



## UvA-DARE (Digital Academic Repository)

### Enhancing the return to work of cancer survivors

*Development and evaluation of an intervention targeted at employers*

Greidanus, M.A.

**Publication date**

2021

**Document Version**

Other version

**License**

Other

[Link to publication](#)

**Citation for published version (APA):**

Greidanus, M. A. (2021). *Enhancing the return to work of cancer survivors: Development and evaluation of an intervention targeted at employers*. [Thesis, fully internal, Universiteit van Amsterdam].

**General rights**

It is not permitted to download or to forward/distribute the text or part of it without the consent of the author(s) and/or copyright holder(s), other than for strictly personal, individual use, unless the work is under an open content license (like Creative Commons).

**Disclaimer/Complaints regulations**

If you believe that digital publication of certain material infringes any of your rights or (privacy) interests, please let the Library know, stating your reasons. In case of a legitimate complaint, the Library will make the material inaccessible and/or remove it from the website. Please Ask the Library: <https://uba.uva.nl/en/contact>, or a letter to: Library of the University of Amsterdam, Secretariat, Singel 425, 1012 WP Amsterdam, The Netherlands. You will be contacted as soon as possible.

# CHAPTER 9

General discussion



## General discussion

The aim of this thesis was to develop and pilot test an intervention targeting employers that enhances the successful return to work (RTW) of cancer survivors. As there were no scientifically sound interventions available that support employers during the RTW of cancer survivors, we developed one, which we called the MiLES intervention (“the Missing Link: optimizing the return to work of Employees diagnosed with cancer, by Supporting employers”).

This chapter presents the main findings of this thesis and discusses and interprets these findings in the context of the international literature and methodological considerations. The chapter ends with implications and recommendations for further research and practice.

### Main findings

#### Developing the MiLES intervention targeted at employers, with the aim of enhancing successful RTW of cancer survivors

We developed the MiLES intervention using the Intervention Mapping approach, based on diverse scientific studies (e.g., an interview study, literature reviews and a Delphi study with expert panels) and meetings with relevant stakeholders and experts (**Chapter 4**). Both the importance and complexity of the role of the employer during the RTW of cancer survivors were underlined by a systematic review of knowledge acquired through qualitative studies, as a large variety of employer actions were perceived as facilitating or hindering cancer survivors’ work participation (**Chapter 2**). Subsequently, employers and cancer survivors selected the most important employer actions, which included providing emotional and practical support, assessing the cancer survivor’s work ability, communicating with the cancer survivor and planning the RTW (**Chapter 3**). The systematic development resulted in a succinct and easily accessible intervention that is tailored to four RTW phases, for various experience types of cancer survivors, and for each employer action. The intervention endeavors to support employers in properly performing these most important employer actions, and to tailor them to the specific needs and preferences of their employed cancer survivor (**Chapter 4**). The intervention is designed to be easily accessible and to suit the

employers' actual practice, aiming to enhance the successful RTW of cancer survivors (**Chapter 4**).

#### Developing and testing an outcome measure to evaluate RTW from the perspective of cancer survivors

We developed an outcome measure that incorporates the perspectives of employed cancer survivors on successful RTW: the Successful Return-To-Work Questionnaire for Cancer Survivors (I-RTW\_CS) (**Chapter 5**). The most important issues that constitute successful RTW, according to cancer survivors, were incorporated as items in the I-RTW\_CS (e.g., “enjoyment at work”, “work without affecting health”, “feeling welcome at work” and “good work-life balance”). The I-RTW\_CS enables the weighting of items on the basis of their perceived importance for the individual cancer survivor.

Subsequently, we determined the psychometric properties of the I-RTW\_CS. The results revealed a correlation of 0.58 with a single-item measure of successful RTW, and 0.85 with the Quality of Working Life Questionnaire for Cancer Survivors (QWLQ-CS). The reproducibility was tested among stable cancer survivors and showed an ICC of 0.72. This provides preliminary evidence of the construct validity and reproducibility of the I-RTW\_CS (**Chapter 5**).

#### Pilot testing the MiLES intervention

We proposed a study design to evaluate the effectiveness of the MiLES intervention on the successful RTW of cancer survivors that would fully respect privacy regulations concerning the exchange of health-related information between the employer and the employee with cancer (**Chapter 6**). In addition, ethical concerns were taken into consideration; for example, by only including employed cancer survivors who had already informed their employer about their cancer diagnosis, to avoid putting unintended pressure on a cancer survivor to disclose their diagnosis to their employer. Cancer survivors were randomized into a waiting list control group or an intervention group in which cancer survivors were asked to inform their employer about the MiLES intervention. The outcomes of the intervention were measured

at cancer survivor level, with RTW and the I-RTW\_CS combined as the primary effect measure (**Chapter 6**).

This design encompassed method and protocol-related uncertainties about the feasibility of studying the effectiveness of the MiLES intervention; for example, regarding the recruitment of cancer survivors and the acceptability of the study protocol. Therefore, we conducted a randomized feasibility trial with a follow-up period of six months to assess feasibility of a future definitive randomized controlled trial (RCT) on the effectiveness of the MiLES intervention for enhancing successful RTW of cancer survivors (**Chapter 7**). Most of the predefined criteria for feasibility were met, including retention of participants and acceptability of the study protocol. However, the current design appeared inappropriate for the future definitive RCT on the effectiveness of the MiLES intervention for enhancing successful RTW of cancer survivors. The design and recruitment strategies used seemed to appeal only to a select group of cancer survivors; that is, predominantly women with breast cancer and a permanent employment contract, who already had a large number of contact moments with their employer before signing up for the study.

In addition to the randomized feasibility trial, a sample of employers was given access to the MiLES intervention for a period of six weeks in order to evaluate the employers' use of the MiLES intervention and their perceptions of its usefulness (**Chapter 8**). Employers considered the MiLES intervention to be a useful tool, as reflected in the overall usefulness score of 7.6 out of 10, and they also indicated that the intervention suited their daily practice.

### **Interpretation of findings**

#### Development of support for employers to enhance RTW of cancer survivors

At the start of this thesis, we suggested that the *workplace system* (upper part of the “Arena in work disability prevention model”; Figure 1) might well be the missing link in efforts to enhance work outcomes of cancer survivors, with the employer being conceived as a gatekeeper between *the cancer survivor* and the *workplace system*. International studies have emphasized the vital and complex role of employers in guiding employed cancer survivors during their sickness absence and RTW, and they also suggest that employers have

# Overall societal context

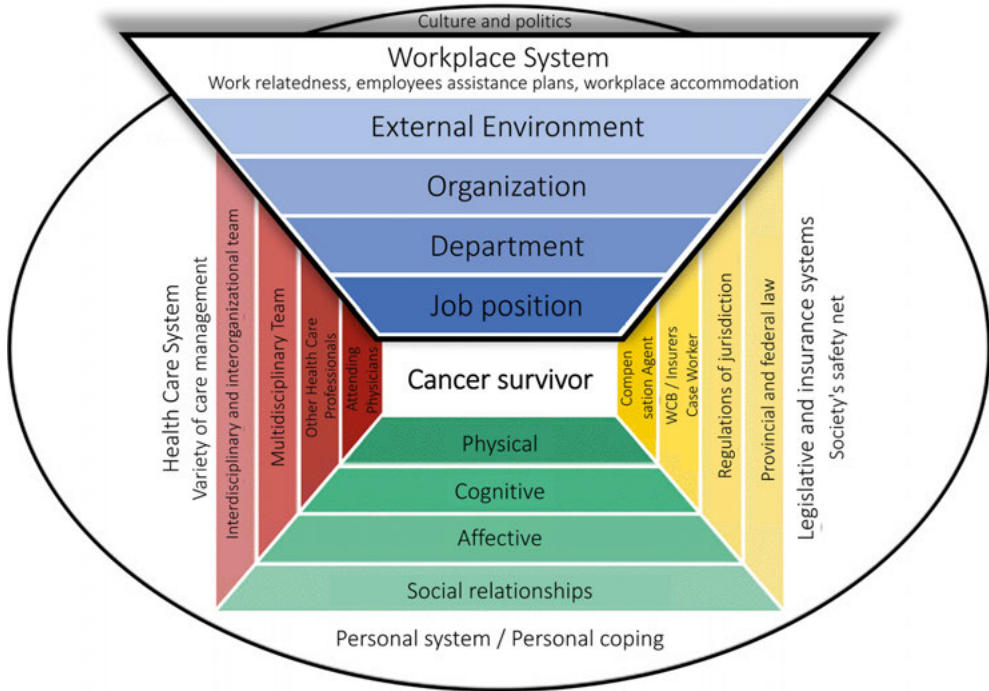


Figure 1. Adjusted version of the “Arena in work disability prevention model” [1]

their own specific support needs in order to fulfill this role. This combination supports the view that the *workplace system*, and in particular the employer, might be the missing link in efforts to enhance the work outcomes of cancer survivors.

Looking at the variation in countries that were included in our systematic literature review, the role of employers, and their support needs, were found to be largely the same irrespective on the specific country context, such as culture or *legislative and insurance systems*. This is in line with a previous study that concluded that the employers’ responsibility, as imposed by national legislation, is only one factor that shapes their role in guiding cancer survivors during their sickness absence and RTW [2]. Other factors, including organizational characteristics and policies, the employer’s personality, skills and experiences,

and factors related to the cancer survivor, such as personality, work motivation and relationship with colleagues, may also influence the role taken by the employer [2]. As a consequence, the needs of employers, such as communication skills training and professional guidelines and protocols, largely correspond across countries with various *legislative and insurance systems* [2]. According to the employers who evaluated the use and usefulness of the MiLES intervention in their daily practice, the intervention met these employer needs, and thus a major part the intervention is assumedly also applicable to employers in other countries.

On the basis of the assessment of the employers' needs in guiding cancer survivors during their sickness absence and RTW, and the experience of employers with the MiLES intervention, it was found that support for employers should consider the incorporation of the following aspects.

First, employer interventions should consider distinguishing between various RTW phases, as the needs assessment developed for this thesis found that employer practices and both the employers' and cancer survivors' needs were specific to different phases [3]. This has also been confirmed in an international context [2]. The RTW phases make the guidance of cancer survivors during their sickness absence and RTW different from the guidance required for "common" short-term sickness absence or episodic sickness absence (e.g., as a result of mental disorders) [4]. Therefore, the RTW phases can put the process into perspective and provide employers with information and guidance tailored to the specific circumstances of their employed cancer survivor. This was deemed useful by employers who used the MiLES intervention in their daily practice. It is, however, important to consider that the intensity of employer involvement and the responsibility taken by employers during these phases may be subject to national policies, and that these phases are considered in a dynamic sense to allow for possible setbacks in the process [2, 3].

Second, the interventions should consider distinguishing different types of cancer survivors based on their experience, since the perspectives of the different cancer survivors on important employer actions varied considerably in the Delphi study. The three experience

types utilized in the MiLES intervention were formulated on the basis of types of experience with work disability due to breast cancer [5]: 1) an emotional cancer survivor, in which intense emotions such as sadness and anger can alternate quickly, 2) a cancer survivor who wants little attention for their health situation, and wants to be involved in work for as long as possible and return to work as quickly as possible, and 3) a cancer survivor who starts to look at work and life differently, and gives other priorities due to their illness. Employers participating in the studies presented in this thesis recognized the different experience types, and most of the participating cancer survivors and employers were able to “classify” themselves or their employed cancer survivor into one of the three experience types. These types were also regarded as illustrative, insightful and helpful by employers who used the MiLES intervention, as it emphasized the importance of tailoring their guidance to the needs of the individual cancer survivor, instead of taking a one-size-fits-all approach [5].

Third, the needs assessment for the MiLES intervention found that employers regard the guidance of cancer survivors during their sickness absence and RTW as a trajectory of complex communication and decision making [3]. This is in line with needs of employers based in other countries [2]. The MiLES intervention, therefore, incorporates a brief communication skills training component, and this was perceived to be useful in preparing employers for complex conversations. In other interventions, the communication skills training component was lengthy (e.g., mostly multi-day programs) [6, 7], but the results of the current thesis showed the potential positive effects of a readily accessible and properly timed form of communication skills training in the workplace setting. Interventions targeted at employers should therefore consider the incorporation of such brief communication skills training components [8].

Fourth, employers who used the MiLES intervention preferred to have the option to consult supportive, specialized services in complex situations. Interventions should therefore frame the responsibilities and expertise of all stakeholders involved in the sickness absence and RTW of cancer survivors, and stimulate employers to consult and cooperate with these stakeholders [2]. In the Netherlands, for example, occupational physicians have a



consultative role for both the employer and the cancer survivor. They are specialized in translating medical limitations into functional, work-related limitations that can be communicated to the employer while respecting privacy regulations concerning the exchange of health-related information [9]. Consequently, employers can consult occupational physicians, who may serve as a bridge between *the health care system* and the *workplace system* of the Arena. Occupational physicians are also well positioned to stimulate cooperation between employer and cancer survivor; are encouraged to do so by the cancer-related guidelines of the Netherlands Society of Occupational Medicine (NVAB) [10]; and even obliged to by law. Taking into consideration that cooperation between the employer and cancer survivor may be at risk during the cancer survivor's sick leave [11] – as also concluded by the Delphi study presented in this thesis – and the fact that cooperation can be regarded as a prerequisite for a successful RTW [12, 13], active involvement of the occupation physician may be crucial. Interventions should thus facilitate active involvement of such specialized stakeholders and services. As such, the intervention itself may be developed to fulfill the employer needs in most reintegration trajectories, and additional interventions, such as specialized services, can be consulted for specific knowledge and, when needed, additional guidance.

#### Defining and measuring work outcomes

This thesis assessed whether the currently most frequently used work-related outcome measure, time until RTW [14], reflected the perspective of cancer survivors. It became apparent that, similarly to people with a mental disorder [15], cancer survivors find specific aspects of their RTW more important than merely returning to the workplace. This is of interest, since these specific subjective aspects of an individual's RTW, such as "enjoyment at work", "work without affecting health" and "feeling welcome at work", are often not taken into account when evaluating the effectiveness of RTW interventions, and hence when deciding on the implementation of these interventions [16]. The focus on specific aspects of the RTW instead of only focusing on having work is in line with national and international movements concerning 'better work'. This is rooted in international attention for the specific values of work by the United Nations and the International Labour Organization, with

“decent work for all” a key goal of their 2030 agenda for sustainable development [17, 18]. In addition, at the Dutch national level, the specific conditions of work are receiving more attention, with the Dutch Scientific Council for Governmental Policy stating that *“having a job is good for the income and self-esteem of individuals as well as for society, but this is especially true if the work conditions are also good”* (p.12) [19]. Furthermore, the independent Committee of Work Regulation stated that *“work should continue to do justice to human dignity”*, as one of the three core values to make work future-proof (p.1) [20]. These approaches clearly show that, alongside work itself, considerable attention should be paid to the specific conditions of work. This should also be transferred to RTW research. By using the I-RTW\_CS as a “patient-centered” outcome measure, RTW is not regarded as the desired endpoint, but also the specific conditions of the RTW and individual work-related goals are taken into consideration [21].

The I-RTW\_CS measures successful RTW from the perspective of cancer survivors. The Cambridge Dictionary (available via: <https://dictionary.cambridge.org/>) distinguishes two definitions of “successful”: 1) “achieving the results wanted or hoped for”, and 2) “having achieved a lot, become popular, and/or made a lot of money”. The first definition seems to be more related to the individual perceptions of “success” and better covers the discussion held in the focus groups for the development of the I-RTW\_CS. This is also reflected in the items of the I-RTW\_CS, as no items are related to the hierarchical or financial position of the cancer survivor. This might also be due to the Dutch situation, where job protection and high levels of financial compensation during the first two years of sick leave are guaranteed by law [9]. This might have led to an underestimation of the importance of hierarchical and financial issues by the Dutch cancer survivors who participated in this study. The dual meaning of the term “successful” may have contributed to finding that the I-RTW\_CS score was closer related to the quality of working life of cancer survivors than to a single-measure on successful RTW. In addition, from a semantic point of view, the items of the I-RTW\_CS seem closer related to what patients regard a meaningful RTW.

### Evaluating RTW interventions targeting employers

This thesis assessed the employers' use of the MiLES intervention and their perceptions of its usefulness, and assessed the feasibility of an RCT on the effectiveness of the intervention with respect to cancer survivors' successful RTW. The first assessment was important to enable evaluation of the *process* of the intervention, and not only the *effect* of the intervention [22]. Positive perspectives of employers can strengthen the uptake and thereby also the impact of the intervention on cancer survivors' successful RTW [22]. The fact that the participating employers used the intervention and were positive about its usefulness in their daily practice is an important finding, since it is not self-evident that attempts to involve employers in cancer-related interventions actually succeed [23]. It also acknowledges that Intervention Mapping is an efficacious method to develop an intervention that is used by employers and aligns with their needs in actual practice [24]. The positive perspectives of employers found in our study should be regarded as an important, although only the initial, step in the evaluation of the MiLES intervention [22]. These positive perspectives are, however, a prerequisite for the behavior changes targeted in employers, and in turn for enhancing work outcomes of cancer survivors [22].

### **Methodological considerations**

#### Development of the MiLES intervention

The Delphi methodology was used to reach consensus on the most important employer actions. Although the Delphi approach has been criticized for its lack of consistent methods and criteria for consensus [25], it was helpful in the systematic development of the MiLES intervention. It enabled the structuring of a wide range of information identified in international research into a consensus on the importance of a number of concrete employer actions tailored to the Dutch context. These concrete actions served as the performed objectives for employers.

The thorough Intervention Mapping approach employed for the development of the MiLES intervention is especially useful for complex interventions, in which different stakeholder perspectives are to be combined [24, 26, 27]. For the MiLES intervention, this systematic,

step-wise and participative approach was perceived to assist the combining of scientific evidence, stakeholder and expert opinions, and evidence-based theories and methodologies, such as goal setting [28] and tailoring [29]. This led to an intervention that was customized to the specific needs of employers in practice, which was also recognized by employers who participated in the study presented in this thesis.

#### Questionnaire development

The I-RTW\_CS was developed with the intention of measuring outcomes of employer interventions at cancer survivor level (Chapter 4). This might have two consequences. First, we only incorporated items that could possibly be influenced by an employer according to cancer survivors. However, we consider that the I-RTW\_CS would be useful for other interventions as well, such as vocational interventions targeting cancer survivors themselves, as this criterion only affected the definitive items of the I-RTW\_CS to a small extent. Only two issues that possibly could have been included in the I-RTW\_CS were excluded on the basis of that criterion (i.e., “that you feel mentally fit enough to work” and “that you feel physically fit enough to work”). Second, the I-RTW\_CS was developed on the basis of perspectives of employed cancer survivors on successful RTW. In Europe, around 15% of working people do not work for an employer. Whether perspectives of self-employed cancer survivors on successful RTW would differ from the perspectives of employed cancer survivors is unclear, but it might be expected [30]. The income of self-employed cancer survivors is usually not covered by the social security system in the case of sickness or disability [31], and successful RTW of self-employed cancer survivors may therefore also include more financial components [32]. As a consequence, unlike the Quality of Working Life Questionnaire for Cancer Survivors (QWLQ-CS) [33], the I-RTW\_CS is not useful for self-employed cancer survivors.

#### Evaluating the MiLES intervention

In developing a study design for the evaluation of the effectiveness of the MiLES intervention on work outcomes of cancer survivors, the main challenge lay in providing the employers with an intervention of interest, and embedding this in a study design that allowed us to measure the work outcomes of their employees. The design was initiated through the *health*

*care system* (left part of the “Arena in work disability prevention model”; Figure 1), that is, usually through the cancer survivors’ treating physician. We assumed that the cancer survivors included could inform their employer about the MiLES intervention, and thereby serve as a bridge between the *health care system* and the *workplace system*, where the MiLES intervention would be used. The results of the randomized feasibility trial clearly showed that this procedure was not appropriate to perform a sound evaluation of the effectiveness of the MiLES intervention. This was because the procedure resulted in a considerable selection bias, with predominantly female cancer survivors who had a permanent employment contract and who already had a relatively high degree of successfulness of their RTW (reflected in high I-RTW\_CS scores at baseline). In addition, they had an intensive and assumedly reasonable relationship with their employer before participating in the study. Cancer survivors at high risk of adverse work outcomes were either not reached through the recruitment strategies used or were not willing to participate under the conditions proposed in the study protocol. It is unclear what caused the selection bias, but possible explanations are: 1) signing up and participating in survey studies requires literacy [34], and 2) informing the employer about the MiLES intervention requires disclosure of cancer, a proactive attitude, and assumedly a good relationship with the employer.

The randomized feasibility trial enabled us to test method and protocol-related uncertainties with regard to a future definitive RCT on the effectiveness of the MiLES intervention [35-38]. This randomized feasibility trial drew attention to a considerable selection bias among the study population and the limited generalizability of the outcomes of the randomized feasibility trial. Although this was not stated beforehand as a criterion of feasibility for a future definitive RCT, the interpretation of sources of potential bias or imprecision should always be taken into consideration when deciding whether or not to proceed with a future definitive RCT [35]. No process evaluation was nested in the randomized feasibility trial. Such a process evaluation might have provide valuable information about what may have caused the selection bias, and how best to implement a different procedure for the future definitive trial, such as the best way to deliver the MiLES intervention to the employer [36].

## **Recommendation for further research**

### Content of the MiLES intervention

We recommend further research to study which aspects of guidance during sickness absence and RTW of cancer survivors employers generally take responsibility for in other countries, and to study which elements of the MiLES intervention should be retained and which need to be adapted to the respective country.

Future studies should also determine the role and support needs of employers in the case of an unfavourable cancer diagnosis not allowing a cancer survivor to return to work. Such distressing situations require specific employer guidance with respect to both the cancer survivor and their colleagues [3], and it is advised that interventions should also support employers during in these situations. Since RTW is irrelevant in these cases, evaluating the effectiveness of such interventions requires alternative outcome measures, such as perceived satisfaction with employer guidance, or outcome measures from the perspective of colleagues or relatives.

Further study of the different experience types of cancer survivors is also recommended to gain a better understanding of the corresponding needs and preferences with regard to guidance during sickness absence and RTW, and whether the experiences of cancer survivors may shift from one type to another type. This will enable employers to tailor their guidance to the cancer survivor's work-related goals [5].

### Evaluation of the MiLES intervention

Future studies on the MiLES intervention should determine: 1) its (cost)effectiveness in relation to the successful RTW of cancer survivors, 2) its effectiveness in enhancing employers' knowledge and skills (e.g., communication skills), and 3) the appropriate route for implementing the MiLES intervention in practice. As such, the effectiveness of the MiLES intervention is evaluated on different levels, which may optimize its impact in daily practice.

An alternative study design is needed to evaluate the effectiveness of the MiLES interventions on the successful RTW of cancer survivors. Such an alternative design should

focus on ruling out or minimizing the above-mentioned potential causes of selection bias while being able to enroll sufficient cancer survivors, and thereby enhance the generalizability of the outcomes with sufficient power. Two potential approaches should be considered: 1) a design initiated through the *health care system*, and 2) a design initiated through the *workplace system*.

The first approach, a design initiated through the *health care system*, was also employed in this thesis. The main advantages of this approach are: 1) full respect for privacy legislation and ethical concerns, 2) measures of work outcomes of cancer survivors and, concomitantly, intervene on the specific employers of these cancer survivors, 3) it enables a large number of cancer survivors to be invited to participate at the same time through their treating physician, and 4) it allows the cancer survivor to determine whether or not to inform their employer about an intervention aiming to enhance their RTW [39].

The randomized feasibility trial clearly identified some drawbacks of this approach, including relatively low inclusion rates and selection bias toward cancer survivors at low risk of adverse work outcomes, and thereby low generalizability of the outcomes. Some adjustments to the protocol may be considered on the basis of these drawbacks. For example, cancer survivors might be invited to participate during a face-to-face consultation with either their medical specialist, occupational physician or specialized nurse (e.g., oncology nurses), preferably soon after diagnosis [40]. Such a face-to-face invitation, including a more personalized explanation of the study, may enhance the participation rate, reduce selection bias, enable the recruitment of cancer survivors soon after diagnosis, and may even contribute to a better targeting of cancer survivors at risk of adverse work outcomes, which is repeatedly recommended by previous studies [41-43]. Nevertheless, the workload in a clinical setting is high, and medical specialists and nurses are not primarily hired to recruit participants for work-related studies, which may hinder the recruitment of cancer survivors using such a design [23, 44]. A hospital-based occupational practitioner, in particular, might be ideally equipped and positioned to serve as a bridge between the *health care system* and the

*workplace system* and may therefore be the best person to invite cancer survivors at risk of adverse work outcomes to participate [45].

An alternative design initiated through the *health care system* might be a nested research design [46, 47], in which participants in a large-sized observational cohort study are invited to participate. In the Netherlands, for example, the Prospective Dutch ColoRectal Cancer cohort provides an opportunity to invite colorectal cancer survivors to participate as the intervention group in additional studies (e.g., work-related studies) [48]. Subsequently, cancer survivors included are matched with a control group whose consent is covered by the informed consent procedure of the ongoing cohort and whose outcomes are assessed automatically through the ongoing cohort. The main advantages of such a nested research design are the possibility to invite cancer survivors at risk of adverse work outcomes and the reduction of data collection efforts [46, 47]. However, the feasibility and costs of all the alternatives above in relation to the evaluation of the effectiveness of the MiLES interventions on the successful RTW of cancer survivors are still to be determined [27].

The second approach, a design initiated through the *workplace system*, also has both advantages and drawbacks. One significant drawback is the fact that it is not permitted to recruit cancer survivors directly through their employer, since employers are, according to the General Data Protection Regulation, not allowed to process health-related information of their employees [49]. This would be the case if the employer invited their employee to participate in a study related to the latter's illness. Therefore, this design only allows the study of the employers' perspective, and not the effectiveness of an intervention on work outcomes from the cancer survivor's perspective, similar to the study of employers in this thesis. An alternative, in which the intervention is implemented organization-wide, followed by the participation of cancer survivors in that organization through contact with the occupational physician, might allow for the measurement of work outcomes of cancer survivors in accordance with the privacy regulations [49-51]. Such a design, combining evaluation and implementation, might also limit selection bias, as the cancer survivors who participate do not have to inform their employer about the intervention, but only have to



agree to fill out online questionnaires to assess successful RTW. This design is not unusual for complex interventions in conditions where: 1) there is a strong base of indirect evidence for the intervention that supports its applicability (which was provided by employers who tested the MiLES intervention), 2) minimal risk is associated with the intervention, and 3) severe constraints prevent a sound evaluation using an experimental design [36, 51]. Advantages of such a design are improved external validity of the outcomes, since the intervention has already been tested in the intended context, more rapid translational gains, the possibility of combining various quantitative and qualitative measures, the possibility of evaluation from different stakeholder perspectives without breaching privacy regulations (i.e., when not matching the perspectives), and the possibility of including cancer survivors at an early RTW phase [36, 51]. There may be drawbacks in: 1) the difficulty of implementing a control group, as organizations have to comply without having access to the intervention, 2) the recruitment of cancer survivors, which is highly dependent on the number of employees who have been diagnosed with cancer in the participating organizations, and 3) strong dependence on an effective implementation strategy, which is a prerequisite for employers being exposed to the intervention, and thus for measuring the effectiveness of it [50]. Sound process evaluation with all stakeholders involved is therefore required to identify possible implementation failure [50, 51].

Taking the advantages and disadvantages of the above-mentioned alternatives into consideration, we recommend the involvement of all relevant stakeholders in the development of an adequate study design to determine the effectiveness of the MiLES intervention. Stakeholder involvement in the development of an appropriate study design is currently not common, yet recommended [42, 52], and even a prerequisite from subsidizing bodies [53]. It would provide a valuable opportunity to develop a design with adequate internal and external validity that aligns with individual preferences with respect to the evaluation of a complex intervention such as the MiLES intervention.

#### Measuring work outcomes

We recommend that future research does not consider RTW after cancer as an endpoint, as successful RTW comprises more than merely returning to the workplace. Instead, we

recommend the use of the I-RTW\_CS as an outcome measure for future interventions aiming to enhance successful RTW of cancer survivors, in addition to conventional work outcomes such as time until RTW. This will enable a more meaningful evaluation of the cancer survivors' RTW [21]. Future studies should also assess the responsiveness and interpretability of the I-RTW\_CS in order to further evaluate its applicability for measuring differences at individual and group level [54]. In addition, the detected ceiling effect of the I-RTW\_CS should be further elucidated. It is also recommended that our findings on aspects that constitute successful RTW be replicated in other countries with different *legislative and insurance systems*. Finally, we recommend determining whether the I-RTW\_CS is also a valid outcome measure for other non-cancer patient populations, and, if not, to develop patient-reported outcome measures that reflect the perspectives of these respective patient populations on a successful RTW.

#### Studies to evaluate feasibility of future definitive trials on effectiveness

We recommend that future studies implement a feasibility study prior to a large, resource-intensive trial, and state clear criteria that guide the decision concerning whether to proceed, to proceed with amendments, or not to proceed with a future definitive trial [37]. These criteria should be based on the main uncertainties regarding the development of the trial, supplemented by criteria that might undermine the validity of the findings of the trial. The latter criteria may relate to the level of heterogeneity of the study population, such as the participants' gender or level of education. We also recommend implementing efforts to incorporate cancer survivors with a low socioeconomic status and poor literacy into feasibility studies [55]. In addition, we recommend future feasibility studies to incorporate a process evaluation, to gain insight into why the design and the intervention are appropriate or not [36]. Finally, it is recommended to view feasibility as an overarching concept for studies assessing whether a future definitive trial can be done, and be consistent with regard to the terminology used to refer to the different types of feasibility studies [38].

#### Research with employers

A common problem among research with employers is selection bias toward positive and willing employers [2, 3, 56, 57]. Therefore, we recommend future studies with employers

systematically register the efficacy of different participant recruitment strategies. This may provide insight into how best to encourage employers to participate in work-related studies, and may identify barriers for employers, such as their concerns about employee privacy. On the basis of the studies conducted in this thesis, we recommend minimizing the threshold for employers to participate; for example, by enabling employers to register without mandatory telephone explanation (when allowed by the ethical standards), to employ targeted instead of open recruitment strategies, and by reaching out to employers through a third-person acquaintance, such as the occupational physician. This could enhance the efficacy of the recruitment strategy and enable the inclusion of a representative sample of employers.

### **Implications for practice**

#### Employers

We recommend employers to be aware of their vital role in guiding their employed cancer survivors during their sickness absence and RTW. It is therefore of great importance that they recognize situations in which they require additional support themselves, and subsequently reach out for this support, such as the MiLES intervention, the occupational physician or specialized reintegration services. As literature shows cancer survivors having different experiences, it is also recommended that employers be aware of differences between cancer survivors; for example, with regard to the individual needs and preferences concerning guidance from their employer. Consequently, employers should not solely rely on their previous experiences, or make assumptions on the basis of the cancer survivor's diagnosis or treatment. Instead, effective communication with the cancer survivor is required to tailor their guidance and enhance successful RTW of the cancer survivor. Finally, it is recommended that employers create a safe and social work climate, in which cancer survivors can be open regarding their support needs and preferences during sick leave and on RTW, as well as regarding possible long-term work-related constraints [58].

### Cancer survivors

Adequate guidance from the employer during sickness absence and RTW is dependent on the level of openness of the cancer survivor regarding support needs and preferences [2, 58]. We therefore recommend that cancer survivors be open about these needs and preferences, and about their perspectives on successful RTW. However, when deciding on the level of openness, potential negative consequences such as stigma or discrimination should always be taken into consideration [58, 59]. Finally, cancer survivors should be aware that offering them guidance is challenging for employers, as the latter may be uncertain about how to provide adequate guidance, and they may also struggle with the conflicting interests of the cancer survivor, their colleagues and the organization. A mutual understanding of each other's perspectives could well be crucial to enhancing effective collaboration with the employer.

### Health care professionals

Oncological health care providers and general practitioners should address the potential consequences of cancer and its treatment on the cancer survivor's ability to work, and thereby encourage cancer survivors to discuss these consequences with their employer and occupational physician at an early stage. Oncological health care providers should also be aware that work may play an important role in the cancer survivor's life, including during treatment. The cancer survivor's work situation should therefore be discussed soon after the diagnosis, during treatment and during follow-up meetings. Finally, we recommend health care providers to document the cancer survivors' employment status in their electronic patient record, as to facilitate better targeting cancer survivors for work-related interventions.

Occupational physicians are well positioned to monitor the progress of the RTW, as well as the guidance provided by the employer. Therefore, occupational physicians are best positioned to inform employers about supporting interventions such as the MiLES intervention. We therefore encourage occupational physicians to contribute to the implementation of interventions targeted at employers, in order to enhance their uptake and impact in practice.

## **Conclusions**

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 an adequate study design. In this respect, the lessons learned in 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. 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 a promising tool to enhance successful RTW of cancer survivors.

## References

1. Loisel P, Buchbinder R, Hazard R, Keller R, Scheel I, van Tulder M, et al. Prevention of Work Disability Due to Musculoskeletal Disorders: The Challenge of Implementing Evidence. *J Occup Rehabil.* 2005;15(4):507-24.
2. de Rijk A, Amir Z, Cohen M, Furlan T, Godderis L, Knezevic B, et al. The challenge of return to work in workers with cancer: employer priorities despite variation in social policies related to work and health. *J Cancer Surviv.* 2019;14:188-99.
3. Tiedtke CM, Dierckx de Casterlé B, Frings-Dresen MHW, De Boer A, Greidanus MA, Tamminga SJ, et al. Employers' experience of employees with cancer: trajectories of complex communication. *J Cancer Surviv.* 2017;11(5):562-77.
4. Gignac MAM, Bowring J, Jetha A, Beaton DE, Breslin FC, Franche RL, et al. Disclosure, Privacy and Workplace Accommodation of Episodic Disabilities: Organizational Perspectives on Disability Communication-Support Processes to Sustain Employment. *J Occup Rehabil.* 2020;doi:10.1007/s10926-020-09901-2.
5. Tiedtke C, Dierckx de Casterlé B, de Rijk A, Christiaens MR, Donceel P. Breast cancer treatment and work disability: patient perspectives. *Breast.* 2011;20(6):534-8.
6. Gorniewicz J, Floyd M, Krishnan K, Bishop TW, Tudiver F, Lang F. Breaking bad news to patients with cancer: A randomized control trial of a brief communication skills training module incorporating the stories and preferences of actual patients. *Patient Educ Couns.* 2017;100(4):655-66.
7. Moore PM, Rivera S, Bravo-Soto GA, Olivares C, Lawrie TA. Communication skills training for healthcare professionals working with people who have cancer. *Cochrane Database Syst Rev.* 2018(7).
8. Brown RF, Owens M, Bradley C. Employee to employer communication skills: balancing cancer treatment and employment. *Psychooncology.* 2013;22(2):426-33.
9. de Rijk A. Work Disability prevention in the Netherlands: A Key Role for Employers. In: MacEachen E, editor. *The Science and Politics of Work Disability Prevention.* 1st edition ed. New York: Routledge. 2018; 223-41.
10. Nederlandse Vereniging voor Arbeids- en Bedrijfsageneeskunde (NVAB) [in English: Netherlands Society of Occupational Medicine]. Richtlijn kanker en werk; voor het handelen van de bedrijfsarts bij behoud van en terugkeer naar werk [in English: Cancer and Work guideline; for the actions of the occupational physician in retaining and returning to work]. Utrecht: Kwaliteitsbureau NVAB; 2019.
11. Hoefsmit N, de Rijk A, Houkes I. Work resumption at the price of distrust: a qualitative study on return to work legislation in the Netherlands. *BMC Public Health.* 2013;13:153.
12. Amir Z, Neary D, Luker K. Cancer survivors' views of work 3 years post diagnosis: a UK perspective. *Eur J Oncol Nurs.* 2008;12(3):190-7.
13. Stochkendahl MJ, Myburgh C, Young AE, Hartvigsen J. Manager Experiences with the Return to Work Process in a Large, Publically Funded, Hospital Setting: Walking a Fine Line. *J Occup Rehabil.* 2015;25(4):752-62.
14. de Boer AG, Taskila TK, Tamminga SJ, Feuerstein M, Frings-Dresen MH, Verbeek JH. Interventions to enhance return-to-work for cancer patients. *Cochrane Database Syst Rev.* 2015(9):CD007569.
15. Hees HL, Nieuwenhuijsen K, Koeter MW, Bultmann U, Schene AH. Towards a new definition of return-to-work outcomes in common mental disorders from a multi-stakeholder perspective. *PLoS One.* 2012;7(6):e39947.
16. Young AE, Roessler RT, Wasiaik R, McPherson KM, van Poppel MN, Anema JR. A developmental conceptualization of return to work. *J Occup Rehabil.* 2005;15(4):557-68.
17. International Labour Organisation (ILO). Decent Work Genève, Switzerland [Accessed: 30-06]. Available from: <https://www.ilo.org/global/topics/decent-work>.
18. United Nations. *Transforming our world: the 2030 agenda for sustainable development.* 2015.
19. Wetenschappelijke Raad voor het Regeringsbeleid (WRR) [in English: Scientific Council for Governmental Policy]. *Het betere werk. De nieuwe maatschappelijke opdracht, WRR-Rapport 102* [in English: The better job. The new social mission, WRR-Rapport 102]. Den Haag; 2020.

## Chapter 9

20. Commissie Regulering van Werk (Commissie Borstlap) [in English: Committee of Work Regulation (Commission Borstlap)]. In wat voor land willen wij werk? Naar een nieuw ontwerp voor de regulering van werk [in English: In what country do we want to work? Towards a new design for the regulation of work]. 2020 23-01.
21. Wells M, Williams B, Firnigl D, Lang H, Coyle J, Kroll T, et al. Supporting 'work-related goals' rather than 'return to work' after cancer? A systematic review and meta-synthesis of 25 qualitative studies. *Psychooncology*. 2013;22(6):1208-19.
22. Nielsen K, Abildgaard JS. Organizational interventions: A research-based framework for the evaluation of both process and effects. *Work Stress*. 2013;27(3):278-97.
23. Tamminga SJ, Verbeek JHAM, Bos MEM, Fons G, Kitzen JJEM, Plaisier PW, et al. Effectiveness of a Hospital-Based Work Support Intervention for Female Cancer Patients – A Multi-Centre Randomised Controlled Trial. *PLOS ONE*. 2013;8(5):e63271.
24. Bartholomew LK, Parcel GS, Kok G, Gottlieb NH. *Planning Health Promotion Programs; An Intervention Mapping Approach*. 2nd ed. San Francisco: Jossey-Bass; 2006.
25. Tugwell P, Knottnerus JA. The need for consensus on consensus methods. *J Clin Epidemiol*. 2018;99:vi-viii.
26. O'Cathain A, Croot L, Sworn K, Duncan E, Rousseau N, Turner K, et al. Taxonomy of approaches to developing interventions to improve health: a systematic methods overview. *Pilot Feasibility Stud*. 2019;5:41.
27. Desiron HAM, Crutzen R, Godderis L, Van Hoof E, de Rijk A. Bridging Health Care and the Workplace: Formulation of a Return-to-Work Intervention for Breast Cancer Patients Using an Intervention Mapping Approach. *J Occup Rehabil*. 2016;26(3):350-65.
28. Locke EA, Latham GP. *A theory of goal setting & task performance*. Englewood Cliffs, NJ, US: Prentice-Hall, Inc; 1990.
29. Noar SM, Benac CN, Harris MS. Does tailoring matter? Meta-analytic review of tailored print health behavior change interventions. *Psychol. Bull*. 2007;133(4):673-93.
30. Eurostat. Self-employed persons Luxembourg: European Union; 2018 [updated 30-04-2019; Accessed: 16-07-2020]. Available from: <https://ec.europa.eu/eurostat/en/web/products-eurostat-news/-/EDN-20190430-1>.
31. MacEachen E. *The science and politics of work disability prevention*. 1st edition ed. MacEachen E, editor. New York: Routledge; 2018.
32. Torp S, Paraponaris A, Van Hoof E, Lindbohm ML, Tamminga SJ, Alleaume C, et al. Work-Related Outcomes in Self-Employed Cancer Survivors: A European Multi-country Study. *J Occup Rehabil*. 2019;29(2):361-74.
33. de Jong M, Tamminga SJ, van Es RJJ, Frings-Dresen MHW, de Boer A. The quality of working life questionnaire for cancer survivors (QWLQ-CS): factorial structure, internal consistency, construct validity and reproducibility. *BMC Cancer*. 2018;18(1):1-13.
34. Ford JG, Howerton MW, Lai GY, Gary TL, Bolen S, Gibbons MC, et al. Barriers to recruiting underrepresented populations to cancer clinical trials: a systematic review. *Cancer*. 2008;112(2):228-42.
35. Thabane L, Ma J, Chu R, Cheng J, Ismaila A, Rios LP, et al. A tutorial on pilot studies: the what, why and how. *BMC Med Res Methodol*. 2010;10:1.
36. Craig P, Dieppe P, Macintyre S, Michie S, Nazareth I, Petticrew M. Developing and evaluating complex interventions: The new Medical Research Council guidance. *Int J Nurs*. 2013;50(5):587-92.
37. Eldridge SM, Chan CL, Campbell MJ, Bond CM, Hopewell S, Thabane L, et al. CONSORT 2010 statement: extension to randomised pilot and feasibility trials. *BMJ*. 2016;355:i5239.
38. Eldridge SM, Lancaster GA, Campbell MJ, Thabane L, Hopewell S, Coleman CL, et al. Defining Feasibility and Pilot Studies in Preparation for Randomised Controlled Trials: Development of a Conceptual Framework. *PLoS One*. 2016;11(3):e0150205.
39. Maiwald K, Meershoek A, de Rijk A, Nijhuis F. How policy on employee involvement in work reintegration can yield its opposite: employee experiences in a Canadian setting. *Disabil Rehabil*. 2013;35(7):527-37.

40. Zaman AG, Tytgat KM, Klinkenbijn JH, Frings-Dresen MH, de Boer AG. Design of a multicentre randomized controlled trial to evaluate the effectiveness of a tailored clinical support intervention to enhance return to work for gastrointestinal cancer patients. *BMC Cancer*. 2016;16:303.
41. de Boer AG, Torp S, Popa A, Horsboel T, Zadnik V, Rottenberg Y, et al. Long-term work retention after treatment for cancer: a systematic review and meta-analysis. *J Cancer Surviv*. 2020;14(2):135-50.
42. de Boer A, Greidanus MA, Dewa CS, Duijts SFA, Tamminga SJ. Introduction to special section on: current topics in cancer survivorship and work. *J Cancer Surviv*. 2020;14:101-5.
43. Tamminga SJ, de Boer AG, Verbeek JH, Taskila T, Frings-Dresen MH. Enhancing return-to-work in cancer patients, development of an intervention and design of a randomised controlled trial. *BMC Cancer*. 2010;10(1):345.
44. Zaman ACGNM. Tailored work-related support for patients with gastrointestinal cancer; Development and evaluation of an early intervention in clinical practice [Thesis]: University of Amsterdam; 2019.
45. Désiron HAM, de Rijk A, Van Hoof E, Donceel P. Occupational therapy and return to work: a systematic literature review. *BMC Public Health*. 2011;11(1):615.
46. Ernster VL. Nested Case-Control Studies. *Preventive Medicine*. 1994;23(5):587-90.
47. Lieberman ES. Nested analysis as a mixed-method strategy for comparative research. *American political science review*. 2005:435-52.
48. Burbach JP, Kurk SA, Coebergh van den Braak RR, Dik VK, May AM, Meijer GA, et al. Prospective Dutch colorectal cancer cohort: an infrastructure for long-term observational, prognostic, predictive and (randomized) intervention research. *Acta Oncol*. 2016;55(11):1273-80.
49. European Union. Data protection under GDPR 2020 [updated 26-05-2020; Accessed: 8-6-2020]. Available from: [https://europa.eu/youreurope/business/dealing-with-customers/data-protection/data-protection-gdpr/index\\_en.htm](https://europa.eu/youreurope/business/dealing-with-customers/data-protection/data-protection-gdpr/index_en.htm).
50. Landes SJ, McBain SA, Curran GM. An introduction to effectiveness-implementation hybrid designs. *Psychiatry Res*. 2019;280:112513.
51. Curran GM, Bauer M, Mittman B, Pyne JM, Stetler C. Effectiveness-implementation hybrid designs: combining elements of clinical effectiveness and implementation research to enhance public health impact. *Med Care*. 2012;50(3):217-26.
52. Abma T, Banks S, Cook T, Dias S, Madsen W, Springett J, et al. *Participatory research for health and social well-being*: Springer; 2019.
53. ZonMw. Relevantiecriteria [in English: Relevance criteria] 2020 [Accessed: 29-06-2020]. Available from: <https://www.zonmw.nl/nl/subsidies/relevantiecriteria/>.
54. de Vet HW, Terwee CB, Mokkink LB, Knol DL. *Measurement in Medicine*. Cambridge: Cambridge University Press; 2011.
55. Nickell A, Burke NJ, Cohen E, Caprio M, Joseph G. Educating low-SES and LEP survivors about breast cancer research: pilot test of the Health Research Engagement Intervention. *J Cancer Educ*. 2014;29(4):746-52.
56. Amir Z, Wynn P, Chan F, Strauser D, Whitaker S, Luker K. Return to Work After Cancer in the UK: Attitudes and Experiences of Line Managers. *J Occup Rehabil*. 2010;20(4):435-42.
57. Tiedtke C, Donceel P, de Rijk A, Dierckx de Casterlé B. Return to work following breast cancer treatment: the employers' side. *J Occup Rehabil*. 2014;24(3):399-409.
58. Brouwers EPM, Joosen MCW, van Zelst C, Van Weeghel J. To Disclose or Not to Disclose: A Multi-stakeholder Focus Group Study on Mental Health Issues in the Work Environment. *J Occup Rehabil*. 2020;30(1):84-92.
59. Stergiou-Kita M, Pritlove C, Kirsh B. The "Big C"-stigma, cancer, and workplace discrimination. *J Cancer Surviv*. 2016;10(6):1035-50.