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### Enhancing the return to work of cancer survivors

*Development and evaluation of an intervention targeted at employers*

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# CHAPTER 10

Summary



## Summary

About half of the people who are diagnosed with cancer are between 18 and 65 of age, and thereby of working age. Due to improved diagnostics and enhanced treatment for cancer, cancer survival rates are increasing. For many cancer survivors, work is an important aspect of their cancer survivorship. Work provides social interaction, structure in a person's daily life, financial security and a feeling of being more than a patient. As such, work can contribute to a person's quality of life, both during and after cancer. In this thesis, every person who has been diagnosed with cancer at some point in their life and is currently still alive is referred to as a "cancer survivor".

Despite work being considered important, cancer survivors may experience problems continuing to work during treatment or in returning to work afterwards. The physical and mental side-effects of cancer and its treatment, such as fatigue and a lack of support in the workplace, are common. As a consequence, about 40% of cancer survivors are unable to remain at work or return to work within a year of their diagnosis. In the longer term, the risk of being unemployed is about 1.5 times higher for cancer survivors compared to the general population.

Moreover, return to work (RTW) in itself is also important, as cancer survivors may have negative perceptions concerning their RTW. For example, they may feel that work will negatively affect their health and therefore not experience their RTW as successful. The importance of work for cancer survivors, combined with the risk of unemployment and negative perceptions of RTW, suggests that efforts are needed to support cancer survivors to stay at or return to work successfully.

Employers play a vital role in guiding employed cancer survivors during their sickness absence and RTW. The term "employer" refers to the specific person who represents the organization that employs the cancer survivor, providing support and guidance during their sickness absence and RTW; for example, the direct supervisor, line-manager or the human resources (HR) manager. Adequate guidance from the employer may enable the employee to remain

at work or RTW, while a lack of guidance from the employer may, in contrast, negatively affect RTW.

However, knowledge about the role of the employer during the RTW of cancer survivors, as well as their experience with guiding cancer survivors, has not received the research attention it deserves. Some studies have found that employers regard the guidance of cancer survivors during their sickness absence and RTW as difficult to manage because they struggle with conflicting interests between the cancer survivor, colleagues and the organization. Employers have also indicated that they have a lack of knowledge and experience to be in a position to adequately guide cancer survivors at the workplace. In addition, there is a lack of supportive interventions for employers who are confronted with an employee diagnosed with cancer.

This thesis argues that the development of an intervention targeted at employers could be of great benefit in promoting and enhancing the successful RTW of cancer survivors. This requires that the individual perspectives of cancer survivors on RTW should be taken into consideration – the cancer survivor should personally regard the RTW as “successful”.

The aim of this thesis is to develop and pilot test an intervention (called the MiLES intervention) targeting the employer that enhances the successful RTW of cancer survivors. MiLES is an acronym that stands for “the Missing Link: optimizing the return to work of Employees diagnosed with cancer, by Supporting employers”. This thesis consists of three parts, each of which addresses two research questions:

#### Part 1: Development of the MiLES intervention targeted at employers

Research questions:

1. How can employers provide adequate guidance to cancer survivors during their sickness absence and RTW, according to both the employers and cancer survivors, and what might underlie this guidance?
2. What methodologies and practical strategies should be incorporated into the MiLES intervention in order to support employers during the RTW of cancer survivors?

### Part 2: Development and testing of an RTW outcome measure

Research questions:

1. How can we measure successful RTW from the perspective of cancer survivors?
2. What are the psychometric properties of this new questionnaire for evaluating successful RTW of cancer survivors?

### Part 3: Pilot testing the MiLES intervention

Research questions:

1. Is it feasible to perform a future definitive randomized controlled trial on the effectiveness of the MiLES intervention for enhancing successful RTW of cancer survivors?
2. How do employers evaluate the use and perceive the usefulness of the MiLES intervention?

### **Development of the MiLES intervention targeted at employers**

The Intervention Mapping (IM) approach was used to develop the MiLES intervention. The first step was to determine the role of employers in the guidance of employed cancer survivors during their sickness absence and RTW, and to assess the employers' needs in this regard. Several studies were conducted to this end.

First, a systematic review of international qualitative studies of either employers or cancer survivors was conducted to identify perceived employer-related barriers to and facilitators for the work participation of cancer survivors (**Chapter 2**). Specifically, we aimed to identify behaviors, attitudes and perceptions of employers that were perceived to hinder or enhance the work participation of cancer survivors. A total of 180 perceived barriers and 236 perceived facilitators were identified and categorized in terms of the following types of employer actions: those related to communication; emotional and practical support; discrimination; knowledge about cancer; and the perception of the cancer survivor's work ability. The plurality and large variety in perceived employer-related barriers to and facilitators for work participation of cancer survivors confirmed the complexity of the role of the employer in guiding cancer survivor employees during their sickness absence and RTW.

Second, we conducted a Delphi study with two expert panels: one with employers (N = 23) and one with cancer survivors (N = 29) (**Chapter 3**). Both expert panels were asked to select the most important employer actions, derived from the systematic review above, for each of the following RTW phases separately:

Phase 1: Disclosure – the period between disclosure of the cancer survivor’s illness to the employer and the first treatment.

Phase 2: Treatment – the period during which the cancer survivor is on sick leave as a result of their treatment.

Phase 3: RTW planning – the period in which concrete planning of and preparation for the cancer survivor’s RTW takes place.

Phase 4: Actual RTW – the period after RTW.

Employers and cancer survivors both reached consensus on the importance of “providing emotional support”, “providing practical support”, “allowing sufficient sick leave”, “adjusting expectations”, “planning the RTW”, “assessing work ability” and “showing appreciation”. These employer actions were each specific for one to three RTW phases. While the perspectives of the employers and cancer survivors exhibited great similarities, they did vary concerning important actions during RTW phase 2. This study reduced the wide range of employer-related barriers and facilitators identified in international qualitative studies into a consensus on the importance of a number of concrete employer actions in different RTW phases.

Subsequently, the MiLES intervention – targeted at employers – was developed, based on the studies above and interviews with employers (N = 30) and e-health experts (N = 7) (**Chapter 4**). The intervention is web-based and contains succinct, tailored tips and information, conversation checklists, interactive communication videos and links to reliable external websites. The content of the intervention is tailored to each RTW phase (see above), for each employer action and for various experience types of cancer survivors. The latter concerned three types of cancer survivor experiences addressed in the intervention, each requiring different kinds of support from the employer. On this basis, the MiLES intervention endeavors to support employers to perform the most important employer actions properly

and in a timely manner, and to tailor them to the needs and preferences of the specific cancer survivor. The intervention is designed to be easily accessible and suitable to the employers' actual practice, with the aim of enhancing successful RTW of cancer survivors.

### **Development and testing of an RTW outcome measure**

Cancer survivors who return to work do not necessarily experience their RTW as successful, and current RTW outcome measures, such as time until RTW, may not be sufficient to capture the personal perspectives of cancer survivors. Therefore, an outcome measure that incorporates such perspectives on what is perceived as successful RTW was developed: the Successful Return-To-Work Questionnaire for Cancer Survivors (I-RTW\_CS) (**Chapter 5**). This was done by organizing three focus groups with cancer survivors (N = 14), in which 45 issues that represent successful RTW, according to cancer survivors, were generated. Subsequently, in a two-round Delphi study, 108 cancer survivors were asked to select the issues that were most important to them in constituting a successful RTW. The following seven issues were most frequently chosen and therefore incorporated as items in the I-RTW\_CS: "enjoyment at work", "work without affecting health", "confidence of employer without assumptions about work ability", "open communication with the employer", "feeling welcome at work", "good work-life balance" and "joint satisfaction with the situation (employer and cancer survivor)" (**Appendix I**). The I-RTW\_CS was designed as an outcome measure weighted on an individual basis. Items that are considered more important for a cancer survivor are given a higher weighting in the I-RTW\_CS score.

Subsequently, the psychometric properties of the I-RTW\_CS were determined (**Chapter 5**). Construct validity was assessed in a sample of 57 cancer survivors, using correlations with the Quality of Working Life Questionnaire for Cancer Survivors (QWLQ-CS) and a single-item measure of successful RTW. The results revealed a correlation of 0.85 with the QWLQ-CS and 0.58 with the single-item measure of successful RTW. To assess the reproducibility (test-retest reliability) of the I-RTW\_CS, we assessed the intraclass correlation coefficient (ICC) among a stable sample of 50 cancer survivors. This resulted in an ICC of 0.72. This provided preliminary evidence for the construct validity and reproducibility of the I-RTW\_CS.

### **Pilot testing of the MiLES intervention**

The MiLES intervention was developed to change the behavior of employers, with the aim of enhancing the successful RTW of cancer survivors. Two studies were conducted to evaluate the MiLES intervention. First, the feasibility of conducting a future definitive randomized controlled trial (RCT) on the effectiveness of the MiLES intervention on successful RTW was evaluated. Second, the employers' use of the MiLES intervention and their perceptions of its usefulness were evaluated.

First, we considered the feasibility of conducting a future definitive RCT on the effectiveness of the MiLES intervention. Such a definitive RCT would be accompanied by method and protocol-related uncertainties; for example, regarding the recruitment of cancer survivors and the acceptability of the study protocol. Therefore, we developed a randomized feasibility trial to evaluate the feasibility of conducting such a future definitive RCT on the effectiveness of the MiLES intervention on successful RTW of cancer survivors. The study design of this randomized feasibility trial respected privacy regulations concerning the exchange of health-related information between the employer and the employed cancer survivor, as well as ethical concerns (**Chapter 6**).

Important aspects of the study design that we developed were: 1) only employed cancer survivors who had already informed their employer about their cancer diagnosis could participate, 2) cancer survivors were randomized into an intervention or waiting list control group (2:1), 3) cancer survivors randomized to the intervention group were encouraged to inform their employer about the MiLES intervention, 4) outcomes were measured on the cancer survivor level, not on the employer level (not permitted due to the privacy regulations), 5) a follow-up period of six months was used, and 6) RTW and the I-RTW\_CS were combined as the primary effect measure. The feasibility of a future definitive RCT was determined using five predefined criteria concerning the main method and protocol-related uncertainties, such as the need for > 90 participants to be included within six months; that ≤ 20% of the participants are lost to follow-up; and that ≤ 20% of the participants are not willing to inform their employer about the MiLES intervention. A future definitive RCT was determined to be feasible if all criteria were met.



A total of 35 cancer survivors were enrolled in the randomized feasibility trial and were randomized to either the intervention group (N = 24) or the control group (N = 11) (**Chapter 7**). Most of the predefined criteria for feasibility were met; for example, only 3% (N = 1) of the participants were lost to follow-up, and almost all cancer survivors randomized to the intervention group informed their employer about the MiLES intervention (N = 21; 88%). However, the criterion related to the study's reach was not met, as it was unable to recruit 90 participants within the six-month period. Furthermore, the randomized feasibility trial revealed that the study design might not be appropriate to evaluate the effectiveness of the MiLES intervention on successful RTW of cancer survivors. This was due to the fact that only a select group of female cancer survivors with a permanent employment contract, who already had a relatively high degree of success in their RTW (reflected in high I-RTW\_CS scores at baseline), and an intensive and assumedly reasonable pre-study relationship with their employer, participated in the study. Cancer survivors at high risk of unemployment were either not reached by the recruitment strategies employed, or were not willing to participate under the conditions proposed in the study protocol. An alternative study design is therefore needed to evaluate the effectiveness of the MiLES intervention on successful RTW of cancer survivors.

In addition to the randomized feasibility trial, we conducted a study to evaluate the employers' use of the MiLES intervention and their perceptions of its usefulness (**Chapter 8**). Participant employers (N = 31) were given access to the MiLES intervention for a period of six weeks, and were subsequently asked to complete an online questionnaire on their use of the intervention and their perceptions of its usefulness (N = 22). In-depth qualitative data was also gathered using semi-structured interviews (N = 20). Most employers used the intervention (82%), typically 2-3 times, and on average for 26 minutes per visit. Employers perceived the intervention to be useful, which was reflected in the overall usefulness score (i.e., 7.6 out of 10 points), and the fact that all employers reported that they would recommend the intervention to their colleagues. The employers appreciated the online availability and practical focus of the MiLES intervention. The combination of textual and visual content also appealed them. These results clearly show that, from the employer

perspective, the MiLES intervention is a useful tool that is suitable to employers' daily practice.

### **Conclusions and recommendations for research and practice**

This thesis offered new insights into the role of employers in guiding employed cancer survivors during their sickness absence and RTW. The most important employer actions and the support needs of employers were identified. On this basis, the MiLES intervention was developed, which is a web-based intervention with succinct, tailored tips and information, communication videos and conversation checklists. Employers perceived the intervention to be a useful tool that well suits their daily practice. This can be seen as an important precondition for the effectiveness of the intervention with respect to successful RTW of cancer survivors. However, whether the intervention is actually effective cannot be concluded on the basis of the studies conducted and presented in this thesis. An alternative study design is needed to evaluate the effectiveness of the MiLES intervention on successful RTW of cancer survivors, and we recommend that all relevant stakeholders be involved in the development of such a study design. In this respect, the lessons learned from the randomized feasibility trial should be taken into consideration and the alternative study design should combine a careful evaluation with prompt and wide implementation in daily practice, in the case of an effective intervention.

This thesis also revealed that RTW after cancer should not be regarded as an endpoint, as a successful RTW comprises more than just returning to the workplace. It is therefore important to incorporate the I-RTW\_CS as an outcomes measure to determine the effectiveness of future work-related interventions for cancer survivors. This will enable an in-depth evaluation of a cancer survivor's RTW, taking into account individual perspectives on what is perceived as a successful RTW. Future studies should assess the responsiveness and interpretability of the I-RTW\_CS, with the aim of further evaluating its ability to measure differences at individual and group levels. The I-RTW\_CS, including its individual items, also provides important input into a broader, more meaningful conversation between employers, cancer survivors and practitioners. As a consequence, a cancer survivor's perception of

successful RTW may be identified, which enables the RTW guidance to be tailored to the preferences and needs of each specific cancer survivor.

It is concluded that employers are an important link in the RTW process of cancer survivors, but need to be supported to fulfill this role. In this respect, the MiLES intervention provides employers a promising tool to enhance successful RTW of cancer survivors.