

Long-term employment status and quality of life after cancer: A longitudinal prospective cohort study from diagnosis up to and including 5 years post diagnosis

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Abstract.

BACKGROUND: Accumulating evidence suggests that cancer survivors are able to return to work. However, little is known about their work situation 5 years after diagnosis.

OBJECTIVE: To explore fluctuations in employment status and its association with quality of life 2, 3, and 5 years after cancer diagnosis of 65 cancer survivors employed at diagnosis.

METHODS: In association with a randomised controlled trial (RCT), questionnaires were administered to eligible cancer survivors at diagnosis, 2, 3, and 5 years thereafter comprising of validated questionnaires related to work (i.e. Work Ability Index (WAI), cancer, and quality of life (QOL) (i.e. SF-36, VAS QOL). The RCT studied a hospital-based work support intervention in female breast and gynaecological cancer survivors who were treated with curative intent and had paid work at diagnosis. Descriptive statistics and longitudinal multi-level analysis were employed.

RESULTS: Sixty-five of the 102 eligible cancer survivors participated, who were primarily diagnosed with breast cancer (63%). Two and 5 years after cancer diagnosis respectively 63 (97%) and 48 (81%) participants were employed. Reasons for not being employed after 5 years included receiving unemployment benefits (7%), voluntary unemployment (3%), receiving disability benefits (3%), and early retirement (3%). Longitudinal multi-level analysis showed that employed cancer survivors reported in general statistically significant better quality of life outcomes at 5 years follow-up compared to those not being employed.

CONCLUSIONS: We found high employment rates and few fluctuations in employment status. The steepest decline in employment rate occurs after the first two years of diagnosis. Employed participants reported better quality of life outcomes. Survivorship care should therefore focus on the population at risk possibly within the first two years after diagnosis.

Keywords: Neoplasm, unemployment, labour participation, work disability, cancer survivorship

1. Introduction

Globally, the number of people living beyond a cancer diagnosis has increased over the past decades and is expected to continue to increase [1]. The late effects of cancer treatment will therefore become

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more significant. One of these problems, the impact of cancer on work, has been identified as a research gap in the scientific literature [2]. However, it is known that work is of importance to cancer survivors [3, 4]. Previously, many benefits of paid work have been reported by cancer survivors such as identity, distraction, self-esteem, return to daily activities, social support and provision of a much needed income [5].

Unfortunately, cancer survivors experience difficulties in returning to work [6] or while at work [7, 8]. Previous studies have identified various factors that can both impede or facilitate the return to work process (e.g. fatigue) [9] as well as various stakeholders that might hamper or enhance the return to work process (e.g. the employer) [10, 11].

Most research in this area has focused on the first one or two years after diagnosis [12]. As we know that 5 years after diagnosis, cancer survivors experience higher levels of fatigue compared to the general population [13] and that this may hamper the possibility to stay employed [14], it might be hypothesised that fluctuations in employment status may occur after the first two years and are therefore of added value to investigate.

The objectives of our study are therefore to explore the employment status, fluctuations in employment status, and the association between employment status and quality of life 2, 3, and 5 years after diagnosis of cancer survivors who were employed at diagnosis.

2. Method

In this study we used a prospective cohort design with four measurements: baseline, 2, 3, and 5 years follow-up. Data were collected from April 2009 until January 2016. Participating in the randomised controlled trial was approved by the medical ethics committee of the Academic Medical Center [MEC 08/267]. All participants signed informed consent forms before participation.

2.1. Setting

This prospective cohort study was conducted, alongside a multi-centre randomize controlled trial studying the effectiveness of a hospital-based work support intervention [15]. As we did not find any statistical significant differences between groups regarding work outcomes and quality of life out-

comes [16], we decided to consider both groups as one cohort.

All data were collected by means of self-administrated questionnaires. At baseline, 2, 3, and the 5-year follow-up, participants completed validated questionnaires related to work, cancer, and quality of life.

2.2. Participants

Eligible criteria for inclusion into the randomised controlled trial were: 1) being a cancer patient between 18 and 60 years of age, 2) treated with curative intent at one of the participating hospital departments, 3) having paid work, and 4) being on sick leave. Patients were excluded who were not sufficiently able to speak, read, or write Dutch, had a severe mental disorder or other severe comorbidity, and for whom the primary diagnosis of cancer had been made more than two months previously. Additional eligible criteria for participation in this prospective cohort study were: 1) completing the randomised controlled trial, 2) giving consent to be contacted for potentially participation in further research, and 3) not receiving palliative treatment.

Eligible criteria for the randomised controlled trial were checked by the treating physician or nurse at the participating hospitals. One of the researchers checked the additional eligibility criteria for participation in this prospective cohort study after the end of the randomised controlled trial.

2.3. Variables

2.3.1. Descriptive variables

Demographic (e.g. age), health-related (e.g. quality of life), and work-related variables (e.g. type of employment contract, work ability index (WAI) [17] were included in the questionnaire at baseline (Tables 1 and 2). The reliability of the WAI is considered to be satisfactory [18].

2.3.2. Employment outcomes

Employment status was measured with an extensive question indicating whether someone was employed or not employed. We considered someone employed for cases in which someone was: employed, employed but on sick-leave, or self-employed. We considered someone not employed for cases in which someone: received disability

Table 1
Baseline characteristics

Patient characteristics	Responders (N = 65)	Non-responders (N = 37)
Socio-demographic characteristics*		
Age (years)	46.9 ± 7.5	48.0 ± 8.6
Gender (N (%) female)	64 (99)	37 (100)
Marital status (N (%) married or living with partner)	54 (83)	24 (65)
Breadwinner position (N (%) sole or shared)	44 (69)	27 (73)
Education level (N (%))		
Low	6 (9)	5 (14)
Intermediate	37 (58)	18 (49)
High	21 (33)	14 (38)
Cancer-related characteristics		
Diagnosis (N (%))		
Breast cancer	40 (62)	24 (65)
Cervix cancer	16 (25)	7 (19)
Ovarian cancer	4 (6)	4 (11)
Vulva cancer	3 (5)	1 (3)
Other	2 (3)	1 (3)
Number of co-morbidities (N (%))		
0	36 (55)	20 (54)
≥1	29 (45)	17 (46)
Surgery (N (%) yes)	54 (83)	30 (81)
Chemotherapy (N (%) yes)	35 (54)	24 (65)
Radiotherapy (N (%) yes)	45 (29)	21 (57)
Hormone treatment (N (%) yes)	22 (34)	16 (43)
Work-related characteristics		
Type of work (N (%) mainly physically work)	25 (39)	10 (27)
Type of contract (N (%))		
Permanent	58 (89)	32 (87)
Temporary	5 (8)	3 (8)
Self-employed	0	2 (5)
Other	2 (3)	0
Fatigue (MFI)** General fatigue (0–20)	12.5 ± 4.8	12.9 ± 4.7
Depression (CES-D)** Sum score (0–60)	12.9 ± 8.5	12.9 ± 8.3
Overall Quality of life (VAS-scale) (0–100)	63.0 ± 18.5	60.4 ± 23.9

Percentages do not always add up due to rounding. *Continuous variables: mean ± standard deviation; nominal and ordinal variables number and percentages. **Higher scores represent higher level of fatigue, feelings of depression, and better quality of life. MFI [27], CES-D [28].

pension, received unemployment benefits, was voluntarily unemployed, did volunteer work, was retired, or received training.

We considered a fluctuation in employment status when a participant went from being employed to not being employed, or vice versa, or when a participant went from one reason for not being employed to another (e.g. from unemployment benefits to disability pension).

2.3.2. Quality of life outcomes

Quality of life was measured with the Short Form 36 (SF-36) including all subscales [19] and a Visual Analogue Scale (VAS) assessing overall quality of life [20]. Both quality of life measures have been validated among cancer survivors [20, 21].

2.4. Statistical analysis

To describe the population, their employment status, and fluctuations in employment status, we used descriptive statistics.

When comparing responders with non-responders on baseline characteristics, a chi-square test was used in the case of a categorical variable and Student's *t*-test in the case of continuous variables. The significance level for these tests was ≤0.01. Differences in quality of life outcomes were assessed at all measurement points between those being employed and not being employed 5 years after cancer diagnosis using longitudinal multi-level analysis. All statistical analyses were performed with IBM SPSS Statistics version 20 [22].

Table 2
Overall quality of life between those reported being employed and not being employed 5 years after cancer diagnosis

		Group at 5 year follow-up	Baseline	1 year	2 years	3 years	5 years	P-value**	
Quality of life* (SF-36) (0–100) (N = 59)	Physical functioning	Employed	80.0 ± 3.3	82.2 ± 2.3	86.1 ± 2.1	83.1 ± 2.7	85.3 ± 3.0	<0.001	
		Not employed	81.4 ± 6.8	73.6 ± 4.7	74.2 ± 4.2	69.5 ± 5.7	65.9 ± 6.2		
	Role-physical	Employed	54.2 ± 6.3	55.3 ± 5.9	79.2 ± 5.8	70.3 ± 6.1	77.1 ± 5.8		0.002
		Not employed	59.1 ± 13.1	36.4 ± 12.2	52.3 ± 11.3	52.3 ± 12.8	40.9 ± 11.9		
	Vitality	Employed	59.1 ± 2.8	57.2 ± 2.6	61.9 ± 2.7	60.7 ± 2.9	61.7 ± 2.8		0.257
		Not employed	65.5 ± 5.9	53.2 ± 5.3	55.9 ± 5.3	56.8 ± 6.0	53.2 ± 5.9		
	General health	Employed	63.2 ± 2.3	66.5 ± 2.5	70.1 ± 2.8	66.7 ± 2.7	66.6 ± 3.1		0.025
		Not employed	65.5 ± 4.8	69.5 ± 5.2	55.9 ± 5.5	54.5 ± 5.7	56.3 ± 6.5		
	Social functioning	Employed	71.1 ± 3.3	80.3 ± 2.6	84.5 ± 2.9	78.4 ± 3.1	80.3 ± 3.2		0.028
		Not employed	79.5 ± 6.9	67.0 ± 5.5	79.5 ± 5.7	64.8 ± 6.6	69.3 ± 6.6		
	Role- emotional	Employed	47.2 ± 6.3	70.3 ± 5.7	77.0 ± 5.8	77.8 ± 5.8	80.1 ± 5.7		0.749
		Not employed	72.7 ± 13.1	75.8 ± 11.7	69.7 ± 11.4	66.7 ± 12.8	77.3 ± 11.7		
	Mental health	Employed	63.8 ± 2.3	74.4 ± 2.2	78.1 ± 2.3	76.4 ± 2.5	77.3 ± 2.4		0.061
		Not employed	66.2 ± 4.8	71.3 ± 4.6	66.2 ± 4.6	71.6 ± 5.2	72.0 ± 4.9		
	Pain	Employed	71.1 ± 4.1	77.2 ± 2.8	81.6 ± 3.1	77.0 ± 3.4	76.2 ± 3.7		0.003
		Not employed	67.2 ± 8.6	69.4 ± 5.7	667.0 ± 6.0	64.0 ± 7.1	62.5 ± 7.7		
	Quality of life* VAS (0–100) (N = 59)	Employed	63.5 ± 2.7	70.4 ± 2.5	73.7 ± 2.9	73.3 ± 2.5	76.1 ± 2.3		0.003
		Not employed	66.3 ± 5.6	69.5 ± 5.0	56.5 ± 5.7	65.9 ± 5.2	59.6 ± 4.9		
Work Ability Index (WAI) (0–10) (N = 59)	Employed	6.0 ± 0.4	6.9 ± 0.3	7.9 ± 0.3	7.6 ± 0.3	7.6 ± 0.2	<0.001		
	Not employed	6.1 ± 0.9	5.9 ± 0.5	6.2 ± 0.5	5.9 ± 0.6	6.2 ± 0.5			
Physical subscale (0–5)	Employed	3.7 ± 0.1	3.7 ± 0.1	4.0 ± 0.1	3.8 ± 0.1	3.8 ± 0.1	<0.001		
	Not employed	3.5 ± 0.3	3.2 ± 0.2	3.2 ± 0.2	3.2 ± 0.3	3.2 ± 0.3			
	Employed	3.2 ± 0.1	3.6 ± 0.1	3.9 ± 0.1	3.9 ± 0.1	3.9 ± 0.1		0.301	
	Not employed	3.9 ± 0.3	3.5 ± 0.2	3.5 ± 0.2	3.4 ± 0.3	3.4 ± 0.3			

Mean ± standard error; *Higher scores represent a higher level of functioning/well-being/quality of life and less pain. **P-value represents the effect of group.

3. Results

3.1. Participants

Of the 133 participants who were included in the associated randomised controlled trial [15], 65 were included in this prospective cohort study, excluding those who deceased during the follow-up period or were not able to invite to participate (Fig. 1). Reasons for not participating were: 13 deceased within 5 years of follow-up, 18 ended participation during the first two years of the randomised controlled trial or did not give consent to be contacted for potentially participation in further research, and 37 declined or gave no response to the invitation to participate in this prospective cohort study.

3.2. Descriptive data

No statistically significant differences between responders and non-responders were found on any of the descriptive variables (Table 1). Cancer diag-

oses included breast cancer (62.7%), cervical cancer (22.5%), cancer of the ovaries (7.8%) or vulva (3.9%), and other (2.9%).

3.3. Employment status and fluctuations in employment status

During the first two years after diagnosis, 63 (97%) participants were employed, this percentage declined to 59 (92%) and 48 (81%) after 3 and 5 years respectively. Reasons for not being employed included disability pension 2 (3%), unemployment 2 (3%), and voluntarily unemployed 1 (2%) at 3 years follow-up and unemployment 4 (7%), disability 2 (3%), voluntarily unemployed 2 (3%) and retirement 2 (3%) at 5 years follow-up.

Fifty-eight participants provided complete work-status information during all follow-up measurements. For this group 3 patterns of employment over time were observed. A total of 81% of the participants were employed at all-time points, while 12% and 5% moved from employed to unemployed after 5 and 3

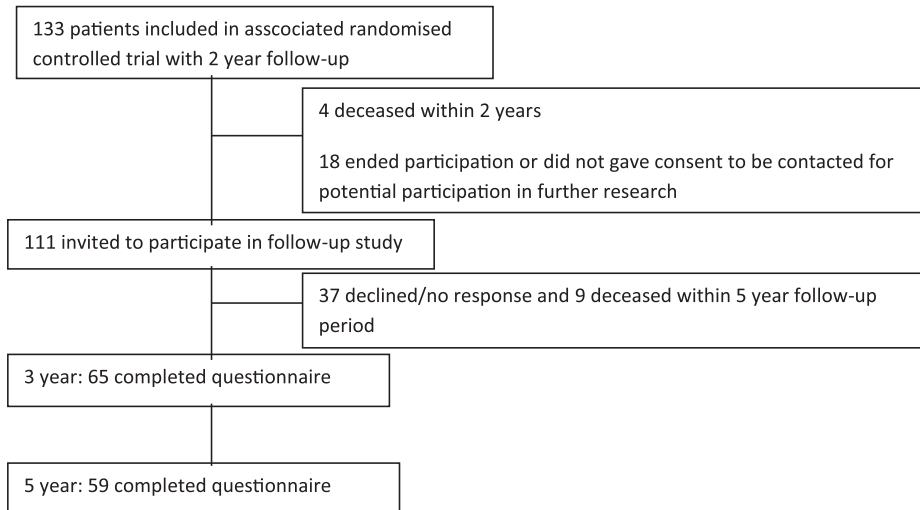


Fig. 1. Flowchart of the study.

years respectively, and 2% stayed unemployed during 2 to 5 years.

3.4. Quality of life

When comparing participants being employed at 5 years follow-up with participants not being employed we found that those being employed reported better quality of life on: overall quality of life, physical functioning, role-physical, and pain (Table 2). We found no interaction effect of being employed and time, or on improvement over time.

4. Discussion and conclusion

Our finding that employed cancer survivors 5 years after diagnosis had better quality of life outcomes compared to those not being employed support the importance of work for cancer survivors. The finding that employed cancer survivors have better quality of life outcomes 5 years after diagnosis, is in line with Timperi et al. (2013) [23] who employed a 2–8 months follow-up period, Mehnert and Koch, 2013 [24] who employed a 1 year follow-up period after rehabilitation, and Duijts et al. (2017) [12], who employed a 4 year follow-up period after cancer diagnosis. Although we employed a prospective cohort study, the direction of the relationship between quality of life and employment might be many-sided as being employed may enhance quality of life but a

certain level of quality of life (e.g. physical functioning) may be needed to be able to work. The first side is supported by Duijts et al. (2017) [12] who found that those experiencing a negative change in employment had worst quality of life outcomes compared to the continuously working cancer survivors. They furthermore found in their final model that quality of life measured at baseline was not statistically significant associated with employment one year later [12]. Additionally, this side is supported by the finding of Mehnert and Koch who found an association between quality of life and job satisfaction [24]. In contrast, our finding that the largest differences between employed and not employed cancer survivors were found for the SF-36 subscales physical functioning, role-physical and pain may suggest that a decline in health may have triggered changes in employment status. To be able to disentangle the relationship between quality of life and employment we therefore recommend for further research to collect data on quality of life and employment status on a very regular basis with a long follow-up period.

Our finding that the overall work ability and physical work ability of the WAI differs between employed and not employed cancer survivors but that these groups did not differ in mental work ability is in line with previous research [12]. This finding may support the need of a certain level of (self-assessed) physical functioning to be able to remain employed.

As we found a high percentage of the cancer survivors being employed, interventions supporting work outcomes should only be targeted at the popula-

tion at risk. The timing of such an intervention based on our results might possibly be during the first 2 years after cancer diagnosis as the major part of those having employment after two years stayed employed. The setting of such an intervention may be best as part of survivorship care as most patients have regular follow-up meetings with their specialised nurse or doctor at the hospital and work-related advice by health care professionals is associated with work outcomes [25]. Additionally, such an intervention should take into account cancer survivors who voluntarily wish to stop working.

Most likely, a selective population of cancer survivors able and willing to participate participated in our study. This assumption is supported by our finding of a comparatively high percentage of cancer survivors being employed 5 years after cancer diagnosis as compared to rates reported more often in the literature [26]. It is furthermore supported by our finding of three employment patterns while Duijts et al. [12] reported a fourth pattern consisting of cancer survivors who went from unemployment to employment. This selective population can be considered a major limitation of our study hampering the generalisability of our results to all cancer survivors 5 years after cancer diagnosis. Additionally, our small sample size limited the statistical strength of our analysis leading to more uncertainty in the results. For further research either using register-based data or specifically involving the population at risk in research could tackle this problem.

We found high employment rates and few fluctuations in employment status. Employed participants reported better quality of life outcomes. Survivorship care should therefore focus on the population at risk possibly within the first two years after diagnosis.

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Conflict of interest

None to report.

Ethics approval and consent to participate

Informed consent was obtained from all individual participants included in the study.

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