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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 1

General introduction



General introduction

As people live longer after a cancer diagnosis, cancer survivorship care has become increasingly important and will continue to do so in the coming decades [1-3]. In this thesis, every person who has been diagnosed with cancer at some point in their life and is currently still alive is considered to be a cancer survivor [3]. In Western countries, almost half of newly diagnosed cancer survivors are between 18 and 65 years old, and thus of working age [4, 5]. For most of them, work is one of the main pillars of survivorship [6, 7]. Work often brings a sense of social belonging and financial security, as well as providing structure and guidance to a cancer survivor's life, thereby giving them the feeling of leaving their "patient role" behind [7]. However, staying at work during cancer treatment or returning to work after a period of sick leave due to cancer treatment can be challenging, since numerous obstacles may impair cancer survivors from participating in work, such as adverse physical and psychosocial effects of cancer and its treatment, or a lack of support from the workplace [8]. In short, being able to participate in work can contribute to a cancer survivor's quality of life [9], but efforts to enhance cancer survivors' work participation are much needed.

Cancer survivors and work

International figures show that the majority of cancer survivors are able to stay at work during treatment or to return to work afterwards [10, 11]. However, there are still major steps to be taken, since approximately 40% of cancer survivors are not able to return to work within a year of diagnosis [10]. Several characteristics (e.g., older age, female gender, low socioeconomic status) are associated with a higher risk of adverse work outcomes (e.g., unemployment, working less compared with pre-diagnosis, or work disability) [11-16]. A cancer survivor's perspective on and motivation to work may also impact their work participation [1, 17, 18]. Even in the longer term, cancer survivors are approximately 1.5 times more likely to be unemployed compared to healthy controls [11, 19]. As such, cancer imposes a substantial economic burden at the individual, organizational and societal levels [7, 20]. Taking these facts into consideration, it is evident that efforts to enhance cancer survivors' work participation are much needed, and are in the best interest of cancer survivors themselves, their families, employers and society at large.

Enhancing work outcomes of cancer survivors

Many factors affect the work participation of cancer survivors. Loisel et al. developed the “Arena in work disability prevention model” for disabled workers, which distinguishes four main types of factors, concerning the *personal system*, the *health care system*, the *workplace system*, and the *legislative and insurance systems* [21]. Figure 1 shows an adapted version of this Arena, which can be considered a metaphor for the complexity of factors that surround and may affect the work participation of cancer survivors.



Figure 1. Adjusted version of the “Arena in work disability prevention model” [21]

To date, scientific research on work outcomes (e.g., work participation, RTW or work functioning) of cancer survivors [22-27], and interventions aiming to enhance these work outcomes, have predominantly focused on the *personal system* (lower part of the Arena) and the *health care system* (left part of the Arena) [28, 29]. These interventions mainly include psycho-education (e.g., counseling, education), physical training, person-centered vocational components (e.g., occupational rehabilitation, work advice), or a combination of these [28, 29]. However, as there are inconclusive results on the effects of these interventions on work outcomes of cancer survivors [28, 29], a focus on other parts of the Arena may be needed.

The *workplace system* (upper part of the Arena) might well be the missing link in efforts to enhance cancer survivors' work outcomes. For employees (i.e., those who work for an employer), this part of the Arena includes the environment in which the cancer survivor ultimately remains in, or to which they return. Studies conducted in this context have repeatedly shown the importance of adequate support, accommodation and assistance at work in order to enhance the work outcomes of cancer survivors [12, 15, 18, 30]. Important stakeholders in this regard are the employer, co-workers and – if available – the occupational physician [15, 18, 30, 31]. Of these stakeholders, the employer is repeatedly identified as the key stakeholder, as they serve as a gatekeeper between the cancer survivor and the *workplace system* [15, 18, 30].

The role of the employer

Within a practical context, the term “employer”, refers to the specific person who represents the organization that employs the cancer survivor, supporting them during their sickness absence and RTW; for example, the supervisor, line-manager or human resources manager (HR manager). The scientific literature has shown that “feeling supported at work” and (perceived) employer support are associated with better work outcomes for cancer survivors [15, 18], even 5-10 years after diagnosis [12]. From a broader point of view, we know that the quality of leadership by employers and their social support is associated with better work outcomes of long-term sick-listed women [32]. We also know that the role taken by the employer in relation to sickness absence and RTW depends to some extent on national and organizational *legislative and insurance systems* (right part of the Arena) [33]. Nevertheless,

knowledge about the role of the employer in the RTW of cancer survivors is still critically under-studied in international research [34, 35], with knowledge about their role thus far mainly based on studies adopting the perspective of cancer survivors. From these studies, we know that survivors perceive ongoing communication with their employer and a structured, though flexible, RTW plan as helpful [36, 37]. Discriminatory employers, and employers with no understanding of the impact of cancer on the cancer survivor's work ability were, by contrast, perceived by cancer survivors as hindering their work participation [38-40].

The few studies published on the perspectives of employers have shown that they regard the guidance of cancer survivors during their sickness absence and RTW as a process that is difficult to manage, due to, among other things, conflicting interests and uncertainty about the guidance needed by the cancer survivor [41, 42]. Employers also indicated that their inadequate knowledge of cancer and lack of experience with guiding cancer survivors made it more difficult for them to get grip on the absence and RTW of the cancer survivor [41].

In summary, current knowledge on the important role of the employer predominantly derives from the perspectives and experiences of cancer survivors. Detailed knowledge about how employers experience their role; concrete employer practices that may enhance work outcomes of cancer survivors; and the support needed by employers to fulfill their role is currently not found in the international scientific research literature. However, a deeper understanding of the role of the employer is much needed and could provide important input for future interventions focusing on the *workplace system*.

Interventions in the workplace system

Cancer-related interventions directed toward to the *workplace system* of the Arena (i.e., vocational interventions) are scarce in the international literature [28]. The interventions that have been studied are all directed at the cancer survivor him- or herself, while, interestingly, other stakeholders in the workplace such as employers have seldom been involved [28, 43, 44]. This is remarkable when compared to interventions in other populations, such as musculoskeletal or mental disorders, where the involvement of the

employer as part of the intervention is more common [45, 46]. Two Cochrane reviews found 16 unique randomized controlled trials of workplace interventions, and such interventions have proven effective in enhancing work outcomes in these populations [45, 46]. The active involvement of the employer was either required or common in 15 of these interventions [45, 46]. This would support the development of a cancer-related workplace intervention with the active involvement of, or even targeting, the cancer survivors' employers.

The call for supportive interventions or guidelines targeting employers is increasingly louder in recent international research [28, 34, 47-54]. Although such interventions are absent from the literature, multiple independent organizations and initiatives do offer training, materials and support to employers in their attempts to assist cancer survivors [55]. This ranges from information tool kits to comprehensive in-company training courses, and from helpline support to succinct online information [55]. However, these training courses and supporting materials are primarily developed on the basis of practice and their effectiveness on the work outcomes of cancer survivors has not been scientifically studied.

Considering the key role of employers, the support they need to provide the appropriate guidance to cancer survivors at work, and the proven effectiveness of workplace interventions involving the employer on work outcomes in other populations, it is imperative to develop a scientifically sound intervention targeting the employers of cancer survivors. More scientific research is needed to determine whether such an intervention is the missing link that will lead to better work outcomes for cancer survivors. This thesis will take the first step toward a better scientific understanding of how the work outcomes of cancer survivors can be enhanced by their employers.

Evaluation of work-related interventions

Measuring work outcomes

In order to achieve a sound evaluation of work-related interventions, it is essential to identify and measure relevant work outcomes [56]. Work outcomes are related to the work situation of the cancer survivor, such as whether he or she is currently working (with or without health-related work limitations), is currently off work, has returned to work, or has withdrawn from

the labor force [56]. Different stakeholder perspectives can also be adopted when choosing a certain work outcome (i.e., the perspective of cancer survivors, employers, health-care providers, insurances agencies or society at large) [57].

Currently, work-related interventions are mainly evaluated on the basis of the number of days from initial sick leave to partial or full RTW [28]. These work outcomes to a large extent determine whether or not an intervention is considered successful, and thus whether or not an intervention is implemented. However, it is hypothesized that these work outcomes predominantly reflect the perspectives of *legislative and insurance systems*. Whether these work outcomes adequately take cancer survivors' individual perspectives and work-related goals into consideration is unclear [58]. Therefore, this thesis will also assess aspects of the RTW that are perceived as important by cancer survivors themselves. The degree to which the RTW meets the cancer survivors desired RTW will be defined as the degree of successfulness of RTW, and will be incorporated into a newly developed work outcome measure. Whether this new work outcome – successful RTW – can contribute to a more meaningful evaluation of a cancer survivor's RTW must be determined, among others, by evaluating its psychometric properties among cancer survivors [59].

Research design

The Arena shown in Figure 1 can be considered as a metaphor for the complexity of factors that may affect the work participation of cancer survivors. Although a work-related intervention targeted at the employer is predominantly related to the *workplace system* (upper part of the Arena), such an intervention would always be subject to a multitude of factors, such as legal, social and cultural factors, and involve several stakeholders related to other parts of the Arena [21]. An intervention targeted at the employer is therefore, by definition, a complex intervention [60]. Evaluation of complex interventions is often undermined by problems concerning the acceptability of the study protocol and difficulties with the recruitment and retention of participants.

Therefore, it is recommended that a randomized feasibility trial be designed and conducted before conducting a future definitive randomized controlled trial (RCT) on its effectiveness

[60-63]. A randomized feasibility trial is usually not powered to identify significant effects of the intervention but provides insight into and understanding of the context in which the intervention takes place [60]. In addition, a randomized feasibility trial provides an opportunity to investigate areas of uncertainty regarding the setup of a future definitive RCT on the effectiveness of the intervention [61, 63]. This thesis will assess feasibility of a future definitive RCT on the effectiveness of an intervention targeted at employers on work outcomes of cancer survivors. Consequently, we may enhance the likelihood of the success of the future definitive RCT on effectiveness and potentially prevent an unfeasible and expensive study being carried out [61].

A previous study found that involving employers in a work-related intervention aiming to enhance the work outcomes of cancer survivors is challenging [43]. It is therefore vital to gain insight into employers' use of the work-related intervention and their perceptions of its usefulness [64]. This may strengthen the uptake and impact of the intervention in daily practice [64]. In addition to the feasibility of a future definitive RCT on the effectiveness of the intervention on the work outcomes of cancer survivors, this thesis will therefore also address the employers' use of the work-related intervention and their perceptions of its usefulness.

Thesis aim, objectives and research questions

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 for "the Missing Link: optimizing the return to work of Employees diagnosed with cancer, by Supporting employers". The thesis aims to address the following objectives and research questions:

Objective 1

To develop the MiLES intervention targeted at employers, with the aim of enhancing successful RTW of cancer survivors.

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? (Chapters 2 and 3)
2. What methodologies and practical strategies should be incorporated into the MiLES intervention in order to support employers during the RTW of cancer survivors? (Chapter 4)

Objective 2

To develop and test an outcome measure to evaluate RTW from the perspective of cancer survivors.

Research questions:

1. How can we measure successful RTW from the perspective of cancer survivors? (Chapter 5)
2. What are the psychometric properties of this new questionnaire for evaluating successful RTW of cancer survivors? (Chapter 5)

Objective 3

To pilot test the MiLES intervention from the perspectives of both employers and cancer survivors, and to gain insight into the feasibility of a future definitive RCT on its effectiveness.

Research questions:

1. Is it feasible to perform a future definitive RCT on the effectiveness of the MiLES intervention for enhancing successful RTW of cancer survivors? (Chapters 6 and 7)
2. How do employers evaluate the use and perceive the usefulness of the MiLES intervention? (Chapter 8)

Outline of this thesis

This thesis presents the development and pilot evaluation of an intervention targeting employers during the RTW of cancer survivors. **Chapter 2** presents a systematic review of work participation of cancer survivors and the role of employers in this. It presents a synthesis of knowledge acquired in qualitative studies which forms the basis of the content of the intervention. The Delphi study presented in **Chapter 3** structures this wide range of knowledge into the most important employer actions, based on the perceptions of employers and cancer survivors. Regarding the intervention, the most important employer actions were set as target behaviors for employers. **Chapter 4** presents an overview of the development of the MiLES intervention, using the Intervention Mapping approach. This chapter presents the objectives, theoretical basis, methodologies and practical strategies of the MiLES intervention. In order to evaluate the effectiveness of the MiLES intervention from the perspective of cancer survivors, the Successful Return-To-Work questionnaire for Cancer Survivors (I-RTW_CS) was developed. **Chapter 5** describes the development of the I-RTW_CS using focus groups and a Delphi study with cancer survivors. It also presents the results of a study of its construct validity and reproducibility in a group of cancer survivors. Following this, a randomized feasibility trial was performed to determine whether an RCT to study the effectiveness of the MiLES intervention for successful RTW of cancer survivors is feasible. **Chapter 6** presents the study protocol of this randomized feasibility trial, while **Chapter 7** presents the outcomes in a group of 35 cancer survivors. To evaluate the MiLES intervention on the level of the employer, **Chapter 8** presents the results of a study on the employers' use of the MiLES intervention and their perceptions of its usefulness. **Chapter 9** concludes the thesis, presenting its main results, with a discussion and interpretation of the findings in the context of the international literature and methodological considerations. This chapter will also consider implications and recommendations for further research and practice.

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