e. therapeutic work. The secondary outcome measures were: rate of RTW, defined as the proportion of participants in the intervention and the control group that returned to work, fatigue (assessed with the FACIT-Fatigue Scale (Version 4) [14]), quality of life (assessed with the European Organization for Research and Treatment of Cancer Quality of Life Questionnaire (EORTC QLQ C-30 version 3.0) [15]), and participation in society (assessed with the Utrecht Scale for Evaluation of Revalidation and Participation (USER-P), (three scales: frequency, restrictions, satisfaction) [16]) after one year of follow-up.

Both register data and self-reported data were used to determine duration until sustainable RTW and rate of RTW in this study. Data regarding sustainable RTW in paid employment were obtained from SSA-registries. In addition, data regarding sustainable RTW in therapeutic work were obtained from self-report, collected using online and paper questionnaires (depending on the participants' preference). Participants in the RCT were asked to complete extensive questionnaires at baseline (T0), after three (T1), six (T2), and 12 months (T3) follow-up.

Sample size and statistical analysis

The calculated sample size for this study was 130 participants, based on a power of (1-b=) 0.80, a two-sided significance level of 0.05 (a). We aimed to include 164 participants, as we anticipated a 20% loss-to-follow-up rate during the study [13]. The entry of the self-reported data from the paper questionnaires was checked by performing a secondary data-entry of 5% of the paper questionnaires at each measurement point, i.e., T0, T1, T2 and T3. The maximum percentage of error allowed between the two data entries was 3%.

To verify the SSA-register data regarding duration until sustainable RTW in paid employment, we compared the register data with the self-reported data from the follow-up questionnaires. In case of conflicts between the register data and self-reported data, the register data were considered valid. Duration until sustainable RTW in therapeutic work was determined based on the self-reported data, as this type of employment is not registered at the SSA. In case that multiple dates of therapeutic work were reported by the participant, the date reported in the first follow-up questionnaire was used, in order to minimize recall bias. In this study, RTW in both paid employment and therapeutic work were considered as sustainable RTW. Therefore, one variable was computed based on the participants' inclusion date in the study and the first date of sustainable RTW, i.e. 'duration until sustainable RTW'. Also, this variable was used to calculate the rate of RTW in the intervention and control group. Further, scores on validated questionnaires for non-RTW outcome measures and parameters, e.g. fatigue, quality of life, and participation in society, were calculated according to the required algorithms. No measures of imputation were used.

Descriptive analyses, t-tests and chi-square tests were used to describe potential differences in characteristics between the intervention and control group. All p-values reported are the results of two-sided tests. The primary outcome measure, i.e. duration until sustainable RTW, was first assessed using Kaplan-Meier estimators and the log rank test.

Second, Cox regression analysis was used to estimate hazard ratios (HRs) for duration until sustainable RTW. All analyses were performed according to the intention-to-treat principle, and carried out on the level of the individual. Additionally, the per-protocol principle was applied in two separate analyses, to correct for participants in the intervention group who did not receive the intervention as intended. In the first per-protocol analysis, all persons in the intervention group who did not actually start with the RTW program were removed from analysis. In the second per-protocol analysis, all persons in the intervention group who did not receive the intervention according to protocol were removed from analysis, based on the results of a previously conducted process evaluation alongside the RCT (unpublished observations).

The following confounders were taken into account in the analyses: age, gender, level of education, marital status, ethnicity, time between date of cancer diagnosis and inclusion in the study, and time between first day of sick leave and inclusion in the study. Also, we evaluated if significant differences in baseline characteristics between the intervention group and control group were confounders in the Cox regression analysis. The crude Cox regression model only contained the main variables of interest: duration until sustainable RTW and intervention/control group. An adjusted model was constructed by entering potential confounding variables, using a forward entry selection method. The cut-off point for relevant confounding was set at >10% change in the regression coefficient for the dependent variable, with a p-value of 0.1. Further, we evaluated effect modification by the strata in which participants were categorized, i.e. type of previous employment contract, by including interaction terms (and their corresponding main effects) into the model. In these analyses, the strata of CSs with a previous temporary contract and temporary agency contract were combined, as there were only a few participants (N=11) with a temporary agency contract. It was tested whether the coefficient of the interaction term was significantly different from zero, at a p-value level of 0.05. Regardless of any significant confounding or effect modification, the final model was adjusted for age, gender and level of education to facilitate comparison with other studies.

Finally, regarding the secondary outcome measures, rate of RTW between the intervention and the control group was compared using a chi-square test. All other secondary outcome measures, i.e., fatigue, quality of life and participation in society, were analysed using linear regression analyses and adjusted for age, gender and level of education. SPSS 22.0 was used to perform the analyses [17].

Results

Recruitment and study population

In total, 2757 cancer survivors were invited to participate in the study from April 2013 to January 2015. Of them, 786 survivors were interested in participation, of whom 474 met the inclusion criteria, based on the screening questionnaire. These 474 CSs were contacted by telephone, of whom 171 were eventually included in the study (Figure 2). Of these, 85 participants were randomly assigned to the tailored RTW program and 86 participants were assigned to the control group. No medical contra-indications for any of the participants were reported by their general physicians.
Also, 715 survivors responded to the initial invitation by returning the postcard. Of these, 647 declined to participate for various reasons. The remaining 68 CSs who returned a postcard, had indicated that they were interested to participate, but not at that particular point in time. These CSs received another invitation to participate in the study at the date they had indicated on the postcard. The postcard data were part of an extensive study on factors and motives associated with (non-)participation, which was published separately [18].

The mean age of the participants was 48.4 years (SD 8.6). The majority was female (69%), had children (66%), and had the Dutch nationality (95%). More than half of the participants was the principal wage earner of the household (56%). Breast cancer was the most common diagnosis in this study population (40%). On average, CSs had worked for 24.1 years (SD 10.1) before being diagnosed with cancer. The majority of participants had a clear intention to RTW at baseline (71%) (Table 1). The final questionnaires from participants were collected in March 2016.

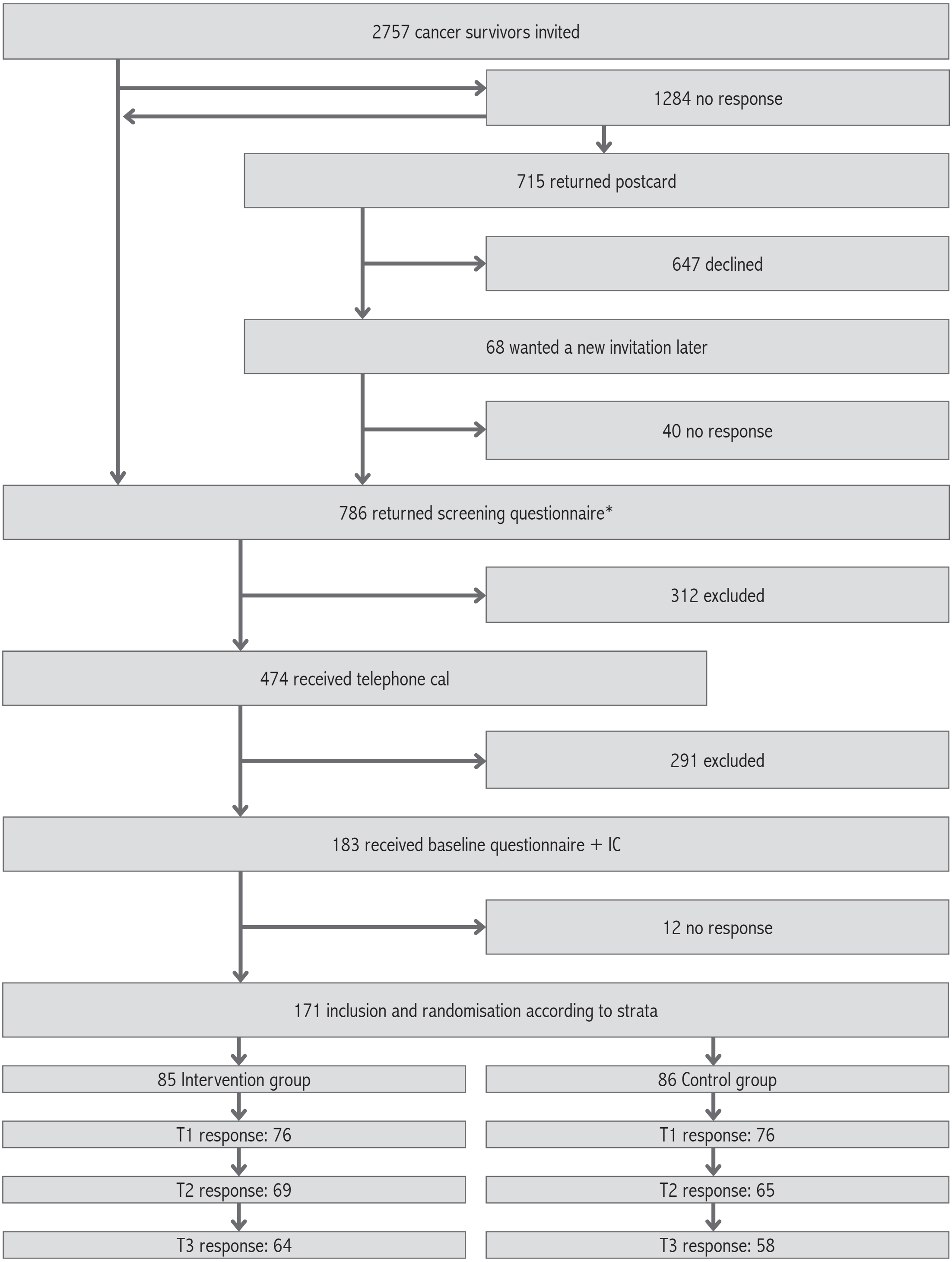
Table 1 Characteristics of the study population

Variable	Categories	Participants (N=171)	Intervention group (N=85)	Control group (N=86)	P-value*
		Mean (SD)	Mean (SD)	Mean (SD)	
Age in years		48.4 (8.6)	47.9 (8.5)	48.8 (8.7)	0.492
Total number of years working		24.1 (10.1)	23.5 (10.1)	24.6 (10.2)	0.502
		N (%)†	N (%)†	N (%)†	
Gender	Male	53 (31.0)	24 (28.2)	29 (33.7)	0.438
	Female	118 (69.0)	61 (71.8)	57 (66.3)	
Type of contract before sick leave	Temporary contract or temporary agency work	96 (56.1)	47 (55.3)	49 (57.0)	0.825
	No contract (unemployed)	75 (43.9)	38 (44.7)	37 (43.0)	
Level of education	None/primary/lower vocational education	30 (17.5)	12 (14.1)	18 (20.9)	0.198
	Secondary school	28 (16.4)	18 (21.2)	10 (11.6)	
	Vocational education/upper secondary school	60 (35.1)	32 (37.6)	28 (32.6)	
	Upper vocational education/ university	53 (31.0)	23 (27.1)	30 (34.9)	
Principal wage earner	No	74 (43.3)	39 (45.9)	35 (41.2)	0.536
	Yes	96 (56.1)	46 (54.1)	50 (58.8)	
Marital status	Living alone	36 (21.1)	17 (20.5)	19 (22.1)	0.776
	Married	81 (47.4)	43 (51.8)	38 (44.2)	
	Living together	28 (16.4)	12 (14.5)	16 (18.6)	
	Divorced/widowed	24 (14.0)	11 (13.3)	13 (15.1)	
Having children	No	59 (34.5)	30 (35.3)	29 (33.7)	0.829
	Yes	112 (65.5)	55 (64.7)	57 (66.3)	
Ethnicity	Dutch	163 (95.3)	77 (90.6)	86 (100)	0.004
	Non-Dutch	8 (4.7)	8 (9.4)	0 (0.0)	
Tumor type	Breast	68 (39.8)	30 (44.1)	38 (55.9)	0.235
	Lung	3 (1.8)	1 (33.3)	2 (66.7)	0.567
	Gynecological	7 (4.1)	4 (57.1)	3 (42.9)	0.688
	Colon	13 (7.6)	10 (76.9)	3 (23.1)	0.041
	Gastro-intestinal	10 (5.8)	6 (60.0)	4 (40.0)	0.502
	Head and neck	8 (4.7)	2 (25.0)	6 (75.0)	0.152
	Prostate	3 (1.8)	2 (66.7)	1 (33.3)	0.553
	Hematological	23 (13.5)	12 (52.5)	11 (47.8)	0.799
	Brain	8 (4.7)	1 (12.5)	7 (87.5)	0.031
	Other type of cancer	24 (14.0)	14 (58.3)	10 (41.7)	0.362
	Cancer recurrence	4 (2.3)	3 (75.0)	1 (25.0)	0.306

Treatment modalities	No treatment	2 (1.2)	2 (100.0)	0 (0.0)	0.152
	Surgery	124 (72.5)	64 (51.6)	60 (48.4)	0.418
	Radiotherapy	84 (49.1)	32 (38.1)	52 (61.9)	0.003
	Chemotherapy	109 (63.7)	52 (47.7)	57 (52.3)	0.488
	Hormone therapy	47 (27.5)	19 (40.4)	28 (59.6)	0.135
	Immunotherapy	13 (7.6)	8 (61.5)	5 (38.5)	0.375
	Other type of treatment	13 (7.6)	7 (53.8)	6 (46.2)	0.756
Type of previous employment contract	Fixed employment	49 (29.3)	25 (51.0)	24 (49.0)	0.995
	Temporary employment	95 (56.9)	47 (49.5)	48 (50.5)	
	Temporary agency work	21 (12.6)	10 (47.6)	11 (52.4)	
	Other type of contract	2 (1.2)	1 (50.0)	1 (50.0)	
Intention to RTW	Uncertain or no intention to RTW	49 (28.7)	23 (46.9)	26 (53.1)	0.646
	Clear intention to RTW	122 (71.3)	62 (50.8)	60 (49.2)	
		Mean (SD)	Mean (SD)	Mean (SD)	
Fatigue	(0-52)	33.0 (9.8)	31.2 (9.6)	34.8 (9.8)	0.017
Health-related quality of life (levels of functioning)	Quality of life(0-100)	63.7 (17.3)	63.9 (18.1)	63.6 (16.6)	0.894
	Physical functioning (0-100)	78.8 (14.8)	77.6 (15.1)	80.0 (14.5)	0.316
	Emotional functioning (0-100)	64.1 (25.0)	64.4 (23.7)	63.9 (26.4)	0.885
	Social functioning (0-100)	69.0 (26.0)	68.8 (27.4)	69.2 (24.6)	0.928
	Cognitive functioning (0-100)	66.5 (26.9)	66.3 (25.3)	66.7 (28.5)	0.924
	Role functioning (0-100)	63.1 (26.4)	63.5 (27.5)	62.6 (25.4)	0.818
	Sleeping problems (0-100)	37.8 (33.8)	41.2 (33.4)	33.7 (33.9)	0.113
	Financial problems (0-100)	40.6 (35.6)	42.4 (38.3)	38.8 (32.9)	0.520
Participation in daily activities	Frequency of participation (0-100)	32.1 (8.2)	31.2 (9.0)	32.9 (7.3)	0.156
	Restrictions in participation (0-100)	81.8 (13.8)	80.2 (14.8)	83.3 (12.6)	0.139
	Satisfaction with participation (0-100)	63.5 (15.2)	63.5 (15.1)	63.5 (15.4)	0.994

* P-values are the result of T-tests and chi-square tests comparing the intervention and control group; † N and calculated percentages may approach or exceed the total N and 100% because of missing values or rounding differences.

Figure 2 Participant recruitment flow diagram

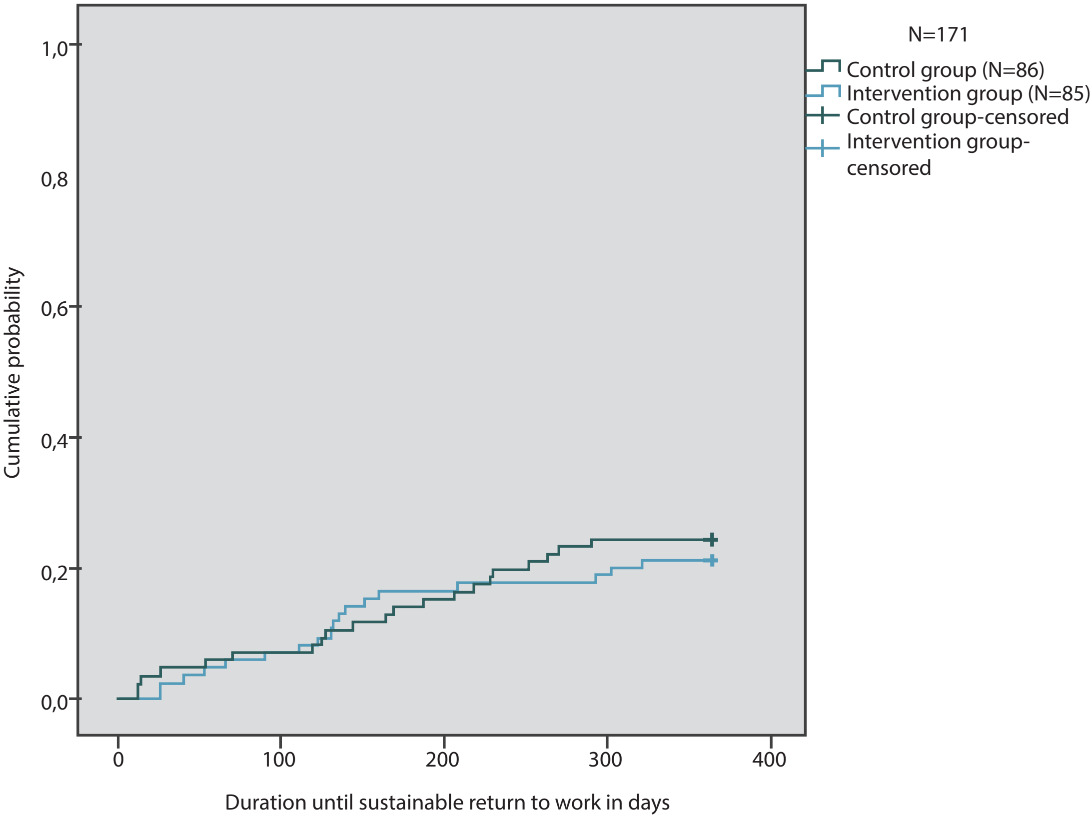


*786 CSs returned the screening questionnaire: 758 CSs returned the questionnaire after receiving the invitation, and 28 CSs returned it later on, after receiving another invitation by their own request.

Duration until sustainable RTW

During follow-up, 39 (22.8%) of the 171 included CSs sustainably returned to work. Of these, 21 participated in the intervention group, and 18 in the control group. In Figure 3, the Kaplan-Meier curves for duration to sustainable RTW are presented. The log rank test revealed no significant differences between the curves of the intervention group and the control group (p=0.642).

Figure 3 Kaplan-Meier curves for duration until sustainable RTW, intention-to-treat analysis



The results of the Cox regression analyses are presented in Table 2. The analyses showed a crude HR for duration until sustainable RTW of 0.86 for the intervention group, compared to the control group. This indicates that participants in the intervention group took more time to sustainably RTW compared to participants in the control group, but this difference was not statistically significant (p=0.642, 95% confidence interval (CI) 0.46-1.62). Age, as well as baseline differences between the groups in levels of fatigue and CSs' active contemplation of RTW, proved to be relevant confounders in the analysis. When adjusting the model for these confounders, the intervention group had sustainably returned to work earlier than the control group (HR 1.11; 95% CI 0.57-2.19), although this effect was far from statistically significant (p=0.754). The final model was corrected for age, fatigue, active contemplation of RTW, and additionally for gender and level of education (Table 2). We found no effect modification by stratum, i.e. type of employment contract prior to job loss (p=0.390).

The first per-protocol analysis, which included the control group and participants in the intervention group who had actually started participation in the program, revealed a crude HR of 0.75 (95% CI 0.38-1.47; p=0.401). Adjusted for age, gender, fatigue, active contemplation of RTW, and level of education, the HR was 1.02 (95% CI 0.49-2.12; p=0.958). In the second per-protocol analysis, which included the control group and participants in the intervention group who had received the whole intervention according to protocol, the crude HR was 1.32 (95% CI 0.65-2.68; p=0.444), and the adjusted HR was 1.49 (95% CI 0.70-3.17; p=0.302) (Figure 4). The per-protocol analyses thus revealed that participants, who received the intervention program according to protocol, had a statistically non-significant improvement in duration until sustainable RTW compared to participants in the control group.

Effect of the intervention program on rate of RTW, health-related outcomes and participation

Regarding rate of RTW, we found no significant difference in the proportion of CSs that returned to work in the control and the intervention group after one year of follow-up (p=0.613). Further, the linear regression analyses showed that there were no statistically significant differences between the intervention and control group with regard to fatigue (p=0.538), quality of life (p=0.940), and participation in society (i.e. frequency, restrictions, and satisfaction (p-values ranged from 0.130-0.953)) (Table 3).

Figure 4 Kaplan-Meier curves for duration until sustainable RTW, per-protocol analysis

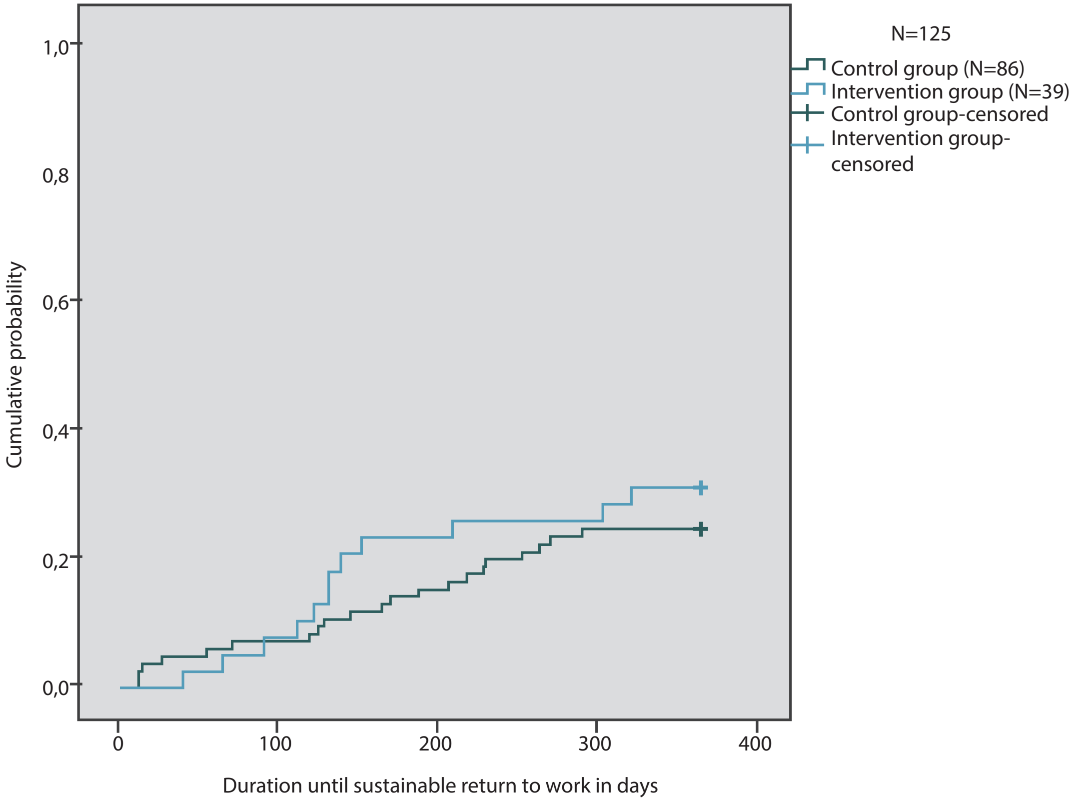


Table 2 Results from the Cox regression analysis for duration until sustainable RTW (N=171)

	Crude model			Adjusted model			Final model		
	HR*	95% CI	P †	HR*	95% CI	P †	HR*	95% CI	P †
Intervention group ‡	0.86	0.46-1.62	0.642	1.11	0.57-2.19	0.754	1.16	0.59-2.31	0.663
Age				0.92	0.89-0.95	<0.001	0.93	0.90-0.96	<0.001
Fatigue				1.05	1.01-1.08	0.009	1.05	1.01-1.08	0.007
Readiness to RTW contemplation phase				0.84	0.72-0.98	0.028	0.85	0.72-0.99	0.042
Gender							0.63	0.30-1.36	0.633
Level of education **									
Secondary school							0.51	0.12-2.14	0.359
Vocational education/upper secondary school							1.31	0.50-3.47	0.582
Upper vocational education /university							0.86	0.29-2.53	0.787

*Hazard Ratio; † P-value; ‡ compared to the control group; ** compared to the reference group "none/primary/lower vocational education"

Table 3 Results of the analyses on secondary outcome measures* (N=122)

Secondary outcome measure	Beta	95% CI	P †
Fatigue	-1.253	-5.275-2.770	0.538
Quality of life	0.284	-7.117-7.684	0.940
Frequency of participation	-2.591	-5.961-0.778	0.130
Restrictions in participation	0.718	-4.695-6.131	0.793
Satisfaction with participation	0.194	-6.308-6.696	0.953

*Results for the intervention group compared to the control group, adjusted for age, gender, and level of education; † P-value.

Main findings

The hypothesis that was tested in this study was that offering a tailored return to work program to CSs with job loss would lead to a significant improvement in duration until RTW in these CSs, compared to the usual care provided by the SSA. The main finding of this study is that this hypothesis is false, i.e. we found no significant differences in duration until sustainable RTW between CSs with job loss in the intervention group, who received the tailored RTW program, and those in the control group, who received usual care. Further, there were no significant differences regarding the secondary outcome measures, i.e. rate of RTW, fatigue, quality of life, and participation in society.

Interpretation of findings

The present study offered a multidisciplinary intervention program to CSs with job loss, but found no statistically significant effect on duration until sustainable RTW. A process evaluation conducted alongside the present RCT showed that the RTW program was only moderately implemented, and that less than half of the participants in the intervention group received the program according to protocol (unpublished observations). As the per-protocol analyses showed that CSs who had received the intervention program according to protocol had sustainably returned to work faster than the control group, although not statistically significant, it could be that implementation failure in this study contributed to the lack of significant results regarding the effectiveness of the RTW program. When comparing our results to other studies, a recent Cochrane review showed that, so far, there is moderate, but conflicting evidence that multidisciplinary interventions for CSs have a positive effect on RTW [19]. That is, a few studies in that review found a significant effect on RTW, while other studies found no effect at all. To illustrate, a study in 1983 by Maguire et al. (1983) offered a multidisciplinary program to CSs, and found significant improvement with regard to RTW [20]. Also, Van Waart et al. (2015) found a significant effect of two physical activity programs on rate of RTW, compared to usual care in breast cancer patients receiving adjuvant chemotherapy, although RTW was not the main outcome of that study, and the study was not aimed at CSs with job loss [21]. In contrast, in other studies, no effect of interventions programs on RTW was found. For instance, a recent study by Tamminga et al. (2013), who offered a hospital-based vocational intervention program to CSs, demonstrated no effect of the intervention program on RTW compared to usual care [22]. It should be mentioned that previous studies were not aimed at CSs with job loss.

Furthermore, in studies conducted in sick-listed workers with job loss, suffering from a different health condition than cancer, the evidence regarding the effectiveness of RTW programs also seems contradictory. To illustrate, a recent study by Audhoe et al. (2016) found no effect of a multidisciplinary intervention on RTW or other work-related outcomes, such as worker participation, in sick-listed workers with psychological problems, who experienced job loss (unpublished observations). In contrast, in a study by Vermeulen et al. (2011), in which a stepped-care participatory RTW program was offered to sick-listed workers with musculoskeletal disorders who experienced job loss, a significant effect on RTW was detected [23]. Overall, it may be concluded that there is a general lack of convincing evidence of RTW interventions in sick-listed workers who experienced job loss, both those with cancer and those with another health condition.

Further, the number of CSs that returned to work in the present study was only 22.8%. Across earlier studies in CSs, although not specifically in those with job loss, the rate of RTW was circa 62% at one-year post diagnosis, 73% at one-and-a-half years after diagnosis and 89% at two-years post diagnosis [6]. It seems that the rate of RTW in the present study was quite low, especially given the fact that CSs in this study were already one year on sick leave at baseline. First, it should be considered that the population in the present study may have suffered from health problems that hindered their RTW. That is, CSs in this study could only participate if they received sickness or disability benefits at baseline, indicating the presence of health problems and/or disabilities in these survivors. In fact, many survivors in the present study, i.e. those who were on sick leave for 12 months, had been re-evaluated for sickness benefits just before study entry. In addition, the process evaluation conducted alongside the RCT confirmed that health problems were an important reason for CSs to drop out of the intervention program (unpublished observations). Overall, it is therefore likely that CSs in this study were suffering from health problems that may have reduced their ability to (return to) work, which may partly explain the low rate of RTW in the present study, compared to other studies among CSs.

Other explanations for the discrepancy in RTW rates between our study and other studies with CSs on sick leave are that previous experimental studies mostly included CSs who still had an employer [19]. As workplace- and employer-related factors, such as workplace accommodation and support from the workplace, are strongly associated with positive RTW outcomes [24], higher RTW rates may be more likely for populations of CSs with an employer, compared to a population of CSs with job loss. It should also be recognized that, during the study period, there was an economic recession in Europe and in the Netherlands [25], which is likely to have contributed to the low RTW rate in the present study.

Finally, the present study showed no effect of the tailored RTW program on fatigue, quality of life, and participation in society. In other RTW studies for CSs, although not specifically for CSs with job loss, the findings on health-related outcomes are, at best, ambiguous. That is, the study by Tamminga et al. (2013) found no significant effect of their RTW program on quality of life [22]. On the other hand, the study by Van Waart et al. (2015) showed improvements in physical functioning and reduction of symptoms such as fatigue [21]. However, it should be considered that this study offered a program that was primarily aimed at improving physical fitness, and not RTW, which may make it more likely to find an effect on physical outcomes compared to studies that have RTW as a primary aim. In conclusion, it seems that multidisciplinary intervention programs for CSs, both those with and without job loss, show conflicting results regarding RTW outcomes, as well as regarding health-related outcomes.

Strengths and limitations

The strengths of this study are that the tailored RTW program was offered in a nation-wide randomized controlled setting, and that the analysis of the primary outcome measure was based on 100% complete follow-up data, as both register data and self-reported data were used. Also, the calculated sample size required for this study was 131, and eventually 171 participants were included in the study. There are also several limitations to this study. First, only a small portion, i.e. 6%, of the invited CSs eventually participated in the study. Therefore, selection bias is a real probability in this study, which limits the generalizability of our results. Another limitation is that we did not measure whether or not participants in the control group received comparable interventions as part of their usual care. Finally, our results should be interpreted in the context of a national social security system. Translation of these results to countries with a different social security context should be done cautiously.

Implications for research and practice

This study provides several key points for researchers and practitioners who are involved in the RTW process of CSs with job loss. First, given the lack of conclusive evidence of the effectiveness of RTW programs in populations of sick-listed workers with job loss, it would be worthwhile for future researchers to identify potential causes of theory, program and/or implementation failure in previous RTW studies. Specifically, researchers could compare the results of previously conducted experimental and observational RTW studies, as well as process evaluations conducted alongside previous RCTs for workers with job loss, suffering from cancer or other health conditions. Comparing studies conducted in workers within a social security context may provide new insights into potential theory and implementation failure of RTW interventions for workers who experienced job loss. This could lay the groundwork for improvements in future interventions to support RTW in workers with job loss, with cancer or with another health condition. Further, we recommend a critical evaluation of implementation methods of future intervention programs in complex settings. Specifically, procedures regarding communication and cooperation between the stakeholders involved in intervention studies for workers with job loss, such as a SSA, health care professionals, (future) employers, re-integration agencies and job hunting agencies, should be discussed and agreed upon before the start of an intervention program. In addition, for future studies offering RTW interventions to sick-listed workers with job loss, it would be beneficial to conduct a pilot study and/or to include a test phase in a RCT, in order to facilitate proper implementation on a larger scale later on. Practitioners could potentially be consulted in order to enhance implementation strategies for future programs, in order to bridge the gap between research and daily practice.

Conclusion

The tailored RTW program for CSs with job loss that was offered in this study did not result in a significant improvement in duration until sustainable RTW, compared to usual care. Considering that the number of CSs with job loss is expected to increase in the future, it is essential to identify new methods of work support for these survivors. As there is still inconclusive evidence with regard to the effectiveness of current RTW programs for CSs with job loss, and for workers with other health conditions who experienced job loss, it is important to gain more knowledge on suitable intervention strategies for these populations of workers.

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Physical and psychosocial problems in cancer survivors beyond return to work: a systemic review

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Physical and psychosocial problems in cancer survivors beyond return to work: a systemic review

Abstract

Objective: Attention for the expanding group of cancer survivors at work, and the late effects they are confronted with while working, has been limited. The objective of this systematic review is to identify and summarize studies, exploring ongoing physical and/or psychosocial problems related to functioning of employees with a history of cancer, beyond their return to work.

Methods: Publications were identified through computerized Medline, PsycINFO, Embase and CINAHL searches (January 2000 - March 2013). Studies had to be directed at cancer survivors, who were employed during the study. Both qualitative and quantitative studies were included. Quality assessment of these studies was performed. Two reviewers independently extracted data from each publication, e.g., physical and/or psychosocial problems (e.g., fatigue and cognitive limitations), outcome measures (e.g., work productivity), qualitative and quantitative results.

Results: The search identified 8979 articles. After exclusion on title and abstract, 64 were retrieved for full text screening, of which 30 met the inclusion criteria.

A total of 20 studies reported quantitative and 10 studies reported qualitative results. The majority of studies assessed psychosocial problems in cancer survivors at work. Cognitive limitations, coping issues, fatigue, depression and anxiety were reported to influence work ability. Physical problems, such as difficulties with lifting and treatment-induced menopausal symptoms, were frequently described to affect functioning at work.

Conclusions: Ongoing physical and/or psychosocial problems are present in occupationally active cancer survivors, which may cause serious difficulties at work. The results of this study may be used as input for developing supportive interventions for these survivors.

Introduction

In Europe, 3,2 million people are diagnosed with cancer each year, of whom about 50% is part of the working population [1]. An increasing part of the cancer survivors is able to return to work (RTW), or (partly) stay at work during treatment, because of continuing developments in treatment. [2,3] Specifically, about 62% (range 30 to 93%) of the cancer patients re-enters the workplace within one to two years after diagnosis [4,5]
Many survivors are doing well in general terms. However, a significant proportion of those occupationally active, with percentages up to 100%, experiences work-related physical and/or psychosocial problems [6]. For example, in a study by Munir (2011) in breast cancer patients, all women reported that cognitive problems negatively affected their work performance [7]. Notwithstanding the fact that treatment burden may vary between cancer stages, ongoing symptoms, such as these cognitive problems, should not stay unrecognized [8,9]. That is, fatigue, depressive or anxious mood, pain, menopausal complaints, and changes in cognitive function, e.g., working memory, organization and multitasking, can persist for years after primary treatment ends, and do not only affect cancer survivors not at work, but also those at work [10-13]. Consequently, impairments may develop that influence their work performance, in terms of productivity loss or diminished work ability. This may lead to presenteeism, recurrent sickness absence or even work disability in the long run.

For several years, studies have documented the impact of cancer on employment, and specifically on RTW [4,14]. Cancer survivors re-enter the workplace, because they are often motivated to RTW as they perceive their ability to work as a symbol of recovery, and a vital aspect of re-establishing normality [15]. To some extent, this may be supported by interventions for RTW, but also changes at work, such as accommodations in tasks, hours or function by the employer may have supported their RTW process [16]. And improved cancer treatment, which enables the patient to perform work-related tasks, during and/or after treatment, may have contributed to (earlier) RTW. Up to now, attention for this expanding group of cancer survivors at work, and the late effects and difficulties they are confronted with while working, has been limited.
A few, mostly cross-sectional, studies have specifically described these functional difficulties cancer survivors experience at work. In a recent qualitative study of breast cancer survivors at work, for example, women stated that cognitive limitations were their most problematic post-treatment symptom [17]. The slightest deterioration in cognitive function was described, in an additional study, as devastating for their quality of working life [18]. Another example was given by Engel (2003) reporting that 38% of 5-year breast cancer survivors experienced arm morbidity, such as movement limitations and swelling, influencing their quality of life [19], and having a restraining effect on those still working. Fenlon (2007) described in a study on treatment-induced menopausal symptoms that the necessity to deal with the physical, emotional and social consequences of hot flushes at work made some of the women alter their daily work patterns [20]. Furthermore, Steiner (2007) showed in a study of cancer survivors that more than half of the sample changed their occupational role after RTW, because of cancer-related physical and psychological symptoms, such as lack of energy, nausea, or feelings of uselessness or depression [21].

Evidence suggests that trying to manage both these ongoing symptoms resulting from cancer and the demands of being (partly) at work can lead to poorer physical and psychological health outcomes [22]. Moreover, work-related difficulties due to deteriorated health may cause additional distress [23]. Consequently, these difficulties may contribute to serious problems with functioning in the workplace [24]. Better understanding of how persistent physical and psychosocial problems impact cancer survivors at work, for example, in terms of productivity loss, may be an important step towards supportive interventions for survivors at work, and potentially towards prevention of work disability [25].

Although previous studies have explored the association between symptom burden and RTW or have evaluated the effectiveness of interventions on RTW, no overview of studies on late effects in cancer survivors beyond RTW has been conducted so far. Therefore, the aim of this systematic review is to identify and summarize studies exploring ongoing physical and/or psychosocial problems related to functioning of employees with a history of cancer, beyond their RTW.
As this study merely consists of an overview of the literature and no data gathering of cancer survivors is involved, approval of the Institutional Review Board was not necessary.

Methods

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Search strategy

Publications were identified by the first author (S.D.) through computerized Medline, PsycINFO, Embase and CINAHL searches for studies published from January 2000 until March 2013, with no language restrictions. We identified studies for this review using search strategies based on the Medline (via OVID) strategy, which uses a combination of MeSH and free text terms. The terms used were related to cancer, physical and psychosocial problems, employment, and functioning at work. To be included in this review, papers had to explore physical and/or psychosocial problems, for example, fatigue, cognitive problems, menopausal symptoms, related to functioning at work, for example, experienced work limitations, presenteeism or reduced capacity to perform tasks, in employees with a history of cancer, after their RTW. Further, studies had to be directed at working-aged adults, who were employed during the study. Both qualitative and quantitative studies were included in the review. Studies were excluded if their focus was on factors predictive for RTW in cancer survivors. Also, if they studied psychosocial needs in employed cancer survivors, ethnic differences between employed cancer survivors, or if changes in hours, position or wages was the main outcome measure.

All titles and abstracts were screened by the first author (S.D.), and those clearly not relevant to this review were eliminated. If title and abstract did not provide all the information needed to enable selection, full paper copies were retrieved and screened. Two authors (S.D., M.v.E.) assessed the remaining studies for their eligibility and discussed inclusion and appropriateness based on the inclusion criteria. In case of disagreement about the selection, the article was discussed until consensus was reached. Reference lists of relevant articles retrieved as full papers were checked for additional studies.

Quality assessment

All included publications were subject to a global assessment of study quality. Criteria derived from Critical Appraisal Skills Programme [26] (for qualitative, case-control and cohort studies) and Strengthening the Reporting of Observational Studies in Epidemiology [27] (for cross-sectional studies) were used, such as a clear statement of the aims of the research, appropriate research design, appropriate recruitment strategy, description of the method of analysis, and a clear description of the data. The quality of the studies (indicated as low, medium, high) was assessed independently by two authors (S.D., M.v.E.), and differences were resolved by consensus.

Data extraction

Two reviewers (S.D., M.v.E.) independently extracted a range of data from each publication, including: (1) general information (e.g., geographic area of the study); (2) study characteristics (e.g., design, measurements); (3) study population characteristics (e.g., size, tumour type, work status); (4) physical and/or psychosocial problems (e.g., fatigue, pain, cognitive limitations), and (5) outcome measures (e.g., work productivity, work limitations). In addition, qualitative and quantitative results were extracted from each paper. Finally, the authors S.D. and M.v.E. compared their extracted characteristics and findings and discussed them until consensus was reached.

Results

Study characteristics

The literature search initially identified 8979 articles, with the majority retrieved by Medline. After removing duplicates, and exclusion on title and abstract, a total of 64 were retrieved for full text screening, of which 30 met the inclusion criteria [2,5,7,17,20,21,24,25,28-49]. Table 1 provides an overview of the main characteristics of these 30 articles, which described 25 studies, and involved a total of 32 027 participants.

Almost all studies were conducted in high income countries, with the greater part of articles describing research from the US (N=12), whereas another 14 articles reported studies in Europe (UK N=7; Norway N=4; Denmark N=1; Finland N=1; The Netherlands N=1), Canada (N=2), and Korea (N=2). Nineteen studies had a cross-sectional design, five presented cross-sectional data within a case-control (N=3) or a cohort study (N=2), and six had a longitudinal design, with follow-up lasting up to 24 months. A total of 20 studies reported quantitative and ten reported qualitative results. Subject of research were breast cancer (N=17), prostate cancer (N=6), testicular cancer (N=4), brain cancer (N=2), non-Hodgkin lymphoma (N=1), lymphoma (N=1), cancer of the uterus (N=1), laryngeal cancer (N=1), stomach cancer (N=1), gynaecological cancer in general (N=1), or a variety of tumour types, mostly including those already mentioned (N=9). The majority of the studies used questionnaires to gather data (N=15), but also (focus group) interviews (N=8), telephone interviews (N=3), (web-based) surveys (N=5), and physical exams (N=2) were conducted.

Physical and psychosocial problems were measured specifically in those who were employed at time of study-entry. If, as in some studies, currently employed participants were only a part of the total study population, this is indicated in Table 1. Next to physical problems (e.g., pain, hot flushes, arm disability, (physical) fatigue and/or general health) and psychosocial problems (e.g., cognitive functioning, confidence, coping, distress, depression, anxiety and/or fatigue), also work-related issues (e.g., support at work, the ability to meet the tasks and duties of the job, problem solving, and adjustments at work) were described (Table 1).

Quality assessment

With regard to the quality assessment of qualitative studies, the Critical Appraisal Skills Programme criterion less described was the adequate consideration of the relationship between the researcher and the participants. Regarding both case-control and cohort studies, the criterion less described was the use of potential confounders in the analyses. In the included cross-sectional studies, the Strengthening the Reporting of Observational Studies in Epidemiology criteria less described were the indication of the study design in the title or abstract, the presentation of key elements of the design early in the paper, potential sources of bias, an explanation of how the study size was arrived at, the presentation of unadjusted estimates, and, finally, the generalizability of the study results. Because 28 of the included studies were of high quality, and only two studies of medium quality, no weight difference was employed in this systematic review (Table 1).

Quantitative studies

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A total of 20 studies [5,21,24,25,28-32,34-36,38,39,42-44,46,47,49] reported quantitative results, of which three described mainly physical problems [32,43,44], such as poor health status, functional limitations, chronic conditions and arm pain/motion limitations, to influence work; six mainly described psychosocial problems [24,28,30,31,34,39], such as depressive symptoms, fatigue, exhaustion and cognitive limitations, to affect work ability; and eleven described both physical and psychosocial problems [5,21,25,29,35,36,38,42,46,47,49,] such as the aforementioned problems, but also lack of energy, nausea, hot flashes, coping issues and the inability to perform physical/cognitive tasks, to influence functioning at work. In Table 2, a detailed and comprehensive overview of all results from these quantitative studies is given.

A selection of physical problems at work

About one quarter (22-30%) of prostate cancer survivors indicated to experience difficulties with physical tasks, such as lifting and stooping [29]. Yet, self-reported physical disability of prostate cancer survivors at work decreased from 29 to 18% over a period of 12 to 18 months of follow-up [42].

With regard to breast cancer survivors, difficulties with physical tasks, such as stooping (32%), physical effort (49%) and heavy lifting (62%), were frequently reported by working women [29]. Overall impaired physical ability was reported in 28% of working women with a history of breast cancer [5]. Specifically, physical fatigue was more common among the survivors than in the non-cancer control group [25.] Also, hot flushes were associated with work performance loss in these survivors [38]. Those reporting some arm pain or some movement limitations were more likely to experience loss in productivity than those without pain or without limitations, respectively [44]. In breast cancer survivors at work, physical disabilities decreased from 60 to 36% over a period of 12 to 18 months follow-up [42].

Looking at physical problems in cancer survivors of various tumour types, employed cancer survivors showed better health status, less functional limitations, and less chronic conditions than unemployed cancer survivors. To be expected, employed cancer survivors showed poorer health status, more functional limitations, and more chronic conditions than those employed without a history of cancer [32].

A selection of psychosocial problems at work

Around one tenth (5-16%) of prostate cancer survivors indicated to experience difficulties with cognitive tasks, such as concentration, keeping up with others, and learning new things [29]. Yet, self-reported cognitive disability of prostate cancer survivors at work decreased from 12 to 7% over a period of 12 to 18 months follow-up [42]. With regard to breast cancer survivors, difficulties with cognitive tasks, such as learning new things (20%) and keeping up with others (39%), were reported by working women [29]. Also, overall cognitive limitations, depressive symptoms, anxiety, fatigue and exhaustion were more common among the survivors than in the non-cancer control group [25,28,31].

Looking at psychosocial problems in brain tumour survivors, cognitive (work) limitations, deficits in working memory, executive function and attention, and negative problem solving orientation were more present in these survivors than in the non-cancer control group [24,30]. Overall, cancer survivors reported poorer mental work ability, higher anxiety scores, but also higher scores on neuroticism and extraversion, compared with matched controls from the general population [35,36.]

Table 1 Characteristics of included studies on physical and/or psychosocial problems and health-related work functioning in cancer survivors

Author, year (ref)	Country	Design *	N (†)	Tumour type ‡	Measurement §
Ahn, 2009 (28)	Korea	Cross-sec.	1595 (498)	Breast	Questionnaire
Amir, 2008 (2)	UK	Cross-sec.	41	Various	Phone interview
Boykoff, 2009 (17)	USA	Cross-sec.	74 (40)	Breast	(Focus group) interview
Bradley, 2007 (29)	USA	Longitudinal	496 / 294	BC / PC	Interview
Calvio, 2010 (31)	USA	Cross-sec.	122	Breast	Web-based survey
Calvio, 2009 (30)	USA	Cross-sec.	113	Brain	Web-based survey
Clarke, 2011 (32)	USA	Cross-sec.	22.952 (7424)	Various	Survey
Fenlon, 2007 (20)	UK	Cross-sec.	8 (5)	Breast	Interview
Feuerstein, 2007 (24)	USA	Cross-sec.	95	Brain	Web-based survey
Grunfeld, 2012 (33)	UK	Longitudinal	55 (34)	Gynaecological	Interview
Gudbergsson, 2008 (35)	Norway	Cross-sec. / Case-cont.	226 / 166 / 54	BC / Test / PC	Questionnaire
Gudbergsson, 2008 (36)	Norway	Cross-sec. / Case-cont.	219 / 150 / 62	BC / Test / PC	Questionnaire
Gudbergsson, 2007 (34)	Norway	Cross-sec. / Case-cont.	208 / 163 / 46	BC / Test / PC	Questionnaire
Hansen, 2008 (25)	USA	Cross-sec.	100	Breast	Web-based survey
Kennedy, 2007 (37)	UK	Cross-sec.	24 / 2 / 2 / 1 (27)	BC / non-HL / Uts / Lar	(Focus group) interview
Lavigne, 2008 (38)	USA	Cross-sec.	83	Breast	Questionnaire
Lee, 2008 (39)	Korea	Cross-sec.	408 (218)	Stomach	Questionnaire
Main, 2005 (40)	USA	Cross-sec.	28 (26)	Various	Interview
Munir, 2010 (41)	UK	Cross-sec.	31 {17}	Breast	Quest. / interview
Munir, 2011 (7)	UK	Cross-sec.	13 {9}	Breast	Interview
Oberst, 2010 (42)	USA	Longitudinal	447 / 267	BC / PC	Phone interview
Quinlan, 2011 (44)	Canada	Longitudinal	372	Breast	Quest. / physical exam
Quinlan, 2009 (43)	Canada	Cross-sec. / Cohort	278	Breast	Quest. / physical exam
Rasmussen, 2008 (45)	Denmark	Longitudinal	23 (6)	Various	Questionnaire
Steiner, 2008 (21)	USA	Cross-sec.	100 (92)	Various	Questionnaire
Taskila, 2007 (5)	Finland	Cross-sec.	394 / 107 / 44 / 46	BC / Lymp / Test / PC	Questionnaire
Taskila, 2011 (46)	Netherlands	Longitudinal	135	Various	Questionnaire
Torp, 2012 (47)	Norway	Cross-sec. / Cohort	563	Various	Questionnaire
Yarker, 2010 (48)	UK	Cross-sec.	26	Various	Phone interview
Yu, 2012 (49)	USA	Longitudinal	1354	Various	Questionnaire

* Design. Cross-sec: cross-sectional; Case-cont: case-control; (†) Number of participants currently employed; ‡ Tumour type. BC: breast cancer; PC: prostate cancer; Test: testicular cancer; non-HL: non-Hodgkin Lymphoma; Uts: cancer of the uterus; Lar: Laryngeal cancer; Lymp: Lymphoma; § Measurement. Quest: questionnaire; (||) A selection of physical and/or psychosocial problems is presented here; QoL: Quality of Life; ** QA: Quality assessment; M: medium quality, H: high quality.

Physical / psychosocial problems	Outcome	QA**
Fatigue, exhaustion	Work-related functioning	H
Fatigue, cognitive functioning, confidence, stress, job demands, coping, support	Work-related functioning	H
Cognitive functioning	Job performance	H
Job requirements, cognitive tasks	Work-related functioning	M
Distress, fatigue, job stress, cognitive functioning	Work limitations	H
Fatigue, depression, anxiety, sleep, problem solving	Cognitive limitations	H
Health status, functional limitations	Work-related functioning	H
Hot flushes	Work ability	H
Fatigue, distress, cognitive limitations, sleep, health behaviour, problem solving	Work limitations	H
Physical (e.g., fatigue) and psychosocial symptoms (e.g., confidence)	Work-related functioning	H
Work-related issues (e.g., demand-control-support), anxiety, QoL, personality	Work ability / engagement	H
Work-related issues (e.g., demand-control-support), fatigue, QoL, personality	Work ability	H
Work-related issues (e.g., demand-control-support), distress, QoL, personality	Job strain	H
Work-related issues, fatigue, emotional distress, cognitive limitations	Work limitations	H
Support, attitude, side effects	Work-related functioning	M
Hot flushes, fatigue, mental health, general health	Work productivity	H
Fatigue	Work-related functioning	H
Feelings about work, priorities	Work-related functioning	H
Fatigue, mood, cognitive functioning, depression	Work ability	H
Cognitive functioning	Work ability	H
Cognitive tasks	Work ability	H
Arm disability, fatigue	Work ability / productivity	H
Arm disability, fatigue	Work ability / productivity	H
Physical (e.g., pain, hot flushes, fatigue), psychosocial side effects	Work-related functioning	H
Physical and psychosocial factors	Work-related functioning	H
Mental and physical health status, social factors at work	Work ability	H
Work-related factors (e.g., pressure, workload)	Fatigue at work	H
Support at work, worksite adjustments, coping	Work ability	H
Support at work, empathy, adjustments	Work ability	H
Mental and physical health status	Work-related experiences	H

Table 2 Quantitative results from studies on physical and/or psychosocial problems and health-related work functioning in cancer survivors

Author (ref)	Participants	Problems / Functioning	Main findings
Ahn (28)	Breast CS vs. general population	Fatigue and exhaustion; reduction in work ability	46.8% vs. 25%; $p<0.0001$; 17.9% vs. 11.6%; $p=0.0059$.
Bradley (29)	Prostate CS ; breast CS	Physical task performance; cognitive task performance	In men, 22-30% found that cancer and its treatment interfered with their ability to perform physical tasks (such as physical effort, heavy lifting, stooping); 5-16% noted an effect on cognitive tasks (such as concentration, analysis, keeping up with others and learning new things). In women, 32-62% of those performing physical tasks found that cancer and its treatment interfered with their ability to perform these tasks; 20-39% noted an effect on cognitive tasks.
Calvio (31)	Breast CS vs. non-cancer control group	Cognitive limitations; work output	Memory $\beta=0.29$; $p<0.05$; executive function $\beta=0.26$; $p<0.05$. Changes in work output were more responsive to changes in job stress and fatigue in breast CS.
Calvio (30)	MBTS vs. non-cancer control group	Cognitive limitations; working memory; executive functioning; attention. Job stress; depressive symptoms; negative problem solving	MBTS reported more overall cognitive limitations $F=48.6$, $p<0.001$; more deficits in working memory $F=86.5$, $p<0.001$; executive function $F=24.8$, $p<0.001$ and attention $F=18.7$, $p<0.001$. Job stress $\beta=3.9$, 95% CI 1.5-6.4, $p<0.01$; depressive symptoms $\beta=0.7$, 95% CI 0.1-1.3, $p<0.05$; negative problem solving $\beta=4.2$, 95% CI 1.5-7.0, $p<0.01$ were associated with higher levels of cognitive limitations in both MBTS and healthy workers.
Clarke (32)	(1) Employed with cancer vs. unemployed with cancer; (2) employed with cancer vs. employed without cancer; (3) blue vs. white collar workers (all cancer)	Health status; functional limitations; chronic conditions; bed-days (> 1 week)	(1) First group less likely to report poor-fair health status OR 0.25 (95% CI 0.24-0.26); functional limitations OR 0.37 (95% CI 0.35-0.38); chronic conditions OR 0.30 (95% CI 0.27-0.32); bed-days (> 1 week) OR 0.28 (95% CI 0.27-0.29); (2) First group more likely to report poor-fair health status OR 2.06 (95% CI 1.96-2.17); functional limitations OR 1.72 (95% CI 1.64-1.80); chronic conditions OR 1.31 (95% CI 1.22-1.41); bed-days (> 1 week) OR 1.89 (95% CI 1.79-2.01); (3) First group more likely to report poor-fair health status OR 1.98 (95% CI 1.53-2.56); functional limitations OR 1.28 (95% CI 1.04-1.59); chronic conditions OR 2.03 (95% 1.35-3.05); bed-days (> 1 week) OR 1.29 (95% 0.98-1.70).
Feuerstein (24)	MBTS vs. non-cancer control group	Work limitations; depressive symptoms; fatigue; cognitive limitations; negative problem solving; sleep quality	Working limitations $M=5.6$, $SD=4.4$ vs. $M=2.6$, $SD=2.7$ ($t=6.2$; $p<0.001$); MBTS had higher levels of depressive symptoms ($\beta=0.32$; $p<0.01$), fatigue ($\beta=0.21$; $p<0.01$), cognitive limitations ($\beta=0.22$; $p<0.01$), and negative problem solving ($\beta=0.15$; $p<0.05$). Also, they reported poorer sleep ($\beta=-0.17$; $p<0.05$).
Gudbergsson (35)	CS vs. matched controls from general population	Current work ability; support at work; physical work ability; mental work ability; engagement (dedication; absorption; vigor); health status; somatic symptoms; anxiety; physical quality of life; neuroticism; extraversion	CSs reported poorer current work ability ($ES=0.25$; $p<0.001$), and expected more on support at work ($ES=0.14$; $p=0.005$); CSs reported poorer physical ($ES=0.34$; $p\leq0.001$); mental work ability ($ES=0.30$; $p\leq0.001$). Engagement (dedication and absorption) did not differ between both groups. CSs had significantly lower vigor score ($ES=0.19$; $p=0.003$). Control group reported better health status ($ES=0.18$; $p=0.001$), lower somatic symptom score ($ES=0.14$; $p=0.03$), lower mean anxiety score ($ES=0.14$; $p=0.02$), better physical quality of life ($ES=0.26$; $p=0.001$). Neuroticism ($ES=0.16$; $p=0.002$) and extraversion ($ES=0.12$; $p=0.02$) were higher in the CSs.
Gudbergsson (36)	CS who made work changes due to cancer vs. those who made no changes	Work changes; current work ability; physical and mental work ability; job demands; support; somatic symptoms; health status; comorbidity; anxiety and depression; physical and mental quality of life; neuroticism	17% vs. 83%; Change group: more females ($ES=0.39$; $p=0.003$); poorer current work ability ($ES=0.75$; $p\leq0.001$), reduced physical and mental work ability ($ES>0.50$ both; $p\leq0.001$); higher demands subscale ($ES=0.38$; $p=0.005$); lower support subscale ($ES=0.38$; $p=0.005$); lower mean score on the somatic symptom scale ($ES=0.44$; $p\leq0.001$); poorer subjective health status ($ES=0.60$; $p<0.001$); more comorbidity ($ES=0.53$; $p\leq0.001$); higher scores on anxiety and depression ($ES\geq0.60$ both; $p\leq0.001$); poorer physical ($ES=0.74$; $p<0.001$) and mental quality of life (QoL) ($ES=0.35$; $p=0.004$); more neuroticism ($ES=0.54$; $p<0.001$).

Gudbergsson (34)	CS vs. matched controls from general population	Job strain; DCS	Female survivors experienced more strain than males (p=0.04). In certain subgroups, statistically significant differences on the DCS questionnaire were found: older survivors showed higher scores on demands than their controls (p=0.01), female survivors reported lower control (p<0.001) and higher strain than male survivors (p=0.04), and older male survivors felt higher demands than younger ones (p=0.04). The effect sizes of these differences were so small (<0.20), that they hardly were relevant for the work situation.
Hansen (25)	Breast CS vs. non-cancer control group	Physical fatigue; depressive symptoms; anxiety; cognitive limitations; work limitations	Physical fatigue (t=5.90; p<0.001); depressive symptoms (t=3.72; p<0.001); anxiety (t=2.79; p<0.01); cognitive limitations (t=4.60; p<0.001). The average score on work limitations was significantly higher in breast CS (mean=5.5, SD=4.0) than in non-cancer controls (mean=2.8, SD=2.7); (t=5.6; p<0.001). This difference was even greater after adjusting for age (mean difference=3.1, t=5.7; p<0.001).
Lavigne (38)	Breast CS	Productivity; fatigue; hot flashes; work performance losses; overall health	Reduction in productivity of 3.1% below the healthy worker norm; fatigue and hot flashes were each associated with work performance losses of 1.6% (p=0.05) and 2.2% (p<0.001). Protective factors included a score of excellent overall health of -1.4% (p=0.08).
Lee (39)	Stomach CS vs. general population	Fatigue; work ability	Stomach CS had more fatigue in performing their work OR 4.02 (95% CI 2.55-6.33); more CS had reduced work ability OR 6.11 (95% CI 3.64-10.27)
Oberst (42)	Breast CS; prostate CS	Physical disability; cognitive disability	Breast cancer: 60% reported physical disability at 12 months, decreasing to 36% at 18 months (p<0.01); cognitive disability was reported by 34% and 22% for 12 and 18 months (p<0.01). Prostate cancer: 29% reported physical disability at 12 months, and 17% at 18 months (p<0.05), cognitive disability decreased from 12% to 7%.
Quinlan (44)	Breast CS with arm pain vs. those without arm pain; Breast CS with motion limitations vs. those without motion limitations	Productivity	At 6-12 months post-surgery, survivors with some arm pain are more likely to experience loss in productivity compared to those without pain (OR 2.39 CI 1.08-5.28; p=0.031); those experiencing some range of motion limitations are more likely to experience loss in productivity than those with no limitations (OR 3.12 CI 1.45-6.69; p=0.003). At 30-36 months post-surgery, survivors with some arm pain are more likely to experience loss in productivity compared to those without pain (OR 7.93 CI 1.82-34.46; p=0.006); and those experiencing some range of motion limitations are more likely to experience loss in productivity than those with no limitations (OR 4.08 CI 1.09-15.34; p=0.037).
Quinlan (43)	Breast CS with arm pain vs. those without arm pain; Breast CS with motion limitations vs. those without motion limitations	Productivity	At 6-12 months post-surgery, survivors with some arm pain are more likely to experience loss in productivity compared to those without pain OR 2.48 (95% CI 1.14-5.43; p=0.023); those experiencing some range of motion limitations are more likely to experience loss in productivity than those with no limitations OR 2.56 (95% CI 1.24-5.43; p=0.015).

Table 2 Quantitative results from studies on physical and/or psychosocial problems and health-related work functioning in cancer survivors (continued)

Steiner (21)	Survivors with reduction in work hours; survivors with changes in occupational role vs. survivors with no changes	Physical symptoms; energy; nausea/vomiting; psychological symptoms or fear (feeling bored or useless, anxiety, feeling down or depressed); physical symptoms; psychological symptoms	Reduction in work hours: physical symptoms ($p=0.002$), specifically lack of energy ($p=0.0008$), or nausea/vomiting ($p=0.009$); psychological symptoms or fears ($p=0.01$), specifically feeling bored or useless, anxiety, or feeling down or depressed (all $p<0.05$). Changes in occupational role: physical symptoms ($p<0.0001$); psychological symptoms or fears ($p=0.02$).
Taskila (5)	CS	Physical work ability; mental work ability; commitment; co-worker support; social climate; other diseases	Physical work ability: 20% ($n=31$) of men and 28% ($n=121$) of women; the higher the commitment to the work organisation, the less the risk of impaired physical work ability among both men OR 0.79 (95% CI 0.69-0.91) and women OR 0.90 (95% CI 0.83-0.97). In women, co-workers support was related to reduced risk of impaired physical work ability OR 0.83 (95% CI 0.73-0.94); Mental work ability: 23% ($n=35$) of men and 18% ($n=79$) of women; good social climate in men OR 0.80 (95% CI 0.70-0.91) and in women OR 0.84 (95% CI 0.76-0.94) and in addition, in women, commitment to the organisation OR 0.87 (95% CI 0.79-0.96) and social support from co-workers OR 0.84 (95% CI 0.73-0.96) were significant. Both men and women who had at least two other diseases had an increased risk of impaired mental work ability OR 5.08 (95% CI 1.49-19.29) and OR 3.82 (95% CI 2.11-6.92) in men and women respectively.
Taskila (46)	CS	Fatigue; work pressure; physical workload; workplace accommodation; depression	At 6 months, fatigue was related to higher work pressure ($p=0.02$), higher physical workload ($p<0.05$), and lack of workplace accommodations ($p=0.03$). At 18 months, fatigue was related to lack of workplace accommodations ($p<0.001$). Depression scores were significantly higher among those who did not have workplace accommodations at 6 months ($p=0.03$) and at 18 months ($p<0.001$).
Torp (47)	CS	Physical work ability; mental work ability; coping	31% reported a reduction of physical work ability due to cancer; 23% reported a reduction of mental work ability. Only 7% and 6% reported that they did not cope well with the physical and mental strains at work, respectively.
Yu (49)	CS	Physical and mental health	At 2 years post-diagnosis, poorer physical and mental health (both $p<0.001$) were associated with having at least one negative work experience (univariate). Multivariate, those reporting at least one negative experience had deteriorating physical OR 0.96 (95% CI 0.94-0.98) and mental OR 0.94 (95% CI 0.92-0.96) health.

MBTS, malignant brain tumor survivors; CS, cancer survivor; QoL, quality of life; DCS, demands, control, support.

Qualitative studies

A total of 10 studies [2,7,17,20,33,37,40,41,45,48] reported qualitative results, of which six mainly described psychosocial problems [2,7,17,40,41,48], such as coping issues, stress, cognitive limitations, fatigue and lack of social support and/or work accommodation, to influence work; and four described both physical and psychosocial problems [20,33,37,45], such as the aforementioned problems, but also hot flashes, susceptibility to infections, hair loss and emotional strain, to influence functioning at work. In Table 3, a detailed and comprehensive overview of all results from these qualitative studies is given.

A selection of physical problems at work

As a result of physical job demands or because of symptoms, continuing longer than expected, cancer survivors were sometimes not able to continue in their old work role. Also, coping with return to the work environment, often as a result of ongoing physical issues, seemed to require a period of adjustment [33]. Regarding the impact of treatment-induced menopausal symptoms, the effect of hot flushes at work were primarily described, for example: “I have deliberately got work where I am working on my own a lot and I can be shut away a lot of the time so people don't even see me” [20,45]. Further, the occurrence of hair loss and wearing a wig was considered a difficulty at work, with some women describing the hair loss as “one of the worst things that happened” [37].

A selection of psychosocial problems at work

Cognitive problems, such as poor concentration, memory and attention problems, and their negative effect at performance, quality and the speed of work, were reported by various studies [7,41]. “Every 2 hours, I was going somewhere to sit down and relax, I couldn't think well. I couldn't coordinate everything that was going on” [17]. Confusion or loss of concentration, influencing confidence and self-esteem was also found, specifically in breast cancer survivors, trying to deal with the emotional and social consequences of hot flushes at work [20].

Next to cognitive limitations, difficulties with coping were described in the larger part of the included qualitative studies. For example, cancer survivors who were already in stressful jobs found it more difficult to cope when returning. Also, coping with expectations from employers and colleagues was difficult for those who felt they could not perform [37]. Many survivors described their colleagues as being over-protective. “The restrictions at work made me feel I was being prevented from getting back to normal, when I was capable to cope with the demands at work” [2].

Finally, the impact of fatigue on work ability was something that took many employees by surprise [48]. It was described as disruptive and difficult to manage at work, even years after treatment [37]. The initial period following return to the workplace was often more tiring than had been anticipated [33]. Cancer survivors indicated that colleagues were soon to forget about their cancer and failed to recognize or understand the impact of late effects of treatment, such as fatigue, upon work and well-being [48]. In order to cope with fatigue, regular short breaks while at work were scheduled and many reported that they went to bed early, sometimes as soon as they returned home, in the first few weeks after returning to work. “One afternoon, when I got very, very tired, I said: ‘Could I just take 10 minutes please?’, and they very kindly said: ‘Do you want to go home?’ But I didn’t want to go home. I had a half hour break and I felt a lot better” [33].

Table 3 Qualitative results from studies on physical and/or psychosocial problems and health-related work functioning in cancer survivors

Problems / Functioning	Author (ref)	Findings and Quotes (Q)
Cognitive functioning	Boykoff (17)	Decreased efficiency and speed at work; reduced chances of being promoted or assigned to projects; no longer able to handle the level of work; getting passed over for opportunities and not getting chances for advancement; memory problems; increased stress. Q: “I am very insecure when I am talking to people professionally, because I am worried I am just going to draw a blank”; “Every 2 hours, I was going somewhere to sit down and relax, I couldn't think well. I couldn’t coordinate everything that was going on.”; “When I began the chemo, I couldn't concentrate at all and I couldn't read academic material. I couldn't work, I couldn't write. I needed to finish my PhD, but I couldn't concentrate adequately.”
	Munir (41)	Problems with remembering tasks.
	Munir (7)	Cognitive side effects; poor concentration, memory problems and difficulties in thinking; hiding cognitive difficulties from the employer rather than discussing them; feeling overwhelmed by the work environment and in some cases found it unbearable; noise affected cognitive functioning and the ability to perform; fatigue affected cognitive functioning; problems with organising information and decision-making.
Coping	Amir (2)	Q: “Being over-protected (…) the restrictions at work made me feel I was being prevented from getting back to normal, when I was capable to cope with the demands at work.”; “Significant changes in duties to be able to cope with the demands at work.”; “I came back on a very slow return and they looked after me every step of the way.”
	Grunfeld (33)	Coping problems related to being back in the work environment and the demands of the role at work, due to ongoing physical issues, including hot flushes, poor concentration and difficulty sitting for prolonged periods; reduced confidence; difficulties with learning new systems or new information; fear of having forgotten previous learned information.
	Main (40)	Survivors needed to work 'smarter' after cancer, to pace and to concentrate on aspects of the job that best utilized strengths; shifts in motivation (do what you love to do), relevance (priority in life) and tolerance (some were more/some less tolerant).
Fatigue	Grunfeld (33)	Returning to work was more tiring than anticipated; regular short breaks were scheduled; going to bed early (sometimes as soon as returning home) in the first weeks after returning at work.
	Kennedy (37)	Side effects (most of all fatigue) were disruptive and difficult to manage at work, even years after treatment.
	Yarker (48)	The delayed impact of fatigue on work ability was not something that had been highlighted by professionals and took the employee, and the line manager, by surprise.
Hot flashes	Fenlon (20)	Social impact; individual difficulties, such as lack of concentration; difficult relationship with colleagues as women found themselves needing to explain what was happening to them; embarrassment; confusion; reduced confidence and self-esteem; physical, emotional and social consequences made women alter their work patterns; changed self-image. Q: “I have deliberately got work where I am working on my own a lot and I can be shut away a lot of the time so people don't even see me.”; “Take measures to reduce stress, work demands.”
	Rasmussen (45)	Q: “Those hot flashes meant that I could not work nights, not being able to do my best. You can't do it to your colleagues and not to oneself either.”
Physical functioning	Kennedy (37)	Increased susceptibility to infections; difficulties with hair loss/wearing a wig, feeling uncomfortable, self-conscious; difficulties about prosthesis and clothing.
Stress	Amir (2)	Q: “I don't get as stressed about things at work. I think it gives you the attitude to enjoy every day and I would never worry about work or let it dominate me now.”
	Kennedy (37)	Those already in stressful jobs found it more difficult when returning.

Support	Amir (2)	Q: “Everybody forgets what you have just gone through, once you get back in the office. They forget you have cancer and have got to muck in like everyone else.”; “Insensitive management.”
	Kennedy (37)	Difficulties with expectations and lack of understanding from employers and colleagues; survivors suggested that if they looked well, this might mislead employers into thinking they had completely recovered; some had to make the time up if specialists appointments were during work hours; a minority described negative reactions and support at work.
	Main (40)	Many found their employers and colleagues to be compassionate, helpful, offering sympathy, and encouragement; several mentioned co-workers' discomfort with the topic of cancer; many reported understanding from employers for time off for medical appointments.
	Rasmussen (45)	Q: "Okay, you are back, and the cancer is gone. What is the problem? The emotional strain afterwards that is your problem, your personal battle. You can't confront your colleagues with that, you just can't.”
	Yarker (48)	No help or support with managing late effects, due to employers not knowing how survivors were affected by their cancer at work; difficulties with employers and colleagues forgetting about their cancer and failing to recognise or understand the impact of late effects of treatment on work and well-being; feeling left isolated in dealing with side effects, symptoms, and work, when no adjustments were made and no long-term support was provided; difficulties, when empathy and support started to wane and was replaced by business-as-usual.
Work accommodation	Amir (2)	Q: “Excessive job demands once back at work.”
	Kennedy (37)	Adjustments were offered around flexibility, gradual assimilation, changes in work tasks; paradox was that survivors wanted to be treated normally, but they also felt they needed support and allowances; this highlights the difficulty for employers to strike the balance in between.
	Main (40)	Many were able to keep working because employers and colleagues helped tailor their work; accommodations were offered without asking.

Discussion

◆

General findings

In this systematic review, a summary of 25 studies, described in 30 articles, exploring physical and/or psychosocial problems related to functioning of employees with a history of cancer, is provided. The majority of the studies in this review assessed psychosocial problems in cancer survivors at work. Particularly, cognitive limitations, such as concentration problems, memory deficits or difficulties learning new things, were found to affect work ability both in quantitative and qualitative studies. Coping issues were extensively described in qualitative studies, with experiences diverging from dealing with insensitive management to over-protectiveness of supervisors and colleagues. The impact of fatigue was both quantitatively and qualitatively assessed, and found to be significantly more present in cancer survivors at work than in the general working population. It was reported to be disruptive for both employee and supervisor, as it unexpectedly affected work ability even years after treatment. Depression and anxiety were significantly more present in those who needed changes at work due to cancer. And, depression was also higher in those who did not have work accommodations at follow-up. Regarding physical problems, cancer and its treatment were reported to interfere with the ability of cancer survivors to perform physical tasks, such as lifting and stooping. Finally, treatment-induced menopausal symptoms, specifically hot flushes, were frequently described as being disruptive at work and affecting work performance.

Interpretation of findings

It was striking to find that only few studies were primarily aimed at functioning of cancer survivors, beyond their RTW. Up to now, most studies have RTW, work status or work disability, as their main focus. It can be reasoned that because occupationally active cancer survivors are indeed working, they represent a high functioning subgroup of this population. As a result, many may not realize that, next to the well-functioning contributors to the workplace, there is a significant proportion of cancer survivors that returns to work with impaired work ability. These survivors are more likely to change or leave employment altogether. Therefore, (occupational) health care professionals, but also employers, colleagues and insurance companies, should be notified that diagnosis- and/or treatment-induced problems may linger long after treatment has been completed.

That said, questions may arise about the duration of the problems. The time period that symptoms still can be indicated as diagnosis- and/or treatment-related needs further exploration. Also, attention for the causality of the findings is important. For example, it is known that treatment-induced hot flushes can be triggered by psychological factors, such as being stressed or overtired [20]. As indicated, cancer survivors often require a period of adjustment to cope with the demands at work again. Ongoing physical issues, such as hot flushes, may increase in frequency and intensity because of high job demands [33]. On the contrary, experiencing menopausal symptoms at work may result in more stress at work and, consequently, in loss of productivity. In line with this, one could question if concentration problems increase because of being at work again, where attention is required for several hours a day, and what could be more tiring than anticipated. Or, if these cognitive limitations are the cause of, for example, more fatigue, which could lead to additional difficulties at work. It would be recommendable to disentangle physical and/or psychosocial problems that are already present at time of RTW, in frequency and intensity, and the influence of being back at work has on the course of these problems. Further, it is advisable to explore the impact coping strategies, used by cancer survivors, may have on physical and psychosocial problems at work.

Exploring functioning at work in the general population, previous studies have shown that, for example, fatigue is associated with sickness absence [50]. Because cancer survivors rarely struggle with only a single late effect of diagnosis and treatment, one could imagine that these employees are more susceptible to potential long-term sickness absence or work disability than the general working population. The findings of this review should be taken into account when developing interventions for cancer survivors to improve functioning at work. For example, worksite health promotion programs on physical activity, directed at the general working population, may also show promising effects in terms of diminishing sickness absence and increasing work ability, when tailored to occupational active cancer survivors. When developing and implementing such supportive interventions, (occupational) health care professionals, but also employers and colleagues, should be included in the organisation of these interventions to keep cancer survivors occupationally active.

Strengths and limitations

The main strength of this systematic review is that this is the first review exploring physical and psychosocial problems related to functioning of employees with a history of cancer, beyond their RTW. Up to now, the period prior to RTW received most attention, disregarding the number of occupationally active cancer survivors nowadays, and the late effects they are confronted with while working. Another strength is that both qualitative and quantitative studies were included, resulting in an overview of all available studies. A limitation of this systematic review is that no inter-rater reliability has been calculated in selecting the studies and in extracting characteristics and findings, nor in assessing the quality of the studies. A second limitation is that it was not possible to pool the results and quantitatively summarize effect sizes, because of heterogeneity in the study characteristics. For overall frequencies of physical and/or psychosocial problems in cancer survivors at work, further research is therefore needed. Regarding the studies included in the review, a limitation was that merely studies with cross-sectional rather than longitudinal designs have been included. Consequently, it was not possible to elaborate on causality of these findings. In addition, the small number of studies with control groups from the general population in this review made it difficult to explore the difference between general physical and/or psychosocial problems at work and cancer-related physical and/or psychosocial problems at work. Finally, studies on breast cancer survivors at work were primarily present. No included studies concerned men only. Consequently, it is difficult to generalize the results to cancer survivors from other tumour types, or to conclude upon physical and/or psychosocial problems men at work mainly experience.

Recommendations and conclusion

RTW in cancer survivors receives a great amount of attention and is an essential part of societal integration and participation. Moreover, employment has been rated by cancer survivors as the third most important aspect of quality of life, after the ability to get out and to engage in social activities. Because it is vital to alleviate physical and/or psychosocial problems related to functioning in the expanding group of occupationally active cancer survivors, it is necessary to monitor cancer survivors, beyond their RTW. This comprehensive overview of most explored and reported problems in cancer survivors impacting functioning at work may be a point of departure for research on, for example, presenteeism and sickness absence in occupationally active cancer survivors. Also, the results from this review could be used to raise awareness in both clinical practice and in research about the presence of long-term effects of diagnosis and/or treatment beyond RTW, and to explore the need of interventions for cancer survivors at work. When employees with a history of cancer are given tailored support, and personal recommendations and work-related adjustments are made, they may be more likely to continue and manage their (former) illness at work.

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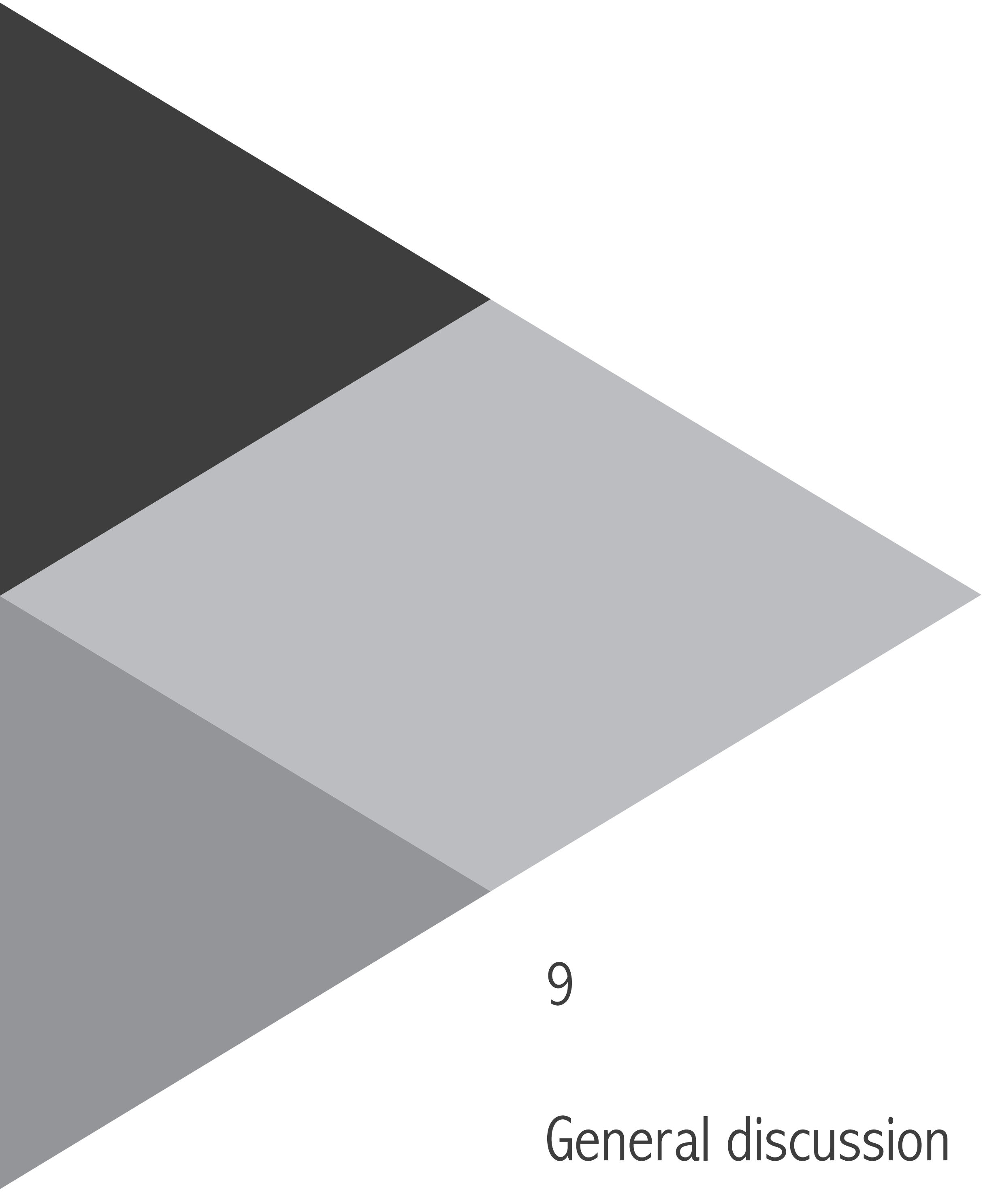

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General discussion

General discussion

The main objective of this thesis was to gain insight into the return to work process of cancer survivors with job loss. In accordance, three specific objectives were formulated:

1. To explore barriers and facilitators for return to work for cancer survivors with job loss, to translate this knowledge into a tailored return to work intervention program for these survivors, and to evaluate process outcomes and the effectiveness of this program on sustainable return to work in cancer survivors with job loss;

2. To obtain a broader perspective on sustainable return to work in cancer survivors with job loss, by exploring therapeutic work as a potential facilitator for return to work;

3. To present an overview of physical and/or psychosocial health problems that cancer survivors may experience beyond their return to work.

Main findings of this thesis

This thesis includes findings from qualitative and quantitative studies regarding return to work in cancer survivors who experienced job loss, as well as findings from a review on problems beyond return to work in cancer survivors. Qualitatively, we found that cancer survivors with job loss essentially experience a situation of double loss, i.e., loss of work on top of loss of health (Chapter two). Specifically, in the turbulent time of a cancer diagnosis and treatment, most of the participants in our focus group study reportedly relied on work to provide structure, social support and financial stability. However, for most of these survivors, their temporary employment contracts were not renewed by the employer. The fact that these cancer survivors lost not only their health because of cancer, but their job as well, in their perception, had a large impact on them, and on their possibilities for return to work. Mainly, cancer survivors with job loss feared for employer stigmatization during job application processes, and lacked return to work support. Further, cancer survivors, as well as participating insurance physicians from the social security agency, reported in these focus groups that cancer survivors with job loss could benefit from gradual return to work, such as work in therapeutic conditions. Therapeutic work could help to increase work ability after cancer, and form the first steps towards paid employment.

Quantitatively, in a longitudinal study in this thesis, which included cancer survivors who were two years on sick leave, we found indeed that participation in therapeutic work was strongly associated with return to paid employment one year later (Chapter four). Furthermore, this study demonstrated that cancer survivors with job loss participated significantly less in therapeutic work, compared to cancer survivors with an employment contract. This can probably be explained by the fact that therapeutic work is often initiated by employers aiming to retain their employee. Therefore, cancer survivors with job loss probably do not have the same chance to participate in therapeutic work, compared to cancer survivors with an employment contract. Indirectly, this may significantly reduce the odds of sustainable return to work in cancer survivors with job loss.

From these studies, it is clear that cancer survivors with job loss are in a different situation regarding return to work, compared to cancer survivors with an employment contract. Hence, cancer survivors with job loss may benefit from tailored return to work support. A study describing the design of a tailored return to work program for cancer survivors with job loss, offered within the context of a randomized controlled trial, was therefore part of this thesis (Chapter three). Given the apparent need for tailored return to work support in cancer survivors with job loss, it is remarkable that a cross-sectional study in this thesis revealed that only a minority (29%) of the invited cancer survivors with job loss was actually interested in participating in the program (Chapter five). In a hierarchical model, we found that marital status, intention and readiness to return to work, as well as type of employment before sick leave, were significantly associated with participation in the program. Furthermore, many of the cancer survivors who were invited reported mental and physical health problems as a reason for declining participation. The reasons for, and factors associated with, non-participation, as well as the overall low level of interest in the program, are important indicators of selective participation of the study population in this return to work program.

A process evaluation conducted alongside the randomized controlled trial, in which the tailored return to work program was offered, revealed that the program was only moderately implemented, and that less than half of the participants in the intervention group received the program according to protocol (Chapter six). Participants were very satisfied with one part of the program, i.e., coaching and preparation for return to work, but not with another part of the program, i.e., finding work in cooperation with two job hunting agencies. Also, various problems in the delivery of the return to work program were reported, including a lack of clear communication between the parties involved, high program intensity and short program duration, and a lack of experience of the job hunters with regard to cancer-related problems. The evaluation of the effectiveness of the tailored return to work program showed no significant differences in duration until sustainable return to work between the intervention and control group (Chapter seven). In the per-protocol analyses in this study, in which only cancer survivors who received the intervention according to protocol were compared to the control group, there seemed to be a positive difference in duration until sustainable return to work. However, this effect was not statistically significant. The lack of statistically significant findings of the tailored return to work program could partly be explained by implementation failure and high drop-out rates in the study due to cancer-related and personal problems, but also by the recent economic recession with corresponding high unemployment rates in the labour market. Finally, we conducted a review that demonstrates that, even after successful return to work, cancer survivors may still experience limitations at work and impairments in work ability due to cognitive and physical problems, for which they may need long-term support (Chapter eight).

Methodological and societal considerations

This thesis holds the first collection of studies dedicated specifically to the return to work process of cancer survivors with job loss. As the group of cancer survivors who are vulnerable for job loss increases, due to the increasing proportions of flexible employment, it was essential to explore the return to work process of these cancer survivors [1,2]. This is especially true as previous return to work interventions are not suitable for cancer survivors with job loss, because these programs were generally aimed at return to work in a (former) workplace [3]. Hence, this thesis has taken the first steps towards an innovative solution for return to work problems in these cancer survivors.

Within this thesis, various methods and designs have been employed in order to explore the return to work process of cancer survivors with job loss, e.g., we used data from focus groups, a randomized controlled trial and a cohort study to obtain our results. An overall concern with regard to the quantitative data in this thesis is that there is a possibility of selection bias. That is, in the randomized controlled trial, only a minority of the invited cancer survivors was interested in participation. This may limit the findings and conclusions of the studies in this thesis that are related to the randomized controlled trial. Therefore, caution is required when extrapolating our results and recommendations to the general population of cancer survivors with job loss, both in the Netherlands and abroad.

Furthermore, the context of the social security system was important in this thesis. For example, this thesis revealed that cancer survivors who enter the social security system after job loss are at a disadvantage with regard to return to work, compared to survivors with an employer. However, it should be mentioned that, in the Dutch system, workers with a fixed employment contract are well-protected from job loss in case of illness. In fact, employers have to substitute their income for at least two years after the first day of sick leave. For workers who experience job loss due to illnesses such as cancer, financial support is offered by the social security system during at least one year of sick leave. We are aware that, compared to many other countries, this is an extremely generous arrangement [4].
Further, the unfavourable position that cancer survivors with job loss hold within the Dutch system, compared to employed survivors, could have affected their perspective on return to work, and their expectations with regard to return to work support. In countries with a different social security system or with higher proportions of flexible employment, the perceived disparity in the return to work process between employed cancer survivors and those with job loss could be either more prominent or completely absent. Additionally, it has been argued that, compared to other countries, the Dutch system holds few incentives for sick-listed workers to return to work within the first years of sick leave, because of the high level and long duration of financial support during sick leave [5]. This could have affected the findings in this thesis with regard to return to work as well.

Finally, the findings of this thesis should be reviewed in the light of the current political and judicial context. Specifically, the social security system in the Netherlands, and in other Western countries, is subject to decisions made on a national, political level. As new legislation is developed, the social security context for sick-listed workers may change. For example, during the period in which the studies in this thesis were conducted, the duration of workers' eligibility for sickness benefits was revisited. That is, workers' eligibility for sickness benefits was to be re-evaluated after one year of sick leave, instead of evaluation after two years of sick leave. Such changes in the social security system are likely to have an effect on the return to work process of cancer survivors with job loss, e.g., it may change their perspective on the need for return to work. As the political and legal contexts of social security systems in Western countries are continuously subject to new developments, these contexts should be carefully considered when conducting studies for cancer survivors, or other workers, with job loss within the social security system.

Interpretation of the findings

The studies in this thesis demonstrate that return to work in cancer survivors with job loss is challenging. This is partly because of cancer-related reasons, including physical, cognitive and psychosocial impairments, and partly because of reasons related to job loss, including a large distance to the labour market, lack of support from employer and colleagues, and limited to no access to therapeutic work. Further, the studies in this thesis show that a tailored return to work program does not instantly bridge the gap between cancer survivors with job loss and the labour market. Moreover, the systematic review in this thesis demonstrated that, even if return to work is realized, further support is necessary for cancer survivors to sustainably participate in work.

When reviewing the findings of this thesis in light of the current literature, the question emerges why return to work interventions fail to show consistent significant effects, despite the fact that there is an apparent need for return to work support in cancer survivors with and without job loss. Specifically, our intervention program for cancer survivors with job loss, as well as previous intervention programs for cancer survivors in general, provide little conclusive evidence with regard to the effectiveness of these programs on return to work [6]. Although some of these studies were statistically underpowered [7] and others were not always primarily aimed at return to work [8,9], there could be another, more fundamental explanation for the lack of convincing evidence across these studies. That is, these programs have in common that they were designed to improve empowerment and readiness for return to work on the side of the cancer survivor, and not on the side of employers. More specifically, these programs may have (partly) removed cancer-related barriers for return to work in cancer survivors, by addressing, e.g., symptom management, quality of life and preparation for return to work [6,10], but potential incentives for the employer in the return to work process have largely been neglected so far. As it has been demonstrated that both cancer survivors and employers need to be engaged to ensure sustainable employability [11-14], a lack of employer engagement may explain why cancer survivors fail to return to work, even after they received an intervention program. To illustrate the importance of employer involvement, two previous reviews demonstrated that employer-related facilitators, such as workplace accommodation and support, are important determinants of return to work [15,16].

Further, a large recent study in rectal cancer patients demonstrated that those who experienced absenteeism or job loss before diagnosis, defined as days of work loss, were more likely to report significantly more days of work loss after diagnosis, compared to those who did not experience absenteeism or job loss before diagnosis [17]. In fact, this study implicated that reduced or no participation in work before diagnosis was more important in predicting participation in work post-diagnosis than any other clinical factors [17]. This, also taking into account the findings in this thesis and the previously mentioned studies on employer engagement [11-14], suggests that once cancer survivors experience job loss, return to work is a challenge that may not be overcome by offering a supportive intervention program. Presumably, involvement of employers in the return to work process of cancer survivors with job loss is an essential element in their return to work process, which has been largely neglected in the design of previous return to work programs [18]. The next step is to examine which factors may facilitate employer engagement in the return to work process of cancer survivors.

Engaging employers in the return to work process of cancer survivors

The literature offers several potential factors that may motivate employers to become engaged in the return to work process of cancer survivors, and particularly in the process of those who have experienced job loss. For example, it has been demonstrated previously that a working relationship between employers and cancer survivors increases the likelihood of the employer to invest in the survivors' return to work [11]. Investments could be, for instance, drawing up a re-integration plan and providing support [2,12]. Particularly for cancer survivors with job loss, the first, rather obvious, problem for employer engagement in return to work, is that generally no prior relationship exists between the (future) employer and the cancer survivor. In order for cancer survivors with job loss to return to work, these survivors have to apply for jobs and employers have to be willing to hire them. In fact, this could be one of the largest bottle-necks in the return to work process of cancer survivors with job loss, i.e., that employers are reluctant to hire cancer survivors [2]. In the literature, several barriers for hiring cancer survivors from an employers' perspective were identified, as well as potential facilitators for employer engagement in the return to work process of cancer survivors.

First and foremost, it is possible that employers perceive the option of hiring workers with cancer as a suboptimal choice for a job vacancy, compared to hiring a supposedly healthy person. Essentially, when offering employment, employers are looking for the best candidate for the job. By definition, cancer survivors with a history of (long-term) sick leave and a need for gradual build-up of the workload are unlikely to be able to compete for a job with a presumably healthy person who does not need, e.g., workplace accommodations or adjusted working arrangements. Although no studies have yet confirmed these exact prejudices in situations where cancer survivors are applying for work, there is evidence of perceived employer discrimination in cancer survivors once they are back at the workplace. Especially in the US, several studies have been conducted that indicate a different treatment of cancer survivors in the workplace, including discrimination, for example when it comes to promotions [19,20]. This has also been found to be true for workers with disabilities in general [21].

The finding that cancer survivors at work can be reluctant to seek support and ask for workplace accommodations [22], may indicate that even beyond return to work, there are several problems related to re-integration, communication and attitudes regarding cancer, which may hinder cancer survivors in their work. Potentially, these prejudices and discrimination regarding workers with a history of cancer at the workplace [23] may also hold true during job applications processes, and prevent employers from hiring cancer survivors.

In order to overcome prejudices that prevent employers from hiring cancer survivors, a sense of societal responsibility in employers may be essential. It has been previously demonstrated that perceived moral obligation is an important factor in employers' decisions to retain or hire workers who were diagnosed with cancer [12]. Furthermore, changing employers' attitude regarding cancer, as well as arranging for communication about cancer [18,24,25], may diminish employers' reluctance to hire cancer survivors [12]. For example, in studies in this thesis, but also in other reports, it shows that employers can have an uncertain or negative attitude towards cancer, which may translate into hesitation to hire cancer survivors [2]. Specifically, employers may assume impaired work ability and a high risk of cancer recurrence in these workers, with corresponding financial and practical consequences [2,26]. In reality, the risk of cancer recurrence, as well as the impact of cancer and cancer treatment on work ability, may vary greatly between individual cancer survivors [27,28]. However, it has been documented before that employers may have wrongful beliefs regarding cancer [24,25], and this could be a barrier for employers to hire cancer survivors. Furthermore, illnesses that are relatively unpredictable in general, such as cancer, but also mental health problems, have proven to be potential taboo topics in communication in the workplace, due to the predefined association with death and loss of health that may make an employer and colleagues feel uncomfortable [29]. These beliefs could eventually translate into a reluctance to hire or retain cancer survivors. It seems that a more positive, educated attitude and increased awareness in employers regarding cancer, as well as practical support for employers in the form of, e.g., a communication plan and tools for appropriate reintegration strategies [30], are necessary changes for employers to consider hiring cancer survivors.

Further, in order to engage employers in the return to work process of cancer survivors with job loss, it is essential to consider the financial and legal context of the labour market [2,4]. Currently, at least in the Netherlands, the financial and legal context does not encourage employers to hire cancer survivors, as employers are vulnerable for high financial costs in case of (long-term) sick leave in workers [4]. For workers with cancer, the trajectory of diagnosis and treatment can take up several months or even years [31], during which the employer must financially provide for the worker and may also need to hire a substitute worker to perform the work previously done by the sick-listed worker [32]. It is therefore not surprising that employers are inclined to release long-term sick-listed workers with cancer as soon as legally possible, which, in case of temporary employment, is quite easily accomplished [2,4]. A previous report from the Dutch Cancer Society confirmed the trend among employers to let go of employees who were diagnosed with cancer and who were working on temporary employment contracts [2]. Therefore, in order to engage and stimulate employers to hire workers with a health condition such as cancer, it is necessary to revisit the legal and financial context for employers [2]. Examples of changing the context for employers are to offer subsidized forms of employment, such as therapeutic work, which reduce the financial risk for employers. To illustrate, a cross-sectional study in this thesis demonstrated that therapeutic work could be an important facilitator for return to paid work in cancer survivors. Moreover, arrangements, such as therapeutic work, provide the cancer survivor with an opportunity to gradually participate in work and increase their work ability, confidence and prove themselves to an employer [33], while the employer is not liable for high financial costs in the case of recurrent sick leave. Therefore, therapeutic work or similar constructs may facilitate employers' involvement in the return to work process of cancer survivors. For example, in a previous study in unemployed workers with musculoskeletal problems, it was already demonstrated that successful participation in therapeutic and paid work is possible with the involvement of employers [34]. Currently, therapeutic work is generally offered only (long) after anti-cancer treatments have been completed. However, there could be much potential in offering therapeutic work shortly after diagnosis or during treatment, in order to support cancer patients to stay at work. For cancer survivors who become unemployed shortly after diagnosis, therapeutic work could keep them engaged in work and provide them with a connection to the labour market. As previously mentioned, avoiding absenteeism and job loss prior to diagnosis, and potentially just after diagnosis, may result in improved participation in work on the long term [17]. Therefore, offering therapeutic work soon after diagnosis and/or job loss might prevent unnecessary long-term sick leave and unemployment in cancer survivors.

Overall, there are several practical, financial, and moral barriers for employers to hire cancer survivors, such as (1) a potentially suboptimal fit between cancer survivors and a job position in terms of best candidacy for the position compared to presumably healthy persons, (2) financial risk in case of recurrent sick leave, and (3) prejudices about cancer at the workplace and a lack of appropriate and effective re-integration strategies and return to work programs. Promoting societal responsibility and an educated (positive) attitude regarding cancer among employers, as well changing the financial and legal context, and early implementation of therapeutic work, could be important facilitators for employer engagement in the return to work process of cancer survivors. Moreover, these facilitators may apply to the return to work process of workers with job loss due to other (chronic) health conditions as well.

Return to work for workers with cancer and workers with other chronic health conditions: an integrated approach

For a long time, cancer was perceived as a life-threatening disease. However, the idea of cancer as a chronic illness is becoming increasingly accepted. The overall increase in cancer survivorship rates [35,36], and the prevalence of long-term or permanent health problems after cancer [37], contribute to the idea that cancer could be classified as a chronic illness. In fact, a few studies have categorized cancer among chronic illnesses as cardiovascular disease and diabetes [38]. However, for some types of cancer, such as lung cancer, the survival chances remain relatively low [39], and the label "chronic illness" would be far from appropriate (yet). Still, with regard to return to work, the identified barriers, including a lack of employer support and opportunities for (therapeutic) return to work, may apply to both workers who survived cancer and those with another chronic health condition [4,15]. The fact that the prevalence of cancer and chronic illnesses, such as cardiovascular disease and diabetes, keep increasing across Western countries, also provides an important argument to develop an integrated approach for return to work [40].

Such an integrated approach for workers with cancer or another chronic health condition was recently recommended by the Social and Economic Council of the Netherlands (SER). On March 18th 2016, the SER released an advisory report on managing long-term and chronic illness at work, including musculoskeletal disorders, psychiatric disorders, cardiovascular disease, and cancer [41]. One of the main recommendations in this report is that employers should become actively involved in managing the condition of their employee in the workplace. Specifically, the SER has recommended that employers become knowledgeable about the condition of their employee, and about its impact on the worker's productivity and wellbeing at the workplace [41]. Another key point identified by the SER is that most employers have not adequately implemented preventive measurements to reduce the chance of adverse work outcomes, such as presenteeism and absenteeism [41]. The SER has recommended that employers should invest more energy, time and financial resources in the prevention and management of health conditions of their workers, for example in the form of providing workplace or workload accommodations. This would support the worker to stay at work, prevent sick leave and potentially work disability. It should be mentioned that the advice for employers to become engaged and to invest in workplace accommodation and preventive measures, is not new. In fact, the Netherlands Society of Occupational Medicine recently stated that, despite efforts to stimulate investments in prevention of sick leave, employers remain more inclined to invest in re-integration after sick leave [34,42]. As a result of the standstill of these developments, the SER's advice is still relevant for employers today, and the findings of this thesis generally support this advice. Specifically, the studies in this thesis show that implementing strategies, in which the workload or workplace can be modified to fit the workers' needs, such as therapeutic work, may facilitate return to work in cancer survivors. Moreover, these strategies may even prevent adverse work outcomes after initial return to work. In line with the SER's advice to develop an integrated approach for workers with chronic health conditions, including cancer, a pilot project was announced in the Netherlands by L.F. Asscher, the Dutch Minister of Social Affairs and Employment [43]. This project aims to remove financial and legal barriers for employers to hire workers with chronic health conditions, including cancer. This project is illustrated in the next paragraph.

Return to work for cancer survivors and workers with another chronic health condition: a pilot project

The pilot project was announced to the Dutch Parliament in a letter, which was drafted as a follow-up of the first letter from July 10th, 2015. The first letter was mentioned in the general introduction of this thesis, and emphasized the importance of stimulating return to work in cancer survivors and particularly in those with job loss [26]. In the follow-up letter, the Minister presented his plans for developing a pilot project in which a so-called "no-risk policy" will be offered [43]. The intention of the no-risk policy is that employers can hire workers with cancer or with another (chronic) health condition, while not risking high financial costs in case of recurrent illness and corresponding sick leave.

Hence, the no-risk policy significantly changes the legal and financial context for employers, and may stimulate participation in work of workers with cancer or with another (chronic) health condition [4]. Still, the effect of the no-risk policy on employer engagement may be limited, as the proposed changes to the financial context of employers are less radical in the no-risk policy, compared to the construct of therapeutic work. That is, in the no-risk policy, employers are only protected from financial burden in case of recurrent sick leave, while in therapeutic work, workers can often participate in work with on-going benefits and employers do not have to pay wages. For therapeutic work specifically, the findings in this thesis implicate that offering therapeutic working conditions may lead to an increase in work participation of cancer survivors, and could potentially be attractive for employers as well. In fact, for cancer survivors specifically, it has already been suggested that avoiding absenteeism or loss of employment, for example by engaging cancer survivors in therapeutic work early on, may have a beneficial effect on their work participation in the long-term [17]. Moreover, findings from a large German cohort study reported remarkable benefits of graded return to work across workers with cardiovascular or musculoskeletal disease, cancer, and mental and behavioural disorders [44]. These benefits included: a significant reduction in duration of sick leave, welfare benefits and unemployment, a reduced risk of disability pension and an increase in income. Interestingly, these effects did not differ between diagnostic groups [44]. These findings suggest that initiatives such as implementation of therapeutic work could improve participation in work, increase financial resilience in workers, and reduce the (financial) burden of sick leave and work disability in employers and in the social security system. Despite the fact that the proposed no-risk policy is less radical in its approach compared to the construct of therapeutic work, its introduction in the Dutch labour market may still lead to promising results with regard to return to work for workers with chronic condition, including cancer. Moreover, within the context of the no-risk policy, these workers may feel encouraged to express potential needs for workplace accommodations, which could prevent productivity loss or recurrent sick leave [25].

Overall, pilot projects such as the no-risk policy in the Netherlands can be considered a first step in the direction to provide employers with a favourable financial and legal context for hiring cancer survivors, as well as workers with other health conditions. However, whether the pilot project will actually facilitate return to work of these workers is yet to be discovered. A remaining point of concern is that the no-risk policy is designed to remove financial and legal barriers for employers to hire workers with cancer or with another (chronic) health condition. However, as discussed previously, other ingredients to stimulate employers to hire these workers are crucial as well. Specifically regarding cancer survivors, the problem of a potential mismatch between a cancer survivor's work ability and job requirements remains, despite a no-risk policy. Further, next to a change in the financial and legal context, a change may be necessary in employers' attitude, beliefs or stigma regarding cancer, as well as in their sense of moral obligation, in order to engage them in the return to work process of cancer survivors [12]. These elements are currently not addressed in the Dutch pilot project, and they could be an important starting point for future research with regard to work participation of workers with cancer. Furthermore, as more emphasis is put on cancer survivors' participation in work, it should also be explored whether return to paid work is the best option for cancer survivors to participate in society.

Participating in society: is return to paid work the best option for cancer survivors?

The general hypothesis supporting most of the previous return to work studies has been that return to work is important for cancer survivors [45], that work is an important determinant of quality of life 46, and that positive outcomes on health status and wellbeing are associated with work [47]. This hypothesis also fuels the on-going changes in the social and political systems in Western countries. Particularly in the Netherlands, society has transformed from the traditional welfare state model, in which the ill, the disabled and the elderly were generously provided for, into a participation society, which aims to include all of her members in work or activities, regardless of their health status or age [48,49].

Although Dutch governmental policies are increasingly aimed at return to work, there is yet no clear solution available for the return to work of cancer survivors, both those with and without job loss. Specifically, despite all the previous studies on return to work, there is still limited and contradicting evidence with regard to effectiveness of return to work interventions for cancer survivors [6]. Furthermore, it is alarming that, across these studies, only a subgroup of cancer survivors seems to be motivated to participate in return to work studies and programs. Perhaps the lack of conclusive evidence and the selective participation of cancer survivors in return to work studies, are indicators that the concept of return to work for cancer survivors should be re-evaluated. Specifically, we should ask the question: "Is return to paid work the best option for cancer survivors to participate in society?"

First, as mentioned previously, it should be evident that there are several reasons why, or situations in which, cancer patients and survivors are unable to return to work, for example due to an extensive decrease in work ability, unfavourable prognosis or comorbidities additional to cancer [50,51]. If these factors are present in cancer survivors, they are likely to rule out any form of participation in paid work. However, for those survivors who are doing relatively well, whether return to work is desirable seems to be determined mainly by individual factors and not by the occasional intervention program they participate in. For instance, it has been documented in this thesis, and also in other studies [45,52], that a change in the preferred balance between work and private life is important with regard to return to work after cancer. Further, some cancer survivors with job loss who participated in the qualitative study in this thesis mentioned that their preference for type of work had changed, for instance they wanted to become an entrepreneur or do voluntary work. Additionally, it has been reported that cancer survivors may become more motivated to return to work or they attribute new values to work, compared to their motivation for work prior to cancer [53,54]. Essentially, it could be stated that cancer has an effect on the meaning of work for cancer survivors, with or without job loss, which may either make them more, or less inclined to return to paid work. Intervention programs may therefore not succeed in changing a cancer survivors' intention to return to work, as they are likely to attract only those survivors who were already motivated to return to paid work.

An argument in favour of supporting return to paid work for all survivors is that there are beneficial effects of return to paid work in cancer survivors, such as a feeling of normalcy and control, but again these effects are not true for all cancer survivors [53,54]. For example, in this thesis, cancer survivors with job loss reported that they were generally motivated to return to work, but also that they had to give up certain things, such as domestic work or hobbies, or relied on support from others to do these things, in order to participate in work again. In summary, it is likely that for (at least part of) the population of cancer survivors with job loss, there is a perceived trade-off between return to paid work and their overall health or wellbeing. Hence, it could be that cancer survivors decide not to return to paid work, even though they might be able to do so based on their health status. This is a point where the current legislation on promoting participation in society, and individual preferences for (not) returning to work in cancer survivors may collide.

In closing, Wells et al. have argued before that the concept of return to work for cancer survivors is overly simplistic and essentially misleading [55]. In line with what is being argued in this paragraph, they suggested that the benefits of return to work, as proposed by e.g., legislators or literature, may not be the same for all survivors. Specifically, it is suggested that work is an expression of a person's identity, talents and foundation of self-esteem, and that the concept of work is therefore far more complex than simply paid employment [55]. A survivor's perception of work could therefore also include volunteer work, housework or caretaking. The discrepancy between an increasingly promoted participation society and cancer survivors' individual preferences for, and attribution to, the concept of return to work, will prove a point of discussion in the years to come. It is up to researchers to explore if return to (paid) work is indeed desirable for the population of cancer survivors, and potentially for workers with other chronic health conditions, and to study the extent to which other forms of participation, such as volunteer or therapeutic work with on-going benefits, can be considered valuable from a societal standpoint as well.

Recommendations for research

- Researchers are advised not to develop new return to work programs aimed solely at preparing cancer survivors with or without job loss for return to work. Instead, researchers should focus on the development and evaluation of methods to engage employers in the return to work process of cancer survivors, particularly for the increasing group of cancer survivors with job loss.
- More attention should be given to effective implementation strategies for (experimental) return to work interventions in daily practice, to prevent implementation failure.
- Participation in therapeutic work could be a high-potential first step towards return to paid employment in cancer survivors and should be evaluated in an experimental study with cancer survivors, particularly in those with job loss, who generally have less access to therapeutic work opportunities.
- Potential benefits of participation in therapeutic work should also be explored in workers with other (chronic) health conditions.
- When conducting experimental or longitudinal studies, researchers should collect data regarding non-response and motives for declining participation. This would provide a solid basis for determining the extent to which the results of these studies can be extrapolated to the general population of cancer survivors. Further, this information can be used to identify workers who are most in need of an intervention, and avoid efforts, time and financial means being spent on workers who can or want to manage without external support.
- Even beyond return to work, cancer survivors may experience physical and psychosocial problems that may decrease their productivity and may lead to sick leave. Therefore, researchers should develop methods to support working cancer survivors with physical and psychosocial problems, in order to prevent recurrent sick leave and future job loss in these cancer survivors.
- Researchers should not only concentrate on return to paid work as a measure for participation in society, but should also explore the meaning and value of other forms of participation, such as voluntary work, therapeutic work or entrepreneurship.

Recommendations for practice

- The intervention program implemented in this study failed to demonstrate a significant effect on duration until sustainable return to work in cancer survivors with job loss. Thus, we cannot recommend UWV to implement the program on a large scale.
- In this thesis, cancer survivors with job loss have repeatedly reported a ‘double loss’ experience, i.e., loss of job on top of loss of health, which created several barriers for return to work, including a lack of confidence, negative expectations about return to work and perceived employer discrimination. Given the importance of the double loss experience, we encourage practitioners to discuss the experience of cancer, as well as the experience of job loss, thoroughly with these survivors. This could lead to a more accurate identification of return to work barriers in a cancer survivors’ situation, which can then specifically be targeted.
- The Dutch social security agency could re-evaluate the protocol for guiding sick-listed workers by tailoring their protocol to the type and duration of a worker’s illness, e.g., by allocating more time for return to work guidance to long-term sick-listed workers than to workers with an acute illness.
- Practitioners should encourage and arrange for cancer survivors to participate in therapeutic work or other forms of work with on-going benefits.

Conclusions

◆

In conclusion, this thesis has provided insight into the return to work process of cancer survivors with job loss, i.e., a group of survivors who were not brought to public notice until recently. The group of cancer survivors with job loss are a part of the working population to be reckoned with, as their numbers will increase in the future due to increase in the prevalence of cancer, and due to the rising retirement age. The findings of this thesis show that, despite long-term or permanent health problems, most of these workers are motivated to return to work and to contribute to society again, instead of being dependent of society in the form of sickness or disability benefits. However, this thesis also illustrates that sustainable return to work in cancer survivors with job loss is complex and difficult to achieve, and that the return to work process is influenced by cancer-related, personal and work-related factors. Examples of these factors are reduced work ability, lack of coping strategies for job loss and return to work, and lack of support from family, an employer and colleagues.

Furthermore, the intervention program in this study failed to demonstrate a significant effect on duration until sustainable return to work in cancer survivors with job loss. Consequently, a solution for the return to work problems in these cancer survivors has yet to be discovered. Still, the per-protocol analyses in the effectiveness study did demonstrate a considerable improvement in duration until return to work for participants who received the intervention according to protocol, compared to the control group. Unfortunately, however, this effect was not statistically significant. Further, the process evaluation in this thesis revealed that there were considerable implementation problems in the intervention group. It is likely that implementation failure contributed to the lack of significant findings regarding the return to work program. Potentially, if the program implementation would be improved and the program would be re-evaluated, the program may show a significant result on duration until sustainable return to work in cancer survivors with job loss. However, considering that prevention of job loss is important for sick workers, regardless of their diagnosis, it would be worthwhile not to re-evaluate the return to work program in this thesis in an exclusive population of cancer survivors. We would rather recommend exploring opportunities for an integrated return to work program for workers with job loss, both those with cancer, and those with other long-term or chronic health conditions.

Finally, this thesis shows that additional potential of return to work and participation initiatives for cancer survivors could lie in improving employer engagement in the return to work process of cancer survivors, as well as in the exploration of therapeutic work and other forms of participation in society for cancer survivors. These are topics that deserve attention in future research on cancer and work.

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Summary

This PhD thesis starts with an appeal to break the taboo of working with (a history of) cancer in the Netherlands, offered by L.F. Asscher, the Dutch Minister of Social Affairs and Employment, to the Chair of the House of Representatives of the Netherlands, on July 10th 2015. In Chapter ove, the background of his appeal is discussed in light of current developments in cancer survivorship and the given state of knowledge on cancer survivors' return to work in the Netherlands and worldwide. Specifically, the number of cancer survivors with job loss in developed countries is rising due to increases in both cancer incidence and cancer survival rates, the rising retirement age and the increasing proportion of flexible employment contracts. For cancer survivors who lose their job, the process of return to work may be particularly challenging because of a large distance to the labour market and a lack of support from an employer or colleagues. Further, the literature shows that supportive interventions to enhance return to work in cancer survivors do not show consistent effects. Also, current return to work interventions are not suitable for cancer survivors with job loss, as these programs are generally developed to support survivors who still have an employer. This thesis states that, considering the increase in the number of cancer survivors with job loss in the Netherlands, and the lack of appropriate interventions to support their return to work, it is necessary to study return to work in these cancer survivors. Therefore, three main objectives were formulated:

1. To explore barriers and facilitators for return to work for cancer survivors with job loss, to translate this knowledge into a tailored return to work intervention program for these survivors, and to evaluate process outcomes and the effectiveness of this program on sustainable return to work in cancer survivors with job loss;
2. To obtain a broader perspective on sustainable return to work in cancer survivors with job loss, by exploring therapeutic work as a potential facilitator for return to work;
3. To present an overview of physical and/or psychosocial health problems that cancer survivors may experience beyond their return to work.

Chapter two presents the results of a focus group study on barriers and facilitators for return to work of sick-listed cancer survivors with job loss, as perceived by these cancer survivors themselves and by insurance physicians from the Dutch Social Security Agency. In this qualitative study, two focus groups and one interview were conducted with cancer survivors ($N = 17$), and three focus groups with insurance physicians ($N = 23$). The discussed topics included, amongst others, cancer survivors' experience of job loss and barriers and facilitators for return to work. Thematic analysis was used to analyse the data. The main finding of this study was that cancer survivors essentially had a double loss experience: loss of job on top of loss of health, both due to cancer. This was mainly explained by the fact that many of these cancer survivors were employed on a temporary basis (fixed-term contract). Cancer survivors reported that their employment contracts were not renewed by the employer. In their perception, this happened because of their cancer diagnosis and corresponding financial risk for the employer in case of sick leave. As a result of the double loss experience, cancer survivors reportedly feared for job applications, lacked opportunities to gradually increase work ability, and they faced reluctance from employers in hiring them.

Insurance physicians in this study expressed a need for more frequent and longer consultations with cancer survivors with job loss. The conclusion of this study was that cancer survivors who experience double loss encounter specific barriers for return to work, for which they may need tailored return to work support.

In Chapter three, the study protocol of a randomized controlled trial and the design of a tailored return to work intervention program for cancer survivors with job loss was presented. The study was designed as a two-armed (intervention/control) randomized controlled trial with a follow-up period of 12 months. From a national sample of cancer survivors in the working age (18-60 years), 164 persons were to be recruited, both retrospectively and prospectively, from the databases of the Dutch Social Security Agency. All participants in the study were to receive usual care as provided by the Dutch Social Security Agency. Participants in the intervention group would also receive a tailored return to work program alongside usual care. The intervention program was designed in cooperation with a re-integration agency, specialized in the return to work process of cancer survivors. The return to work program started with an introductory interview with a coach from the re-integration agency. During this interview, it was assessed how much, and which type of, support a participant needed for return to work. After the introductory interview, the participant would start with either the first or the second part of the program. The first part was 'Preparation for return to work', delivered by the re-integration agency. The second part was 'Return to work', delivered by two job hunting agencies. The re-integration agency would offer vocational rehabilitation and supportive psychosocial elements, and the job hunting agencies would offer (therapeutic) placement at work. Participants could immediately start with the 'Return to work' part, but they could also follow the 'Preparation for return to work' part if they needed time and support before starting with actual return to work. The maximum duration of the complete program was set at six to seven months.

The primary outcome measure of the study was determined to be 'duration until sustainable return to work'. Data for the primary outcome measure was collected through the social security agency registries and by questionnaires from participants. Participants in the study would complete questionnaires at baseline, and after three, six and twelve months. These questionnaires contained questions regarding, e.g., sociodemographic characteristics, levels of fatigue, cognitive failure, quality of life, depression, readiness to return to work, attitude towards work, and participation in society. The data collected during the study were to be analyzed with descriptive analysis and Cox regression analysis. Alongside the trial, a process evaluation was conducted, for which data were collected with an additional questionnaire at six months of follow-up. The study protocol was published for the sake of good scientific practice, in order to enable comparison with the evaluation of the study's results and procedures (Chapter six and seven).

Chapter four presents the results of a longitudinal study on the role of therapeutic work as a potential facilitator for return to work of cancer survivors. The rationale for this study was that the increase of flexible employment in European labour markets contributes to workers' risk of job loss, in case of long-term sick leave due to cancer. Therapeutic work could be a potential facilitator for return to work in populations of cancer survivors with job loss, as it involves flexible working arrangements. Since we found in the focus group study (Chapter two), that unemployed workers generally have less access to therapeutic work, this study also examined the potential difference in participation in therapeutic work between workers with and without an employment contract. The study used data from a cohort of Dutch cancer survivors (N=192), who applied for disability benefits after two years of sick leave. The primary outcome measure was return to paid work after one year. Logistic regression analysis showed that cancer survivors without an employment contract participated significantly less in therapeutic work ($p < 0.001$) compared to those with an employment contract. Also, those without a contract were significant less likely to return to paid work after one year ($p = 0.001$). We also found that participation in therapeutic work significantly increased the odds of return to paid work after one year (OR 6.97; 95% CI 2.94-16.51). The main conclusion of this study was that participation in therapeutic work could be an important facilitator for return to paid work in sick-listed cancer survivors, and that therapeutic work should be studied as a potential intervention for return to work in these survivors.

In Chapter five, the findings of a cross-sectional study are described, in which factors and motives associated with (non-)participation of cancer survivors with job loss in the tailored return to work program were examined. The data for this study were gathered from the recruitment phase of the randomized controlled trial, as described in Chapter three. Cross-sectionally, information on socio-demographics, health-related, psychosocial, and work-related characteristics of participants in the tailored return to work program was collected. Similar data were collected from those who declined participation.

In total, data from 286 cancer survivors was used in this study. Descriptive and multivariable logistic regression analyses were conducted to obtain the results. We found that being married (odds ratio (OR) 0.23; 95% confidence interval (CI) 0.08-0.69) or living together (OR 0.25; 95% CI 0.07-0.96) decreased the likelihood of survivors' participation in the return to work program. Further, having a temporary employment contract prior to unemployment (OR 2.60; 95% CI 1.20-5.63), reporting a clear intention to return to work (OR 2.65; 95% CI 1.20-5.82), and having higher scores on a readiness to return to work instrument, i.e., contemplation scale (OR 2.00; 95% CI 1.65-2.40) and prepared for action-self-evaluative scale (OR 1.27; 95% CI 1.04-1.54), significantly increased the likelihood of participation. Further, we found that physical (50%) and mental problems (36%) were leading motives for declining participation. The results of this study can be used to distinguish survivors most in need of return to work support, from those that may not need such support. Another conclusion of this study is that practitioners and researchers should tailor their return to work support to cancer survivors' socio-demographic, health-related and work-related characteristics.

In Chapter six, a process evaluation of the randomized controlled trial procedures and the program procedures of the tailored return to work program, is presented. The process evaluation consisted of six components: Recruitment, Reach, Dosage, Implementation, Satisfaction, and Experienced Barriers. The data for this study were provided by intervention and study logbooks, as well as by questionnaires from participants in the intervention program, from occupational health care (OHC) professionals employed at the Dutch Social Security Agency, and from re-integration coaches and job hunting officers who delivered the return to work program. At the start of the randomized controlled trial, 85 cancer survivors were randomly allocated to the intervention group. The program reached 88% of the target population. Of the participants in the intervention group who had started the program, 52% received the adequate dosage. The overall program implementation score was 46%. Further, we found that the re-integration coaches reported higher scores of satisfaction, compared to the job hunting officers and OHC professionals. Likewise, participants reported higher levels of satisfaction with the program delivery by the re-integration coaches, compared to the delivery by the job hunting officers. Several barriers for program implementation and delivery were reported, including a lack of communication between the re-integration coaches, OHC professionals and job hunting officers, high program intensity and short program duration, and, specifically regarding the job hunting officers, a lack of experience with cancer-related return to work problems. The main conclusion of this study is that the participants, OHC professionals, re-integration coaches and job hunting officers generally reported positive experiences with the tailored return to work program, but that there were several barriers for implementation and delivery of the program. As a result, only less than half of the participants in the intervention group received the intervention as intended.

Chapter seven describes the most important results of this thesis, i.e., the results regarding the effectiveness of the tailored return to work program on duration until sustainable return to work for cancer survivors with job loss. These results were based on the data gathered within the randomized controlled trial, of which the study procedures are described in Chapter three. The study was carried out from April 2013 to March 2016, with the recruitment starting in April 2013 until January 2015. In total, 171 cancer survivors were included, which was more than the pre-estimated needed sample size of 164. The primary outcome measure was duration until sustainable return to work. Secondary outcome measures included rate of return to work, fatigue, quality of life, and participation in society. We used descriptive analyses, Kaplan-Meier estimators and Cox regression analyses to obtain the results. The population in the randomized controlled trial (N=171) had a mean age of 48.4 years (SD=8.6). The majority of participants was female (69%) and had survived breast cancer (40%). The crude Hazard Ratio (HR) for duration until sustainable return to work was 0.86 (95% CI 0.46-1.62, p=0.642) in the intervention group, compared to the control group. In the adjusted model, we found that the intervention group had a slight, but statistically non-significant, improvement in duration until sustainable return to work compared to the control group (HR 1.16; 95% CI 0.59-2.31; p=0.663). Further, the program did not have any significant effects on secondary outcome measures. The conclusion of this study is that the tailored return to work program did not demonstrate a statistically significant effect on duration until sustainable return to work in cancer survivors with job loss. The lack of effectiveness in this study could be explained to a certain extent by the outcomes of the process evaluation (Chapter six).

In Chapter eight, the results of a systematic review on physical and psychosocial problems experienced by cancer survivors beyond return to work, are presented. The rationale for this study was the gap in the literature regarding the period beyond return to work, and the fact that studies show that cancer survivors may quit working even after initially successfully returning to work. For this review, publications were identified through Medline, PsycINFO, Embase and CINAHL searches. We searched for qualitative and quantitative studies published in the period of January 2000 to March 2013. To be included in this review, studies had to be aimed at cancer survivors who were employed during the study period. Two reviewers independently extracted data from each publication and performed a methodological quality assessment of each publication. The initial search identified 8,979 articles, which were evaluated based on title and abstract, of which 64 publications were retrieved for full text screening. Of these, 30 met the inclusion criteria, of which 20 publications described quantitative studies and 10 publications described qualitative studies. Across studies, several psychosocial problems were reported to influence survivors' work ability, including cognitive limitations, coping issues, fatigue, depression and anxiety. Functioning at work was also affected by physical problems, including problems with heavy tasks as lifting, and treatment-induced menopausal symptoms including hot flashes. The main conclusion of this review is that long-term or permanent physical and psychosocial problems are present in working cancer survivors, and that these problems may impair their work ability or functioning at work.

In Chapter nine, the main findings of this PhD thesis are discussed in the context of cancer survivorship and the changing labour market. One of the main finding of this thesis is that cancer survivors with job loss essentially experience a double loss: loss of employment on top of loss of health due to cancer. As a result, the return to work process of these cancer survivors is complicated by additional barriers related to job loss, which reduce the likelihood of participation in the labour market. Another main finding of this thesis is that the tailored return to work program developed for these survivors was not effective. These findings are discussed in light of the current societal and political context. Moreover, it was discussed how the findings of this thesis may apply to sick-listed workers with job loss in general, suffering from a different health condition than cancer. Finally, recommendations for future research and practice are offered. One key recommendation is that researchers and practitioners should not focus only on preparing cancer survivors, or other long-term sick-listed workers, for return to work. That is, methods for employer engagement in the return to work process of these workers should be developed as well. The increasing emphasis in Western societies on participation, the decay of the traditional welfare state, and the increase in the prevalence of cancer and other chronic illnesses, form the main arguments to construct a realistic model in which both the worker and the employer are committed and willing to invest in work participation, regardless of health problems.

Samenvatting

Dit proefschrift begint met een voornemen om het taboe van kanker en werk in Nederland te doorbreken. Dit voornemen werd uitgesproken op 10 juli 2015 door L.F. Asscher, de minister van Sociale Zaken en Werkgelegenheid, en werd gedeeld in een brief aan de Tweede Kamer. In Hoofdstuk één van dit proefschrift wordt de aanleiding voor het voornemen van de minister uiteengezet, en de context van dit voornemen geschetst. In de context spelen de volgende factoren een belangrijke rol: de toenemende aantallen mensen die kanker krijgen en de stijgende overlevingskansen van kanker, de snelle ontwikkelingen in de Nederlandse arbeidsmarkt, inclusief de toename van flexibel werk en de stijgende pensioenleeftijd, en het huidige (inter-)nationale kennisniveau op het gebied van kanker en werkhervatting. Specifiek wordt in dit hoofdstuk aangedragen dat de mensen die kanker overleven problemen ervaren om hun leven, inclusief werk, weer op te pakken. Het feit dat werkenden in toenemende mate een tijdelijk arbeidscontract hebben, draagt bij aan het feit dat tot wel 50% van de kankerpatiënten wereldwijd hun baan verliezen tijdens of na het ziekteproces, omdat hun arbeidscontract niet wordt verlengd. Baanverlies maakt werkhervatting na kanker naar verwachting ingewikkeld, omdat er geen werkplek is voor de kanker-overlever om te re-integreren, en de steun van een werkgever en collega's tijdens het re-integratieproces ontbreekt.

Het Uitvoeringsinstituut Werknemersverzekeringen (UWV) heeft in Nederland de taak om kanker-overlevers die hun baan verliezen, vanuit een uitkeringssituatie (Ziektewet, WW of WIA) terug naar werk te begeleiden. In 2011 heeft het UWV aangegeven dat de re-integratiebegeleiding voor kanker-overlevers die hun baan verliezen, gecompliceerd is. Tevens heeft UWV een vraag om meer kennis neergelegd bij het Kenniscentrum voor Verzekeringsgeneeskunde (KCVG). Specifiek heeft het UWV aangegeven dat er meer kennis nodig is over terugkeer naar werk voor deze doelgroep.

Samenvattend vormen de volgende feiten de directe aanleiding voor dit proefschrift: (1) er is een toename van kanker-overlevers die geen werkgever meer hebben en die vanuit een uitkeringssituatie (Ziektewet of de WIA) proberen om weer aan het werk te gaan, (2) er wordt in de Nederlandse samenleving van iedereen in de beroepsbevolking, ook kanker-overlevers, verlangd om te participeren in arbeid, (3) terugkeer naar werk na kanker vanuit een uitkeringssituatie is erg gecompliceerd, en (4) werkhervattingsinterventies voor deze groep kanker-overlevers ontbreken. In overeenstemming met deze feiten, zijn voor dit proefschrift drie hoofddoelen geformuleerd, ten einde deze te beantwoorden door de bevindingen beschreven in de afzonderlijke hoofdstukken van dit proefschrift:

1. Het verkennen van beperkende en ondersteunende factoren voor werkhervatting van kanker-overlevers die hun baan hebben verloren, het vertalen van de opgedane kennis naar een op maat gemaakt interventieprogramma voor deze doelgroep, en het evalueren van het proces van implementatie, en de effectiviteit, van het interventieprogramma;
2. Het verbreden van het perspectief op duurzame werkhervatting voor kanker-overlevers die hun baan hebben verloren, door het bestuderen van de mogelijkheden voor therapeutisch werk als facilitator voor werkhervatting;
3. Het presenteren van een overzicht van fysieke en psychosociale problemen die kanker-overlevers ervaren nadat zij het werk hebben hervat.

In Hoofdstuk twee worden de resultaten van een kwalitatief onderzoek gepresenteerd. In dit onderzoek is, door middel van groepsgesprekken, onderzocht welke barrières en kansen voor werkhervatting er zijn voor kanker-overlevers die geen werkgever meer hebben. In totaal werden zes gescheiden groepsgesprekken georganiseerd, drie met in totaal 17 kanker-overlevers en drie met in totaal 23 verzekeringsartsen van het UWV, die de doelgroep dienen te begeleiden bij werkhervatting. In de groepsgesprekken zijn diverse thema's behandeld, waaronder baanverlies en betekenis van werk, de begeleiding door de verzekeringsarts, en barrières en kansen voor werkhervatting. Een belangrijk resultaat aangaande baanverlies en betekenis van werk was dat veel kanker-overlevers gehoopt hadden aan het werk te kunnen blijven tijdens en na de behandeling. De klap van baanverlies kwam extra hard aan omdat de vorige klap, de diagnose kanker, vaak pas kort geleden was. Ondanks deze negatieve ervaringen waren de meeste kanker-overlevers gemotiveerd om weer te gaan werken.

Kanker-overlevers rapporteerden gemengde ervaringen met de begeleiding door verzekeringsartsen. De kanker-overlevers die erg tevreden waren, bezochten bij het UWV steeds dezelfde arts, die geïnteresseerd was en hen motiveerde om weer te gaan werken, zonder druk op te leggen. Deze kanker-overlevers voelden zich ondersteund door de arts. Andere kanker-overlevers waren teleurgesteld in de begeleiding door de verzekeringsarts. Dit kwam vooral omdat zij steeds een verschillende arts zagen aan wie zij dan opnieuw hun verhaal moesten vertellen. Ook kwam het voor dat een arts niet geïnteresseerd was in hun situatie, of hun ziekte afdeed als onbelangrijk. Deze kanker-overlevers hadden het gevoel zich te moeten verdedigen bij hun arts. De verzekeringsartsen zelf gaven aan dat zij regelmatig problemen ervaren bij het begeleiden van kanker-overlevers, vanwege de diversiteit van het ziektebeeld en de impact van de behandelingen. Ook werd aangegeven dat er te weinig tijd is om een band met de patiënt op te bouwen, en zo werkhervatting te stimuleren. Een laatste belangrijke bevinding was dat artsen rapporteerden dat zij bepaalde zaken (zoals mogelijkheden voor werkhervatting) niet uitvroegen aan de kanker-overlever, omdat ze er niets concreets tegenover kunnen stellen in termen van behandeling of re-integratie. De kanker-overlevers ervoeren verder veel lichamelijke problemen die werkhervatting bemoeilijkten of zelfs onmogelijk maakten. Hieronder vielen klachten als vermoeidheid, maar ook zorgen, angst en onzekerheid over het werkvermogen. Daarnaast zeiden veel kanker-overlevers dat zij een verwerkingsproces ondergingen. Ze moesten op een gegeven moment stoppen met nadenken over wat ze verloren hadden door kanker, en weer gaan nadenken over de toekomst. Pas als dat proces voltooid was, konden ze weer aan werk denken. Hier gaat het dus om een cognitief proces, waar een arts, therapeut of praktijkprofessional bij zou kunnen ondersteunen.

Verder bleek dat, na baanverlies, het ontbreken van steun van een werkgever en collega's de werkhervatting bemoeilijkte. Met name het sollicitatieproces zelf was een barrière voor werkhervatting, bijvoorbeeld doordat werkgevers huiverig zijn om kanker-overlevers aan te nemen. Ook werden door zowel kanker-overlevers als verzekeringsartsen genoemd dat vormen van beschermd werk, zoals werk op therapeutische basis, een ideaal startpunt zou kunnen zijn voor kanker-overlevers, omdat ze in zo'n functie geleidelijk de werklast kunnen opbouwen. De belangrijkste conclusie van dit onderzoek was dat kanker-overlevers die hun baan verliezen, erg onzeker zijn over werkhervatting door hun dubbel-verlies ervaring (verlies van werk én van gezondheid door kanker). Zodoende ervaren zij specifieke barrières voor werkhervatting, waarvoor zij aangepaste ondersteuning kunnen gebruiken.

In Hoofdstuk drie wordt de onderzoeksopzet gepresenteerd van een gerandomiseerde, experimentele studie, inclusief de opzet van een op-maat gemaakt interventieprogramma ter bevordering van werkhervatting van kanker-overlevers die hun baan zijn verloren. Het doel was om 164 kanker-overlevers in de werkende leeftijd (18-60 jaar) in te laten stromen in het onderzoek en hen te werven middels een uitnodiging van het UWV, waar zij geregistreerd staan vanwege hun Ziektewet- of WIA-uitkering. Het plan was om de doelgroep geleidelijk uit te nodigen voor deelname aan het onderzoek, zodat de instroom in het onderzoek gespreid werd.

Wanneer personen reageerden op de uitnodiging, werd door de onderzoekers gekeken of zij voldeden aan de voorwaarden voor deelname (screening). Nadat een kanker-overlever de instroomprocedure had doorlopen, werd hij/zij deelnemer in het onderzoek voor een periode van 1 jaar. Tevens werd hij/zij door loting ingedeeld in een van de twee groepen in het onderzoek: de interventiegroep of de controlegroep. Ongeacht in welke groep een deelnemer ingedeeld werd, ontving de deelnemer de gebruikelijke begeleiding van het UWV. Deelnemers in de interventiegroep ontvingen daarnaast het op maat gemaakte interventieprogramma. Het interventieprogramma was ontwikkeld door de onderzoekers, in samenwerking met een re-integratiebedrijf dat gespecialiseerd is in werkhervatting na kanker. Elke deelnemer in de interventiegroep startte dit programma met een introductiegesprek met een coach van het re-integratiebedrijf. Het doel van dit gesprek was om in te schatten wat de mogelijkheden voor werkhervatting waren, en welke ondersteuning de deelnemer kon gebruiken. Na het introductiegesprek startte de deelnemer met ofwel het eerste, ofwel het tweede deel van het interventieprogramma. Het eerste deel van het programma was gericht op voorbereiding op werkhervatting, en bestond uit het maken van een werkprofiel en het volgen van coaching sessies. Dit gedeelte werd uitgevoerd door het re-integratiebedrijf. Het tweede deel van het programma was gericht op daadwerkelijke werkhervatting en zoeken naar werk. Dit gedeelte werd uitgevoerd door twee uitzendbureaus. Het doel was om iemand in betaald of therapeutisch werk te plaatsen. Deelnemers konden zowel starten met deel een om daarna deel twee van het programma te volgen, of direct starten met deel twee, wanneer zij geen voorbereiding op werk nodig hadden. De totale duur van het programma bij het doorlopen van alle elementen was gesteld op zes tot zeven maanden.

De belangrijkste uitkomstmaat van dit onderzoek was 'tijd tot duurzame werkhervatting'. In het onderzoek werd geëvalueerd of deelnemers in de interventiegroep sneller aan het werk gingen, dan mensen in de controlegroep. De data voor dit onderzoek werd verzameld via vragenlijsten en via de UWV datasystemen. De vragenlijsten werden door deelnemers ingevuld bij aanvang van het onderzoek, na drie, zes en twaalf maanden. De vragenlijsten bestonden uit vragen over sociaal-demografische kenmerken, aanwezigheid klachten zoals vermoeidheid en geheugenproblemen, bereidheid om terug te keren naar werk, en participatie in werk. Het plan was om de data aan het eind van het onderzoek te analyseren met beschrijvende analyses en Cox regressieanalyse. Tevens werd naast het onderzoek een procesevaluatie uitgevoerd. Hiervoor werden logboeken bijgehouden door de onderzoekers en de re-integratie organisaties, en werden vragenlijsten verstuurd gedurende de looptijd van het onderzoek. Het volledige onderzoeksprotocol is gepubliceerd om rekenschap te geven van eventuele aanpassingen gaandeweg het onderzoek, en om de onderzoeksopzet te delen met collega-wetenschappers.

In Hoofdstuk vier worden de resultaten van een longitudinaal onderzoek naar de rol van therapeutisch werk bij werkhervatting van kanker-overlevers gepresenteerd. Het doel van dit onderzoek was om te bepalen of participatie in therapeutisch werk geassocieerd is met werkhervatting in betaald werk, in een cohort van kanker-overlevers die hun baan zijn verloren en kanker-overlevers die hun baan nog wel hebben. Van juli 2011 tot februari 2012 werden mensen die zich bij de WIA-poort meldden vanwege kanker, uitgenodigd voor deelname aan dit cohort. Deze deelnemers waren dus al twee jaar met ziekteverlof vanwege kanker. Deelnemers vulden een vragenlijst in bij aanvang van de studie en na één jaar follow-up. Voor het huidige onderzoek werd een selectie uit dit cohort genomen; namelijk mensen die bij aanvang van het onderzoek nog geen betaald werk hadden, mensen die geen volledige arbeidsongeschiktheidsuitkering (IVA) hadden gekregen bij de WIA-beoordeling, en mensen die na één jaar de vervolgvragenlijst hadden teruggestuurd. In totaal werden in deze studie gegevens van 192 mensen met kanker gebruikt, waarvan 60 mensen die hun baan zijn verloren, en 132 mensen die hun baan nog wel hadden. Uit de analyses bleek dat kanker-overlevers die bij aanvang van de studie therapeutisch werk deden, een grote kans hadden om één jaar later betaald aan het werk te zijn, ten opzichte van de groep die geen therapeutisch werk deed bij aanvang van de studie. De ruwe 'kans' op werkhervatting was in deze groep ruim twaalf keer zo groot (Odds Ratio (OR) 12.26; 95% betrouwbaarheidsinterval (BI) 5.68–26.50).

In de analyses is daarna gecorrigeerd voor leeftijd, geslacht en opleidingsniveau, en de uitkomst van de arbeidsongeschiktheid beoordeling. Gecorrigeerd voor deze factoren, was de 'kans' op werkhervatting in betaald werk nog steeds bijna zeven keer zo groot voor de groep die therapeutisch werk deed, vergeleken met de groep die geen therapeutisch werk deed (OR 6.97; 95 % BI 2.94–16.51). Verder viel op dat kanker-overlevers die hun baan zijn verloren een significant kleinere kans hadden om te participeren in therapeutisch werk, in vergelijking met werknemers met kanker ($p < 0.001$). De conclusie van dit onderzoek is dat participatie in therapeutisch werk een belangrijke faciliterende factor kan zijn voor werkhervatting in betaald werk voor mensen met kanker in de WIA. Eén van de aanbevelingen van het onderzoek is dat UWV-professionals mogelijkheden voor participatie in therapeutisch werk voor hun cliënten zoeken en realiseren. Ook is het nodig om experimenteel onderzoek te doen naar het aanbieden van therapeutische werkplekken aan mensen met kanker, of met andere langdurige aandoeningen, in de WIA.

Hoofdstuk vijf bespreekt de resultaten van een cross-sectioneel onderzoek, waarvoor wervingsdata van het experimentele onderzoek, zoals beschreven in Hoofdstuk drie, zijn gebruikt. In het experimentele onderzoek is een interventieprogramma aangeboden aan kanker-overlevers in de Ziektewet en de WIA. In het cross-sectionele onderzoek is onderzocht hoeveel interesse er vanuit deze doelgroep was om aan het programma deel te nemen, en welke factoren en motieven (bijvoorbeeld motieven gerelateerd aan ziekte of aan de persoonlijke sfeer) geassocieerd zijn met wel of niet deelnemen aan het programma. Er is specifiek gekeken naar sociaal-demografische factoren, zoals leeftijd en geslacht; gezondheidsgerelateerde en psychosociale factoren, waaronder kwaliteit van leven en tumortype; en factoren gerelateerd aan werk, zoals werkvermogen en intentie om werk te hervatten. In totaal werd data met behulp van uitgebreide vragenlijsten verzameld bij 286 kanker-overlevers. Hiervan namen 171 personen deel aan het interventieprogramma, en 115 personen wilden niet deelnemen aan dit programma. Ook werden antwoordkaartjes verzameld van 647 kanker-overlevers die niet de uitgebreide vragenlijsten wilden invullen, maar wel een korte reactie wilden geven.

Uit de analyses bleek dat met name werkgerelateerde factoren een belangrijke invloed hadden op wel of niet deelnemen aan het interventieprogramma. Zo bleek dat mensen vooral deelnamen aan het programma als zij een duidelijke intentie hadden om het werk te hervatten (OR 2.65; 95% BI 1.20-5.82), als zij een tijdelijk dienstverband hadden voor ziekteverlof (in vergelijking met mensen met een vast dienstverband) (OR 2.60; 95% BI 1.20-5.63), en als zij mentaal al bezig waren zich voor te bereiden op werkhervatting en hierover nadachten (OR 2.00; 95% BI 1.65-2.40 en OR 1.27; 95% BI 1.04-1.54 op twee schalen van het meetinstrument). Tevens bleek dat mensen die getrouwd waren (OR 0.23; 95% BI 0.08-0.69) of samenwoonden (OR 0.25; 95% BI 0.07-0.96) veel minder geneigd waren deel te nemen aan het interventieprogramma. Uit de analyses bleek verder dat gezondheidsgerelateerde en psychosociale factoren niet belangrijk waren in het wel of niet deelnemen aan het interventieprogramma. Daarnaast gaven veel mensen op de antwoordkaartjes aan dat fysieke en mentale problemen ervoor zorgden dat zij nog niet met werkhervatting bezig waren, en daarom niet wilden deelnemen aan het onderzoek of het interventieprogramma. De conclusie van dit onderzoek is dat werkgerelateerde factoren, waaronder intentie voor werkhervatting, en het zelf al mentaal bezig zijn met (voorbereiding op) werkhervatting erg belangrijk zijn als het gaat om deelnemen aan een programma dat ondersteuning biedt bij werkhervatting. Voor UWV-professionals is het belangrijk om deze werkgerelateerde factoren in een gesprek over werkhervatting met kanker-overlevers te bespreken. Tevens kan er aandacht besteed worden aan het bewerkstelligen van een positieve attitude voor werkhervatting, bijvoorbeeld door kanker-overlevers te motiveren en barrières voor werkhervatting te bespreken. Daarnaast is het belangrijk om de burgerlijke staat van de kanker-overlever in het achterhoofd te houden bij een dergelijk gesprek.

In de Hoofdstukken zes en zeven worden de resultaten gepresenteerd van de experimentele studie (zie Hoofdstuk drie), te weten de procesevaluatie (Hoofdstuk zes) en de effectiviteits-evaluatie (Hoofdstuk zeven). Omdat de bevindingen van de procesevaluatie sterk verband houden met de effectiviteits-evaluatie, worden deze bevindingen hier samen gepresenteerd.

Van april 2013 tot januari 2015 werden kanker-overlevers uitgenodigd om deel te nemen aan dit onderzoek. Na screening werden zij willekeurig ingeloot voor de interventiegroep of de controlegroep. In totaal namen 171 kanker-overlevers deel aan het onderzoek. Hiervan zijn 85 personen in de interventiegroep ingedeeld, en 86 in de controlegroep. De belangrijkste vraag die beantwoord moest worden, was of deelnemers die het interventieprogramma volgden (interventiegroep) een verbetering in de tijdsduur tot duurzame werkhervatting hadden, in vergelijking met degenen die de gebruikelijke begeleiding vanuit het UWV kregen (controlegroep).

In Hoofdstuk zeven staat beschreven dat uit de gecorrigeerde effectiviteitsanalyses bleek dat het interventieprogramma geen verschil liet zien op de tijd tot duurzame werkhervatting, in vergelijking met de gebruikelijke begeleiding van UWV (Hazard Ratio 1.16; 95% BI 0.59-2.31; p=0.663). Ook werd geen verschil gevonden tussen de interventie- en de controlegroep op de secundaire uitkomstmaten, zoals vermoeidheid en kwaliteit van leven. Uit de procesevaluatie die beschreven staat in Hoofdstuk zes, bleek dat slechts ongeveer de helft (52%) van de deelnemers in de interventiegroep het interventieprogramma volgens het protocol had gevolgd. De implementatiescore, een score die uitdrukt hoe goed het programma was geïmplementeerd, bleek relatief laag, namelijk 46%. Er waren dus duidelijk implementatieproblemen in het onderzoek, die mogelijk het gebrek aan effect van het interventieprogramma verklaren. Uit de procesevaluatie bleek verder dat de implementatieproblemen voornamelijk ontstonden als gevolg van de complexe situatie waarin diverse partijen, waaronder UWV teams en interventieaanbieders, moesten samenwerken. Zo ontstonden er communicatieproblemen en vertragingen in overdrachten van dossiers en belangrijke documenten, waardoor het interventieprogramma voor deelnemers soms niet goed of niet volledig werd uitgevoerd.

Deelnemers en betrokken partijen, waaronder de begeleidende teams vanuit het UWV, waren over het algemeen wel erg tevreden met het eerste deel van het interventieprogramma (‘voorbereiding op werk’, uitgevoerd door het re-integratiebedrijf). Over het ‘werkhervatting’ deel waren de meningen minder positief. Dit kan deels verklaard worden door organisatorische problemen die speelden bij de uitzendbureaus, maar ook door een slechte arbeidsmarkt en een gebrek aan praktijkervaring van de uitzendbureaus met kanker-overlevers. Omdat uit de procesevaluatie naar voren kwam dat er implementatieproblemen waren, zijn ook per-protocol analyses uitgevoerd. In deze analyses zijn alleen de deelnemers in de interventiegroep meegenomen, die de interventie geheel volgens protocol hebben gevolgd. Hieruit bleek dat er een aanzienlijk verschil was in tijd tot duurzame werkhervatting tussen de interventie- en de controlegroep. Echter, door het kleine aantal deelnemers was ook dit verschil niet statistisch significant (Hoofdstuk zeven). De conclusie van deze onderzoeken is dat een interventieprogramma voor kanker-overlevers die hun baan zijn verloren niet leidt tot een verbetering in tijd tot duurzame werkhervatting, in vergelijking met de gebruikelijke begeleiding van UWV. Een kanttekening hierbij is dat er aanwijzingen zijn dat het interventieprogramma tot een verbetering in tijd tot duurzame werkhervatting zou kunnen leiden, mits een dergelijk programma goed geïmplementeerd wordt en de betrokken partijen beter samenwerken.

De resultaten van deze onderzoeken staan niet op zich. Eerdere, vergelijkbare interventieprogramma’s hebben ook een gebrek aan effectiviteit laten zien bij mensen met een uitkering, met kanker of een andere chronische aandoening. Eén van de belangrijkste aanbevelingen van dit onderzoek is dan ook om mogelijkheden en obstakels voor implementatie voor de bestaande interventieprogramma’s te bestuderen, aangezien dit een rol zou kunnen hebben gespeeld bij de effectiviteitsmeting van deze programma’s. Ook is het waardevol om binnen chronisch zieken als gehele groep te evalueren wat prikkels en obstakels voor werkhervatting zijn, en hoe hierop ingespeeld kan worden, aangezien deze prikkels en obstakels waarschijnlijk vaak niet ziekte-gebonden zijn.

In Hoofdstuk acht worden de resultaten van een systematische literatuurstudie gepresenteerd. Deze studie had als doel om een overzicht te krijgen van fysieke en psychosociale problemen die kanker-overlevers na werkhervatting ervaren, zoals gerapporteerd in eerdere onderzoeken. De directe aanleiding voor dit onderzoek was dat er tot op dat moment weinig bekend was over het welzijn van kanker-overlevers die erin geslaagd zijn het werk te hervatten na kanker. Ook was er geen inzicht in de ervaren gezondheidsproblemen die deze kanker-overlevers rapporteren, terwijl er wel aanwijzingen waren dat kanker-overlevers het moeilijk kunnen hebben tijdens en na werkhervatting. Sommige kanker-overlevers stoppen zelfs weer met werken, nadat zij in de eerste instantie succesvol het werk hadden hervat. Om een beeld te krijgen van de ervaren problemen na werkhervatting, zijn de databases Medline, PsycINFO, Embase en CINAHL doorzocht naar eerdere studies die over deze problemen rapporteren. Zowel kwantitatieve als kwalitatieve studies werden meegenomen. De periode waarin het onderzoek gepubliceerd moest zijn, was gesteld op januari 2000 tot maart 2013. In de eerste instantie leverde de zoektocht in de databases 8979 artikelen op. Na een check van de titels en, indien nodig, het doorlezen van de samenvatting van de artikelen, bleven er nog 64 artikelen over. Hiervan voldeden 30 artikelen aan de eisen voor deze literatuurstudie, waarvan 20 kwantitatieve studies en 10 kwalitatieve studies. Twee onderzoekers lazen de publicaties afzonderlijk en vatten de resultaten samen. Ook werd er gekeken naar de kwaliteit van de studies, om zo een schatting te geven van de betrouwbaarheid van de gerapporteerde bevindingen. Het bleek dat kanker-overlevers die het werk weer hebben hervat, tijdens hun werk vaak nog gehinderd worden door lichamelijke en psychosociale problemen, waaronder vermoeidheid, geheugenproblemen, depressie, angst en stress. Deze problemen beïnvloedden het werkvermogen van de kanker-overlevers, en zorgde soms voor verminderde productiviteit en complexe sociale situaties met collega's. Dit speelde met name wanneer het werk verdeeld moest worden, wanneer collega's werk van de kanker-overlever moesten overnemen, of wanneer de kanker-overlever bijvoorbeeld meer pauze moest nemen dan collega's. De belangrijkste conclusie van deze literatuurstudie is dat langdurige of chronische fysieke en psychosociale problemen vaak gerapporteerd worden door kanker-overlevers die het werk hebben hervat, en dat deze problemen hun werkvermogen of functioneren op het werk negatief kunnen beïnvloeden.

Hoofdstuk negen behandelt de belangrijkste bevindingen van dit proefschrift. Een van de belangrijkste bevindingen van dit proefschrift is dat kanker-overlevers die hun baan zijn verloren, een dubbel-verlies ervaring hebben: zij verliezen hun baan én hun gezondheid door kanker. Als gevolg hiervan is hun werkhervattingsproces dermate complex, en is de kans dat zij succesvol terugkeren op de arbeidsmarkt, relatief klein. Een andere belangrijke bevinding van dit proefschrift is dat een op maat gemaakt interventieprogramma ter bevordering van werkhervatting voor deze doelgroep niet effectief is gebleken in experimenteel onderzoek.

Deze bevindingen worden geplaatst in de context van de verbeterde overlevingskansen voor kankerpatiënten, de veranderende arbeidsmarkt, en de toenemende sturing van beleid en wetgeving richting participatie in de samenleving, ondanks ziekte. Daarnaast wordt in dit hoofdstuk besproken in hoeverre de bevindingen van dit proefschrift van toepassing zijn op mensen die hun baan verliezen vanwege een ander chronisch gezondheidsprobleem. Tenslotte worden in dit hoofdstuk aanbevelingen gedaan voor toekomstig onderzoek, voor beleidsmakers, en voor praktijkprofessionals zoals verzekerings- en bedrijfsartsen. Een van de belangrijkste aanbevelingen van dit proefschrift is dat praktijkprofessionals zich niet alleen moeten richten op het voorbereiden van de kanker-overlever op werkhervatting. Zij moeten zich ook realiseren dat er voorbereiding nodig is aan de kant van de werkgever, waaronder het leren omgaan met een werknemer met een langdurige of chronische ziekte. Ook is het belangrijk voor praktijkprofessionals om mogelijkheden voor therapeutisch werk voor de zieke werkende te verkennen, als opstap naar betaald werk. Dit is essentieel voor het ontstaan van een goede arbeidsrelatie en duurzame werkhervatting. Tenslotte is er in de Nederlandse maatschappij sprake van een immer toenemende druk op de, al dan niet zieke, burger om te participeren. Daarnaast zien we een toename in de prevalentie van kanker en chronische ziekten. Deze ontwikkelingen vormen de belangrijkste argumenten om een realistisch model voor werkhervatting te construeren, waarin zowel de werkende (ex-)patiënt als de (toekomstige) werkgever betrokken zijn en bereid zijn te investeren in werkhervatting, ongeacht de ziektegeschiedenis of aanwezige gezondheidsproblemen.

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About the author

Maartje Plonia (Martine) van Egmond was born on the 10th of June in 1988 in Uithoorn, The Netherlands. She graduated from secondary school (VWO) in 2006. She started her studies in Health Sciences at the VU University in Amsterdam in 2006. During this period, she was elected vice-president of the student faculty board, and member of the faculty board as a student representative. After graduating in 2009 as a Bachelor in Science, Martine started the Master Program Health Sciences in 2010. Early 2011, she went to Uganda to conduct a study on risk-management of infectious-disease-related diarrhea in schoolchildren. After she returned to the Netherlands, she graduated from the Master's program Health Sciences, Cum Laude.

Martine has had an interest in cancer survivorship ever since she conducted a series of in-depth interviews with cancer survivors during her Bachelor studies. Further, she became more knowledgeable about the long-term effects of cancer treatment as a courier and assistant-coordinator for stem cell transplantations at the Hematology departments of the academic hospitals VUmc and AMC. In her personal life she also saw the effects of cancer on wellbeing and participation in work. This kindled in her a desire to contribute to a solution for the work-related problems of cancer survivors. Therefore, she instantly applied when a position was announced for a PhD project on return to work for cancer survivors with job loss. The rest is history.

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Anekdotes: Martine made sure to keep busy during her PhD project. In 2015, she graduated from the three-year international Work Disability Prevention Strategic Training Program, organized in Toronto. In 2016 Martine also graduated from the postgraduate Epidemiology Master's program at VUmc. She was president of the PhD Day Committee of ProVU, and she participated in certified courses on scientific writing, academic educational skills and disability studies. She also joined the working group for scientific research at the Nederlandse Vereniging Psychosociale Oncologie. Since 2016, she is employed at TNO in Leiden, as a junior scientist innovator in the expertise group Work, Health & Technology. In this position, she dedicates her knowledge and skills to projects regarding healthy working and living.