Quality of Working Life of cancer survivors

Development and evaluation of a measurement instrument

de Jong, M.

Citation for published version (APA):

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 7

General discussion
The aim of this thesis was to assess and evaluate the Quality of Working Life (QWL) of cancer survivors. As there was no measurement instrument available for measuring the QWL of cancer survivors, we developed a self-administered questionnaire to evaluate the QWL of cancer survivors. The following objectives were formulated:

1. To develop a questionnaire to evaluate the QWL of cancer survivors.
2. To test the psychometric properties of the newly-developed questionnaire for evaluating the QWL of cancer survivors.
3. To describe the QWL of cancer survivors.

The main findings are presented in this chapter, followed by methodological and theoretical considerations and an interpretation of the findings. Finally, we consider implications for future research and recommendations for practice.

Main findings

Developing a questionnaire to evaluate the QWL of cancer survivors

The development of the QWL questionnaire for cancer survivors was based on the guidelines for developing Questionnaire Modules of the European Organisation for Research and Treatment of Cancer (EORTC) Quality of Life Group [1]. In Phase 1, following the EORTC guidelines, we generated relevant QWL issues for the development of the self-administered Quality of Working Life Questionnaire for Cancer Survivors (QWLQ-CS). First, we conducted a systematic literature review to identify issues that contribute to QWL of employees with a chronic physical disease (Chapter 2). This review yielded 73 QWL issues. Second, we generated and selected QWL issues for cancer survivors in a qualitative study (Chapter 3). We held focus groups with cancer survivors and oncological occupational physicians, and interviews with employers, immediate supervisors and other organisation officers. We combined the QWL issues from the systematic literature review with the issues generated in the qualitative study, which resulted in 222 QWL issues. Cancer survivors were presented with these 222 QWL issues in an online questionnaire, and rated the relevance of the issues to their own QWL. After deleting 44 issues that were rated as not relevant to QWL, 178 relevant QWL issues remained. In Phase
2, these 178 remaining issues were transformed into a 102-item initial version of the QWLQ-CS. In Phase 3 of the questionnaire development, a pre-test study was conducted to investigate whether the items in the initial QWLQ-CS were relevant, acceptable and comprehensible to cancer survivors (Chapter 4). After adjusting 73 items that were considered to be difficult, confusing, twofold or redundant, the preliminary version of the QWLQ-CS was constructed, containing 104 items.

Testing the psychometric properties of the newly-developed questionnaire for evaluating the QWL of cancer survivors

In Phase 4, following the EORTC guidelines on developing questionnaire modules [1], we field-tested the preliminary QWLQ-CS. Two field studies were conducted in order to reduce the number of items, determine the factorial structure and assess the psychometric properties of the QWLQ-CS, including its internal consistency, construct validity (i.e., convergent validity and discriminative validity) and reproducibility (Chapter 5). In field study I, an Explorative Factor Analysis (EFA) was performed on the preliminary version of the QWLQ-CS with 104 items. QWLQ-CS data for 302 cancer survivors were used to reduce the number of items and determine the factorial structure and internal consistency of the QWLQ-CS. The sample comprised employed or self-employed cancer survivors who had been diagnosed with various types of cancer in the last 0-10 years. Cancer survivors had a mean age of 52 years and 28% were male. They had a range of educational and work-related backgrounds. Based on the results of the EFA, we constructed the final version of the QWLQ-CS, which contained 23 items and five subscales: those of 1) Meaning of work, 2) Perception of the work situation, 3) Atmosphere in the work environment, 4) Understanding and recognition in the organisation, and 5) Problems due to the health situation. Responses were given on a 6-point Likert scale (Totally disagree – Totally agree). An extra response category, ‘Not applicable’, was available for items related to the work situation of self-employed cancer survivors, such as items about colleagues or supervisors. The QWLQ-CS scores ranged from 0-100, with a higher score indicating a higher QWL. The internal consistency of the overall QWLQ-CS was adequate, with a Cronbach’s alpha of 0.91, as were the subscales (Cronbach’s alpha ranged from 0.83-0.86). In field study II, 130 cancer survivors completed the QWLQ-CS at baseline, and 100 cancer survivors at a follow-up after four weeks. The samples comprised cancer survivors with various demographic, health- and work-related backgrounds. Data at baseline were utilised to assess the convergent and discriminative validity of the QWLQ-CS. To assess convergent validity, we formulated hypotheses about the magnitude and direction of the correlations between the QWLQ-CS and its subscales on the one hand, and other validated questionnaires and subscales.
on the other. More than 75% of the hypotheses were confirmed. To test the discriminative validity, data from cancer survivors at baseline were compared to the QWLQ-CS data of 45 employed people without cancer or other physical/mental limitations affecting their job performance. The overall QWLQ-CS mean (M) score of cancer survivors was 75 with a Standard Deviation (SD) of 10, and employed people without cancer had a mean score of 79 (SD = 11). The difference in mean scores on the QWLQ-CS statistically differed (p = 0.04) between the two groups, as did the mean scores on the subscale ‘Problems due to the health situation’ (p = 0.00). However, no statistical differences between the two groups were found on the other subscales. To assess the reproducibility of the QWLQ-CS, data from a subgroup of stable cancer survivors regarding health- and work changes (N = 87) at baseline and the four-week follow-up were examined. The Intraclass Correlation Coefficient (ICC) and Standard Error of Measurement (SEM) were calculated. The QWLQ-CS had an ICCagreement of 0.84 and a SEMagreement of 9.59. No floor or ceiling effects were detected. Overall, the QWLQ-CS showed adequate construct validity and reproducibility for use at group level.

Describing the QWL of cancer survivors
The QWL of cancer survivors was evaluated in field study I with 302 employed and self-employed cancer survivors. The aim of this study was to describe QWL and to explore associations between the QWL of cancer survivors and health- and work-related variables (Chapter 6). The QWL mean score of cancer survivors was 75 (SD = 12). The subscale with the lowest mean score was ‘Problems due to the health situation’ (M = 49, SD = 27), and the subscales ‘Meaning of work’ (M = 83, SD = 15) and ‘Perception of the work situation’ (M = 83, SD = 14) had the highest mean scores. The subscale ‘Atmosphere in the work environment’ had a mean score of 81 (SD = 15), and ‘Understanding and recognition in the organisation’ a mean score of 75 (SD = 19). The health-related variables associated with a low QWL in cancer survivors were ‘type of treatment’ and reporting having at least one co-morbidity. Furthermore, work-related variables, such as physically demanding work, being in a non-managerial position, having a low income and working a proportion of the contract hours, were associated with a low QWL.

Theoretical and methodological considerations

Conceptual model of QWL
QWL cannot be observed directly by looking at someone’s behaviour. For this reason, it is called a construct [2], and measuring a construct comes
with challenges [3]. For instance, there is no single approach to construct measurement, which means that because the construct is indirectly measured, researchers may differ in their operationalisation of the construct [4]. This also applies to the operationalisation of the construct ‘QWL’ in this thesis; many definitions and theories about QWL have been proposed over the years. As none of these definitions corresponded exactly with our vision of QWL among cancer survivors, we postulated a new definition: ‘the experiences and perceptions of a cancer survivor in the work environment’ (Chapter 4). The three problems with existing QWL theories and models were: 1) they described only a few aspects in the work environment that contributed to QWL, 2) they described aspects of the work environment and not so much the experiences of these aspects, and 3) they described or measured the QWL of ‘healthy’ employees or employees in specific occupations. Overall, in our opinion, the existing theories and models produced an incomplete picture of the QWL of cancer survivors.

One example of a model that described only a few aspects of the working environment that influenced the quality of work performance is the ‘job characteristics model of work motivation’ used by Hackman and Oldman [5]. As the name of the model suggests, core job dimensions (i.e., skill variety, task identity, task significance, autonomy and feedback) are included in the model, but other aspects, such as the role of colleagues or occupational physicians, are not considered. Consequently, we could not use this model to assess the overall work situation of cancer survivors, since having a supportive work environment is found to be important for cancer survivors [6]. Furthermore, some models describe aspects in the work situation that are related to QWL, but not to how cancer survivors might experience these aspects [7, 8]. For instance, one analysis of QWL resulted in dimensions such as control over work, use of skills and abilities, work variety and participation in organisational decision-making [7]. Other models did cover perceptions of the work situation, such as job satisfaction, job involvement and work-role overload [9, 10]. Cancer survivors can experience several aspects as difficulties in returning to work, however, such as work ability or a changed perception of work [11]. Consequently, these experiences and perceptions might influence their QWL and should therefore be assessed. Finally, QWL is described or measured among employees in general [12-15] or specific occupations [16, 17]. However, these questionnaires are not suitable for cancer survivors because they do not include all factors in the work environment which might influence QLW of cancer survivors. For instance, some focus mainly on work characteristics, such as work design and work context [17]. Although others take a wider perspective and focus on work experiences in the broadest sense,
they do not include items on the possible consequences of health on QWL [16]. Work and non-work are believed to be linked; aspects such as health, physical and psychological problems and emotional well-being are associated with work [18], and potentially with QWL. Therefore, the measurement and description of QWL among cancer survivors by these existing questionnaires is insufficient. In summary, previous QWL theories, models and questionnaires did not describe the complete work situation of cancer survivors. Our definition does so, by including different aspects of the work situation as well as health-related aspects and cancer survivors’ experiences and perceptions.

Our definition and measurement of QWL differs from existing definitions and measurements, and may differ from future ones. One explanation for the differences in approach lies in the construct’s multi-dimensionality. According to Law et al., a construct is multidimensional ‘when it consists of a number of interrelated attributes or dimensions and exists in multidimensional domains’ [19]. Therefore, the focus on the dimensions of QWL may depend on the field of the researcher. The present thesis focused on psychosocial oncology, and attention was paid to the overall experiences and perceptions of cancer survivors who had returned to work or continued working after diagnosis and treatment. However, researchers from different fields might be more interested in other QWL factors. For instance, a study on QWL in the automobile industry refers to four domains of QWL: employee empowerment, workload, health and safety, and management policies [20]. This implicates that due to the multidimensionality of the construct ‘QWL’, researchers will continue to approach QWL differently.

**Questionnaire development**

The development of the QWLQ-CS was based on the guidelines for developing questionnaire modules set out by the EORTC [1]. The guidelines were composed for the development of questionnaire modules for Quality of Life (QoL) questionnaires, and have been shown to produce questionnaire modules with good levels of psychometric properties [21]. By following these guidelines, we were able to conduct very thorough research and strengthen the quality of the QWLQ-CS. Nevertheless, we made some additions to the guidelines that we thought would benefit the development of the QWLQ-CS.

The aim of Phase 1 of the EORTC guidelines is to generate relevant QoL issues, and it is suggested that the literature should be searched for issues and that patients (cancer survivors) and healthcare professionals should be interviewed. We decided to include occupational physicians, who were specialized in oncology,
as healthcare professionals [22]. However, more actors, such as employers, are involved in the return-to-work or work continuation of cancer survivors [23]. Research suggests that employers find the return-to-work of employees with breast cancer difficult to manage, as they have been involved throughout the process of reintegration [24]. Therefore, in order to gather different perspectives on QWL we also included employers, supervisors and organisation officers to generate QWL issues (Chapter 3). In sum, we achieved a wider breadth of coverage and good content validity.

Phase 2 entailed the construction of the item list. The guidelines advised that the items should refer to the experiences of the patient over the last week, which is in line with other questionnaires, such as the Rotterdam Symptom Checklist (RSCL) [25]. We chose for a reference period of four weeks, however, because: 1) it might be the case that cancer survivors had not performed any work activities over the past week due to absence, meaning that they would be unable to complete the questionnaire, 2) some issues might not have come up in that particular week, meaning that it would not be possible to complete the item (e.g., ‘I consider that employees with health problems are treated well in my organisation’). Furthermore, we presumed that a reference period of four weeks would still be sufficient to diminish the possibility of a time-memory bias, by which people find it difficult to recall events that happened some time ago [26]. A reference period of four weeks is also similar to other work-related questionnaires, such as the Work Role Functioning Questionnaire 2.0 (WRFQ), which has proven to be a valid and reliable measurement instrument [27].

After we pre-tested the QWLQ-CS in Phase 3, we adjusted the 4-point response scale (recommended by the EORTC) to a 6-point Likert scale. The reason for this change was that cancer survivors during the pre-test study found the response categories confusing due to the addition of ‘a little bit’: disagree completely – disagree (a little bit) – agree (a little bit) – agree completely. This was also confirmed by previous research, where respondents had indicated that while shorter scales were easy to use, having fewer response options did not allow them to express their feelings adequately [28]. We continued to use an even-numbered response scale and to not provide a middle category, because cancer survivors might see this response option as an ‘opt-out’ for cognitively difficult choices [29], and we had already added an extra response option, ‘Not applicable’, for self-employed cancer survivors. If we had added another middle category, this might have confused self-employed cancer survivors. Another reason why cancer survivors might need the response option ‘Neither agree nor disagree’ is
when items are unclear or personally intrusive [29]. Since we had pre-tested the items, we assumed that cancer survivors would not need the response option for this reason. The final reason for adjusting the response scale was that research suggested that scales with four response options or fewer scored worse on reproducibility, validity and discriminate power in comparison to seven or more response options [28]. To conclude, we decided that a 6-point Likert scale would better fit the purpose of the QWLQ-CS, and this was eventually confirmed by the adequate psychometric properties of the QWLQ-CS.

A further aspect of the QWLQ-CS was developed in Phase 4. Since the QWLQ-CS consisted of 104 items after the pre-test study, we conducted an extra field study in order to perform an Explorative Factor Analysis (EFA) and reduce the number of items before we tested the psychometric properties of the final version of the QWLQ-CS. The number of items in the final QWLQ-CS was reduced from 104 to 23 items. This reduction was important for the utility of the QWLQ-CS. Having a short questionnaire is preferable for responses, as participation rates drop when it is announced that a questionnaire will take 30 minutes instead of 10 minutes [30]. Furthermore, a shorter questionnaire lessens the response burden for the cancer survivor and the ‘fatigue point effect’, which suggests that the accuracy of the responses decreases at the end of a long questionnaire [31]. The 23 items of the QWLQ-CS can be completed in approximately 10 minutes, meaning that is easy to administer to cancer survivors in research and practice.

**Description of the QWL of cancer survivors**

We started this research project with a systematic literature review to generate QWL issues for cancer survivors. The search was extended to workers with physical chronic diseases, because not many studies were conducted among cancer survivors about QWL, return-to-work or work continuation. We generated 73 issues by labelling the work experiences and perceptions of employees with physical chronic diseases as possible contributors to QWL. We based this synthesis on previous literature on the QWL of ‘healthy’ employees [10, 16, 18, 32]. In retrospect, knowing that the final QWLQ-CS would include many generic items next to cancer-specific items, it might have been helpful to include QWL questionnaires for ‘healthy’ employees in the search as well. It would have simplified the procedure of generating items for the QWLQ-CS in the qualitative study, because we could have presented issues or items from existing questionnaires and inquire which QWL issues for cancer survivors were missing. Now, we formulated an open question about QWL at the focus groups and interviews, which resulted in a large number of QWL issues (i.e. N = 178).
Presenting items from existing QWL questionnaires might have lowered the number of relevant QWL issues, because similar issues would not have been mentioned as new issues (e.g. job duties and job responsibilities). This might have resulted in fewer items to process and a shorter initial QWLQ-CS, which would have been more user-friendly during the pre-test study [26]. However, presenting items from existing QWL questionnaires might also have reduced the issues diversity, because it could have pushed responses in a certain direction. When developing the current questionnaire, we explored every aspect of QWL among cancer survivors, oncological occupational physicians and employers, which contributed to the content validity of the QWLQ-CS [33]. To conclude, fewer items would have been easier to process and would have produced a shorter QWLQ-CS at an earlier stage of this research project. However, it might also have lowered the content validity of the QWLQ-CS in comparison to our current approach.

**Interpretation of the findings**

In this thesis, we reported the QWLQ-CS scores of three different samples of cancer survivors (N = 130, N = 87, N = 302). The overall mean score on the QWLQ-CS for these samples was 75, 76, and 75 respectively \((SD = 10-12)\). Some subscale scores differed from these overall scores. For instance, the scores on the subscale ‘Problems due to the health situation’ were much lower than the overall QWL score and ranged between 49 and 57 \((SD = 24-27)\). These low scores indicate that it was mainly the cancer-specific items that negatively contributed to QWL, and emphasise the need for cancer-specific items in assessing QWL. However, the initial version of the QWLQ-CS contained more cancer-specific items than the final version. For instance, items on concentration/memory problems, acceptance of disease and limitations, and difficulties in recovering due to symptoms and/or side effects were deleted during the Explorative Factor Analysis (EFA) (Chapter 5). Items were deleted due to low inter-item correlations or low factor loadings, indicating that the items did not contribute or did not clearly contribute to the subscales of the QWLQ-CS [33], in this case the subscale ‘Problems due to the health situation’. One explanation might be that a large part of the sample did not experience cancer-related problems, due to the diversity in diagnosis, time of diagnosis and treatment. Furthermore, some cancer-related problems may only exist shortly after time of diagnosis and decrease over time. For instance, a study among breast cancer patients found that acceptance played a prominent role as a coping response, resulting in an increase in acceptance from the day
before surgery to 12 months later [34]. This suggests that the issue ‘acceptance of disease and limitations’ might have greater impact on recently diagnosed cancer survivors than cancer survivors who were treated longer ago. Since the study sample contained fewer cancer survivors who had been treated recently, these items were deleted. However, deletion of these kind of items contributed to the generalisability of the QWLQ-CS, because the remaining items contributed to the QWL of cancer survivors in general.

An examination of the content of the cancer-specific items in the final QWLQ-CS suggests that the items might not be cancer-specific at all. For instance, the subscale with cancer-specific items contains the items ‘Because of my health situation I have problems in my work with fatigue and/or lack of energy’ and ‘Because of my health situation I feel uncertain about the future’. However, previous research indicated fatigue as a much reported complaint in the workplace among employees with other chronic diseases [35], and psychological problems such as uncertainty about the future were also reported among patients with chronic diseases, such as stroke [36]. Therefore, these items are more likely to be related to having a disease rather than having cancer. Since people with chronic diseases other than cancer also experience work-related difficulties [37], it would be interesting to validate the QWLQ-CS for other chronic diseases in order to use it in occupational clinical practice or research for the reintegration of employees with other chronic diseases. Subsequently, it would be possible to compare the QWL of people with different chronic diseases in order to describe the situation of these groups in the working population. One example of a questionnaire that was originally developed for cancer survivors, and now used among other chronic diseases is the Multidimensional Fatigue Inventory (MFI-20) [38, 39]. The MFI-20 has proved to be a reliable tool for assessing fatigue in patients with fibromyalgia and chronic widespread pain, as well as cancer [40].

A possible explanation of why the content of the items is disease-generic instead of cancer-specific might lie in the prevalence of co-morbidity among cancer survivors. Co-morbidity is common among cancer survivors, especially in elderly cancer survivors [41]. Since the sample in the qualitative study had a mean age of 52, cancer survivors may have reported health problems that were not directly related to cancer but to other co-morbidities as well. Consequently, this might have influenced the content of the items. However, we did not assess the existence of co-morbidities in this sample. From the sample of cancer survivors whose QWLQ-CS scores were used to delete items for the final QWLQ-CS, 25% reported co-morbidity, as assessed by the item ‘Are you limited in your work by other
physical diseases?’. This suggests that the items that were applicable to more chronic diseases may have remained in the QWLQ-CS.

To assess the discriminative validity of the QWLQ-CS, the scores of cancer survivors and employed people without cancer or other physical/mental limitations affecting their job performance were compared. The two groups differed statistically in their overall QWLQ-CS scores and the subscale ‘Problems due to the health situation’, with cancer survivors having a lower QWL score (M = 57, SD = 24) than employed people without cancer or other physical/mental limitations affecting their job performance (M = 81, SD = 16). These results confirmed our hypotheses that the two groups would differ in their overall QWLQ-CS scores and on the subscale with cancer-specific items. Previous research on health-related issues found similar results; the discriminative validity of the Multidimensional Fatigue Symptom Inventory (MFSI) resulted in significant differences in fatigue, emotional fatigue, physical fatigue and vigour between cancer patients and comparison subjects without cancer [42]. These outcomes suggest that cancer survivors experience poorer health, which in our case may have affected QWL. However, cancer survivors and employed people without cancer or other physical/mental limitations affecting their job performance did not differ statistically in scores on the other subscales ‘Meaning of work’, ‘Perception of the work situation’, ‘Atmosphere in the work environment’ and ‘Understanding and recognition in the organisation’. These outcomes were not in line with our hypotheses, which predicted statistical differences between the two groups on all subscales. One possible explanation is that the items were generic, and therefore relevant to the QWL of both groups. It also indicates, however, that cancer survivors do not experience poorer QWL with regards to these subscales. These outcomes were surprising since cancer survivors report having problems with issues such as the ‘generic’ items in the QWLQ-CS. For instance, previous research identified work problems such as a non-supportive work environment [43], task modifications and decrease in earnings [44]. These issues are indirectly related to poorer health, so it was expected that cancer survivors would have lower scores on the other subscales as well. Perhaps we are dealing with a ‘healthy worker effect’; healthy cancer survivors are more likely to be employed and participate in this study than less healthy cancer survivors [45]. However, if this were the case, we would expect the scores on the subscale ‘Problems due to the health situation’ to be higher (after reversing the scores). Perhaps another effect which is similar to the healthy worker effects influenced the results. For instance, cancer survivors who were not satisfied or had problems at work already stopped working [46], and are therefore not included in the
sample which influenced the QWLQ-CS scores in a positive way.

In sum, cancer survivors had a lower score on the overall QWLQ-CS and subscale 'Problems due to the health situation', but not on the other subscales. This suggests that health-related problems are important to the overall QWL of cancer survivors, and that the QWLQ-CS can be used to assess the QWL of cancer survivors at group level. To extend the usability of the QWLQ-CS, it would be useful for future research to validate the QWLQ-CS and its subscales among a sample of randomly selected employees. Research has shown that 24% of the working population in the European Union describe their health as fair, bad or very bad [47], so we would expect the QWLQ-CS to be applicable to a larger part of the working population. Furthermore, organisations nowadays are interested in employee satisfaction, and since this is an item on the QWLQ-CS, it would be possible for organisations not only to indicate their workers’ satisfaction level, but also their QWL. As QWL is related to employees’ turnover intentions [48, 49], these outcomes may help organisations in maintaining their employees to stay in the organisation.

**Generalisability**

The QWLQ-CS was developed as a generic QWL questionnaire for cancer survivors from different health- and work-related backgrounds. In the developmental phases, we included cancer survivors with different types of cancer who had been diagnosed recently (<1 year) or longer ago (1-10 years). This means that the QWLQ-CS is relevant to cancer survivors who returned to work recently and longer ago. In order to make the QWLQ-CS applicable to cancer survivors who are self-employed, we added an extra response option, 'Not applicable', and we did not specify a compulsory number of working hours. This approach resulted in study samples with a variety of cancer survivors. However, the results of the QWLQ-CS may not be generalisable to all cancer survivors, as our sample mainly contained Dutch native cancer survivors (92-96%). We know from previous research that cancer survivors from diverse ethnic backgrounds can have different perceptions on cancer diagnosis [50, 51]. For instance, South Asian women with breast cancer experience statistically higher levels of anxiety and depression, poorer quality of life and higher levels of internal and fatalistic beliefs than White women [50]. The same study found that Black and South Asian women are more concerned with body image (i.e., vulnerability, limitations, body concerns, body stigma and transparency) than White women [50]. It is not common for Asian, Latina and Afro-American breast cancer survivors to discuss cancer openly, and to some extent it is even considered a taboo [51]. We do not know whether these different
perceptions on cancer diagnosis and discussing cancer also affect QWL, but studies have identified a few differences between ethnically diverse urban women in terms of experiences of work after diagnosis (e.g., relating to appearance and privacy) [52]. A consequence of the lack of ethnic diversity in our study sample is that we are presently unable to generalize the results on validity to other ethnic groups of cancer survivors. In order to do that, we need to conduct more research. This would also require taking a different recruitment strategy, since our previous recruitment strategy (hospital and online platforms) did not recruit many cancer survivors from different ethnic backgrounds. Effective strategies for engaging ethnic minority groups are rarely described, but Martinez et al. do outline a few strategies for the recruitment and retention of Latino immigrant families for family-focused longitudinal prevention research: Latino family-focused events, home visits, flexible assessment methods, and incentives for ongoing participation [53]. It seems that going into the community [54] or working through churches [55] are the most effective strategies. In order to include ethnic minorities, future researchers should try to get in touch with community initiatives for cancer survivors, such as physical activities or church support groups. A further adjustment could be made to the inclusion criteria for study participation. In this research project, cancer survivors were excluded if they were unable to read Dutch fluently. This led to fewer participants with different ethnic backgrounds. If the QWLQ-CS were to be cross-culturally translated into other languages and offered alongside the Dutch version, this might produce a more diverse ethnic sample.

Although occupational healthcare differs between countries in terms of legislation and actors [56], it is assumed that the results of the QWLQ-CS can be generalised to other countries with similar cultures. This is because the items in the final QWLQ-CS are focused on the experiences and perceptions of cancer survivors. Previous items examining the role of certain actors (e.g., occupational physicians, treating physicians) or organisations (e.g., role of the Human Resources department) that might differ between countries were deleted during the Exploratory Factor Analysis (EFA). To test this assumption, a cross-cultural adaption of the QWLQ-CS should be conducted to assess its validity and reproducibility in the country of interest. Cross-cultural adaptation has proved successful for other work-related questionnaires, such as the Work Role Function Questionnaire (WRFQ 2.0) [27] and the Work Limitation Questionnaire (WLQ) [57], which were both translated into Dutch and had good validity.
Psychometric properties

The QWLQ-CS showed overall adequate internal consistency, construct validity and reproducibility, but there are a few outcomes that need to be addressed. The ICC agreement of the subscale ‘Perception of the work situation’ was lower (0.57) (95% CI: 0.41-0.69) than the criteria for adequate ICC agreement at group level (≥0.70) [58]. ICC agreement is a parameter of test-retest reliability, which determines how well cancers survivors can be distinguished from each other, despite measurement error [58]. A low ICC indicates less agreement between the measurement points, because the error variance is large compared to the ‘true’ variance. It is suggested that ICC is sample-dependent and a lower ICC indicates a more homogenous sample that is difficult to distinguish on QWL scores [33]. We compared the QWL scores of cancer survivors who had different health- and work-related variables and did not find differences between cancer survivors on all variables, such as ‘The number of years in the job’. There were no statistical differences in QWL scores between cancer survivors who had spent 0-3 years or >11 years in a job. This might indicate that in regard to some variables, we included a more homogenous sample. It might be that the lack of difference on QWL based on the number of years in a job influenced the outcomes on the subscale ‘Perception of the work situation’ that comprises items on self-efficacy, which may be similar for most cancer survivors who have had the same job for some time. This may explain the low ICC for this subscale. Research indicates that the scale format may affect reproducibility; scales with fewer response categories yield lower reproducibility and clearly labelled response options result in higher reproducibility [59]. The latter explanation is not applicable to the QWLQ-CS, as we clearly labelled the response options, but the ICC could be possibly improved by extending the number of response categories of the QWLQ-CS.

One psychometric property that influences the evaluative characteristics of the QWLQ-CS is the Standard Error of Measurement (SEM) [33], which on a scale of 0-100 was 9.59 for the QWLQ-CS and 24.17 for the subscale ‘Problems due to the health situation’. The SEM of the overall QWLQ-CS score was quite large, and implied that if a change score is <10 points, it is not possible to indicate whether this is a real change or measurement error. This is not ideal for an evaluative measurement instrument. In order to draw conclusions about the ability of the QWLQ-CS to measure clinical changes over time, it is therefore important to assess its responsiveness through the parameters Smallest Detectable Change (SDC) and Minimal Important Change (MIC) [58]. One explanation for the relatively large SEM might lie in the stability of cancer survivors. We composed a subgroup of stable cancer survivors based on which cancer survivors had indicated
no change in reply to the two anchor questions (‘Did a major change occur in your health situation/work situation within the last four weeks?’). However, these two anchor questions were initially included as a check for the original anchor questions. The original anchor questions informed us as to whether QWL (or one of the subscales) had changed in the last four weeks. Unfortunately, there was extremely low correlation between the answers to the original anchor and the change scores on the QWLQ-CS and with the anchors that acted as a check (data not shown). We had presumed that QWL would be stable if no major changes in health and work had taken place, but perhaps this was incorrect, and QWL can change without major changes. Perhaps even, a small change can affect the experiences and perceptions of cancer survivors, and consequently QWL. Because it seems not possible to measure stability in QWL with anchor questions, future research might determine a stable subgroup of cancer survivors by conducting an interview to assess small or large changes in the health- and work situation. Furthermore, a possible explanation for the high SEM of the subscale ‘Problems due to the health situation’ is that the sample of cancer survivors differed in the experience of health-related problems, which may be a consequence of including cancer survivors who were diagnosed between 0 and 10 years ago. To test this assumption we should analyse the reproducibility of the QWLQ-CS only among cancer survivors who are diagnosed <1 year ago. Reproducibility (and therefore the SEM) may be improved by adjusting the scale design [60]. While the ICC can be improved by the number of response categories, the SEM might be improved by reversing the negative items in the QWLQ-CS. This was suggested by Beaton et al., who found poorer psychometric properties on a reversed subscale of the Work Limitation Questionnaire [61]. If the SEM of the overall QWLQ-CS were improved by reversing the items of the subscale ‘Problems due to the health situation’, this would most likely also lower the large SEM of this specific subscale.

**Implications for future research**

Since the psychometric properties of the QWLQ-CS proved to be adequate for measurements at the group level and not at the individual level, we discuss the future research implications of the QWLQ-CS at a group level. First of all, the QWLQ-CS can be used as an outcome measure in research, in addition to commonly measured employment outcomes [62]. Currently, interventions that are developed within research settings and that aim to improve reintegration of cancer survivors use outcome measures such as the return-to-work rate, employment status or work retention [63]. However, it is conceivable that these
outcomes might be influenced by external factors as well, such as a concentrated labour market. In order to describe the effectiveness of an intervention which contains psycho-educational, physical training or vocational counselling [64], it would therefore be useful to measure and describe QWL.

To help cancer survivors return to work or continue working successfully, interventions might also be developed in research settings to improve QWL. However, before we can use the QWLQ-CS to measure the effectiveness of QWL interventions, we must assess its responsiveness: i.e. can the QWLQ-CS measure clinically changes over time [33]. If the responsiveness of the QWLQ-CS is adequate, this would implicate that the QWLQ-CS can measure improvement or deterioration in QWL of cancer survivors. Interventions aimed at improving the work situation of cancer survivors usually contain psychosocial, vocational, cognitive, physical or counselling activities (either individually or in combination) [64, 65]. These activities might also form effective components in an intervention to improve the work experiences and perceptions of cancer survivors. In addition, we know from the items in the QWLQ-CS that support from colleagues and immediate supervisors also contributes to the QWL of cancer survivors. Therefore, educational meetings about the consequences of cancer for work might also improve support and QWL respectively. Since QWL is a multidimensional construct involving a complex interplay of different factors [66], we suggest multiple intervention components to improve overall QWL.

It will be important to carry out future research on the QWLQ-CS in order to determine its further applicability. For instance, it would be useful to address the interpretability of QLWQ-CS scores and establish cut-off points and norm scores. This would enable researchers to interpret the QWLQ-CS scores of cancer survivors and compare these scores to the QWLQ-CS scores of other groups of workers. However, the QWLQ-CS should first be validated among employed people with other chronic diseases and among the working population. If the QWLQ-CS is valid in other groups of employed people, the QWLQ-CS scores might be useful for assessing which groups of workers are at risk of a low QWL, and consequently less successful return-to-work or work continuation processes. However, in order to make predictions about cancer survivors or other employed people who are possibly at risk of a low QWL, more research is needed on the prognostic factors of QWL. As a result of this research project, we also suggest that the QWLQ-CS should be cross-culturally validated among cancer survivors with different ethnic backgrounds and in other countries.
Recommendations for practice

The following recommendations have been written for occupational physicians, but they may also be relevant for general practitioners and occupational therapist or nurses in other countries, depending on their role during the work reintegration of cancer survivors. First, introducing the QWLQ-CS may increase awareness among occupational physicians of the experiences and perceptions of cancer survivors in work situations and the difficulties they can encounter in the workplace. Since work may be beneficial for cancer survivors, paying attention to this topic could stress the importance of preventing cancer survivors from leaving employment, either voluntarily or involuntarily. It may broaden the view of occupational physicians in terms of assessing QWL next to cancer survivors’ working hours or days of absence.

The QWLQ-CS has been tested as valid and reproducible at the group level, which means that the QWLQ-CS cannot produce reliable outcomes when used to evaluate and monitor QWL at an individual level. However, the QWLQ-CS may be used at an individual level as an indication of the need for interventions to improve QWL. For instance, occupational physicians could recommend counselling or adjustments in the workplace as a result of health-related problems. Cancer survivors could also use the QWLQ-CS to start a conversation about their experiences and perceptions of their work situation and discuss facilitators for work continuation.

Furthermore, the QWLQ-CS could be used in organisations that employ cancer survivors. Within organisations, the department that deals with personnel issues is the Human Resources (HR) department. The HR department might play an important role for cancer survivors who were diagnosed with cancer a few years ago and are no longer visiting an occupational physician. Although these cancer survivors are returned to work, they might need support in their work due to the late effects of cancer diagnosis and treatment [67]. The HR department could support these cancer survivors by providing advice on QWL by means of the QWLQ-CS. In organisations with many cancer survivors, the HR department could also examine QWLQ-CS scores at a group level to assess the overall QWL of this specific group of employees. HR departments could subsequently implement effective interventions to monitor, evaluate and improve the QWL of cancer survivors. Today’s organisations are more concerned with social awareness and sustainable employability than in the past [68]. For instance, the Dutch Cancer Society offers a special programme for organisations on how to deal with cancer in the workplace [69]. The QWLQ-CS could also play a useful role in educating
employees in organisations about the effect of cancer on work. The overall aim of assessing QWL is to assist cancer survivors with a successful return-to-work or continuation of work.

In conclusion, the QWL of cancer survivors was assessed and evaluated by developing the Quality of Working Life Questionnaire for Cancer Survivors (QWLQ-CS). The five-factor QWLQ-CS is a self-administered questionnaire that consists of 23 items. The QWLQ-CS is a measurement instrument that has overall adequate internal consistency, construct validity and reproducibility among cancer survivors at a group level. The QWLQ-CS can function as an outcome measure in research, but can also be used in practice to monitor and evaluate QWL of cancer survivors at a group level. Further research is needed to optimise the use of the QWLQ-CS in research and practice.
References


