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Do cancer survivors differ from the general population at eight years after diagnosis: a longitudinal study of their physical and psychosocial adjustment over time

Abstract

In the present study, we examined to what extent cancer survivors ($n = 206$) experience long-term physical and psychosocial consequences of the illness and its treatment. Using a longitudinal, case-control design, we compared survivors' physical and psychological functioning and their psychosocial resources at 3 months (T1), 15 months (T2), and 8 years (T3) after diagnosis with a reference group of similar-aged individuals without cancer from the general population ($n = 120$). The findings indicated that, at T3, survivors reported levels of psychological functioning and psychosocial resources similar to those in references. However, levels of physical problems were significantly higher in survivors than in references. During the first year after diagnosis, survivors showed significant improvements in their physical and psychological functioning. However, in the seven years thereafter, both survivors and references showed a decrease in physical functioning, demonstrating the effect of ageing on patients' long-term adjustment. Levels of psychosocial resources were stable over time, both in survivors and in references. During the interview at T3, however, both survivors and references reported (retrospectively) positive changes in their resources. Overall, the findings of the study not only demonstrate the persistence of physical symptoms and somatic distress but also shed light on the role of positive beliefs and a search for meaning in the adjustment process.

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Introduction

A diagnosis of cancer is a major stressful life event, that affects nearly one of every three individuals in the Netherlands (Visser et al., 1998). As a result of medical advances in the field of cancer screening, detection, and multimodal treatment, the survival rate in cancer patients has increased within the past thirty years (Coebergh et al., 1995; Levi et al., 2000). For instance, among women with breast cancer, the 5-year survival rate has increased from 52% to 76%. Consequently, many cancer patients are presently faced with a long period of uncertainty and the late consequences of cancer and its treatment. Information about the long-term adjustment of cancer survivors may identify areas in which cancer treatment can be improved and patient services that should be maintained or developed (Dorval et al., 1998). Furthermore, knowledge about the specific late physical and psychosocial sequelae of cancer survivors may help health-care providers to target problems that need special attention during follow-up visits. The purpose of this article was to explore the long-term adjustment to cancer in patients who have survived cancer for eight years beyond the initial diagnosis. In the first five years after diagnosis, patients are monitored more regularly and the likelihood of a recurrence is greater, and therefore, cancer patients who have survived for five years or longer are considered as truly *long-term* survivors of cancer.

The initial period after a diagnosis of cancer may be regarded as a life crisis and patients may have to face manifold distressing physical and psychosocial problems (e.g. feelings of uncertainty, a diminished self-esteem, changes in relations, and depressive symptoms) as a result of cancer and its treatment (Courtens et al., 1996; Moos & Schaefer, 1984). As time passes, the traumatic impact of the event will eventually become less salient and most studies showed significant improvements in patients' overall quality of life in the first year following diagnosis (Ganz et al., 1996). Nevertheless, particular problems, such as certain physical symptoms and uncertainty about the future, may persist till years after diagnosis (Kornblith, 1998; Tross & Holland, 1989). Moreover, cancer survivors are at increased risk of developing a recurrence or new primary tumour, which may have a devastating effect on their long-term adjustment (Leigh, 1998).

Recently, there is a growing realization and interest that a life-crisis may also have positive consequences (Folkman & Greer, 2000; Schaefer & Moos, 1998; Taylor et al., 2000; Tedeschi et al., 1998). The confrontation with a life-threatening disease may challenge patients' fundamental assumptions about their personal invulnerability, their self-worth, and the meaningfulness of life, and may therefore be regarded as a period of "existential crisis" (Janoff-Bulman & Frieze, 1983). In such periods of uncertainty and confusion, patients often actively search for meaning, in an attempt to understand why the

unexpected and stressful event happened and its significance for one self and one's future (Taylor, 1983). In the aftermath of a life crisis, people often show resilience and eventually personal growth in terms of a more positive self-image, better social relationships, more empathy for others, altered priorities, and a greater appreciation of life (Schaefer & Moos, 1998; Tedeschi et al., 1998).

Since previous studies among cancer patients have focused primarily on the short-term effects of a diagnosis of cancer and its treatment (i.e. less than 1-2 years after diagnosis), comparatively little is known about the long-term adjustment of cancer survivors. Furthermore, the studies among long-term survivors showed considerable diversity in design (e.g. cross-sectional, case-control, or longitudinal), methods (e.g. quantitative or qualitative), and sample characteristics (e.g. type of cancer, prognosis, and time since diagnosis), which makes it difficult to draw definite conclusions about the late consequences of cancer. In the following paragraphs, we critically review the results of previous studies among cancer survivors.

According to a recent review of studies on the psychosocial adjustment of cancer survivors (2 to 15 years after diagnosis), the majority of the survivors seem to adjust remarkably well to the cancer experience (Kornblith, 1998). However, several studies indicated that cancer survivors still experience physical problems (Bush et al., 1995; Dow et al., 1999; Ferrell et al., 1998b; Greaves-Otte et al., 1991; Schag et al., 1994). For instance, in a quantitative study in a mixed sample of 278 short- and long-term survivors, Schag et al. (1994) found that survivors still reported difficulty in doing physical activities, reduced energy, sexual problems, and disfigurement. Physical symptoms may remind survivors of the cancer experience and may be a barrier to achieve normalcy (Dow et al., 1999).

Regarding survivors' psychological functioning, qualitative studies consistently showed that cancer survivors are still concerned about a recurrence of the cancer (Ferrans, 1994; Ferrell et al., 1998a; Fromm et al., 1996; Pelusi, 1997). For instance, in a phenomenological study among eight breast cancer survivors 2 to 15 years (mean 8 years) after completing treatment, Pelusi (1997) found that each woman experienced uncertainty about the future and a fear of cancer recurrence. However, the results of quantitative studies on psychological functioning were mixed (Bush et al., 1995; Ferrell et al., 1998b; Kurtz et al., 1995; Schag et al., 1994; Wyatt & Friedman, 1996). Among 125 cancer survivors 6 to 18 years after bone marrow transplantation, Bush et al. (1995) found low levels of general psychological distress. However, Ferrell et al. (1998) found that breast cancer survivors, on average nine years after diagnosis, were still worried about a fear of a recurrence of the cancer. Collectively, these studies suggest that survivors' psychological

functioning is not globally impaired but rather specifically, in terms of a fear of cancer recurrence and uncertainty about the future.

Despite the physical and psychological sequelae, cancer survivors also reported positive consequences of the cancer experience, in terms of enriched personal and social resources. For instance, among 14 breast cancer survivors 8 to 30 years after diagnosis, Fredette (1995) found that survivors reported altered priorities, more assertiveness, and more concern for others. Other studies have shown that survivors experience a greater sense of purpose and appreciation of life (Dow et al., 1999; Ferrans, 1994; Ferrell et al., 1998a; Ferrell et al., 1998b; Pelusi, 1997; Wyatt & Friedman, 1996). In contrast to these mainly positive findings, a qualitative study of Fromm et al. (1996) among 90 cancer survivors 1 to 10 years after bone marrow transplantation showed that, although half of the survivors reported a greater appreciation of life (47%) and improved family relationships (52%), about a quarter reported worsened family relationships (23%) and a lack of empathy from others (28%).

Unfortunately, the aforementioned studies among cancer survivors had a cross-sectional design, thus examining patients at one point in time, often with a wide variable time after diagnosis. Consequently, little is known about the *course* of survivors' physical and psychological functioning and resources over time. It can be expected that certain aspects of functioning (e.g. physical symptoms) are likely to be most prominent in the period following diagnosis and during treatment, whereas other aspects (e.g. a greater appreciation of life) may not be evident until years after diagnosis. In order to understand the process of long-term adjustment, longitudinal studies are needed. The few longitudinal studies that have been conducted among long-term survivors suggest an improvement in survivors' psychological functioning and overall psychosocial adjustment over time (Grassi & Rosti, 1996; Omne-Ponten et al., 1994). For instance, among 66 breast cancer survivors, Omne-Ponten et al. (1994) found that overall psychosocial maladjustment decreased over time in the six years after diagnosis. As far as we know, there are no longitudinal studies among cancer survivors that have examined other aspects of long-term adjustment.

Another issue that is overlooked by most studies is the impact of a recurrence or new primary tumour on survivors' long-term adjustment. Studies that examined how survivors' functioning is affected by such an event demonstrate that a recurrence or new primary tumour may have a devastating effect on survivors' functioning (Bull et al., 1999; Dorval et al., 1998; Frost et al., 2000; Okamura et al., 2000). For instance, in a prospective, longitudinal study among 69 women with recurrent breast cancer, Bull et al. (1999) found an increase in physical symptoms, emotional and social distress immediately following the diagnosis of a recurrence. In the six months following recurrence, they found no significant improvement in the amount

of physical symptoms. They did find significant improvements in emotional and social distress in this period.

A major problem in the assessment of long-term adjustment is distinguishing effects due to cancer from those due to ageing and/or other comorbidities (Gotay & Muraoka, 1998). Most cancer patients are in the age of 60 years or older when they receive a diagnosis of cancer. Therefore, they are likely to suffer from other physical problems (e.g. less energy and decreased physical activity), chronic diseases, and stressful life events (e.g. the care and concerns for a seriously ill partner or the death of their spouse) (Coebergh et al., 1995; Mor, 1992; Penninx et al., 1999; Rowland, 1989a). Inherent in such life events are losses (e.g. of good health or loved ones) which may affect feelings of depression and anxiety and which may diminish one's resources (Ormel et al., 1998; Stuck et al., 1999). On the other hand, greater maturity and more extensive coping experience with previous life events may provide ageing persons with richer resources (e.g. greater appreciation of life) (Debats et al., 1995; Schaefer & Moos, 1998).

In order to distinguish the late consequences of a diagnosis of cancer from those of ageing, the inclusion of a reference group of similar-aged individuals *without* cancer from the general population is needed. Only a few studies among long-term survivors included such a reference group (Bjordal et al., 1995; Dorval et al., 1998; Van Tulder et al., 1994; Weitzner et al., 1997). These studies generally showed that, compared to healthy references, survivors report more physical restrictions, lower perceived overall health, less satisfaction with their sexual life, and more worries about their health (Dorval et al., 1998; Van Tulder et al., 1994). The findings regarding psychological functioning, however, were inconsistent. In a study among long-term breast cancer survivors, at least five years after diagnosis, Weitzner et al. (1997) found that cancer survivors were significantly more depressed and anxious than women attending breast cancer screening. In contrast, in a relatively younger group of long-term survivors of Hodgkin's disease, on average 14 years after diagnosis, Van Tulder et al. (1994) found that survivors reported similar levels of psychological distress as a healthy group of hospital visitors who were accompanying patients for a medical check-up or radiotherapy. Finally, regarding patients' personal and social resources, most studies focused on the first years after diagnosis (Andrykowski et al., 1996; Carpenter, 1997; Zemore & Shepel, 1989). The only available information on the resources of long-term cancer survivors showed that cancer survivors experienced similar levels of available emotional support and satisfaction with the partner relationship as references (Dorval et al., 1998; Van Tulder et al., 1994). All together, these studies provide important information on survivors' long-term adjustment. However, conclusions based on these data are limited, due to their cross-sectional design, the variable or long time after diagnosis,

the use of screening patients or individuals accompanying patients to the clinic as references, the limited range of outcome variables, and the lack of qualitative data.

Therefore, the aim of the present study was to examine the long-term adjustment of 206 cancer survivors, in comparison with a reference group of 120 individuals *without* cancer from the general population. Both groups were interviewed and filled out a questionnaire at three fixed points in time since diagnosis: 3 months (T1), 15 months (T2), and 8 years (T3). A wide variety of aspects of long-term adjustment were measured: physical functioning (i.e. physical symptoms and limitations in household and social activities), psychological functioning (i.e. depressive symptoms and feelings of anxiety), and personal and social resources (i.e. overall satisfaction with life, meaning in life, self-esteem, emotional support, and marital satisfaction). These quantitative data were supplemented with the data from a more in-depth, qualitative interview at eight years after diagnosis. Additional analyses were performed to examine the impact of a recurrence or new primary tumour on survivors' long-term adjustment.

As far as we know, this is the first longitudinal study that examined such a large group of cancer survivors and similar-aged references without cancer on a wide variety of outcome measures (both quantitative and qualitative), hereby taking into account the impact of a cancer recurrence or a new primary tumour. We expected differences between cancer survivors and references in physical and psychological functioning to be most prominent in the first year after diagnosis. Regarding personal and social resources, it might be expected that positive changes herein are more likely to occur somewhat later in the process of adjustment. On the other hand, when acknowledging the impact of a diagnosis of cancer on one's resources and the importance of these resources for patients' adjustment, we might also expect changes in these resources in the first year after diagnosis.

Methods

Subjects and Procedures

The study was conducted among cancer survivors of a cohort of 475 newly diagnosed patients who have previously participated in a study on the social network of cancer patients and their adjustment to cancer in the first 15 months after diagnosis (De Ruiter, 1995; Van der Zee et al., 1996). This study also included a cohort of 255 references without a history of cancer from the general population.

Initial study

Cancer patients were recruited from 12 hospitals in the northern part of the Netherlands, with the assistance of the Dutch Cancer Registration of the

Comprehensive Cancer Centre North Netherlands (CCCNN). The inclusion criteria for study participation were: (a) age 18 years or older, (b) newly diagnosed with cancer, (c) no distant metastases, (d) a life expectancy of at least one year, and (e) informed on the diagnosis of cancer. A letter containing information about the project and a participation form was attached to the patients' medical status and patients were approached for participation in the study by their physician.

In the period from 1990 to 1992, 516 patients returned a participation form. At approximately three months after diagnosis, 475 of the 516 (92%) eligible patients entered the study. Patients were also interviewed and filled out a questionnaire at 9 and 15 months after diagnosis. In total, 403 patients (85% of 475) participated at 15 months after diagnosis. The main reasons for drop out during the first year were serious illness and death.

Based on the gender and age distribution of the patient group, 559 references were selected from the register office of five townships in the same region as patients and sent a participation form. Of the 559 eligible references, 255 references (46%) participated in the first interview. Similar to the patient group, references were also interviewed and filled out a questionnaire twice with time intervals of 6 months. In total, 225 references (88% of 255) participated at 15 months after diagnosis. The main reasons for drop out during the first year were unwillingness to participate, the impossibility to locate, or incomplete questionnaire data.

Follow-up study

At 15 months after diagnosis, 358 (of the 403) patients and 194 (of the 225) references gave informed consent to be approached for a follow-up study. Of these persons, 102 patients and 27 references died in the following seven years. For the present study, the 256 patients and 167 references who were still alive were sent a participation form, accompanied with a letter informing them of the follow-up study. A research assistant then telephoned participants when participants had not returned the participation form within 14 days of sending the letter.

In total, 206 patients participated in the study at eight years after diagnosis. The main reasons of non-response of the 50 patients who dropped out were ill health, unwillingness to participate, and reluctance to talk about the cancer experience. Compared to cancer survivors who participated at eight years after diagnosis, cancer survivors who dropped out since the first interview were significantly more often diagnosed with colorectal cancer or lung cancer, stage III or IV, and treated with radiotherapy or chemotherapy ($p < .01$). Patients who were older, male, and lower educated were also more likely to drop out ($p < .01$).

In addition, 128 references participated in the follow-up study. The main reasons of non-response of the 39 references who dropped out were unwillingness to participate and ill health. For the analyses in the present study, we excluded eight

references who were diagnosed with cancer in the past eight years, leading to a final sample of 120 references. Compared to the references who participated at eight years after diagnosis, references who dropped out of the study since the first interview were significantly older, lower educated, and less often had a partner ($p < .05$).

Measures

For the present study, we used the data collected at 3 months (T1), 15 months (T2), and 8 years after diagnosis (T3). At all three points in time, survivors and references were interviewed at home, using a semi-structured interview. During the interview, information was collected about limitations in activities, social network, life events, chronic illnesses, and sociodemographic characteristics. Both groups also filled out a self-report questionnaire at all three points in time. At T3, the semi-structured interview was followed by a more qualitative interview. During this interview, persons were asked in a more open way about their current functioning and possible changes herein over time in the past eight years.

Physical symptoms were measured with the 17-item subscale Physical Symptom Distress from the Rotterdam Symptom Checklist (RSCL) (De Haes et al., 1990; De Haes et al., 1996). Persons were asked to indicate the degree to which they had been bothered by the indicated symptoms (e.g. fatigue, low back pain, dizziness, stomach ache, shortness of breath, and decreased sexual interest) during the last week on a 4-point scale (ranging from 1 to 4). Cronbach's alpha was .85 in survivors and .80 in references.

Limitations in household activities were measured with the Groningen Activities Restrictions Scale (GARS) (Kempen et al., 1993). The subscale consists of seven items. Examples of household activities include: doing light or heavy household jobs and preparing meals. In order to measure *limitations in social activities*, four additional items were developed. Examples of social activities include: paying a visit to someone, participating in outdoor activities, and doing strenuous hobbies. On both scales, persons were asked to indicate the degree to which they are able to do certain activities on their own on a 5-point scale (ranging from 1 to 5). For the Limitations in Household Activities subscale, Cronbach's alpha was .90 in survivors and .93 in references. For the Limitations in Social Activities subscale, Cronbach's alpha was .83 in survivors and .88 in references.

Depressive symptoms were assessed with the Dutch version of the Center for Epidemiologic Studies Depression (CES-D) scale (Bouma et al., 1995; Radloff, 1977; Weissman et al., 1977). Persons were asked to indicate how often they felt each of the symptoms during the last week on a 4-point scale (ranging from 0 to 3).

In the present study, we used a sumscore based on the 16 negatively formulated CES-D items. In a previous study, we found that a sumscore based on the 16 negatively formulated CES-D items, excluding the four positively formulated items, was a more valid measure of depressive symptoms, both in cancer patients and healthy individuals (Schroevers et al., 2000). Cronbach's alpha was .90 in survivors and .89 in references.

Situational or current anxiety was measured by the 20-item State-Anxiety subscale from the State-Trait Anxiety Inventory (STAI) (Spielberger et al., 1970). Persons were asked to indicate to what extent they currently experience each of the symptoms on a 4-point scale (ranging from 1 to 4). Cronbach's alpha was .93 in survivors and .94 in references.

Overall satisfaction with life was measured by the Satisfaction With Life Scale (SWLS) (Arrindell et al., 1991). This self-report questionnaire consists of five items (e.g. I am satisfied with my life). On a 7-point scale (ranging from 1 to 7), participants were asked to indicate whether they agree or not with each of the five statements. Cronbach's alpha was .88 in survivors and .89 in references. It has been found that such global measures of subjective well-being are rather stable over time and strongly influenced by personality traits (DeNeve & Cooper, 1998). Therefore, we used overall life satisfaction as a personal resource.

The Life Regard Index (LRI), a 23-item self-report questionnaire, was used to measure *meaning in life* (Battista & Almond, 1973; Debats, 1990; Debats, 1998). This questionnaire was assessed at T3 only. The scale consists of two subscales: "Framework" (10 items) and "Fulfilment" (13 items).

The Framework scale measures the degree to which individuals can envision their lives within some meaningful perspective or have derived a set of life goals, whereas the Fulfilment scale measures the degree to which people see themselves as having fulfilled or being in the process of fulfilling their life goals. On a 3-point scale (ranging from 1 to 3), persons were asked to indicate whether they agree or not (or no opinion) with each of the statements. For the Framework subscale, Cronbach's alpha was .75 in survivors and .82 in references and for the Fulfilment subscale .87 and .90, respectively.

Self-esteem was measured by the Rosenberg Self-Esteem (RSE) scale (Rosenberg, 1965). A factor-analysis on the 10 items of this self-report questionnaire yielded two independent factors, differentiating the five negatively formulated items (e.g. "I think I'm no good at all", "I feel useless", "I feel like a failure") and the five positively formulated items (e.g. "I feel satisfied with myself", "I feel positive about myself") (Andrews, 1998; Ranchor et al., 1996). Since previous studies have demonstrated conceptual differences between positively and negatively formulated self-esteem (Brown et al., 1990a; Brown et al., 1990b), we used both subscales. Persons were asked to indicate whether they agreed with each of the statements on a

4-point scale (ranging from 1 to 4). Cronbach's alpha was .73 in survivors and .78 in references for the positively formulated self-esteem scale and .81 and .82, respectively for the negatively formulated self-esteem scale.

Social support was measured by the 8-item subscale Lack of Problem-Focused Emotional Support Interactions from the Social Support List (SSL) (Van Sonderen, 1991; Van Sonderen, 1993). This scale measures a lack of emotional support characterized by reassuring, comforting, problem-solving, and advice. Items can be scored on a 3-point scale: (1) "just right, this is as I would like to have it", (2) "I do not really miss it, but it would be pleasant if it happened somewhat more often", and (3) "I really miss it, I would like it to happen more often". Cronbach's alpha was .88 in survivors and .86 in references.

Marital satisfaction was measured with the Maudsley Marital Questionnaire (MMQ) (Arrindell et al., 1983). This 10-item scale focuses on the communication with the partner, feelings of warmth and understanding, and satisfaction with the time spent together. Persons were asked to consider these aspects of the relationship on a 9-point scale (ranging from 0 to 8). Cronbach's alpha was .92 in survivors and .94 in references.

During a more *qualitative interview* at T3, both survivors and references were asked about their current physical and psychological functioning and the appreciation of their activities, relationships with others, themselves, and life in general as well as about possible changes herein in the past eight years since diagnosis. Thus the interview covered partly the same dimensions of functioning as the self-report questionnaires. In addition, survivors were asked more specific questions about the cancer experience, for instance, about their thoughts about a recurrence, possible causes of the cancer, and the question "Why me?".

Based on pilot interviews and the literature on long-term adjustment, categories of response were developed to code these open-ended responses. During the interview, survivors and references were encouraged to talk freely at their own past, but carefully prompted to talk about the aforementioned aspects of functioning. The trained interviewer then scored the answer to the questions on one or more response categories.

When cancer survivors reported a change, they were asked to indicate to what extent cancer had influence this change. Thus, rather than asking cancer survivors directly about the consequences of cancer, they were first asked to indicate changes in general, and subsequently, the influence of cancer upon these changes. By formulating the questions in such a neutral way, we wanted to avoid influencing patients' response about the consequences of cancer. It also enabled us to ask the reference group the same questions.

Information about the *sociodemographic characteristics* (gender, age, education, and marital status) and the number of *chronic illnesses* was collected during the semi-structured interview. Regarding the latter, we used a standardized list including 21 chronic illnesses (such as asthma, hypertension, diabetes, disease of the joints, chronic headache, and heart disease). *Medical data* (site, stage, and treatment) were derived from the cancer registration from the Comprehensive Cancer Centre North Netherlands. During the interview, we asked patients whether they still went to follow-up visits in the hospital for the cancer and whether they had experienced a recurrence of the cancer or a new primary tumour in the past eight years. Of 13 survivors no medical information about a recurrence or a new primary tumour was available).

Statistical analyses

T-tests for independent samples were conducted to examine differences between survivors and references in physical and psychological functioning and their resources at T1 to T3. Changes in physical and psychological functioning and resources within the group of survivors and references were examined with paired t-tests.

In order to examine differences between survivors and references in these changes over time, difference scores were calculated by subtracting T3 – T2 scores and T2 - T1 scores. T-tests for independent samples were used to examine differences between survivors and references in these difference scores. The interview data was analysed with cross-tabs and differences between survivors and references were tested with Chi-square analyses.

Results

Sample characteristics

The characteristics of the present sample at eight years after diagnosis are shown in Table 1. As can be seen, the mean age of survivors and references was 62 years and 59 years, respectively. The majority of both groups were female, living with a partner, and lower educated. Almost half of both groups suffered from two or more chronic illnesses. Using Chi-square analysis and Student's t-test, we found no significant differences between survivors and references in the sociodemographic characteristics and the number of chronic illnesses. Among cancer survivors, the most important cancer sites were breast cancer (53%), colorectal cancer (22%), and gynaecological cancer (19%). The majority of the cancer survivors (91%) were diagnosed with stage I or II, indicating a relatively good prognosis. Most of the patients were treated with surgery (48%) or surgery and radiotherapy (22%).

Physical functioning

Quantitative data

At eight years after diagnosis (T3), survivors reported significantly higher levels of physical symptoms ($p < .001$) and more limitations in their household ($p < .05$) and social activities ($p < .01$) than references (Table 2).

In the first year after diagnosis (T1 to T2), survivors showed a significant decrease in physical symptoms and limitations in their household and social

Table 1. Sample characteristics at eight years after diagnosis

	Survivors (n = 206)	References (n = 120)
Gender (% female)	79	71
Current age (mean \pm SD)	61.9 \pm 13.6	59.3 \pm 13.2
Marital status (% having a partner)	74	78
Education (%)		
Primary	31	27
Lower vocational/secondary	43	37
Middle vocational/secondary	15	21
Higher vocational/university	11	15
Number of chronic illnesses (%)		
0	31	31
1	29	31
2 or more	40	38
Cancer site (%)		
Breast	53	
Colorectal	22	
Gynaecological	19	
Lung	4	
Other	2	
Stage (%)		
I	49	
II	42	
III-IV	9	
Initial treatment (%)		
Only surgery	48	
Surgery and radiotherapy	22	
Surgery and chemotherapy	9	
Surgery, radio- and chemotherapy	9	
Surgery and hormonal therapy	4	
Surgery, radio- and hormonal therapy	5	
Other	3	
Recurrence or new primary tumor (%)	20	
Still going to follow-up visits (%)	84	

Table 2. Mean scores on quantitative measures of functioning in survivors and references at 3 months (T1), 15 months (T2), and 8 years (T3) after diagnosis

	Survivors Mean (SD)	References Mean (SD)	p ^b
Physical functioning			
Physical symptoms ^c			
T1	24.65 (5.78)	21.17 (4.45)	***
T2	22.61 (5.16)	21.38 (4.72)	*
T3	24.79 (6.66)	22.05 (4.64)	***
T1-T2	-1.96 (4.55) *** ^a	.21 (3.46)	***
T2-T3	2.11 (4.94) ***	.75 (4.40)	*
Limitations in household activities			
T1	11.67 (5.44)	7.89 (2.34)	***
T2	9.33 (3.98)	7.98 (3.33)	**
T3	10.41 (5.72)	9.09 (4.80)	*
T1-T2	-2.34 (5.31) ***	.09 (3.41)	***
T2-T3	1.05 (4.62) **	1.01 (4.82) *	
Limitations in social activities			
T1	10.00 (4.89)	5.00 (2.18)	***
T2	7.50 (4.09)	5.60 (2.83)	***
T3	7.38 (4.41)	6.03 (3.71)	**
T1-T2	-2.32 (4.95) ***	.60 (2.99)*	***
T2-T3	-.09 (4.25)	.41 (3.81)	
Psychological functioning			
Depressive symptoms			
T1	6.22 (6.38)	3.68 (4.29)	***
T2	4.94 (6.36)	3.68 (4.97)	*
T3	5.60 (6.33)	4.37 (5.53)	
T1-T2	-1.31 (4.91) ***	-.01 (4.00)	**
T2-T3	.63 (5.09)	.74 (5.04)	
Anxiety			
T1	34.48 (9.69)	33.94 (9.30)	
T2	33.68 (10.89)	32.52 (9.99)	
T3	35.23 (10.16)	34.34 (10.25)	
T1-T2	-.95 (9.19)	-1.43 (8.61)	
T2-T3	1.52 (9.28) *	1.23 (8.88)	

^aPaired t-test *within* survivors and references: * p < .05; ** p < .01; *** p < .001.

^bIndependent t-test *between* survivors and references: * p < .05; ** p < .01; *** p < .001.

^cHigher scores on the RSCL, GARS, CES-D, and STAI indicate *higher* levels of physical and psychological problems. Higher scores on the SWLS, LRI, RSE, and SSL indicate *higher* levels of satisfaction, whereas higher scores on the MMQ indicate *lower* levels of satisfaction.

	Survivors Mean (SD)	References Mean (SD)	p ^b
Personal resources			
Overall satisfaction with life			
T1	27.33 (7.01)	27.84 (6.16)	
T2	27.81 (6.42)	27.88 (6.36)	
T3	26.73 (6.99)	27.09 (6.95)	
T1-T2	.46 (5.85)	.04 (5.80)	
T2-T3	-.99 (6.72)	-.78 (6.02)	
Meaning in life (fulfilment)			
T3	32.96 (5.66)	32.72 (6.04)	
Meaning in life (framework)			
T3	26.15 (3.41)	26.40 (3.58)	
Self-esteem (positively formulated)			
T1	15.76 (2.19)	15.58 (2.04)	
T2	15.67 (2.15)	15.65 (2.07)	
T3	15.57 (2.14)	15.53 (2.07)	
T1-T2	-.10 (1.69)	.07 (1.70)	
T2-T3	-.08 (1.98)	-.16 (1.76)	
Self-esteem (negatively formulated)			
T1	15.35 (2.53)	15.52 (2.51)	
T2	15.45 (2.78)	15.58 (2.39)	
T3	15.44 (2.79)	15.53 (2.61)	
T1-T2	.10 (1.97)	.06 (2.17)	
T2-T3	-.01 (2.28)	-.09 (2.12)	
Social resources			
Lack of emotional support			
T1	9.94 (3.29)	10.11 (2.93)	
T2	9.97 (3.25)	9.89 (2.88)	
T3	10.41 (3.35)	10.15 (2.97)	
T1-T2	.02 (2.67)	-.22 (2.50)	
T2-T3	.41 (3.29)	.23 (2.75)	
Marital satisfaction			
T1	10.83 (11.38)	13.17 (12.37)	
T2	11.92 (12.77)	13.93 (12.28)	
T3	12.91 (11.31)	16.50 (14.15)	
T1-T2	1.01 (8.11)	.60 (6.32)	
T2-T3	1.59 (11.16)	2.61 (9.25) *	

activities ($p < .001$). Nevertheless, compared to references, survivors reported elevated levels of physical symptoms ($p < .05$), limitations in their household ($p < .01$) and social activities ($p < .001$) till 15 months after diagnosis (T2).

In the seven years between T2 and T3, we found a significant increase in limitations in household activities, both in survivors ($p < .01$) and in references ($p < .05$). Among survivors, we also found a significant increase in physical symptoms ($p < .001$), which was significantly stronger than in references ($p < .05$).

Qualitative data

In line with the quantitative data, 52% of the survivors reported during the interview that they still experienced cancer-related physical problems (especially fatigue and arm problems) at eight years after diagnosis. However, we found no significant differences between survivors and references in the limitations in their current daily life, with 75% of the survivors and 84% of the references reporting no or few limitations. Regarding changes over time, 56% of the survivors and 41% of the references said that, in general, they did less on a day now than eight years ago. Moreover, 35% of the survivors and references reported that they did less household activities now than eight years ago. No significant differences between survivors and references were found in the amount of these changes over time.

Psychological functioning

Quantitative data

At eight years after diagnosis (T3), cancer survivors did not differ significantly from the references in their levels of depressive symptoms and feelings of anxiety (Table 2).

In the first year after diagnosis (T1 to T2), we found a significant decrease in depressive symptoms in survivors, compared to references ($p < .01$). Still, survivors reported significantly more depressive symptoms till 15 months after diagnosis (T2) than references ($p < .05$).

In the seven years between T2 and T3, we found no significant changes in depressive symptoms, neither in survivors nor in references, but both groups showed a tendency towards an increase of anxiety over time.

Qualitative data

The results of the interview supplemented these findings, showing that 94% of the survivors reported no or little emotional distress as a result of cancer. Moreover, 96% of the survivors said that they had learned to live with the disease. However, the majority of the survivors still had recurrent thoughts about the cancer (51% once in a while and 25% even regularly), especially when experiencing physical symptoms (47%) and when talking to other cancer patients (46%). The most important issues they still thought about were the disease period itself (37%), a fear of recurrence (36%), and changes in body image (19%). Furthermore, 42% of the survivors had become more attentive to physical symptoms over time, compared to 25% of the references ($p < .05$).

Psychosocial resources*Quantitative data*

No significant differences between survivors and references were found in their overall satisfaction with life, meaning in life, self-esteem, lack of emotional support, and marital satisfaction, neither in the first year after diagnosis (T1 and T2) nor at eight years after diagnosis (T3) (see Table 2). We also found no significant differences between survivors and references in the course of these resources over time. Both groups showed stable levels of these resources from T1 to T2 and T2 to T3. The only exception was found for marital satisfaction. In the seven years between T2 and T3, references reported a decrease in marital satisfaction ($p < .05$).

Qualitative data

Similar to the quantitative data, we found no significant differences between survivors and references in the appreciation of themselves, their life in general, and their social relationships during the interview at eight years after diagnosis (T3). Specifically, the majority of the survivors and references appreciated themselves (76% and 75%, respectively), their life in general (91% and 88%, respectively), and their relationships with the partner, family, and others (90% to 98% of the survivors and 92% to 94% of the references).

However, in contrast to the quantitative data showing stable levels of resources, a large number of survivors as well as references reported during the interview that their resources had changed over time. Specifically, more than half of both survivors and references reported no change in the appreciation of themselves (64% and 70%, respectively), their life in general (45% and 55%, respectively), and their social relationships (66% to 73% of the survivors and 64% to 74% of the references). But a large number of survivors and references did report a greater appreciation of themselves (30% and 28%, respectively), their life in general (48% and 41%,

respectively), and their social relationships (26% to 30% of the survivors and 21% to 28% of the references). We found no significant differences between survivors and references in these changes over time.

We also asked survivors and references whether specific aspects of themselves and of their lives had changed in the past eight years. Compared to references, survivors more often reported that they took life less for granted (34% versus 12%, respectively) ($p < .001$). However, other positive changes were reported about equally frequent by survivors and references. For instance, survivors as well as references reported that they had become more emotional (14% and 10%), more self-confident (28% and 30%), and had a greater empathy and understanding of others (16% and 10%). In addition, survivors and references reported that they had a heightened awareness of mortality (11% and 19%), lived more conscious (25% and 20%), lived more at ease (16% and 15%), and put life more into perspective (17% and 13%).

Intriguingly, when we asked survivors to what extent *cancer* had influenced these changes, many survivors said that cancer had affected changes in the appreciation of themselves (40%), life in general (54%), relationships with the partner, family, and others in general (30% to 45%), and specific aspects of themselves (39%) and of their life (47%). In other words, although we found no significant differences between survivors and references in changes in their resources, many survivors did *attribute* changes to the cancer experience.

The impact of a recurrence of the cancer or new primary tumour

In order to examine the impact of a cancer recurrence or a new primary tumour on survivors' long-term adjustment, cancer survivors were categorized into two groups: those who had remained disease-free and those who had developed a recurrence or a new primary tumour in the eight years following diagnosis. In all, 38 survivors had experienced a recurrence or a new primary tumour.

First, we compared disease-free survivors and survivors who had developed a recurrence or a new primary tumour on their sociodemographic (i.e. gender, age, marital status, and education) and medical characteristics (site, stage, and treatment). We also compared the sociodemographic characteristics of these two groups of survivors with those in the reference group. The only significant difference that was found was that survivors with a recurrence or a new primary tumour were significantly older (i.e. mean age 65.8) than disease-free survivors (i.e. mean age 60.6) and than references (i.e. mean age 59.3) ($p < .05$).

Next, we compared disease-free survivors and survivors who had developed a recurrence or new primary tumour with the reference group on all quantitative aspects of functioning at eight years after diagnosis (T3). Since the survivors who

had developed a recurrence were significantly older, we controlled these analyses for age. The results indicated that survivors who had remained disease-free reported significantly higher levels of physical symptoms than references ($p < .01$). However, survivors who had developed a recurrence or new primary tumour reported, besides higher levels of physical symptoms, also more limitations in household and social activities than references ($p < .01$). They also showed a tendency towards higher levels of depressive symptoms than references ($p = .07$). No other significant differences between survivors and references were found.

The results of the interview were in line with these quantitative findings. Compared to references, survivors who had experience a recurrence or new primary tumour reported more often that they generally did less on a day now than eight years ago (76% versus 41%) ($p < .01$) and they showed a tendency towards more limitations in their current daily life (35% versus 16%) ($p = .06$). However, consistent with the quantitative data, they did not report lower levels of resources than references.

Compared to disease-free survivors, survivors who had developed a recurrence or a new primary tumour reported more cancer-related physical problems (e.g. fatigue, short of breath, and decreased appetite) (65% versus 48%) and more regularly cancer-related thoughts (43% versus 20%) ($p < .05$) and a tendency towards more cancer-related emotional distress (14% versus 4%) ($p = .06$).

The cancer experience through the eyes of long-term cancer survivors

At the end of the interview, we asked cancer survivors a few general questions about their experiences with cancer. In response to the question “Overall, how would you describe your cancer experience?”, 36% said positive as well as negative, 20% negative, 16% positive, and 28% neither positive nor negative.

When we asked survivors to what extent cancer had changed their life, 28% of the cancer survivors responded not at all, but the majority said that cancer had changed their life (36% a little and 36% a lot). Cancer survivors who reported that cancer had not changed their lives said that other factors had more impact on their well-being, such as the ability to do things for oneself (autonomy), other chronic illnesses and life events (such as the death of a partner or a divorce), ageing in general (which made them living more conscious and putting life more into perspective), and a positive attitude. Others mentioned that, only in the initial year after diagnosis, they had experienced problems in their daily functioning as a result of cancer. In contrast, survivors who said that cancer had changed their lives reported both negative effects (e.g. experiencing persistent physical problems and a fear of a recurrence) and positive effects (e.g. taking life less for granted, living more conscious, experiencing a greater appreciation of life and more joy) as a result of cancer.

In order to examine whether the presence of negative consequences affects the presence of positive consequences, we performed additional correlation analyses at eight years after diagnosis (T3). The results showed that survivors who experienced higher levels of physical symptoms reported *higher* levels of limitations in household ($r = .48$) and social activities ($r = .51$), depressive symptoms ($r = .64$) and feelings of anxiety ($r = .49$) and, during the interview, *higher* levels of cancer-related emotional distress ($r = .24$) and a fear of recurrence ($r = .26$). At the same time, they reported *lower* levels of overall satisfaction with life ($r = -.38$), meaning in life (framework, $r = -.22$; fulfilment, $r = -.37$), self-esteem ($r = -.29$), emotional support ($r = .31$), and satisfaction with the marital relationship ($r = .32$). The strength and direction of these correlations suggest a rather weak to moderate negative relationship between the positive and the negative consequences. In other words, the negative and positive consequences of cancer seem to be relatively independent of each other and cancer survivors may experience them both at the same time.

Discussion

In this study, we have investigated the long-term adjustment to cancer in a large group of cancer survivors who were diagnosed with a relatively early disease stage and had survived cancer for eight years after diagnosis. The findings indicated that, at eight years after diagnosis, cancer survivors experience similar levels of psychological functioning and psychosocial resources as similar-aged references with no history of cancer. However, cancer survivors did report significant higher levels of physical symptoms and limitations in household and social activities than references. Additional analyses showed that these higher levels of functional limitations were especially seen in survivors who had experienced a recurrence or new primary tumour. The longitudinal analyses showed significant improvements in survivors' physical and psychological functioning in the first year after diagnosis. In the seven years thereafter, both survivors and references showed an increase in limitations in household activities and survivors also showed an increase in physical symptoms during this period. Regarding the personal and social resources, the longitudinal analyses showed stable levels of these resources over time, whereas during the interview, survivors as well as references reported positive changes in their resources.

The results of the study clearly demonstrated the persistence of physical symptoms and survivors' greater attentiveness to these symptoms. Moreover, many survivors still had recurrent thoughts about the cancer, especially about the initial period after diagnosis and a fear of a recurrence. These results are in line with previous studies showing elevated levels of physical impairment and somatic

distress in cancer survivors (Ferrell et al., 1998b). In the context of persistent physical symptoms and a decrease in medical surveillance and contact with the health care providers, it can be expected that cancer survivors are focused on physical changes and concerned about a recurrence of the cancer. Providing information about the process of physical recovery and self-monitoring of physical symptoms may help survivors to manage their feelings of uncertainty (Ferrell et al., 1998b; Gray et al., 1998). Although heightened somatic distress may to some degree be an unavoidable consequence of cancer, such information may help survivors to establish or maintain a balance between inattentiveness and preoccupation with physical symptoms (Somerfield et al., 1999).

Besides higher levels of physical symptoms, survivors who had developed a recurrence or new primary tumour also reported elevated levels of limitations in household and social activities and more depressive symptoms, compared to references. But we found no significant negative impact of a recurrence or new primary tumour on survivors' resources. These findings are consistent with those of other studies, showing the negative impact of a recurrence on survivors' physical and psychological functioning (Dorval et al., 1998; Okamura et al., 2000). The physical symptoms and functional limitations in cancer survivors with a recurrence experience may increase feelings of dependency and isolation. Some studies among cancer survivors have found no significant effect of a recurrence on depression and anxiety (Frost et al., 2000). The discrepancy in the results regarding psychological functioning may be due to differences in the instrument used to measure distress, sample characteristics (e.g. age, concurrent treatment), the duration of the disease-free interval between initial diagnosis and recurrence, and the time since recurrence. Further longitudinal research is needed to examine the specific needs and concerns of survivors with recurrent cancer and the course of adjustment to a cancer recurrence over time.

Both in survivors and references, we found an increase in limitations in household activities in the past seven years. This finding shows that the process of ageing influences survivors' long-term physical functioning. Interestingly, survivors also reported a sharp increase in physical symptoms in the past seven years, which was significantly greater than the increase in physical symptoms in references. Other studies among cancer survivors have also found such a recurring worsening of functioning in cancer survivors after initial improvement (Ganz et al., 1996; Holzner et al., 2001). The question is whether this stronger increase in physical symptoms in survivors is because of the cancer or because of other factors. A common factor that is related to emotional stability as well as to the tendency to be more attentive of and concerned about physical sensations is *neuroticism* (Somerfield et al., 1999). Indeed, additional analyses showed that especially high neurotic cancer survivors reported an increase in physical symptoms in the past seven years. This finding, akin to those


of others (Bower et al., 2000; Chaturvedi & Maguire, 1998), suggests that physical symptoms in cancer patients probably have both an somatic and a psychological component.

Despite the elevated levels of physical problems at eight years after diagnosis, survivors' psychological functioning and resources at this point in time were similar to those in the reference group. The finding is in line with other studies that showed that most cancer survivors are able to cope with the cancer experience (through positive thinking and the support from others and religion) and report a good overall quality of life (Dorval et al., 1998; Fredette, 1995; Halstead & Fernsler, 1994).

Regarding the resources, the quantitative (longitudinal) data showed stable levels of personal and social resources, both in survivors and in references. In contrast, during the interview, many survivors and references reported (positive) changes in their resources over time, such as a greater appreciation of life. This finding is consistent with the results from Cordova et al. (2001), which showed that cancer patients and healthy references reported similar improvements in self-respect, relationships with others, and outlook on life. Why do people report these positive changes? According to Taylor (2000), people hold mildly distorted positive beliefs ("illusions") about themselves and their life. This might explain the tendency of both survivors and references to evaluate their past in a positive way. Furthermore, as mentioned in the introduction, both survivors and references are likely to have been confronted with other life-events and chronic illnesses. Successful coping with such events may eventually increase feelings of control, self-confidence, and self-understanding, strengthen social relationships, and change the individual's perspective on problems and important values and beliefs.

Intriguingly, many survivors said that cancer had influenced the changes in their resources. Thus, although survivors did not report more positive changes in their resources than references, they did attribute these changes to the cancer experience. Festinger's theory of *cognitive dissonance* (Festinger, 1957) may be relevant to understand the underlying mechanisms of survivors' attribution of positive changes to the cancer experience. According to this theory, dissonance (e.g. the disruption of a sense of personal invulnerability and meaning in life), being psychologically uncomfortable, motivates people to reduce the dissonance, for instance by denying or minimizing the negative consequences or by looking for positive ones. Other researchers have also demonstrated that, in the context of a threatening event, people will attempt to reduce the negative implications and search for and *create* positive meaning in the event (through causal attributions and positive reappraisal) (Folkman, 1997; Moos & Schaefer, 1984; Taylor, 1983; Taylor & Armor, 1996). The co-occurrence of negative and positive consequences, also observed by other studies (Folkman, 1997; Schroevers et al., 2000; Vickberg et al., 2000), seems to serve an important function. Finding positive meaning may provide a psychological

break, enhance the individuals' coping efforts and resources, and *buffer* the negative consequences of the event (Folkman & Moskowitz, 2000; Vickberg et al., 2000). It remains unclear to what extent these processes are conscious or unconscious. Probably, people use both unintentional and intentional strategies to process threatening information and to reconstruct their lives.

 It should be kept in mind that the majority of the cancer survivors in the present study were diagnosed with a low stage of disease and mainly treated with surgery and/or radiotherapy. In a longitudinal study on the long-term adjustment to cancer, it is inevitable to examine those patients with a relatively good prognosis and life expectancy. Furthermore, the examination of group data may undermine individual differences and minimize the difficulties experienced by some cancer survivors.

The present study has important methodological strengths and extends prior research among cancer survivors in several ways. First, we examined a wide variety of negative as well as positive aspects of physical and psychological functioning and psychosocial resources, using both quantitative and qualitative data. Second, we examined a large group of cancer survivors and a reference group of individuals without cancer at three fixed points in time since diagnosis. Using such a longitudinal, case-control design enabled us to explore the process of adjustment in-depth. Furthermore, the inclusion of a reference group appeared to be very useful in distinguishing the long-term effects of cancer from those of the other factors (e.g. the ageing process) and in understanding the role of cognitive processes in psychological adjustment.

With respect to the clinical relevance, the findings of the present study challenge the idea that psychosocial functioning is permanently and globally impaired by a diagnosis of cancer and treatment. Thus the majority of cancer survivors probably do not need organized late psychosocial treatment. Nevertheless, some survivors may experience ongoing problems, and therefore, health care providers should be alert for continuing psychosocial problems during follow-up visits. When observed, these persons should be carefully monitored and offered some form of psychosocial intervention, such as education and individual/group counselling (Ferrell et al., 1998b; Henderson, 1997). In order to facilitate the early recognition of cancer survivors who are at increased risk of long-term problems, longitudinal studies are needed to investigate risk factors of long-term maladjustment to cancer. The persistence of cancer-related physical problems and other chronic diseases, a lack of personal and social resources (e.g. optimism, mastery, social support), and premorbid dysfunction may place individuals at a greater risk for long-term maladjustment.