

PAPER

Cancer survivors' activation to self-management and its relationship with participation in paid work and work-related problems

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Abstract

Objective This study aimed to explore cancer survivors' level of patient activation, ie, their knowledge, skills, and confidence for self-management, and to examine its relations to their participation in paid work and work-related problems.

Methods A total of 524 Dutch cancer survivors, 208 younger than 65 years, completed the Patient Activation Measure (PAM-13) and the Research and Development (RAND-36) General Health scale. Cancer survivors younger than 65 years also reported on their participation in paid work and work-related problems.

Results The mean PAM-13 score of cancer survivors was 58.1, and of those younger than 65 years 58.7. Patient activation was not associated with participation in paid work. Employed cancer survivors with a low level of patient activation experienced more problems working accurately (34% vs 17%), finishing their work (47% vs 22%), and concentrating (59% vs 31%) than those with a higher level of patient activation. The former group also reported more work stress (62% vs 28%).

Conclusions Patient activation of cancer survivors deserves more attention, as a substantial proportion of these survivors have low activation levels, which relate to more work-related problems. Longitudinal studies are needed to explore the development of patient activation over time and its potential to improve important outcomes for people living with cancer in both the health and work domains.

KEYWORDS

cancer, cancer survivors, labour participation, oncology, patient activation

1 | BACKGROUND

Improvements in the early detection and treatment of cancer have substantially increased the number of cancer survivors.^{1,2} Among survivors of working age,³⁻⁵ returning to work is an important goal, as work could reduce depressive symptoms and provide a sense of normalcy.^{6,7} Studies have shown that many cancer survivors do return to work.^{5,8,9} However, the labour participation rate (ie, the proportion of the working-age population actually participating in the labour market) is lower among cancer survivors than among the general population,¹⁰ and compared with healthy controls, they are more likely to be unemployed.¹¹⁻¹³ Cancer survivors who are employed usually work less hours than they did before their diagnosis.^{8,12} This may be because of

long-lasting (treatment-induced) health problems such as fatigue or depression that hinder their work performance.^{12,14-17}

Although many cancer survivors encounter work-related problems,¹⁸ there seems to be substantial variety in the extent to which they succeed in participating in the labour market. Illness-related characteristics including the type of cancer, treatment, illness duration, and comorbidity play a role in this respect, in addition to sociodemographic characteristics such as gender, age, and education level.^{8,12} In addition, work-related factors, such as the type of work or support received from the employer, influence cancer survivors' labour participation.^{12,19} Unfortunately, it is difficult to intervene on many of these factors.

Interventions to help cancer survivors participate in paid work might benefit from the insights gained by health behaviour and lifestyle

interventions, which focus on behavioural determinants proven to be modifiable, such as motivation, attitude, and self-efficacy (eg, Teixeira et al²⁰ and Greaves et al²¹). Duijts and colleagues recommend in their review to focus on cancer survivors' attitudes and values regarding work, their perceptions of social support, and their self-efficacy, while also accounting for (theoretical) stages of change, when developing work-related interventions.²² In this study, we contribute to these insights by exploring the concept of patient activation in relation to cancer survivors' participation in paid work.

Patient activation has been described by Hibbard and colleagues as "all the knowledge, skills and confidence a person has to manage his own health and health care."²³ In studies among chronically ill people, patient activation has been proven to positively relate to self-monitoring symptoms, maintaining adherence to treatment regimens and making lifestyle changes.^{24–29} However, whether this also applies to cancer survivors' self-management is unknown, as their self-management may (partially) involve other tasks. For instance, van Houtum and colleagues³⁰ showed that cancer patients face more tasks in coping with their condition than patients with (other) chronic diseases, who seem to place more emphasis on the medical management of their condition and lifestyle changes. Moreover, until now, little attention has been paid to the role that patient activation may play in people's self-management in other life domains, such as work. We found 1 study showing that higher activation of employees in the United States positively related to presenteeism, defined as a person's self-assessed job performance.^{31,32} In that study, positive associations with patient activation were also found for self-rated health, which might suggest that (perceived) health may mediate the relationship between patient activation and job performance. The promising results of this study inspired us to explore the relationship between patient activation and cancer survivors' participation in paid work and the potential mediating role of self-rated health.

We addressed the following research questions:

1. How are patient activation levels distributed among cancer survivors and among cancer survivors of working age?
2. Are cancer survivors' activation levels related to their participation in paid work, and to what extent is this relationship mediated by their self-rated health?
3. Are activation levels of employed cancer survivors related to the extent to which they experience work-related problems?

2 | METHOD

2.1 | Study sample

We used data from a panel study on cancer patients' perspectives and experiences conducted in the Netherlands.³³ Inclusion criteria were (1) being diagnosed with a type of cancer with an expected 5-year survival rate of at least 20% and (2) being 18 years or older at diagnosis. Exclusion criteria were (1) being diagnosed more than 15 years prior to the study and (2) having distant metastases at diagnosis. Based on these criteria, samples were drawn from the

Netherlands Cancer Registry in 2011 (N = 1500) and 2012 (N = 2250). The selected persons were presented to their (former) oncologists to assess additional exclusion criteria, ie, inability to participate because of (3) terminal illness, (4) severe mental disorder, (5) intellectual disability, or (6) insufficient literacy to participate in postal surveys. In addition, some oncologists decided to exclude persons they were no longer seeing, as they felt unsure about their current health status. This procedure resulted in 1697 eligible persons (893 in 2011 and 804 in 2012). The reasons for excluding a patient were not registered by the oncologists. All persons who were found eligible received written information about the panel study and were asked to participate in 2 surveys a year for a period of 4 years.

Of the 1697 eligible persons, 761 (44.8%) gave informed consent. Since we lost panel members over the years (predominantly because of death and severe illness), we sent a questionnaire including questions about participation in paid work in November 2013 to 642 panel members. A total of 533 people responded (83%); 524 of whom had been examined with cancer more than 2 years prior to inclusion. Of these cancer survivors, 459 (88%) also participated in the survey of May 2013, which included questions about patient activation.

The study was conducted according to the precepts of the Helsinki Declaration, Dutch legislation on privacy, and the regulations of the Dutch Data Protection Authority. So as to use the Netherlands Cancer Registry, the panel study was approved by the privacy committee of the Netherlands Cancer Registry.

2.2 | Measures

2.2.1 | Patient activation

Patient activation was assessed^{34,35} with the short form Patient Activation Measure (PAM-13). The 13 items assess people's knowledge, skills, and confidence in self-management, with 5 response options: (1) "strongly disagree," (2) "disagree," (3) "agree," (4) "strongly agree," and (0) "not applicable." Patients' activation scores were calculated according to the official guidelines,³⁶ resulting in standardized scores ranging from 0 to 100. Higher scores indicate that people are more activated. Cronbach alpha was .84, indicating good reliability.

Based on the PAM scores, respondents were classified into 4 levels: level 1, "individual does not yet grasp the need to play an active role"; level 2, "individual has the confidence and knowledge necessary to take action"; level 3, "individual actually takes action and knows how to prevent further problems"; and level 4, "individual has adopted new behaviours but may not be able to maintain them under stress."²³

2.2.2 | Participation in paid work and work-related problems

Respondents younger than 65 years reported the number of hours per week they performed paid work, as an employee and/or self-employed (from now on referred to as being employed). On the basis of this, we constructed the variable "labour participation" in accordance with the definition of Statistics Netherlands,³⁷ ie, being employed for at least 12 hours per week. As having any paid work may be more important for quality of life, we also constructed the variable "participation in paid work," ie, being employed regardless of the number of hours of work.

Respondents who were employed also rated the extent (0 = none, 1 = some, 2 = much, 3 = very much) to which they experienced 9 problems in their paid job, ie, problems with travelling to work, moving at work, reading, working accurately, understanding others, feeling fatigued/a lack of energy, experiencing work stress, finishing work, and concentrating. For descriptive purposes, the scores were dichotomized: 0 (none) vs 1 (to some extent, much, very much).

2.2.3 | Sociodemographic and illness-related characteristics

Age, gender, education level, living with or without a partner, and comorbidities were self-reported by the participants. To assess the presence of comorbidity, we used the Checklist Chronic Conditions (version 2001) of Statistics Netherlands,³⁸ which consists of 19 common chronic conditions including cancer. In our survey, we left out the item on cancer. Respondents indicated the presence or absence of each of the conditions over the past year. On the basis of this, we created a dichotomous variable: comorbidity present or not.

Type of tumour, time since diagnosis, and cancer treatment were derived from the Netherlands Cancer Registry. When registration data were missing (varying between $n = 38$ and $n = 52$), we imputed self-reported data from the patient survey. In the survey, we also included a question about whether the respondent had visited a hospital for cancer treatment or follow-up over the past year.

2.2.4 | Self-rated health

To assess perceived health, we used the General Health scale³⁹ of the RAND-36 (validated Dutch version⁴⁰). This scale consists of 5 items scored on 5-point Likert scales and assesses the overall subjective evaluation of one's health. In accordance with the guidelines, respondents' scores on the 5 items were summed and transformed to a scale from 0 to 100, with higher scores indicating more favourable health. Cronbach alpha was .82, indicating good reliability.

2.3 | Data analysis

We computed patient activation scores and the distribution of respondents over the 4 PAM levels for the total sample and the subsample of people younger than 65 years. To gain more insight, we also cross-tabulated the distribution of respondents over the 4 PAM levels according to their sociodemographic and illness-related characteristics. In addition, we computed the percentage of respondents younger than 65 who participated in paid work and the frequency at which employed persons experienced work-related problems (to some extent, much, or very much).

Next, we conducted bivariate analyses (see Supporting Information), followed by logistic regression analyses. Since we were interested in whether patient activation could be a point of action to support reintegration, we estimated the effect of patient activation on participation in paid work (ie, working in a paid job or not). We generated a first model with patient activation as a continuous, independent variable and participation in paid work as the dichotomous dependent variable (model 0). Next, sociodemographic characteristics and illness-related characteristics were added to the model (model 1). Type of cancer treatment and whether respondents were still visiting

the hospital for cancer treatment or follow-up were not included in model 1, because these variables did not relate to either patient activation or participation in paid work. To examine whether self-rated health mediated the relationship between patient activation and participation in paid work, we estimated the effect of patient activation (as a continuous independent variable) on self-rated health (as a continuous dependent variable) by using linear regression analysis. Subsequently, we estimated a final logistic regression model (model 2) predicting participation in paid work by adding self-rated health as a continuous independent variable.

We calculated the percentages of employed cancer survivors who experienced work-related problems and conducted chi-square tests to estimate whether the frequency of experienced problems differed between persons with a low (1 or 2) and high (3 or 4) level of patient activation (question 3). In all analyses, statistical significance was set at $P < .05$.

3 | RESULTS

3.1 | Sample characteristics

The sample consisted of 271 men and 253 women with a mean age of 66 years (see Table S1). Breast cancer (23.5%) and cancer of the digestive system (20.2%) were the most prevalent types of cancer. Almost half of all participants had been examined 2 to 5 years prior to the study. Most participants had undergone surgery in combination with some other type of treatment or surgery only. About a fifth still visited a hospital for cancer treatment or follow-up care.

3.2 | Patient activation

Of the 459 cancer survivors who participated in the survey of May 2013, PAM scores could be computed for 417 (38 were excluded because they responded to less than 7 items and 4 because they answered all items with "strongly disagree"). The mean score of this sample was 58.1 (SD = 13.8, $N = 417$). Most respondents were categorized at activation level 3 (33.6%), about a quarter at either level 2 (24.0%) or 4 (24.0%), and the fewest at level 1 (18.5%). Patient activation was related to age and education level (see Table S2).

The mean PAM score of the respondents younger than 65 years was 58.7 (SD = 15.6, $N = 163$). Most of these younger survivors were categorized at level 3 (29.4%) or 4 (28.8%). However, a substantial proportion (more than in the total sample) were also categorized at level 1 (22.7%), and the remaining at level 2 (19.0%).

3.3 | Participation in paid work and work-related problems

Of the respondents younger than 65 years ($N = 208$), 60.6% reported that they worked, but only 55.8% worked at least 12 hours a week and could thus be considered to participate in the labour market. These people worked on average 30.6 hours a week (SD = 10.0), and the great majority worked for an employer (85.7%). More than half of the persons with paid work reported problems with working due to fatigue or a lack of energy (53.3%) (Table 1, left side). Additionally, problems

TABLE 1 Work-related problems of employed cancer survivors (N = 126), total sample and according to patient activation level: low (PAM level 1 or 2) versus high (PAM level 3 or 4)

Problems:	Employed Cancer Survivors N = 122-125 %	Low Level of Patient Activation N = 40 %	High Level of Patient Activation N = 59 %	Low versus High Activation Level $\chi^2(1)$ P
Travelling to work	9.8	7.9	11.9	.53
Moving at work	8.2	10.5	6.8	.51
Reading	14.8	18.4	15.3	.68
Working accurately	22.8	34.2	16.9	.05
Understanding others	8.2	10.5	8.5	.73
Fatigue/lack of energy	53.3	69.2	50.8	.07
Work stress	37.9	61.5	27.6	.001
Finishing work	32.5	47.4	22.4	.01
Concentrating	38.4	59.0	30.5	.005

Abbreviation: PAM, Patient Activation Measure.

N, total number of respondents; %, proportion of the total number of respondents; χ^2 , Chi-square test statistic; P, statistical significance of evidence.

with concentrating (38.4%), work stress (37.9%), and finishing work (32.5%) were frequently reported.

3.4 | Patient activation and participation in paid work

Patient activation was not related to whether cancer survivors younger than 65 years participated in paid work (Table 2). Model 2 shows that a high education level (compared to a low level), a diagnosis of breast cancer (compared with a diagnosis of other types of cancer) and better self-rated health significantly increased the likelihood of participation in paid work. Although patient activation was positively related to self-rated health ($\beta = .28, P < .001$), self-rated health did not mediate the relationship between patient activation and participation in paid work, as the (nonsignificant) regression coefficient of patient activation did not substantially change after adding self-rated health to the model. Hence, self-rated health had an additive effect on participation in paid work.

3.5 | Patient activation and work-related problems

Table 1 (right side) shows that a larger proportion of employed cancer survivors with a low level of patient activation experienced work stress and problems working accurately, finishing work, and concentrating than of the employed survivors with a high activation level. Persons at a high activation level also seemed to experience fatigue or a lack of energy less often (51%) than persons with a low activation level (69%), although the difference was of borderline significance ($P = .07$), and fatigue/lack of energy was a frequent problem in both groups.

4 | DISCUSSION

The purpose of our study was to explore patient activation among cancer survivors and to examine its relations to participation in paid work and work-related problems. Regarding patient activation, the mean scores found in the total sample (58.1) and in the sample of people younger than 65 years (58.7) were relatively low compared with the

mean scores of a sample of Dutch patients with a variety of somatic chronic diseases (61.3 in total sample; 61.5 [<55 y] and 62.4 [$55-64$ y]).³⁵ The mean scores of our cancer survivors were also relatively low compared to Danish and American samples of chronically ill people.^{41,42} Furthermore, 58% of both the total sample and the sample younger than 65 years had a high level (3 or 4) of patient activation. These percentages were again relatively low compared to percentages found among Dutch chronic disease patients (63% of the total sample, 63% of patients younger than 55 years, and 66% of patients aged 55-64 years).³⁵ It may be that the concept is less salient to cancer survivors, as patient activation is defined as "taking an active role in healthcare,"²³ whereas the great majority of the cancer survivors in our sample had not visited a hospital for their cancer in the past year. However, the level of patient activation was not related to whether respondents still visited a hospital for cancer treatment or follow-up nor to the time since diagnosis. Moreover, an increased use of primary care, even years after active cancer treatment, has been demonstrated among Dutch cancer survivors,⁴³ which suggests that taking an active role in health care remains relevant for cancer survivors. So as to gain more insight in the relevance of patient activation over time, longitudinal studies are needed to assess patient activation in every phase of a cancer patient's illness trajectory.

We expected higher activation scores to increase the likelihood that cancer survivors would participate in paid work and that this would be explained by higher activated people feeling healthier (as a result of better health behaviours) and thus being more capable of participating in paid work. However, patient activation was not related to participation in paid work. This may be explained by the fact that one's participation in paid work is often the result of decisions made in the past.¹⁰ This would imply that patients' activation levels in the first years after diagnosis, when decisions to return to work or to leave the labour market are made, may be more important for their actual work status than their current level of patient activation. Considering this, it seems well explainable that patient activation was related to the extent to which employed cancer survivors experienced work-related problems rather than to whether cancer survivors participated in paid work at all.

TABLE 2 Logistic regression models predicting the likelihood of cancer survivors (18-64 y) to participate in paid work

	Model 0 (N = 160)			Model 1 (N = 148)			Model 2 (N = 145)		
	B (SE)	P	Odds Ratio (95% CI)	B (SE)	P	Odds Ratio (95% CI)	B (SE)	P	Odds Ratio (95% CI)
Patient activation	0.02 (0.01)	.120	1.02 (1.00-1.04)	0.02 (0.01)	.145	1.02 (0.99-1.05)	0.02 (0.02)	.296	1.02 (0.99-1.05)
Gender									
Female (ref: male)				-0.49 (0.54)	.359	0.61 (0.22-1.75)	-0.58 (0.55)	.296	0.56 (0.19-1.65)
Age (years)									
Age (years)				-0.85 (0.53)	.110	0.43 (0.15-1.21)	-0.93 (0.56)	.095	0.39 (0.13-1.18)
Education level									
(ref: low)									
Mid				0.99 (0.54)	.067	2.69 (0.93-7.77)	0.81 (0.55)	.139	2.25 (0.77-6.63)
High				1.09 (0.58)	.058	2.98 (0.97-9.18)	1.15 (0.58)	.048	3.16 (1.01-9.92)
Living with a partner									
Yes (ref: no)				0.63 (0.52)	.226	1.87 (0.68-5.17)	0.45 (0.54)	.402	1.57 (0.55-4.51)
Type of tumour									
(ref: other)									
Breast				1.66 (0.56)	.003	5.25 (1.77-15.57)	1.40 (0.57)	.015	4.05 (1.32-12.43)
Digestive system				1.72 (0.78)	.028	5.59 (1.21-25.81)	1.36 (0.81)	.092	3.90 (0.80-19.03)
Male reproductive organs				-0.24 (0.73)	.748	0.79 (0.19-3.30)	-0.50 (0.76)	.512	0.61 (0.14-2.69)
Skin (excl. Basal cell carcinoma)				0.55 (0.56)	.325	1.74 (0.58-5.20)	0.07 (0.60)	.910	1.07 (0.33-3.46)
Time since diagnosis (ref: 2-5 y)									
5-10 y				-0.79 (0.41)	.053	0.46 (0.21-1.01)	-0.74 (0.42)	.075	0.48 (0.21-1.08)
≥10 y				0.37 (0.71)	.603	1.44 (0.36-5.78)	0.41 (0.74)	.580	1.51 (0.35-6.42)
Comorbidity									
Present (ref: absent)				-0.07 (0.43)	.867	0.93 (0.40-2.15)	0.15 (0.45)	.738	1.16 (0.49-2.78)
General health									
							0.02 (0.01)	.049	1.02 (1.00-1.04)

N, total number of respondents; B, regression coefficient; SE, standard error; P, statistical significance of evidence; CI, confidence interval; ref., reference category.

Employed cancer survivors at a high level of patient activation experienced less work-related problems than working cancer survivors with a low activation level. The reported problems suggest that job performance in particular positively relates to patient activation, which is in line with the findings of the study by Fowles and colleagues.³¹

4.1 | Study limitations

Although the Netherlands Cancer Registry can be considered a good sampling frame because it covers (nearly) the whole Dutch population diagnosed with cancer, we could not invite all randomly selected persons to participate in the study. This was partly as intended, as we used some necessary exclusion criteria that had to be assessed by the (former) oncologists of the selected persons. However, some oncologists decided to exclude all persons whom they were no longer seeing, because they felt unsure about their current health status. As this approach excluded cancer survivors who had been diagnosed more than 5 years prior to the study and who no longer needed supervision in particular, this may have caused selection bias. Comparing our participants with the target population (information from the Netherlands Cancer Registry), it showed indeed that a larger proportion of our participants had been examined less than 5 years before the study (49% vs 40% of the target population). In addition, our participants were older, but similar to the target population with respect to gender and tumour type.

We used a limited number of self-developed items to explore cancer survivors' work-related problems, as the survey used in the panel study had to cover many other themes. Future studies may benefit from a more extensive, validated instrument to assess these problems. Finally, the design of our study did not allow causal conclusions. Although patient activation was assessed 6 months before assessing respondents' participation in paid work, we lacked information about the respondents' work status prior to measuring their activation level as well as other (exogenous) factors that could have influenced both patient activation and participation in paid work.

4.2 | Clinical implications

Some insights gained in this study could already be applied by employers of cancer survivors and by health care professionals who see employed cancer survivors. The relatively low level of patient activation and its associations with work-related problems underline the importance of paying attention to patient activation, whereas employer-based health promotion programmes have shown the potential to increase patient activation among employees.³² Strategies to increase patient activation may include problem solving, providing feedback, using action plans, building skills, strengthening support, and providing psychological counselling. Which of these strategies works best cannot be determined in advance²⁴; as a general rule, we recommend tailoring the strategies to the specific characteristics of the individual cancer survivors, their health, and the work context, as well as to their level of patient activation in stages of change, skills, and self-confidence.

5 | CONCLUSIONS

A substantial proportion of cancer survivors experience low levels of patient activation, and activation level is related to the experience of work-related problems. Whether it is also related to cancer survivors' chances of participating in paid work remains unclear. In addition to the need to study patient activation longitudinally, it would be interesting to conduct prospective studies assessing both patient activation and participation in paid work at several time points in the illness trajectory of cancer patients. Through this approach, the role of patient activation in decision making about participation in paid work could be clarified.

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CONFLICT OF INTEREST

The authors declare that they have no competing interests.

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SUPPORTING INFORMATION

Additional Supporting Information may be found online in the supporting information tab for this article.

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