Chapter 1
General introduction
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Cancer prevalence and incidence

Cancer is a disease that affects people worldwide. In the last four years, approximately 32.6 million people across the world were living with cancer and were diagnosed in the previous five years [1], while another 14 million new cancer cases were detected [2]. These numbers are expected to increase; it is predicted that the number of cancer cases will rise by 70% in the coming 20 years [3]. The present research was conducted in the Netherlands, but the figures for prevalence and incidence in this country follow the same global trend. In 2013, the five-year prevalence figure indicated that there were 330,967 cancer survivors in the Netherlands, and this number increased in 2014. In that year 104,694 new patients were diagnosed with cancer [4]. The growing number of people that are diagnosed with cancer at some point in their lives is related to the ageing population [5]. Besides, cancer is no longer an incurable and therefore fatal disease in all cases. Fortunately, due to early detection and improved treatment, more people are surviving cancer today than in the past [6]. In this thesis, ‘cancer survivors’ are defined as people who have been diagnosed with cancer at some point in their lives and are still alive.

Cancer occurs often in older people [5], but in the developed world many young people are diagnosed with cancer as well. Approximately 50% of diagnosed cancer cases are assessed in people younger than 65 years of age [7]. This implies that many cancer survivors are still of working age. In the Netherlands, 38,647 newly diagnosed cancer patients were of working age (15-64 years) in 2014 [4]. The working population currently consists of all people between the ages of 18 and 65, but this group might become larger if the government continues to raise the retirement age. To summarize, as more people survive cancer and continue to work for longer, the number of cancer survivors of working age will increase in the near future.
Cancer diagnosis

Cancer is one of the four global chronic diseases [8] that can cause cancer survivors to experience poor physical and mental health-related quality of life [9]. The impact of the health problems caused by cancer may depend on several factors. For instance, the stage of the cancer describes the size and extent of the tumour, the involvement of regional lymph nodes and the presence of metastases [10]. If the cancer can be treated, the most common treatments are surgery, chemotherapy, or radiotherapy [6]. In case of treatment with the intent to cure, whether single or combined treatment is chosen depends on the severity of the disease, the prognosis and the patient’s characteristics (e.g. age, patient preferences or co-morbidity) [11]. All treatments can cause side effects, which differ per person [12, 13]. Common treatment-related side effects of surgery include pain, fatigue, nausea and higher risk of thromboembolism [14]. Some of these side effects are also common in other treatments. For instance, the treatment-related side effects of chemotherapy include fatigue, pain, diarrhoea, nausea and vomiting, hair loss and appetite loss [13, 15]. Patients receiving radiotherapy can experience fatigue and nausea as well, but also red and sore skin [16]. Fatigue is also common when being treated with hormones, in addition to bone pain and menopausal symptoms in women (e.g. flushes, night sweats, irritability) [17]. With stem cell transplants, general treatment-related side effects are mouth sores, nausea, vomiting, diarrhoea and fatigue [18]. Most of these treatment-related side effects will disappear after completing treatment [19]. Any treatment-related side effects that do continue after treatment are described as ‘late effects’ or ‘long-term side effects’ [20]. For instance, lymphedema of the arm may appear in breast cancer survivors due to surgery and radiation therapy [10]. Some late effects or long-term side effects may persevere for years after treatment. Survivors of colon, rectum and prostate cancer can experiences bowel dysfunction due to cancer treatment [10, 21]. This may ultimately result in a late effect or long-term side effect such as an ostomy [10]. Some of the long-term side effects most commonly reported by cancer survivors are (chronic) fatigue, cognitive impairment and physical problems [19, 22]. Cancer survivors find fatigue to be the most distressing side effect [23].

Cancer may not only influence cancer survivors’ physical and cognitive state, but it can also affect their psychosocial well-being [20]. Cancer survivors often experience emotional difficulties and psychosocial problems such as anxiety, depression, and body image-problems [24]. These problems may affect cancer survivors’ daily lives, and survivors often experience problems adapting to their new situation [25]. Together with the physical and cognitive long-term side
effects, these psychosocial problems may have a negative impact on the quality of (working) life of cancer survivors.

**Cancer survivors and work**

Work is important to many cancer survivors. After a period of sickness and uncertainty, work provides structure, financial stability and contributes to a person's overall quality of life [26, 27]. Furthermore, work is important for a person's self-image, self-esteem and feelings of normalcy [28]. On average, 62% of cancer survivors return to work within 12 months or keep work during treatment [29]. However, the process of returning to work or maintain working is likely to be influenced by a cancer survivors’ physical, cognitive and psychosocial well-being [30, 31]. For instance, fatigue and other physical problems can act as a barrier to returning to work [29]. Furthermore, cognitive problems are reported to have a negative influence on work performance [32]. These physical, cognitive and psychosocial problems may have serious consequences for the working lives of cancer survivors. Research shows that cancer survivors (including survivors of breast cancer, cancer of the reproductive organs and gastrointestinal cancers) have a 37% higher chance of unemployment compared to healthy individuals [33]. Cancer survivors can also experience social problems in their work environment, such as lack of understanding in the workplace [34]. This can prevent cancer survivors from having a fulfilling work-life; they may not enjoy their work, may be less happy and become less satisfied with their work. Thus on the whole, cancer survivors are less likely to be employed and experience difficulties in returning to work after treatment due to physical, cognitive and psychological problems. This is an undesirable situation, as work is important to most cancer survivors. Research and occupational health care professionals should therefore focus on improving the working life of cancer survivors.

**Quality of working life of cancer survivors**

The working lives of cancer survivors have been studied extensively. For instance, work participation in cancer survivors is often studied by measuring their employment status or days of absence. Another outcome, work productivity, has frequently been measured in working cancer survivors [35-37]. Unfortunately, these studies offer little insight into the effects of the physical, cognitive and psychosocial problems experienced by cancer survivors at work. For instance,
previous research shows that cancer survivors experience (chronic) fatigue and cognitive problems at work [38, 39]. Moreover, psychosocial problems may affect the working life of cancer survivors, as some cancer survivors evaluate their lives and alter their priorities, including work [34, 40]. In this thesis, the working life of cancer survivors are described and evaluated by examining the experiences and perceptions of cancer survivors in the work environment. The knowledge that is gained from this subjective perspective may contribute to the guidelines used for occupational support during the return-to-work or work continuation of cancer survivors.

A multidimensional construct, the ‘Quality of Working Life’ (QWL) of cancer survivors is used to define the experiences and perceptions of cancer survivors in the work environment. When cancer survivors have a high QWL, they experience positive feelings about their work and enjoy their work. Furthermore, cancer survivors with a high QWL perceive their work as satisfying and are happy in their work environment. On the other hand, some cancer survivors can have the opposite experience (i.e., negative feelings about work, disliking work, feeling dissatisfied and unhappy at work) or can experience feelings that lie between these two extremes. Research on QWL indicates that having high QWL prevents a worker from having ‘turnover intentions’ [41-43]; in other words, the intention to leave their employment. Since work is beneficial for cancer survivors, intentional or unintentional loss of employment is an outcome that should be avoided.

In order to assess and measure the QWL of cancer survivors, a measurement instrument is needed. Previously developed questionnaires have measured the QWL in healthy employees [44-46] or for specific occupations [47], such as nursing [48]. However, these questionnaires do not take account of the effects of cancer and treatment on the experiences and perceptions of cancer survivors in the work environment. Existing questionnaires therefore do not allow for the accurate assessment or measurement of the QWL of cancer survivors, and we thus need to develop a new measurement instrument.

**Questionnaire development**

Developing a new measurement instrument is an extensive process. For this thesis, we based the development of a QWL questionnaire for cancer survivors on the guidelines for developing Questionnaire Modules of the European Organisation for Research and Treatment of Cancer (EORTC) Quality of
Life Group [49]. These guidelines take a systematic approach in which the measurement instrument is developed and evaluated in four phases. The EORTC guidelines are used extensively in quality of life research and have shown to produce reliable and valid questionnaires [50, 51]. Phase 1 of the guidelines is aimed at generating relevant issues by means of a literature search and interviews with patients and healthcare professionals. In Phase 2, the researchers convert the list of issues into items. In Phase 3, the items are pre-tested for relevancy, acceptability and comprehensiveness. The final phase, Phase 4, encompasses a field study in which the psychometric properties of the questionnaire are evaluated. However, one step – the choice of measurement method – is not specifically elaborated in the EORTC. The choice of method depends on the construct that is being measured [52]. Since we wanted to measure QWL, we required direct information from cancer survivors, as we were interested in their personal work experiences and perceptions. We therefore decided to develop a self-administered questionnaire to measure the QWL of cancer survivors.

Relevancy of quality of working life

The QWL of cancer survivors is relevant for occupational health services and also for employers. In addition to supporting cancer survivors during reintegration and employment, actors in the occupational healthcare may use QWL as an indication of how successful the process of returning to work or continuing working has been. If a cancer survivor has returned to work and has high QWL, the likelihood of this cancer survivor keeping their job may increase. By contrast, a low QWL could indicate that an intervention is needed to prevent loss of employment.

Measuring the QWL of cancer survivors within organisations might help to prevent absenteeism. Monitoring the QWL of employees who have (or have had) cancer and treatment, might make it possible to identify changes amongst employees. Employers could offer an employee with a lower QWL a change of tasks or working environment. This might help to reduce the risk of cancer survivors for being on long-term sick leave or receiving unemployment benefits. Finally, the QWL of cancer survivors could be used in research to assess the success of interventions that are focused on the process of cancer survivors’ return-to-work or work continuation.
Thesis aim, objectives and research questions

The aim of this thesis is to assess and evaluate the QWL of cancer survivors. As there is no measurement instrument available for measuring the QWL of cancer survivors, we will develop a self-administered questionnaire to evaluate the QWL of cancer survivors. The aim of this thesis results in the following objectives and research questions.

**Objective I**

The first objective is to develop a questionnaire to evaluate the QWL of cancer survivors.

Research question (i): What issues are of relevance when developing the Quality of Working Life Questionnaire for Cancer Survivors (QWLQ-CS), and are the constructed items in this newly-developed questionnaire relevant, acceptable and comprehensible to cancer survivors? (Chapters 2, 3 and 4)

**Objective II**

The second objective is to test the psychometric properties of the newly-developed questionnaire for evaluating the QWL of cancer survivors.

Research question (ii): What is the factorial structure, internal consistency, construct validity and reproducibility of the QWLQ-CS? (Chapter 5)

**Objective III**

The third objective is to describe the QWL of cancer survivors.

Research question (iii): How can we describe the QWL of cancer survivors, and which health- and work-related variables are associated with the QWL of cancer survivors? (Chapter 6)

Outline of the thesis

This thesis presents the development of a questionnaire to describe and evaluate the QWL of cancer survivors. The development of the questionnaire was based on the guidelines for developing Questionnaire Modules set out by the EORTC Quality of Life Group [49]. Chapter 2 presents a systematic review of the literature, with the aim of assessing the issues that contribute to the QWL of employees with a chronic physical disease. It forms the first step in generating issues for the questionnaire. Chapter 3 describes the results of a qualitative study that focused on generating QWL issues for cancer survivors. In order to produce a definitive list of issues for the questionnaire, employed or self-employed cancer
survivors were asked to select relevant QWL issues from those identified in the systematic literature review and qualitative study. We developed the Quality of Working Life Questionnaire for Cancer Survivors (QWLQ-CS) by converting these issues into items. In Chapter 4, this initial version of the QWLQ-CS was pre-tested among employed or self-employed cancer survivors. The items were tested for relevancy, acceptability and comprehensibility. Based on these results, the items in the QWLQ-CS were adjusted in the preliminary version of the questionnaire. Chapter 5 presents two studies in which the QWLQ-CS was tested among a group of employed or self-employed cancer survivors. First, the factorial structure of the QWLQ-CS was studied, which resulted in the deletion of certain items and a final version of the QWLQ-CS. In the second study, the psychometric properties of this final version of the QWLQ-CS were assessed. The outcomes present the internal consistency, the construct validity (i.e. convergent validity and discriminative validity) and the reproducibility of the QWLQ-CS. In Chapter 6, the QWL of cancer survivors is described and the associations between the QWL of cancer survivors and health- and work-related variables are examined. To conclude the thesis, Chapter 7 presents a general discussion in which the main findings of the thesis are summarised and interpreted. Methodological and theoretical considerations, implications for future research and recommendations for practice are discussed.
References


