

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

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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, among 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.

Keywords: cancer survivors, precarious employment, qualitative, return to work, barriers, facilitators.

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INTRODUCTION

Work ability and employment are negatively affected by long-term effects of cancer diagnosis and treatment (de Boer *et al.* 2009; Munir *et al.* 2009). As a result, it can be challenging for cancer survivors to meet job demands

(Taskila & Lindbohm 2007; Duijts *et al.* 2014). Studies have shown that, overall, cancer survivors have a 1.4 times higher risk of unemployment compared to healthy controls (de Boer *et al.* 2009). Furthermore, across studies, between 26% and 53% of cancer survivors lose their job or quit working during or after treatment (Mehnert 2011). 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 (Feuerstein *et al.* 2007). 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 (Vermeulen *et al.* 2009). 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 (Vermeulen *et al.* 2009). 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 (Uitvoeringsinstituut Werknemersverzekeringen [Dutch Institute for Employee Benefit Schemes] 2014a). 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 (Uitvoeringsinstituut Werknemersverzekeringen [Dutch Institute for Employee Benefit Schemes] 2014b). 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 (Uitvoeringsinstituut Werknemersverzekeringen [Dutch Institute for Employee Benefit Schemes] 2014c). 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 (Bray *et al.* 2012; Ferlay *et al.* 2014), a rise in retirement age (Hoppers 2012; Reichert 2014), and a changing labour market (Benach *et al.* 2004). 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 (Centraal Bureau voor de Statistiek [Statistics Netherlands] database 2014). 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 (Benach & Muntaner 2007). 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 well-being 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 (Jin *et al.* 1995; Dooley *et al.* 1996; Benach *et al.* 2000; Benavides *et al.* 2000). 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 (Braun & Clarke 2006). We used the COREQ checklist for reporting qualitative studies (Tong *et al.* 2007). 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 was 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; specialised 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.

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).

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	

Table 2. Phases of thematic analysis

Phase	Task	Performed by MvE and AL
1	Familiarise 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 3 is satisfactory and plausible	Independently
5	Discuss results of analysis	In cooperation
6	Report results	In cooperation

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 (Scientific Software Development ATLAS.ti 2008). The initial coding tree consisted of themes that were outlined in the topic list that was used during the focus groups (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 (Braun & Clarke 2006). 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.* (2006). 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.

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 was 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 women. The median age of insurance physicians was 52 years (range 28–63) and eight were women. 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. Furthermore, additional quotes per theme are provided in the Appendix.

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

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

Variable	<i>N</i> or mean (range)
<i>Cancer survivors</i> ($N = 17$)	
Age (years)	51 (31–58)
Gender, female	16
Year of cancer diagnosis	
2007	1
2008	4
2009	3
2010	8
2011	1
Type of employment (contract) when diagnosed	
Temporary contract	7
Fixed contract	3
Temporary agency worker	3
Other type of employment	3
Unemployment benefits	1
Employment status at time interview	
Unemployed	6
Voluntary job	5
Fixed contract	4
Temporary contract	2
Type of work after return to work	
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
<i>Insurance physicians</i> ($N = 22^*$)	
Age (years)	52 (28–63)
Gender, female	8
Years of experience as insurance physician	14.5 (0.5–33)
Specialty in insurance medicine	
Sickness benefits	8
Combination of specialties	6
Disability benefits	3
Other tasks (e.g. judicial, education)	3
Young disabled persons benefits	2

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

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.

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. (Cancer survivor, woman, age 46)

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 programme.

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.

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. (Cancer survivor, woman, age 53)

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. (Insurance physician, man, age 54)

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 com-

pleted. 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.

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

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

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 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.

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'. (Insurance physician, woman, age 53)

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? (Cancer survivor, woman, age 51)

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 subsidised 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 sur-

vivors 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 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 recognised 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.

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'. (Cancer survivor, woman, age 48)

A main issue with these cancer survivors is that they get laid off because they have cancer. And that

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

bluntness from an employer hits them hard. (Insurance physician, woman, age 49)

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 61)

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. (Insurance physician, man, age 52)

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.

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

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?' (Cancer survivor, woman, age 48)

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.

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 (Mehnert 2011; Mehnert & Koch 2013). 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 (Peteet 2000; Foster *et al.* 2009).

Furthermore, 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 (Kennedy *et al.* 2007; Sesto *et al.* 2011; Duijts *et al.* 2014). 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 (Mehnert 2011).

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 (Weisman 1979; Cassileth *et al.* 1985), cancer survivors may go through various stages of loss and grief, e.g. stages of denial, anger and acceptance (Kübler-Ross & Kessler 2007), to deal with the diagnosis and loss of health (Hottensen 2010; McCauley & Spriggs 2013). 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 pur-

poseful sampling procedure may be virtually impossible (Guest *et al.* 2006). 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 generalisability of our results to other cancer survivors remains. Furthermore, 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 sur-

vivors with job loss experience, e.g. by developing and testing tailored return to work intervention programmes 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 programmes should ideally be part of integrated cancer care (Tamminga *et al.* 2010). Furthermore, return to work intervention programmes 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 programmes (de Boer *et al.* 2011). This is complementary to our findings, which indicate that a tailored return to work programme 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 programme, 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 programme 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 programmes. Our findings provide a convincing argument that there is a need for a tailored approach in return to work among can-

cer survivors. Practitioners and financial parties may realise that investing in such programmes, 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 programmes may not only benefit cancer survivors with job loss experience, but 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 (Uitvoeringsinstituut Werknemersverzekeringen [Dutch Institute for Employee Benefit Schemes] 2005; Vermeulen *et al.* 2009). 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.

CONFLICT OF INTEREST

None.

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APPENDIX

SUMMARY OF MAIN FOCUS GROUP THEMES AND ILLUSTRATIVE QUOTES.

Focus group themes and subthemes	Quotes from participants
<i>Job loss experiences</i>	
Intention to keep working after diagnosis	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 46)
	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. (Cancer survivor, woman, age 51)
Emotions and thoughts regarding job loss	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 46)

Appendix. *Continued*

Focus group themes and subthemes	Quotes from participants
<i>Guidance by insurance physician</i> Perceived characteristics of cancer survivors	<p>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. (Cancer survivor, woman, age 58)</p> <p>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, woman, age 49)</p> <p>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)</p> <p>We see that cancer survivors generally have a lower level of education than the average population. (Insurance physician, man, age 61)</p>
Experience of guidance	<p>In a number of examples, it was very noticeable that the survivors had been written off [by insurance physicians]. (Insurance physician, woman, age 30)</p> <p>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 31)</p> <p>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 51)</p> <p>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 53)</p> <p>I must say I have never had any complaints about the social security agency. The help I received from everyone there was excellent. (Cancer survivor, woman, age 51)</p>
Suggestions for improvement of guidance	<p>Time, I need time [...] There is no time for proper guidance. (Insurance physician, woman, age 49)</p> <p>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 58)</p> <p>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, man, age 63)</p> <p>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. (Insurance physician, woman, age 52)</p>

Appendix. *Continued*

Focus group themes and subthemes	Quotes from participants
<i>Motivation for return to work and meaning of work</i>	
Motivation for work and meaning of work	For just a moment, you are not a patient. And that mattered a great deal to me. (Cancer survivor, woman, age 51)
	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 53)
	[it gave me] Energy. It's just nice to have people, colleagues, around you. (Cancer survivor woman, age 51)
<i>Psychosocial and cancer-related barriers and facilitators for return to work</i>	
Changed cognitions and life preferences	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. (Insurance physician, woman, age 49)
Health problems and illness	I really want to [work], but my body just does not allow me. (Cancer survivor, woman, age 54)
	I refuse to give up, but actually, I just can't [work]. (Cancer survivor, woman, age 53)
Role of the social environment	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 53)
	They did support me, because I really wanted to [work]. It's not as if they said: 'Shouldn't you go back to work?' (Cancer survivor, woman, age 48)
Doubts about work ability and starting return to work	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 52)
	I missed that you cannot start by just coming in for a therapeutic cup of coffee. (Cancer survivor, woman, age 48)
	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.' (Cancer survivor, woman, age 53)
<i>Work-related barriers and facilitators for return to work</i>	
Labour market characteristics	In the current labour market, who would hire these people? (Insurance physician, Man, age 58)
	We are presently in a terrible labour market and that naturally counts for a great deal. (Insurance physician, woman, age 53)

Appendix. *Continued*

Focus group themes and subthemes	Quotes from participants
Employers' prejudice	<p>Even voluntary work or whatever else I apply for, there is just no one that will have me. (Cancer survivor, woman, age 48)</p> <p>They often get rejected. They also have to defend themselves a lot. (Insurance physician, man, age 58)</p>
Advice from insurance physicians	<p>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, man, age 61)</p> <p>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.' (Insurance physician, woman, age 53)</p>
<i>Experiences with return to work</i> Mental and physical challenges	<p>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 48)</p> <p>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 51)</p> <p>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. (Cancer survivor, woman, age 46)</p>
Dealing with work environment and changes in type of job and wages	<p>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 48)</p> <p>I do not go there [to my occupational physician]. I am hired on a temporary contract and I do not want to jeopardize that. (Cancer survivor, woman, age 53)</p>