Sustained employability of cancer patients and survivors: are we getting any closer?

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  - The Netherlands Cancer Institute (NCI)
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[Graph showing the stages of diagnosis, treatment, return to work, and sustained employability]
1970s – 2010s

- Return to work of cancer patients and survivors is a topic of interest for about 40 years already
  - Job discrimination
  - Denied access to life and health insurances
- In the 80s and 90s: studies on predictive factors for return to work
- From 2000 onwards, the ‘cancer and work’ research area expanded
  - Next to the patient perspective, the perspectives of employers, colleagues, caregivers, physicians and many others started to receive more attention.
Facts & Figures

• Global level
  o 12.7 million new cancer cases each year
  o 50% of the cases are of working age

• Europe
  o 3.5 million new cancer cases
  o 50% of the cases are of working age

• National (the Netherlands)
  o 110,000 new cancer cases each year
  o 40% of the cases are of working age
Facts & Figures

- At 6 months after diagnosis → 40% (range 24 – 72%)
- At 12 months after diagnosis → 62% (range 50 – 81%)
- At 18 months after diagnosis → 73% (range 64 – 82%)
- At 24 months after diagnosis → 89% (range 84 – 94%)

At 5 years after diagnosis → 67% of patients able to return to work.
  - Part-time or fulltime? Same or different position?

Overall: most cancer survivors are able to return to work!
Facts & Figures

At 5 years after diagnosis → 67% of patients able to return to work.

Question: can this percentage be much higher?
Factors related to return to work

- Socio-demographics
  - Age, gender and education

- Disease related factors
  - Cancer type, chemotherapy, surgery alone
  - Fatigue, depression, anxiety, cognitive functioning

- Work related factors
  - Type of work, physical job demands, employer accommodations

September 26th 2018; Mehnert et al, 2002; Taskila et al, 2004; Banning et al, 2011
Interventions to support return to work

Cochrane review 2015; de Boer et al.

• 15 RCTs included
  o 7 studies on medical interventions
  o 5 studies on multidisciplinary interventions
  o 2 studies on psycho-educational interventions
  o 1 study on physical exercise intervention
  o No studies on vocational interventions

• Only moderate quality evidence that multidisciplinary interventions enhance the return to work of patients with cancer!
Interventions to support return to work

Cochrane review 2015; de Boer et al.

- More high-quality RCTs
- Multidisciplinary interventions
- Vocational components

AND:

After patients have returned to work, it is important that cancer patients are able to remain working. Research beyond return to work, focusing on work retention and factors associated with it, is highly needed!
Looking back at the last decades...

- We have a pretty good idea about which factors are predictive for returning to work relatively shortly after diagnosis;
- Numerous interventions have been developed and evaluated so far to support cancer patients and survivors to return to work;
- Only multidisciplinary interventions seem to be moderately effective!
- Supporting cancer patients to return to work is still necessary;
- We should also focus on those survivors who were able to return to work, but experience long-term problems at work!
## Sustained employability

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[Diagram showing the stages of diagnosis, treatment, return to work, and sustained employability.]
Adverse work outcomes 10 years after diagnosis

JOBS study: Employment outcomes in breast cancer survivors 5-10 years after diagnosis.

- A third of all women diagnosed with breast cancer is under the age of 55;
- The current 10-year breast cancer survival is approaching 80% for patients diagnosed before age 55;
- A large proportion of these women is working at time of diagnosis;
- It is known that – even in early breast cancer – work ability is negatively influenced at least up to 5 years after diagnosis;
- But: it remains largely unknown what happens after these first years.
Adverse work outcomes 10 years after diagnosis

JOBS

• Cohort of 26,120 women diagnosed with breast cancer before the age of 55;
• Period 2000 – 2005;
• Patients were identified through the Netherlands Cancer Registry;
• Data were linked with individual social security data (Statistics Netherlands), such as individual income, receipt of disability or unemployment benefits, and welfare;
• Each breast cancer patient was matched with 4 women from the general healthy population.
Adverse work outcomes 10 years after diagnosis

**JOBS**

Breast cancer survivors experienced:

- Higher risk of losing paid employment (HR 1.6, 95% CI 1.4–1.8) (5-7 years)
- Higher risk of any work-related event (HR 1.5, 95% CI 1.3–1.6) (5-7 years)
- Higher risk of receiving disability benefits (HR 2.0, 95% CI 1.6–2.5) (10 years)
- Risk of disability benefits was increased among patients receiving mastectomy and radiotherapy (HR 1.2; 95% CI 1.1–1.3) and after chemotherapy (HR 1.7; 95% CI 1.5–1.9) during the first 5 years after diagnosis.

... compared to the general healthy population.
Adverse work outcomes 10 years after diagnosis

JOBS
Since breast cancer survivors have a higher risk of adverse work outcomes up to 10 years after diagnosis, compared to the general healthy population...

... work and return to work should be a standard topic to discuss after completion of treatment. Oncologists should timely refer patients, whenever patients may need support with work reintegration.
Predictive factors for adverse work outcomes

JOBS

With questionnaire data, we also explored:

• which factors – associated with adverse work outcome 0-5 years after breast cancer diagnosis – were also associated with adverse work outcome 5-10 years after diagnosis;
• which additional factors were associated with adverse work outcome 5-10 year after diagnosis.
Predictive factors for adverse work outcomes

JOBS

Of the 936 participants, 348 (37%) had an adverse work outcome 5-10 years later.

The probability of an adverse work outcome increased with:

• age (OR 1.03, 95% CI 1.00-1.07)
• time since breast cancer diagnosis (OR 1.20, 95% CI 1.03-1.4)
• changed meaning of work / work less important (OR 2.9, 95% CI 1.9-4.6)
Predictive factors for adverse work outcomes

JOBS

The probability of an adverse work outcome decreased with:

- having more children involved in daily tasks (OR 0.7, 95% CI 0.5-0.8)
- having sufficient money (OR 0.22, 95% CI 0.08-0.66)
- higher total work ability (OR 0.6, 95% CI 0.5-0.7)

Prior to diagnosis:

- having more social support (OR 0.52, 95% CI 0.33-0.80)
- ability to make work adjustments (OR 0.55, 95% CI 0.36-0.83)
Predictive factors for adverse work outcomes

JOBS

Compared to predictive factors for return to work, relatively shortly after diagnosis, at the long-term, factors are predominantly personal- or work-related.

This implies that interventions targeting work-related factors should be developed to prevent adverse work outcome 5-10 years after breast cancer diagnosis.
Survivors’ experiences with work at the long-term

JOBS

Focus group interviews with breast cancer survivors.

**Aim:** to qualitatively investigate experienced changes in employment status, barriers to and facilitators of (return to) work in breast cancer survivors 5-10 years after diagnosis.
Survivors’ experiences with work at the long-term

**JOBS**

- 19 women participated in 3 focus groups
- 18 reported a change in employment status 5 – 10 years after diagnosis

- Perceived barriers to (return to) work shortly after breast cancer diagnosis tended to be **disease- and treatment-related**, while 5-10 years later, they were **personal- and work-related**.
Survivors’ experiences with work at the long-term

JOBS

Barriers

Shortly after diagnosis: fatigue, depression, little flexibility from the employer
Long-term after diagnosis: age, economic circumstances

“The amount of work I had to do was too much for a part-time job. I could not handle this workload, so I resigned.”
Survivors’ experiences with work at the long-term

JOBS

Facilitators

Shortly after diagnosis: good prognosis, social support
Long-term after diagnosis: ongoing flexibility from the employer

Control of the RTW process

Shortly after diagnosis: self-employed; pressure by the employer/occupational physician
Long-term after diagnosis: quote.

“I have learned to say ‘this is where I draw the line’.”
Survivors’ experiences with work at the long-term

JOBS

Meaning of work
Shortly after diagnosis:
sense of normalcy
Long-term after diagnosis:
social and financial significance

Your work is going to fill a large part of your life, and the only way to be truly satisfied is to do what you believe is great work. And the only way to do great work is to love what you do. ~ Steve Jobs
Survivors’ experiences with work at the long-term

**JOBS**

**Social support**

Shortly after diagnosis: highly present;

Long-term after diagnosis:

social environment disregarded their breast cancer history and the continuous impact of the diagnosis and treatment on their life.
Survivors’ experiences with work at the long-term

JOBS

• Breast cancer survivors still experience changes in employment status 5-10 years after diagnosis;
• (Occupational) health care professionals should be alert that perceived barriers for returning to work change over time.

Future research should focus on increasing awareness (at work) of breast cancer survivors’ needs, providing adequate information and support to all involved, and developing interventions to sustain survivors’ work ability at the long-term.
Physical and psychosocial problems at work

Systematic review

- Publications were identified through computerized Medline, PsycInfo, Embase, and Cinahl searches (January 2000-March 2013);
- Studies had to be directed at cancer survivors at work;
- Both qualitative and quantitative studies were included;
- Quality assessment of these studies was performed.
Physical and psychosocial problems at work

Systematic review

- 30 studies met all inclusion criteria
  - 20 quantitative studies
    - 3 explored the effect of physical problems, such as functional limitations, chronic conditions, and arm movement limitations, on work outcomes
    - 6 explored the effect of psychosocial problems, such as depressive symptoms, fatigue, and cognitive limitations, on work outcomes
    - 11 explored the effect of both physical and psychosocial problems on work outcomes.
Physical and psychosocial problems at work

Systematic review

Some examples:

• Impaired physical ability was reported in 28% of working women with a history of breast cancer;
• Hot flushes were associated with work performance loss in breast cancer survivors;
• About 10% of prostate cancer survivors indicated to experience difficulties with cognitive tasks, such as concentration, keeping up with others, and learning new things.
Physical and psychosocial problems at work

Systematic review

- 30 studies met all inclusion criteria
  - 10 qualitative studies
    - 6 mainly described psychosocial problems, such as coping issues, stress, cognitive limitations, fatigue, lack of social support, and/or work accommodation, to influence work;
    - 4 described both physical and psychosocial problems, such as hot flashes, hair loss, and emotional strain, to influence functioning at work.
Physical and psychosocial problems at work

Systematic review

• Regarding experiencing hot flushes at work, someone said:

  ‘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’.

• Regarding experiencing cognitive problems, someone said:

  ‘Every 2 hours, I was going somewhere to sit down/relax, I couldn’t think well. I couldn’t coordinate everything that was going on’.
Physical and psychosocial problems at work

Systematic review

- Ongoing physical and/or psychosocial problems are present in occupationally active cancer survivors, which may cause serious difficulties at work;
- Awareness is important in clinical practice and in research about the presence of long-term effects of diagnosis and/or treatment beyond return to work;
- There is a high need for interventions to support cancer survivors at work.
Sustained employability

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Diagram showing the process from diagnosis to sustained employability.
Interventions to support cancer survivors at work

A systematic review of interventions to retain chronically-ill occupationally active employees in work: can findings be transferred to cancer survivors?

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Introduction
In Europe, there are about 3.5 million new cancer cases each year, and up to 50% of patients are working at time of diagnosis. Numerous studies have been performed exploring factors related to return to work (RTW) in cancer survivors, and evaluating the effectiveness of interventions to support return to work (RTW) process. Studies have focused on survivors who were able to continue work during or after treatment.

Up to 80% is non-normalizable barriers to return work two years after diagnosis; however, many survivors experience active work maintenance/return (HAM) programs requiring occupational active survivor support to retain work and prevent such adverse work outcomes (Ham et al., 2014). Concerning, ample information on how to retain employees with other chronic diseases is available.

"Lifestyles may be normal form survivors that have been developed for and typically evaluated in working environments with other chronic diseases other than cancer."

Objective
To systematically evaluate the literature on occupational active survivors eligible for work maintenance/return (HAM) programs requiring occupational active survivor support to retain work and prevent such adverse work outcomes (Ham et al., 2014). Concerning, ample information on how to retain employees with other chronic diseases is available.

Material and methods
Study design: We included studies that systematically evaluated occupational active survivors eligible for work maintenance/return (HAM) programs requiring occupational active survivor support to retain work and prevent such adverse work outcomes (Ham et al., 2014). Concerning, ample information on how to retain employees with other chronic diseases is available.

Literature search: A comprehensive search of PubMed, Embase, PsycINFO, and other electronic databases was performed by the first author (S.M.H.) with the aid of a second author (H.C.B.) using predefined keywords.

Study selection: Studies were included if they met the following criteria: they were published in English; they were original research; they examined occupational active survivors eligible for work maintenance/return (HAM) programs requiring occupational active survivor support to retain work and prevent such adverse work outcomes (Ham et al., 2014). Concerning, ample information on how to retain employees with other chronic diseases is available.

Data extraction: Data were extracted by the first author (S.M.H.) with the aid of a second author (H.C.B.) using a predefined data extraction form.

Critical appraisal: The quality of the included studies was assessed using the Joanna Briggs Institute (JBI) critical appraisal tool. Studies were assessed for internal and external validity (Murphy et al., 2013).

Data synthesis: The primary outcome was the effectiveness of interventions to support return to work (RTW) process. Studies were assessed for internal and external validity (Murphy et al., 2013).

Results
A total of 56 studies were included in the systematic review. Of these, 38 were RCTs, 12 were non-randomized controlled trials, and 6 were cohort studies. The majority of studies evaluated interventions to support return to work (RTW) in cancer survivors, with the remainder evaluating interventions to support return to work (RTW) in other chronic diseases. The quality of the included studies was variable, with many studies lacking a clear description of the intervention or the outcomes measured.

Conclusion
In conclusion, occupational active survivors eligible for work maintenance/return (HAM) programs requiring occupational active survivor support to retain work and prevent such adverse work outcomes (Ham et al., 2014). Concerning, ample information on how to retain employees with other chronic diseases is available.

Practical implications
We propose several elements when developing an intervention for occupationally active survivors to return to work:

1. Tailor the intervention to the specific needs of the survivor, taking into account factors such as job demands, physical abilities, and personal preferences.
2. Incorporate multifaceted interventions, including occupational therapy, physical therapy, and psychological support.
3. Ensure that the intervention is culturally appropriate and accessible to all survivors.
4. Monitor the survivor’s progress and adjust the intervention as needed.
5. Evaluate the effectiveness of the intervention through pre- and post-assessments.

European Cancer Survivorship and Rehabilitation Conference
Copenhagen 2018
Interventions to support cancer survivors at work

Material and methods

- **Search strategy**: databases PubMed, EMBASE and PsycINFO, without any language or year of publication restrictions;
- **Study selection**: the initial search captured 560 abstracts, of which 24 were duplicates. Studies were independently screened on title and abstract by two authors. Exclusion criteria were: 1) no randomized controlled trial; 2) no chronic disease; 3) ≥ 50% of the participants on sick leave at baseline; 4) outcomes measures related to return to work instead of staying at work.
Interventions to support cancer survivors at work

Material and methods

- **Data extraction**: 1) general study characteristics (e.g., author, year of publication), 2) participant characteristics (e.g., age, gender, type of chronic disease), 3) intervention characteristics (e.g., content), 4) outcome measure(s) (e.g., work functioning), and 5) main findings of the study;

- **Quality assessment**: risk of bias within studies was scored independently by two authors.

![Risk of Bias Chart]
Results

• Study characteristics:
  o 536 unique studies were found and screened on title and abstract;
  o 18 studies met the inclusion criteria;
  o All studies (publication year range 2003 – 2017) were performed in Western, high-income countries, and included a total of 3,546 participants;
  o Chronic diseases of these occupationally active participants were, among others, rheumatic diseases, mental disorders, and musculoskeletal pain.
Interventions to support cancer survivors at work

Results

• **Quality assessment**: all included studies in our review were rated as having an overall low risk of bias;

• **Content and effectiveness of the interventions**: findings of included studies reported on two (psycho-)educational, three physical, five vocational, and eight multidisciplinary interventions for chronically-ill employees to retain work.
Interventions to support cancer survivors at work

We propose **seven elements** when developing an intervention for occupationally active cancer survivors to retain work:

1. **Aim to prevent** job loss, (recurrent) sickness absence and/or work disability, or **to improve** work ability, work functioning, productivity and/or supervisor support;

2. **Involve important stakeholders**, such as employers, occupational and physical therapists, social workers, counsellors, nurses, and medical specialists;
Interventions to support cancer survivors at work

3. **One-size-does-not-fit-all:** assess the occupationally active cancer survivor’s job, roles and responsibilities, in relation to the severity of diagnosis and/or treatment and in relation to activity limitations, and assess perceived work barriers;

4. **Focus on vocational components** in the intervention (potentially as part of a multidisciplinary intervention with (psycho-)educational or exercise components; avoid overburdening the working cancer survivor);

5. **Monitor** the occupationally active cancer survivor during several months, immediately after returning to work;
Interventions to support cancer survivors at work

6. **Make the workplace part of the intervention** (e.g., consultations with the supervisor or occupational physician/occupational health services);

7. **Engage skilled trainers** to guide the intervention.

“We believe that these seven generic elements can be used to develop an intervention for occupationally active cancer survivors.”
i-WORC: online cognitive rehabilitation working survivors

i-WORC study

• Randomized controlled trial in occupationally active cancer survivors;
• To evaluate the effectiveness of an online cognitive rehabilitation program in working cancer survivors on individually defined work-related treatment goals and quality of life.
i-WORC: online cognitive rehabilitation working survivors

Study population

• 192 cancer survivors (18 – 65 years) who have returned to (paid) work (with at least 6 months of their contract left); who are currently between 6 months to 3 years after completion of treatment; who experience (subjectively/objectively measured) cognitive problems.
• Patients with and without cognitive dysfunction established in a neuropsychological assessment will be eligible; stratification will take place based on the presence of this measured cognitive dysfunction.
i-WORC: online cognitive rehabilitation working survivors

Neuropsychological assessment.

Trail making test; 1, A, 2, B, 3, C and so on...
i-WORC: online cognitive rehabilitation working survivors

Study design / recruitment

• A three-armed randomized controlled trial with two intervention groups (i.e., a high-intensity and a low-intensity cognitive rehabilitation programme) and one waitlist control group;
• Occupationally active cancer survivors who have been treated in several hospitals in the Netherlands will be included.
i-WORC: online cognitive rehabilitation working survivors

**Intervention**

- Participants receive access to a secured personal webpage;
- **Low-intensity arm** will consist of a brief cognitive training programme without individual guidance, involving three to five sessions (approximately 60 minutes in length) which have to be completed in a period of 12 weeks;
- **High-intensity arm** will consist of a comprehensive training programme, including personal guidance by a therapist, involving five to eight sessions (approximately 60 minutes in length) which have to be completed in a period of 12 weeks;
- **Waitlist control group.**
## i-WORC: online cognitive rehabilitation working survivors

### Intervention

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<td>Introduction</td>
<td>Neuropsychological assessment results will discussed; Personal goals will be formulated.</td>
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<td>2</td>
<td>Psycho-education</td>
<td>Information about cancer-related cognitive impairment.</td>
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<tr>
<td>3</td>
<td>Fatigue management</td>
<td>Coping with fatigue at work.</td>
</tr>
<tr>
<td>4</td>
<td>Attention and concentration training</td>
<td>Learn and practice concentration strategies at the workplace.</td>
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... .... ...

September 26\textsuperscript{th} 2018
i-WORC: online cognitive rehabilitation working survivors

Outcome measures

- Primary outcome: goal attainment scale (GAS)
- Secondary outcomes:
  - Cognitive complaints
  - Work ability
  - Work functioning
  - Absenteeism and presenteeism
  - Need for recovery
  - Health related quality of life
i-WORC: online cognitive rehabilitation working survivors

Recruitment of working cancer survivors will start in January 2019!
Predictors for work continuation in cancer survivors

- Data from a prospective cohort of working cancer survivors;
- Predictors for work continuation in survivors working at baseline;
- Two years after diagnosis (T0);
- Follow-up of one year (T1);
- A high score on current work ability was associated with work continuation one-year later (OR 1.46; 95% CI 1.11-1.92).
Sustained employability
Are we getting any closer to sustained employability?

- We know which factors are predictors for return to work in cancer patients and survivors;
- Many interventions have been developed to support survivors to return to work, but just a few of them showed an effect so far;
- Since the return to work rate is primarily related to the survivor rate, we should aim at supporting the return to work process, instead of only looking at return to work as an outcome;
- This is specifically true for the period shortly after diagnosis, as disease- and treatment related factors are most important, which are difficult to influence.
Are we getting any closer to sustained employability?

- Support for cancer survivors to return to work is still important!
- We have learned a lot in the last decades, but maybe we have reached the best possible outcome and should we shift our focus:
  - Support the return to work process and return to work at the long-term;
  - Focus on those who returned to work and support them to stay at work.

- YES…. we are getting closer! It is important that this shift in focus towards sustained employability is taking place!
Are we getting any closer to sustained employability?

- Are we there yet...?
- NO!

- Attention for retaining cancer survivors at work is still limited;
- Two third of all cancer survivors at working age are at work again and many of them are still dealing with all kind of physical and psychosocial complaints at the workplace.
Are we getting any closer to sustained employability?

• There is a lack of knowledge and awareness regarding these problems in important stakeholders, such as employers, colleagues and even occupational physicians and oncologists.

• Example: Chris Oostdam.
“Just before the start of my sixth cycle of chemotherapy, I am meeting my oncologist. I am telling her that I am feeling really well, and that I am considering to return to work again. I am a bit concerned though that it will take a lot of energy, and that it might cause that I am feeling exhausted in the evening. She is listening quietly, but then says that she doesn’t think it is a good idea to go back to work. You have cancer, she says, and even if you are feeling well now, the cancer will not go away anymore, so why not use your energy for more important things. I start crying. My work is important to me. The conversation made me realize though how bad the situation actually is....”
Questions?

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