


Optimistic, Realistic, and Pessimistic Illness Perceptions; Quality of Life; and Survival Among 2457 Cancer Survivors: The Population-Based PROFILES Registry

Belle H. de Rooij, MSc^{1,2} ; Melissa S.Y. Thong, PhD³; Janneke van Rooij, MSc²; Cynthia S. Bonhof, MSc²; Olga Husson, PhD⁴; and Nicole P.M. Ezendam, PhD^{1,2}

BACKGROUND: Threatening illness perceptions (IPs) have been associated with poorer health outcomes. However, to the authors' knowledge, it remains unclear whether threatening IPs that are consistent with disease severity are equally harmful. The aim of the current study was to: 1) identify subgroups of cancer survivors based on IPs and prognosis; and 2) assess the health-related quality of life (HRQOL) and survival associated with these subgroups. **METHODS:** The authors used survey data from the population-based Patient Reported Outcomes Following Initial treatment and Long term Evaluation of Survivorship (PROFILES) registry, which were collected between 2008 and 2015 and included 2457 cancer survivors who were <5 years after their cancer diagnosis (colon, rectal, prostate, endometrial, or ovarian cancer or non-Hodgkin lymphoma). Clinical and survival data were collected through the Netherlands Cancer Registry. Subgroups were defined by IPs (Brief Illness Perception Questionnaire) and prognosis (conditional 5-year relative survival) into survivors with 1) IPs consistent with prognosis ("realistic"); 2) less threatening IPs than expected based on prognosis ("optimistic"); and 3) more threatening IPs than expected based on prognosis ("pessimistic"). **RESULTS:** Compared with survivors with realistic IPs (1230 survivors), those with optimistic IPs (582 survivors) were found to have a higher HRQOL ($P < .01$ on all European Organization for the Research and Treatment of Cancer Quality of Life Questionnaire Core 30 [EORTC QLQ-C30] scales) and a lower all-cause mortality (hazard ratio, 0.72; $P < .01$), whereas those with pessimistic IPs (645 survivors) had a lower HRQOL ($P < .01$ on all scales) and a higher all-cause mortality (hazard ratio, 1.52; $P < .01$). **CONCLUSIONS:** Optimistic IPs are associated with better HRQOL and survival, even if they may appear to be unrealistic with respect to cancer survivors' prognosis. Survivors with pessimistic IPs appear to have the worst outcomes. Therefore, efforts are needed to provide better support to patients with pessimistic IPs to improve their outcomes. *Cancer* 2018;124:3609-17. © 2018 The Authors. *Cancer* published by Wiley Periodicals, Inc. on behalf of American Cancer Society. This is an open access article under the terms of the Creative Commons Attribution-NonCommercial-NoDerivs License, which permits use and distribution in any medium, provided the original work is properly cited, the use is non-commercial and no modifications or adaptations are made.

KEYWORDS: cancer survivors, health-related quality of life (HRQOL), illness perceptions (IPs), prognosis, survival.

INTRODUCTION

The illness perceptions (IPs) of patients, comprising both cognitive and emotional responses to their illness, are increasingly being studied in relation to physical and psychological outcomes.¹ Threatening IPs, such as concern regarding the disease and the number of symptoms experienced, have been associated with poor health-related quality of life (HRQOL), psychological morbidities, and low survival among cancer survivors.²⁻¹⁰ These findings suggest that having threatening IPs affects survivors' outcomes. However, IPs may accurately reflect a patient's true disease status, indicating that the associations between IPs and outcomes largely are explained by disease severity (ie, prognosis).⁴ Conversely, patients also could hold more optimistic or pessimistic beliefs regarding their disease that are not consistent with disease severity or prognosis.

The IPs of cancer survivors may become more concordant with disease severity or prognosis when these individuals receive explicit information regarding the diagnosis, side effects, and prognosis of their cancer.¹¹⁻¹³ In patients with cancer who are receiving palliative care, realistic perceptions of prognosis may contribute to acceptance of the disease and its consequences, without the patients being disappointed with or frustrated by unachievable expectations.¹⁴⁻¹⁶ However, to the best of our knowledge, the advantages of realistic IPs among cancer survivors remain unclear. Efforts to investigate

Corresponding author: Belle H. de Rooij, MSc, Center of Research on Psychology in Somatic Diseases (CoRPS), Department of Medical and Clinical Psychology, Tilburg University, Warandelaan 2, PO Box 90153, 5000 LE Tilburg, the Netherlands; b.h.derooij@uvt.nl

¹Center of Research on Psychology in Somatic Diseases (CoRPS), Department of Medical and Clinical Psychology, Tilburg University, Tilburg, the Netherlands;

²The Netherlands Comprehensive Cancer Organisation, Utrecht, the Netherlands; ³Department of Medical Psychology, Academic Medical Center, University of Amsterdam, Amsterdam Public Health Research Institute, Amsterdam, the Netherlands; ⁴The Institute of Cancer Research and the Royal Marsden NHS Foundation Trust, London, United Kingdom

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the benefits of realistic, pessimistic, or optimistic IPs relative to prognosis among cancer survivors may provide insights into survivors' perspectives, and may provide information with which to guide information provision and support to those at risk of physical and emotional symptoms.

In a large observational cohort of cancer survivors with various cancer diagnoses, we sought to identify subgroups of survivors with realistic, pessimistic, or optimistic IPs relative to prognosis at the time of the questionnaire. In addition, we aimed to assess the HRQOL and survival associated with these subgroups. In parallel with literature demonstrating the benefits of prognostic awareness in patients receiving palliative care,^{14,15} we hypothesized that realistic IPs among cancer survivors are associated with better outcomes compared with either optimistic or pessimistic IPs.

MATERIALS AND METHODS

Design/Setting

We used data from the Patient Reported Outcomes Following Initial treatment and Long term Evaluation of Survivorship (PROFILES) registry.¹⁷ Patient-reported outcomes are collected within a sampling frame of the Netherlands Cancer Registry (NCR) and can be linked with clinical data from all individuals newly diagnosed with cancer in the Netherlands.

Data Collection

A detailed description of the data collection has been presented previously.¹⁷ In brief, in each study sample, cancer survivors were informed about the study via a letter from their attending specialist. This letter contained either an informed consent form and a paper questionnaire or a secured link to a Web-based informed consent form and online questionnaire. In study samples in which the secured link was provided, the patient could return a postcard to request a paper-and-pencil questionnaire if preferred. Data from the PROFILES registry are freely available for noncommercial scientific research, subject to study question, privacy and confidentiality restrictions, and registration (www.profileregistry.nl).

Study Population

The current analysis included 5 study samples from the PROFILES registry for which data were available regarding dependent and independent variables. Only short-term cancer survivors (<5 years after diagnosis) were included, because, among long-term cancer survivors, the IPs may be less likely to be related to the cancer diagnosis

and more likely the consequence of comorbid conditions. Cancer types included colon, rectal, prostate, endometrial, and ovarian cancer as well as non-Hodgkin lymphoma. In all study samples, a core set of the same questionnaires was used, with inclusion between May 2009 and March 2014. Participants were excluded if they were not able to complete a Dutch questionnaire according to their (ex-)attending specialist (ie, due to cognitive impairment, being a non-native speaker, being too ill to participate). Also excluded were individuals who died or emigrated before the initiation of the study, according to data from the hospital of diagnosis and/or data from the Dutch municipal personal records database (ie, mortality and residential data from all citizens through municipal registries). Ethical approval was obtained for all study samples separately from a local certified medical ethics committee.

Measures

Clinical data, such as the date of diagnosis, tumor type, tumor stage, and primary treatments received were obtained from the NCR. The NCR routinely collects data concerning newly diagnosed patients with cancer in all hospitals in the Netherlands. Tumor type was classified according to the *International Classification of Diseases for Oncology, 3rd Edition* (ICD-O-3),¹⁸ and cancer stage was classified according to the TNM¹⁹ or Ann Arbor (Non-Hodgkin lymphoma) staging system. Primary treatments received were classified as surgery, systemic therapy (chemotherapy, targeted therapy, or immune therapy), radiotherapy (including brachytherapy), hormone therapy, no treatment/active surveillance, or unknown. The time from diagnosis at the time of questionnaire invitation was categorized into quartiles (0-2 years, 2-3 years, 3-5 years, and >5 years). Sociodemographic information (ie, educational level, marital status, employment status, and comorbidity) was assessed in the questionnaire. Marital status ("married/living together" vs "divorced/widowed/never married") and employment status ("having a paid job" vs "not having a paid job") were dichotomized. Comorbidity was assessed using the adapted Self-Administered Comorbidity Questionnaire and categorized into no comorbidities, 1 comorbidity, or > 1 comorbidities.²⁰ Comorbidities included heart disease, stroke, hypertension, airway disease (asthma, chronic bronchitis, or chronic obstructive pulmonary disease), diabetes, stomach disease, kidney disease, liver disease, anemia or other blood disease, thyroid disease, depression, arthritis, back pain, and rheumatic disease.

The Brief Illness Perception Questionnaire (BIPQ) was used to assess IPs.²¹ The BIPQ includes 8 items.

Test-retest reliability (Pearson correlations, 0.42-0.75) of the items is reported to be fair.²¹ Similar to earlier studies,²²⁻²⁵ a 2-factor structure was found using principal components factor analysis. A multi-item scale was computed of 5 BIPQ items selected through the factor analysis (factor loadings >0.70), and included consequences (“How much does your illness affect your life?”), timeline (“How long do you think your illness will continue?”), identity (“How much do you experience symptoms from your illness?”), concern (“How concerned are you about your illness?”), and emotional response (“How much does your illness affect you emotionally?”). A multi-item scale was computed of these items by averaging the item scores, when ≤ 1 item response was missing. The internal validity of the scale was good (standardized Cronbach alpha, .85). Higher scores indicated more threatening IPs.

Prognosis at the time of the questionnaire was determined by conditional 5-year relative survival (ie, the probability of surviving an additional 5 years on the condition that the patient has survived x number of years after diagnosis). Estimates were calculated using data from the NCR, including mortality data from patients diagnosed between 1989 and 2008 who were followed for up to 15 years, and were determined by years survived after diagnosis, tumor type, tumor stage, age group (ages 15-44 years, ages 45-59 years, ages 60-74 years, and ages 75-89 years), and sex. Conditional relative survival data from the NCR has been described previously for colorectal²⁶ and prostate²⁷ cancer as well as for non-Hodgkin lymphoma.²⁸ For survivors of endometrial and ovarian cancer in the current study sample who were included within 1 year after diagnosis, the 5-year survival at the time of diagnosis by cancer stage was determined (www.cijfersoverkanker.nl).

To create the optimistic, realistic, and pessimistic IPs groups, the sample was divided into conditional 5-year relative survival strata (<60%, 60%-69%, 70%-79%, 80%-89%, and 90%-100%). Then, in each stratum, quartiles of BIPQ multi-item scores were defined. Survivors with the lowest quartile of BIPQ scores in their stratum (<25%) were allocated to “pessimistic” IPs, those with interquartile scores (25%-75%) were allocated to “realistic” IPs, and those with the highest quartile (>75%) were allocated to “optimistic” IPs (Table 1).

The European Organization for the Research and Treatment of Cancer Quality of Life Questionnaire Core 30 (EORTC QLQ-C30; version 3.0) was used to assess HRQOL among the participants.²⁹ The scores were linearly transformed into a score between 0 and 100.³⁰ Higher scores on the functioning scales indicated better functioning and global QOL, whereas higher scores on the symptom scales indicated more symptom complaints and financial difficulties. Vital status and date of death data were obtained from the Dutch municipal personal records database and last were verified on February 1, 2017. Anxiety and depression were measured in survivors of colon cancer, rectal cancer, and lymphoma using the Hospital Anxiety and Depression Scale (HADS).³¹ The HADS assesses separate anxiety and depression scales, both of which consist of 7 items. Higher scores indicate more anxiety and depressive symptoms.

Statistical Analysis

Statistical analyses were conducted using SAS statistical software (version 9.4; SAS Institute Inc, Cary, North Carolina). Frequencies with percentages and means with standard deviations were used to describe the baseline characteristics, and chi-square tests, independent Student

TABLE 1. Group Allocation of Survivors Into Optimistic, Realistic, and Pessimistic IPs Within 5-Year Conditional Survival Strata

Prognosis at time of questionnaire (conditional 5-y relative survival ^b)	No. Total=2457	Quartiles of IPs Scores ^a		
		<25 th : Optimistic N=582	25 th -75 th : Realistic N=1230	>75 th : Pessimistic N=645
<60%	148	<4.4	4.4-7.3	>7.3
60%-69%	234	<2.4	2.4-6.2	>6.2
70%-79%	384	<2.4	2.4-5.8	>5.8
80%-89%	806	<2.6	2.6-6.0	>6.0
90%-100%	885	<2.0	2.0-5.2	>5.2

Abbreviation: IPs, illness perceptions.

^aThe IPs score was based on the average of Brief Illness Perception Questionnaire (BIPQ) scores (1-10) of items selected in factor analysis (consequences, timeline, identity, concern, and emotional response). A higher score indicates a more threatening IPs.

^bThe probability of surviving an additional 5 years on the condition that the patient has survived x number of years after diagnosis, based on years survived from diagnosis, tumor type, tumor stage, age group, and sex.

t tests, and Mann-Whitney *U* tests were used to test the differences between patients with optimistic, realistic, and pessimistic IPs. *P* values < .05 were considered to be statistically significant.

Correlations were computed to assess whether BIPQ items were interrelated with HRQOL scales. General linear models were conducted to assess differences in HRQOL between survivors with optimistic, realistic, and pessimistic IPs. Bonferroni-corrected pairwise comparisons were made to compare survivors with optimistic versus realistic IPs and pessimistic versus realistic IPs, adjusted for a priori selected covariates (age at the time of the questionnaire, sex, educational level, years from diagnosis, tumor type, tumor stage, treatment [surgery, radiotherapy, or systemic therapy], number of comorbidities, employment, and marital status). Additional analyses were adjusted for anxiety and depression.

Kaplan-Meier curves were conducted to show differences in survival between the 3 subgroups. A Cox proportional hazards regression model was performed to assess differences in survival between patients with optimistic, realistic, and pessimistic IPs. The survival duration was specified as the time from the questionnaire until either death or the censoring date (February 1, 2017). To adjust for survivorship bias, a variable with the left truncation time (time between diagnosis and questionnaire) was added as an argument and the time of the questionnaire was set as the entry time. In addition, the model was adjusted for covariates controlling for factors influencing survival (age at the time of the questionnaire, sex, educational level, tumor type, tumor stage, treatment [surgery, radiotherapy, or systemic therapy], number of comorbidities, employment, and marital status).

RESULTS

A total of 3882 cancer survivors were invited to participate in 1 of the 5 studies, 2744 of whom (71%) returned the questionnaire. The current analysis included 2457 cancer survivors (63%) for whom no data were missing regarding the grouping variable (tumor stage to determine prognosis, BIPQ scale) (see Supporting Fig. 1). Cancer survivors were classified into those with optimistic (582 survivors), realistic (1230 survivors), and pessimistic (645 survivors) IPs (Table 1).

Compared with survivors with realistic IPs, those with optimistic IPs tended to be older, were more often male, were more often survivors of colon cancer and less often survivors of rectal and ovarian cancer, had lower stages of disease, had fewer comorbidities, and were less

often employed. Survivors with pessimistic IPs tended to be younger, were more often female, were more often less educated, were less often survivors of colon cancer and more often survivors of rectal cancer, had more comorbidities, less often had a partner, and more often received radiotherapy (Table 2).

Correlations between BIPQ items that were included in the IPs scale were weak to moderate (correlation coefficient, -0.53 to 0.45) (see Supporting Table 1). For all HRQOL scales, functioning and global QOL were higher and symptom burden was lower in those with an optimistic IPs compared with those with a realistic IPs (all *P* < .01). According to guidelines for clinical relevance, mean differences were trivial or small.³² Functioning was lower and symptoms were higher in those with pessimistic IPs compared with those with a realistic IPs (all *P* < .01), and mean differences were trivial to large (Table 3).³² Differences remained significant after additional adjustment for anxiety and depression, and when analyses were stratified by prognosis group.

Overall, all-cause mortality was found to be higher in survivors with a pessimistic IPs compared with those with realistic IPs (adjusted hazard ratio, 1.52; 95% confidence interval, 1.27-1.84 [*P* < .01]). In addition, all-cause mortality was found to be slightly but significantly lower in survivors with optimistic IPs compared with those with a realistic IPs (adjusted hazard ratio, 0.72; 95% confidence interval, 0.57-0.90 [*P* < .05]) (Table 4) (Fig. 1).

DISCUSSION

We demonstrated that having optimistic IPs, even when they may appear unrealistic with respect to prognosis, are associated with higher HRQOL and lower mortality, whereas having pessimistic IPs is associated with poorer outcomes compared with IPs that are consistent with disease severity (ie, realistic IPs). This violates our hypothesis that realistic IPs are more beneficial than more optimistic IPs, and demonstrates that IPs are important predictors of survivors' health outcomes regardless of disease prognosis. In addition, the comparison of the 3 IPs groups in the current study elucidated that differences in outcomes were much larger between the pessimistic IPs group and the realistic IPs group compared with between the optimistic and realistic IPs groups, specifically with respect to social functioning, cognitive functioning, fatigue, nausea, insomnia, and global QOL.

Similar to previous work focusing on the relationship between IPs and physical and psychological outcomes, including HRQOL, psychological distress, and

TABLE 2. Sociodemographic and Clinical Characteristics of Survivors With Optimistic, Realistic, or Pessimistic IPs

	Total N=2457	Optimistic IPs N=582	Realistic IPs N=1230	Pessimistic IPs N=645	<i>P</i> for Optimistic Versus Realistic ^a	<i>P</i> for Pessimistic Versus Realistic ^a
Age at survey, y						
Mean (SD)	68.1 (10.1)	69.3 (9.5)	68.3 (10.3)	66.7 (10.2)	.03	<.01
Sex, no. (%)						
Male	1457 (59)	380 (65)	730 (59)	347 (54)	.02	.02
Female	1000 (41)	202 (35)	500 (41)	298 (46)		
Education, no. (%)						
Lower education	420 (17)	91 (22)	200 (48)	129 (20)	.63	.03
Secondary education (high school)	684 (28)	153 (22)	341 (28)	190 (30)		
Secondary education (vocational)	823 (34)	195 (34)	412 (34)	216 (34)		
Higher education (vocational or university)	504 (21)	139 (28)	260 (52)	105 (16)		
Y from diagnosis						
Median (IQR)	2.7 (1.9-3.6)	2.8 (2.0-3.7)	2.7 (1.9-3.6)	2.6 (1.9-3.6)	.40	.60
<2	680 (17)	150 (26)	345 (28)	185 (29)	.42	.86
2-3	809 (21)	190 (33)	411 (33)	208 (32)		
3-4	968 (25)	242 (42)	474 (39)	252 (26)		
Cancer type, no. (%)						
Colon	779 (32)	239 (41)	356 (46)	184 (24)	<.01	<.01
Rectal	449 (18)	79 (14)	227 (18)	143 (22)		
Prostate	516 (21)	107 (18)	297 (24)	112 (17)		
Ovarian	142 (6)	16 (3)	79 (6)	47 (7)		
Endometrial	197 (8)	42 (7)	112 (9)	43 (7)		
Non-Hodgkin lymphoma (aggressive)	228 (9)	78 (13)	87 (7)	63 (28)		
Non-Hodgkin lymphoma (indolent)	146 (6)	21 (4)	72 (76)	53 (8)		
Comorbidities, no. (%)						
None	742 (30)	215 (37)	381 (31)	146 (23)	<.01	<.01
1	714 (29)	182 (31)	361 (29)	171 (27)		
≥2	1001 (41)	185 (18)	488 (40)	328 (51)		
Marital status, no. (%)						
Partner	1949 (80)	456 (79)	992 (81)	501 (78)	.28	.10
No partner	484 (20)	119 (21)	226 (19)	139 (29)		
Employed, no. (%)						
Yes	444 (19)	94 (17)	238 (20)	112 (18)	.09	.28
No	1939 (81)	473 (83)	952 (80)	514 (82)		
TNM/Ann Arbor stage of disease, no. (%)						
I	627 (25)	154 (25)	317 (26)	156 (24)	.01	.18
II	931 (38)	243 (42)	449 (37)	239 (37)		
III	683 (28)	157 (27)	355 (29)	171 (27)		
IV	195 (8)	23 (4)	99 (8)	73 (37)		
Treatment, no. (%)						
Surgery	1696 (69)	412 (71)	845 (69)	439 (68)	.37	.78
Radiotherapy	688 (28)	138 (20)	338 (27)	212 (31)	.09	.01
Systemic therapy	818 (33)	183 (31)	406 (33)	229 (36)	.51	.28

Abbreviations: IPs, illness perceptions; IQR, interquartile range; SD, standard deviation.

Percentages do not always add up to 100 because they were rounded off to whole numbers.

^aBold type indicates statistical significance ($P < 0.05$).

mortality,²⁻¹⁰ we found that less threatening (ie, more positive) IPs were associated with more favorable outcomes, whereas more threatening (ie, more negative) IPs were associated with unfavorable outcomes. The results of the current study demonstrate that IPs are associated with HRQOL and survival independent of disease severity (ie, prognosis). According to the common sense model of self-regulation of Leventhal et al, the relationship between IPs and health outcomes is mediated through coping.³³ Accordingly, threatening IPs have been associated with passive coping strategies, such as anxious preoccupation and helplessness/hopelessness among cancer

survivors,⁴ which may explain the relation to poor health outcomes. An alternative explanation may be that the IPs in the current study simply were a more inclusive reflection of disease severity, comprising symptoms, disease progression, and comorbidities. This is in parallel with self-rated health as an inclusive measure of health status, reflecting bodily sensations or symptoms indicating physiological dysregulations or preclinical disease,^{34,35} as well as internal or external resources that affect health (ie, educational level, financial status and social support, optimism, or self-control).³⁶ Inclusiveness also may explain why IPs in the current study appeared to be predictive

TABLE 3. General Linear Models Comparing HRQOL and Symptoms Between Cancer Survivors With Optimistic, Realistic, and Pessimistic IPs Shown as Crude Means and SDs

	Total N=2457	Optimistic IPs N=582	Realistic IPs N=1230	Pessimistic IPs N=645	<i>P</i> for Optimistic Versus Realistic (Size of Difference) ^a	<i>P</i> for Pessimistic Versus Realistic (Size of Difference) ^a
Global QOL	75.0 (19)	85.2 (14)	77.1 (16)	61.9 (22)	<.01 (S)	<.01 (L)
Functioning scales						
Physical functioning	80.5 (20)	88.0 (15)	82.4 (18)	70.1 (23)	<.01 (S)	<.01 (S)
Social functioning	85.0 (23)	95.5 (12)	88.0 (19)	70.0 (29)	<.01 (S)	<.01 (L)
Cognitive functioning	83.7 (21)	90.2 (15)	85.1 (19)	75.2 (26)	<.01 (S)	<.01 (M)
Emotional functioning	84.4 (20)	94.4 (11)	87.4 (17)	69.9 (24)	<.01	<.01
Role functioning	77.8 (28)	89.8 (19)	80.2 (25)	62.4 (33)	<.01 (S)	<.01 (S)
Symptom scales						
Fatigue	25.1 (25)	13.4 (17)	23.0 (22)	40.0 (27)	<.01 (S)	<.01 (M)
Nausea/vomiting	4.4 (13)	1.7 (7)	3.4 (11)	8.5 (18)	<.01 (T)	<.01 (S)
Pain	17.5 (25)	9.5 (18)	15.7 (23)	28.3 (30)	<.01 (S)	<.01 (S)
Dyspnea	15.3 (25)	8.2 (19)	13.4 (23)	25.4 (31)	<.01 (S)	<.01 (M)
Insomnia	21.8 (30)	11.7 (22)	20.3 (28)	33.6 (34)	<.01 (S)	<.01 (M)
Appetite loss	6.8 (18)	2.7 (11)	5.3 (16)	13.5 (25)	<.01 (T)	<.01 (S)
Constipation	9.4 (21)	5.2 (15)	9.3 (20)	13.3 (25)	<.01 (T)	<.01 (T)
Diarrhea	9.6 (21)	5.0 (14)	9.2 (20)	14.1 (26)	<.01 (S)	<.01 (S)
Financial problems	7.2 (19)	2.7 (11)	5.4 (16)	14.7 (26)	<.01 (T)	<.01 (S)

Abbreviations: HRQOL, health-related quality of life; IPs, illness perceptions; L, large difference, M, medium difference; S, small difference; SD, standard deviation; T, trivial difference.

^aAnalyses were adjusted for age at the time of the survey, sex, educational level, years from diagnosis, tumor type, tumor stage, treatment (surgery, radiotherapy, or systemic therapy), number of comorbidities, employment, and marital status. Higher scores on global QOL and functioning scales and lower scores on symptom scales indicate a better HRQOL. The size of the mean difference was determined based on guidelines of clinical relevance from Cocks et al.³² The guideline for the emotional functioning subscale is unknown.

TABLE 4. Cox Proportional Hazards Regression Models for Optimistic Versus Realistic IPs and Pessimistic Versus Realistic IPs

	No.	No. of Person-Years	Deaths	Unadjusted HR (95% CI) ^a	Adjusted HR (95% CI) ^{a,b}
Total					
Realistic IPs	582	6194.4	288	1.00 (referent)	1.00 (referent)
Optimistic IPs	1230	3159.4	106	0.74 (0.58-0.91)^c	0.72 (0.57-0.90)^c
Pessimistic IPs	645	3065.2	218	1.52 (1.28-1.81)^d	1.52 (1.27-1.84)^d

Abbreviations: 95% CI, 95% confidence interval; HR, hazard ratio; IPs, illness perceptions.

^aBold type indicates statistical significance.

^bAdjusted for age at the time of the survey, sex, educational level, tumor type, tumor stage, treatment (surgery, radiotherapy, or systemic therapy), number of comorbidities, employment, and marital status.

^c*P* < .01.

^d*P* < .05.

of health outcomes independent of prognosis, reflecting that all groups in the current study were rather “realistic” about their outcomes.

Consistent with literature regarding threatening IPs, pessimistic IPs were found to be associated with sociodemographic factors, including younger age, being female, and having a low educational level.^{37,38} In addition, we found that higher cancer stage and more comorbidities were associated with having pessimistic IPs. Furthermore, survivors with pessimistic IPs more often received radiotherapy, which previously has been associated with higher levels of psychological distress,³⁹ fatigue,⁴⁰ and a lower HRQOL.

Limitations

Using comprehensive historical cancer registry data to estimate prognosis at the time of the questionnaire, we tried to adjust for the (clinical) factors that interfere with IPs and health outcomes (ie, years from diagnosis, cancer stage at the time of diagnosis, patient age and sex). However, other factors comprising prognosis were not covered in this estimate, such as comorbidities, disease progression, or disease recurrence. For example, the high prevalence of comorbidities in the group with a pessimistic IPs may explain their low survival. Although adjustment for comorbidities at the time of the questionnaire did not alter the current study results, we could not adjust

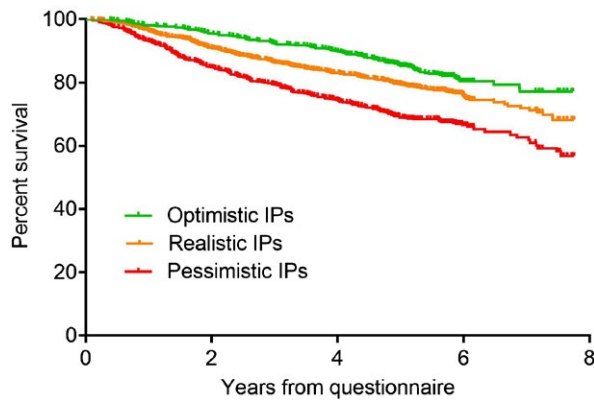


Figure 1. Kaplan-Meier survival curves for survivors with optimistic, realistic, and pessimistic illness perceptions (IPs).

for comorbidities at the time of diagnosis or in the years after questionnaire completion. In addition, no data were available regarding disease progression or recurrence. The inclusion of survivors with recurrent disease may have inflated the results of the current study because these individuals were likely allocated to the pessimistic IPs group and inevitably had poorer health outcomes.

Furthermore, our composite BIPQ scale was based on a factor structure that was similar to that of other studies,²²⁻²⁵ but does not support the theoretical model by Leventhal et al that presents emotional and cognitive representations as distinct factors.³³ As a consequence, the groups in the current study were not only based on cognitive perceptions regarding disease severity, such as perceptions of how long the disease will continue, but also on emotional representations. Therefore, it is not surprising that the groups were strongly associated with HRQOL subscales. To further elucidate whether more optimistic perceptions of prognosis are indeed more beneficial for cancer survivors than (clinically) accurate perceptions of prognosis, a prognostic awareness measure could be used to create the groups, similar to the questionnaires used in palliative research.⁴¹ In addition, the use of supportive care services should be measured because this may influence survivors' IPs.

The current study included a large and heterogeneous sample of survivors of various cancer types, but there were relatively many survivors with favorable prognoses, and a lack of common cancer types such as breast and lung cancer. Thus, despite our high response rate (71%), the findings of the current study may not be fully generalizable to other cancer survivor populations. Furthermore,

although our survival analyses demonstrated longitudinal associations, we could not confirm the causal relationship between IPs and HRQOL using a cross-sectional survey. Longitudinal surveys are needed to confirm the long-term benefit of optimistic perceptions of illness and prognosis. It also should be noted that our groups were created based on quartile cutoff values of the BIPQ scores, which are clinically arbitrary and are not validated using specific questionnaires for optimistic, realistic, or pessimistic IPs. Future studies are needed to confirm these IPs groups in other cancer survivor populations.

Future Directions

Although we acknowledge that the current study had limitations with regard to its design and the availability of data, and that further research is needed, we believe that its results provide valuable new insights into the importance of IPs among cancer survivors in relation to HRQOL and survival. The classification of survivors into groups based on IPs relative to their prognosis is a novel way with which to assess the impact of having threatening IPs on health outcomes, in contrast to a body of literature focusing on linear relationships between IPs and outcomes.²⁻¹⁰ In a previous trial in which survivorship care plans were found to provide accurate and honest diagnostic and prognostic information, they induced more threatening IPs among cancer survivors.¹¹⁻¹³ Because the results of the current study indicate that holding realistic or pessimistic IPs may be associated with lower HRQOL and survival, we may need to be careful when providing information to survivors, such as diagnostic or prognostic information. However, further research regarding this topic is warranted. Therefore, future interventions that include diagnostic or prognostic information should include an assessment of the potential harmful effects through more threatening IPs. Furthermore, rather than assuming that we need to encourage survivors with pessimistic IPs to be more optimistic, we believe it is important to understand why these individuals have pessimistic or threatening IPs. It is possible that their perceptions are a much more inclusive reflection of their state of health than a set of objective measures comprises.³⁶

Survivors with IPs that are relatively optimistic with respect to their prognosis appear to have the most favorable health outcomes, whereas those with pessimistic IPs relative to their prognosis have the worst outcomes compared with those with realistic IPs. Hence, IPs may be important predictors of health outcomes independent of prognosis.

We need to acknowledge the pessimistic or threatening IPs among cancer survivors and provide support that is appropriate for this group to improve their outcomes.

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CONFLICT OF INTEREST DISCLOSURES

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AUTHOR CONTRIBUTIONS

Conceptualization: **Belle H. de Rooij** and **Nicole P.M. Ezendam**. Methodology: **Belle H. de Rooij** and **Nicole P.M. Ezendam**. Formal analysis: **Belle H. de Rooij**. Investigation: **Melissa S.Y. Thong**, **Olga Husson**, and **Nicole P.M. Ezendam**. Data curation: **Belle H. de Rooij** and **Nicole P.M. Ezendam**. Writing—original draft: **Belle H. de Rooij** and **Nicole P.M. Ezendam**. Writing—review and editing: **Belle H. de Rooij**, **Melissa S.Y. Thong**, **Janneke van Roij**, **Cynthia S. Bonhof**, **Olga Husson**, and **Nicole P.M. Ezendam**. Supervision: **Nicole P.M. Ezendam**.

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