Unmet information needs and impact of cancer in (long-term) thyroid cancer survivors: results of the PROFILES registry

O. Husson^{1,2}*, F. Mols^{1,2}, W. A. Oranje³, H. R. Haak⁴, W. A. Nieuwlaat⁵, R. T. Netea-Maier⁶, J. W. A. Smit⁶ and L. V. van de Poll-Franse^{1,2}

¹CoRPS—Center of Research on Psychology in Somatic diseases, Department of Medical and Clinical Psychology, Tilburg University, Tilburg The Netherlands

²Comprehensive Cancer Centre Netherlands South, Eindhoven, The Netherlands

³Department of Internal Medicine, TweeSteden Hospital, Tilburg, The Netherlands

⁴Department of Internal Medicine, Maxima Medical Centre, Eindhoven, The Netherlands

⁵Department of Internal Medicine, St. Elisabeth Hospital, Tilburg, The Netherlands

⁶Department of Internal Medicine, Radboud Medical Centre, Nijmegen, The Netherlands

Abstract

*Correspondence to: Tilburg University, Warandelaan 2, PO Box 90153, 5000 LE Tilburg, The Netherlands. E-mail: O.Husson@tilburguniversity.edu

Objective: The objective of this study was to provide insight into the following: (a) the perceived level of, satisfaction with, and helpfulness of received information and unmet information needs among thyroid cancer (TC) survivors and (b) the relation between unmet information needs and impact of cancer (IOC).

Methods: All patients diagnosed with TC between 1990 and 2008, as registered in the Eindhoven Cancer Registry, received a survey on information provision (European Organization for Research and Treatment of Cancer Quality of Life Questionnaire Information module) and IOC.

Results: Thyroid cancer survivors (n = 306; response rate = 86%) indicated to receive no or only a little information about different aspects of their disease (27–86%), medical tests (20–27%), treatment (21–90%), and aftercare (86–91%). Almost half of the survivors (47%) were not at all or a little satisfied with the amount of information received; 31% found the received information not or a little helpful; a third of the patients (34%) indicated that they wanted to receive more information (defined as unmet needs). TC survivors with unmet informational needs scored significantly higher on both the positive (mean 3.2 vs. 2.9) and negative IOC scale (mean 2.5 vs. 2.2) compared with survivors without unmet needs (p < 0.01). In multivariate linear regression analyses, unmet information needs were positively associated with all positive IOC scales except positive self-evaluation (betas ranging from 0.16 to 0.24; p < 0.05), and all negative IOC scales except for appearance concerns (betas ranging from 0.12 to 0.19; p < 0.05).

Conclusion: Thyroid cancer survivors experienced several areas of information provision as insufficient, suggesting room for improvement. Unmet information needs among TC survivors are associated with both positive and negative impacts of cancer. Copyright © 2014 John Wiley & Sons, Ltd.

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Introduction

In recent years, the incidence of thyroid cancer (TC) has increased drastically in the USA and most European countries [1-3]. In the Netherlands, the incidence of TC is 3.1 cases per 100,000 people per year, or 570 new patients [3]. As a result of the very good prognosis of differentiated TC (exceeding >90% 5-year relative survival rates), the number of TC survivors is growing (20-year prevalence of 2700 in 1990 vs. 5500 in 2010) [4].

As the number of TC survivors is growing, it is important to pay attention to the long-term effects of TC and its treatment. Recent studies showed that TC survivors report statistically significant and clinically relevant lower levels of physical and psychosocial functioning, and significantly more symptoms (e.g., fatigue, dyspnea, insomnia, and appetite problems) compared with an age-matched and sex-matched normative population [5–7]. TC-specific neuromuscular, concentration, sympathetic (problems of sympathetic nervous system, e.g., hot flushes or sensitivity to heat), and psychological problems were most strongly associated with worse self-reported physical and psychosocial functioning [5].

Despite the experience of symptoms, patients are sometimes informed by healthcare providers that TC is not a serious problem, partly because of the good prognosis for differentiated TC [8,9]. This attitude trivializes the importance of the condition and causes patients to feel dismissed as not having a serious disease [8]. Two recent international studies showed that TC survivors have substantial unmet psychosocial needs including information needs [9,10]. It is important to meet these information

needs as research showed that satisfaction with received information is strongly associated with better healthrelated quality of life (HRQoL), lower levels of anxiety and depression, and more positive illness perceptions [11,12]. Next to these factors, information provision could also have an influence on the psychosocial impact of TC on the long run. Long-term survivors have unique concerns as well as positive experiences related to their cancer, which are not captured by standard HRQoL measures. To optimize aftercare for TC survivors, it is important to have insight into the perceived level of received information, the positive and negative impacts of TC on the lives of survivors, and the possible relation between unmet information needs and impact of cancer. Therefore, the aims of the current study were as follows: (a) to provide insight into the perceived level of, satisfaction with, and helpfulness of the received information and unmet information needs and (b) to study the relation between unmet information needs and impact of TC. We hypothesize that TC survivors report some unmet information needs especially regarding aftercare and that these unmet information needs are associated with higher negative but not positive impact of cancer.

Materials and methods

Setting and population

This study is based on a population-based survey among TC survivors registered within the Eindhoven Cancer Registry (ECR) of the Comprehensive Cancer Centre South. The ECR compiles data of all individuals newly diagnosed with cancer in the southern part of the Netherlands, an area with 10 hospitals serving 2.3 million inhabitants [13]. All individuals diagnosed with TC between 1990 and 2008 as registered in the ECR were eligible for participation (N = 568). We excluded patients who had cognitive impairment or were too ill at time of the study (on the basis of medical records and advice from the attending medical specialist N=31), had unverifiable addresses (N=90), or died prior to the start of the study (according to the ECR, the Central Bureau for Genealogy, which collects information on all deceased Dutch citizens via the civil municipal registries, and hospital records; N=6). One hospital declined to participate (N=86). Questionnaires were sent to the remaining 355 patients. This study was approved by the certified Medical Ethics Committee of the Maxima Medical Centre in Veldhoven.

Data collection

Data collection started in November 2010 and was performed within Patient Reported Outcomes Following Initial treatment and Long term Evaluation of Survivorship (PROFILES) [14]. PROFILES is a registry for the study of the physical and psychosocial impacts of cancer and its treatment from a dynamic, growing populationbased cohort of both short-term and long-term cancer survivors. PROFILES contains a large web-based component and is linked directly to clinical data from the ECR. Details of the PROFILES data collection method have been previously described [14].

Study measures

Sociodemographic and clinical characteristics

Survivors' sociodemographic and clinical characteristics at the time of cancer diagnosis were available from the ECR. The ECR routinely collects data on tumor characteristics, including date of diagnosis, tumor grade, and stage according to the tumor-node-metastasis clinical classification [15], treatment, and patient background characteristics, for example, date of birth. Self-reported comorbidity at the time of survey was categorized according to the adapted Self-administered Comorbidity Questionnaire [16]. Questions on marital status, educational level, and current occupation were added to the questionnaire.

Information provision

The Dutch version of the internationally validated European Organization for Research and Treatment of Cancer Quality of Life Questionnaire Information module (EORTC QLQ-INFO25) was used to evaluate the information received by TC survivors [17]. This 25-item questionnaire incorporates four information provision subscales: perceived receipt of information about the disease (four items), medical tests (three items), treatment (six items), and aftercare (four items). The answer categories for these questions were 'not at all', 'a little', 'quite a bit', and 'very much'. Additionally, the questionnaire contains eight single items on perceived receipt of information about other areas (e.g., different places of care); two items on the perceived receipt of written information and information on CD, tape, or video (yes/no answer categories); two items on the qualitative aspects satisfaction with the amount of received information and the *helpfulness* of the information disclosed (answer categories: not at all, a little, quite a bit, and very much); and two items on the wish to receive more or less information indicating unmet information needs (yes/no answer categories). Patients who answered with 'yes' on these last two questions also filled in an open-ended question about the topics they want to receive more information about. All scores of the four subscales and the single items satisfaction and helpfulness of the received information are linearly transformed to a scale of 0 to 100 according to the guidelines of the EORTC [17]. The questionnaire has been internationally validated, and internal consistency for all scales is good ($\alpha > 0.70$), as is test-retest reliability (intraclass correlations > 0.70) [17,18].

Impact of cancer

The Impact of Cancer version 2 (IOCv2) was used to measure perceptions of positive and negative impacts of cancer on aspects of the survivors' lives. Development of the IOC was spurred by the need to measure aspects of survivorship not addressed by existing HRQoL measures [19]. The IOCv2 uses 37 items to measure four positive (altruism/empathy, health awareness, meaning of cancer, and positive self-evaluation) and four negative (appearance concerns, body change concerns, life interferences, and worry) subscales, which total to two summary scores (positive and negative impacts) [20]. Respondents indicate their level of agreement from 1 (*strongly disagree*) to 5 (*strongly agree*). Higher scores on the positive and negative impact scales indicate respectively greater positive and negative impacts of cancer.

Statistical analyses

Differences in sociodemographic and clinical characteristics between respondents, nonrespondents, and patients with unverifiable addresses or between patients with and without unmet information needs were compared using chi-square statistics for categorical variables and *t*-tests or analysis of variance for continuous variables. The nonparametric Mann–Whitney *U*-test or Kruskal Wallis was applied when normality and homogeneity assumptions of continuous variables were violated.

Differences in mean EORTC QLQ-INFO25 subscale scores and IOC single item and subscale scores between survivors with and without unmet information needs were compared by independent *t*-tests. Clinically meaningful differences were determined with Norman's 'rule of thumb', whereby a difference of ≈ 0.5 SD indicates a threshold of discriminant change in scores of a chronic illness [21].

Multivariate linear regression analyses were carried out in order to investigate the association between unmet informational needs and IOC subscale scores, corrected for a priori determined sociodemographic and clinical characteristics (age, sex, time since diagnosis, disease stage, comorbid conditions, educational level, and marital status) [22].

All statistical analyses were performed using SPSS version 19.0 (Statistical Package for Social Sciences, Chicago, IL, USA), and *p*-values < 0.05 were considered statistically significant.

Results

Patient and tumor characteristics

Three hundred and six patients returned a completed questionnaire (response 86%). A comparison of respondents, nonrespondents, and patients with unverifiable addresses indicated that patients with unverifiable addresses were younger compared with nonrespondents and respondents (mean 52, 54, and 56 years, respectively; p = 0.04, these results have been published previously) [5]. No differences between groups were seen regarding sex, type of TC, stage of the disease, or primary treatment.

Sociodemographic and clinical characteristics of respondents are described in Table 1.

Perceived information provision

The *single* questions of the EORTC QLQ-INFO25 showed that most patients indicated to receive no or only a little information about different aspects of their disease (27-86%), medical tests (20-27%), treatment (21-90%), and aftercare (86-91%); Table 2). Almost half of the survivors (47%) were not at all or a little satisfied with the amount of information received, and 31% found the received information not or a little helpful. More than a

Table I.	Sociodemographic	and	clinical	characteristics	of
responde	nts (<i>n</i> = 306) ^a				

Age at time survey in years (mean $(\pm SD)$)	56.4 (14.5)
Years since diagnosis	9.6 (5.5)
Sex	
Male	76 (24.8%)
Female	230 (75.2%)
Type of thyroid cancer	
Papillar	217 (70.9%)
Follicular (including Hurthle cell)	73 (23.8%)
Medullary	13 (4.2%)
Stage	
I	172 (57.1%)
II	59 (19.6%)
III	48 (15.9%)
IV	20 (6.6%)
Primary treatment	
Surgery	83 (27.1%)
Surgery + iodine-131 ablation	212 (69.3%)
Surgery + radiotherapy	9 (2.9%)
Other	2 (0.7%)
Comorbidity (self-report)	
None	68 (22.2%)
I	70 (22.9%)
≥2	168 (54.9%)
Partnership	
Partner	238 (77.8%)
No partner	68 (22.2%)
Educational level ^b	
High	80 (26.2%)
Middle	192 (63.0%)
Low	33 (10.8%)
Current occupation	
Employed	154 (51.3%)
Not employed	146 (48.7%)

^aNumbers sometimes do not count to 306 because of missing values. ^bEducation: low (no or primary school), medium (lower general secondary education/vocational training), and high (pre-university education/high vocational training/university).

Table 2. Perceived information provision characteristics

	N (%)						
	No information at all	A little information	Quite a bit information	Very much information			
Subscale information about disease (mean = 50.5 ; SD =	21.8)						
Diagnosis	14 (5)	69 (24)	138 (48)	66 (23)			
Spread disease	28 (9)	98 (35)	112 (40)	44 (16)			
Cause disease	172 (61)	72 (25)	25 (9)	15 (5)			
Under control	16 (6)	59 (21)	122 (43)	87 (31)			
Subscale information about medical tests (mean = 66.6;	SD = 24.1)						
Purpose test	13 (5)	59 (21)	133 (47)	78 (28)			
Course test	13 (5)	62 (22)	141 (50)	68 (24)			
Results test	4(1)	53 (19)	143 (51)	83 (29)			
Subscale information about treatment (mean = 41.1 ; SE	D = 21.6)						
Medical treatment	7 (2)	53 (19)	141 (50)	81 (29)			
Expected result	50 (18)	79 (28)	(39)	44 (15)			
Side effects	64 (23)	97 (34)	92 (33)	29 (10)			
Expected results on disease symptoms	50 (18)	88 (31)	109 (38)	36 (13)			
Expected results on social life	148 (52)	79 (28)	45 (16)	(4)			
Expected results on sexual life	214 (76)	39 (14)	17 (6)	10 (4)			
Subscale information about aftercare (mean = 14.3 ; SD	= 20.0)						
Additional help	203 (72)	48 (17)	22 (8)	8 (3)			
Rehabilitation	207 (75)	38 (14)	23 (8)	9 (3)			
Cope with cancer at home	180 (64)	63 (22)	31 (11)	8 (3)			
Psychological assistance	205 (72)	56 (20)	21 (7)	3 (1)			
Single items							
Different care locations	193 (68)	55 (19)	29 (10)	7 (3)			
Things to do to get better	150 (52)	90 (32)	39 (14)	7 (2)			
	Not satisfied	A little satisfied	Quite a bit satisfied	Very satisfied			
Satisfaction with information (mean = 52.3; $SD = 27.8$)	27 (9)	106 (37)	116 (41)	37 (13)			
	Not helpful	A little helpful	Quite a bit helpful	Very helpful			
Helpfulness of information (mean = 61.5 ; SD = 25.6)	10 (4)	77 (27)	139 (50)	54 (19)			
	Yes	No					
Received written information	190 (65)	101 (35)					
Received information on video or CD-ROM	0 (0)	291 (100)					
Wanted more information	100 (34)	190 (66)					
Wanted less information	12 (4)	267 (96)					

Scale means can range from 0 to 100.

third (34%) of the patients wanted to receive more information especially regarding the cause of their cancer (11%), complications and long-term effects of treatment and medication use (67%), aftercare and rehabilitation options (19%), and overall information on TC and the function of the thyroid gland (18%). Direct comparison between patients with (n = 100) or without unmet informational needs (n = 190) with regard to patient and tumor characteristics revealed no differences (data not shown) except for time since diagnosis, which was shorter for patients with unmet needs (7.9 years vs. 10.4 years; p < 0.01).

Patients with unmet information needs perceived to receive less information about the disease (mean 46 vs. 53; p = 0.01), treatment (36 vs. 44; p < 0.01), and aftercare (8 vs. 18; p < 0.01) and were less satisfied with the received information (37 vs. 60; p < 0.01). No significant differences between the two groups were seen on information

about medical tests (64 vs. 68; p = 0.12) and helpfulness of the received information (59 vs. 63; p = 0.14)

Impact of cancer and unmet information needs

t-tests showed that patients with unmet information needs scored significantly higher on scales of altruism and empathy (3.3 vs. 3.0; p < 0.01), health awareness (3.7 vs. 3.2; p=0.05), meaning of cancer (2.7 vs. 2.4; p < 0.01), positive impact (3.2 vs. 2.9; p < 0.01), body change concerns (2.9 vs. 2.4; p < 0.01), life inferences (2.2 vs. 1.9; p < 0.01), worry (2.8 vs. 2.5; p < 0.01), and negative impact scale (2.5 vs. 2.2; p < 0.01; Table 3). This difference was clinically relevant for health awareness (difference of ≈ 0.5 SD).

In multivariate linear regression analyses including a priori defined confounding variables, unmet information

 Table 3. Impact of cancer single item and subscale scores,

 stratified by presence of unmet information needs

	No unmet needs (n = 190) (mean (SD))	Unmet needs (n = 100) (mean (SD))
Altruism and empathy	3.0 (0.9)	3.3 (0.9)*
Health awareness ^a	3.2 (0.9)	3.7 (0.8)*
Meaning of cancer	2.4 (0.9)	2.7 (0.9)*
Positive self-evaluation	3.1 (0.9)	3.3 (0.9)
Positive impact scale	2.9 (0.7)	3.2 (0.7)*
Appearance concerns scale	1.8 (0.8)	1.8 (0.8)
Body change concerns scale	2.4 (1.1)	2.9 (1.1)*
Life inferences scale	1.9 (0.8)	2.2 (0.8)*
Worry scale	2.5 (0.9)	2.8 (1.0)*
Negative impact scale	2.2 (0.8)	2.5 (0.7)*

^aClinical relevant difference.

*p < 0.01.

needs were positively associated with all positive impact of cancer scales (betas ranging from 0.16 to 0.24), except positive self-evaluation (Table 4). Unmet information needs were also positively associated with all negative impact scales (betas ranging from 0.12 to 0.19), except for appearance concerns.

Discussion

This population-based study showed that TC survivors perceived that they received no or only a little information about different aspects of their disease (27–86%), medical tests (20–27%), treatment (21–90%), and aftercare (86–91%). Almost half of the survivors were not at all or a little satisfied with the amount of information received; 31% found the received information not at all or only a little helpful; and a third of the patients indicated that they wanted to receive more information, indicating unmet informational needs; whereas 4% wanted less. TC survivors with unmet information needs scored significantly higher on both the positive and negative impacts of cancer scales compared with those without unmet needs.

Our results are in line with those of previous studies among other groups of cancer survivors (melanoma, endometrial, colorectal, (non-)Hodgkin, and multiple myeloma) showing that survivors received quite a bit of information about their disease, medical tests, and treatment; however, information on aftercare was scarce [23–25]. The unmet information need percentage for TC survivors (34%) was somewhat higher compared with that for other cancer survivor populations previously studied (15–28%) [23].

Table 4. Standardized betas of multivariate linear regression analyses evaluating the association between unmet information needs and impact of cancer

	Altruism and empathy	Health awareness	Meaning of cancer	Positive self- evaluation	Positive impact scale	Appearance concerns	Body change concerns	Life inferences	Worry	Negative impact scale
No unmet need Unmet need Age	0.21** 	0.24** —0.17*	0.16** 0.05	0.11 0.12	0.24** 	0.04 -0.15*	0.18** -0.13*	0.19** -0.08	0.12* -0.15*	0.16** -0.12
Sex Male Female	0.10	0.16**	-0.03	0.06	0.06	-0.01	-0.07	-0.07	0.02	-0.04
Time since diagnosis Disease stage I + II III + IV	0.07	-0.07	0.03	0.07	0.04	-0.01	-0.02	0.02	-0.09	-0.04
Comorbid conditions 0 I or more	-0.05	0.02	-0.05	-0.12	-0.09	0.14*	0.25**	0.10	0.14*	0.17**
Educational level Low High	0.09	-0.04	0.04	0.15*	0.09	0.10	0.15*	0.16**	0.03	0.11
Partnership Partner No partner Explained variances (R ²)	0.05 6.7%*	0.04 4.2%**	-0.04 3.8%	-0.03 6.7%*	0.02 8.7%**	0.11 5.1%	0. 4* 6.7%**	0.18** 12.9%**	0.15* 12.4%**	0.19**

*p < 0.05.

, ***p < 0.01. Moreover, an American study found that TC patients felt that they received inadequate information on lifestyle factors that might affect recurrence, negative consequences of body scans, symptoms of recurrence, causes of TC, how to manage side effects, and where to obtain the latest information on diagnoses, treatments, and side effects [10]. These topics are in line with the ones reported in our study, indicating that survivors are relatively satisfied with information related to their diagnosis, prognosis, and primary treatment but less satisfied with information related to long-term effects, recurrence, aftercare, and current information about the disease [10]. In accordance with our results, a recent international study showed that TC survivors have important unmet informational needs, which were reported as one of the most difficult aspects of their cancer experience [9]. A potential explanation for the fact that especially information about long-term effects and aftercare are reported as topics that patients want more information about is that healthcare providers are not aware of the health problems that TC patients are dealing with even long after their primary treatment.

In contrast to our hypotheses, our results showed that patients with unmet informational needs had both higher positive and negative impacts of cancer compared with those with no unmet needs. This is in line with three previous showing that cancer patients do experience both positive and negative impacts of cancer and that these two are not inversely correlated but may co-occur [26–28]. This may be an indication that mental health is not a single continuum with negative impact (distress) on one side and positive impact (growth) on the other side but rather represents a bivariate construct with two separate dimensions [29]. Therefore, it could be possible that patients with unmet information needs have a strong negative emotional reaction as well as a positive emotional reaction. Nevertheless, several other explanations for our findings could be given. First, patients with unmet informational needs might have a monitoring coping style, resulting in a continuous search for more disease information and lower levels of satisfaction compared with blunting patients [30]. This informationseeking style of monitoring patients can be seen as engagement coping aimed at dealing with the stressor. Engagement coping is associated with extraversion, conscientiousness, openness, and optimism [31]. It is therefore possible that patients with unmet informational needs have positive cancer experiences. The other way around, unmet informational needs are also associated with high distress levels and negative adjustment anxious-preoccupation and helplessness-hopelessness [11,32], which could explain the negative impact of cancer for this group. Second, as disease-related information is often emotionally loaded, it could be that part of the survivors forget or repress a substantial amount of the received information. This blunting style of avoiding disease-related information is often seen in the diagnostic phase or when the disease progresses.

Disengagement coping is associated with denial, withdrawal, and wishful thinking [33]. Blunting patients often use various cognitive strategies such as belief, posttraumatic growth, or benefit finding to try to counteract the negative effects of cancer [34]. In this way, it is also possible that these blunting patients experience both positive and negative impacts of their cancer. More research into the relation between perceived information provision and coping styles needs to be conducted. Third, survivors without unmet information needs could be well adjusted to their cancer diagnosis; they accept their disease history and returned to 'normal' life. In that case, they do not experience explicit negative or positive impacts of cancer. Fourth, as the direction of the relation could not be determined, it might also be possible that the positive and/or negative impact of cancer leads to more questions and unmet information needs among cancer survivors.

Irrespective of the direction of the found relations between unmet information needs and impact of cancer, our results highlight the importance to satisfy the patient by meeting their information needs and by adapting the way of providing information to the coping style of the individual patient. The information needs of a patient can be unraveled by consulting the patient himself or herself and regularly checking the understanding of the patient [35,36]. Furthermore, healthcare practitioners need to become aware of the health problems that TC survivors are dealing with even years after diagnosis. Long-term TC survivors report persistent problems including negative effects of thyroid hormone withdrawal for radioiodine follow-up procedures, fear and uncertainty related to a cancer diagnosis, feelings of diagnosis being dismissed as not serious, confrontation with daily medication use, and fluctuating hormone levels [7,37]. Therefore, identifying survivors who may experience physical and/or psychological problems and addressing these problems by for instance giving appropriate information may be important objectives of care and can possibly lead to more positive and less negative impacts of cancer for this group of survivors.

The present study has limitations that should be mentioned. First, our results are not generizable to anaplastic TC patients as they were not included in our study because of their worse prognosis. Second, the cross-sectional design of this study limits the determination of causal associations between the study variables. The relation between perception of received information and impact of cancer can be bidirectional; for example, adequate information provision can lead to improved HRQoL; however, high levels of distress can also inhibit information processing. Furthermore, because the mean time since diagnosis was almost 10 years, this could have biased the perception of the patients of the information they received. In addition, the EORTC QLQ-INFO25 only measures the information patients indicated to have received; it is not clear how much information was actually

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provided. It would therefore be interesting for future studies to compare data on actual information provision with data from self-reported questionnaires.

In conclusion, the present study shows that TC survivors experience several areas of information provision

References

- Ferlay J, Shin HR, Bray F, Forman D, Mathers C, Parkin DM. Estimates of worldwide burden of cancer in 2008: GLOBOCAN 2008. *Int J Cancer* 2010:127:2893–2917.
- Davies L, Welch HG. Increasing incidence of thyroid cancer in the United States, 1973–2002. *JAMA* 2006;295:2164–2167.
- Cijfers over kanker. 2012. http://www. cijfersoverkanker.nl. Accessed 16 August 2013.
- Davies L, Welch HG. Thyroid cancer survival in the United States: observational data from 1973 to 2005. Arch Otolaryngol Head Neck Surg 2010;136:440–444.
- Husson O, Haak HR, Buffart LM, et al. Health-related quality of life and disease specific symptoms among (long-term) thyroid cancer survivors: a study from the population-based PROFILES registry. Acta Oncol 2013;52:447–454.
- Singer S, Lincke T, Gamper E, *et al.* Quality of life in patients with thyroid cancer compared with the general population. *Thyroid* 2012;**22**:117–124.
- Roerink SH, de Ridder M, Prins J, *et al.* High level of distress in long-term survivors of thyroid carcinoma: results of rapid screening using the distress thermometer. *Acta Oncol* 2013;**52**:128–137.
- Sawka AM, Goldstein DP, Brierley JD, et al. The impact of thyroid cancer and postsurgical radioactive iodine treatment on the lives of thyroid cancer survivors: a qualitative study. PLoS One 2009;4:e4191.
- Banach R, Bartes B, Farnell K, *et al.* Psychosocial/informational support needs, treatment side effects, and international differences in care: results of the thyroid cancer alliance international patient/survivor survey. *Hormones* 2013;**12**:3.
- Roberts KJ, Lepore SJ, Urken ML. Quality of life after thyroid cancer: an assessment of patient needs and preferences for information and support. J Cancer Educ 2008;23:186–191.
- 11. Husson O, Mols F, van de Poll-Franse LV. The relation between information provision and health-related quality of life, anxiety and depression among cancer survivors: a systematic review. *Ann Oncol* 2011;**22**: 761–772.
- Husson O, Thong MS, Mols F, Oerlemans S, Kaptein AA, van de Poll-Franse LV. Illness perceptions in cancer survivors: what is the role of information provision? *Psycho-Oncology* 2013;22:490–498.

- Janssen-Heijnen MLG, Louwman WJ, Van de Poll-Franse LV, Coebergh JWW. Results of 50 Years Cancer Registry in the South of the Netherlands: 1955–2004 (in Dutch). Eindhoven Cancer Registry: Eindhoven, 2005.
- 14. van de Poll-Franse LV, Horevoorts N, Eenbergen MV, et al. The Patient Reported Outcomes Following Initial treatment and Long term Evaluation of Survivorship registry: scope, rationale and design of an infrastructure for the study of physical and psychosocial outcomes in cancer survivorship cohorts. Eur J Cancer 47:2188–2194.
- UICC. TNM Classification of Malignant Tumours (6th edn), Wiley-Liss: New York, 2002.
- 16. Sangha O, Stucki G, Liang MH, Fossel AH, Katz JN. The Self-Administered Comorbidity Questionnaire: a new method to assess comorbidity for clinical and health services research. *Arthritis Rheum* 2003;49:156–163.
- Arraras JI, Greimel E, Sezer O, *et al.* An international validation study of the EORTC QLQ-INFO25 questionnaire: an instrument to assess the information given to cancer patients. *Eur J Cancer* 46:2726–2738.
- Singer S, Engelberg PM, WeiSsflog G, Kuhnt S, Ernst J. Construct validity of the EORTC quality of life questionnaire information module. *Qual Life Res.* 2013;22:123–129.
- Zebrack BJ, Ganz PA, Bernaards CA, Petersen L, Abraham L. Assessing the impact of cancer: development of a new instrument for long-term survivors. *Psycho-Oncology* 2006;15:407–421.
- Crespi CM, Smith SK, Petersen L, Zimmerman S, Ganz PA. Measuring the impact of cancer: a comparison of non-Hodgkin lymphoma and breast cancer survivors. J Cancer Surviv 2010;4:45–58.
- Norman GR, Sloan JA, Wyrwich KW. Interpretation of changes in health-related quality of life: the remarkable universality of half a standard deviation. *Med Care* 2003;41:582–592.
- Babyak MA. What you see may not be what you get: a brief, nontechnical introduction to overfitting in regression-type models. *Psychosom Med* 2004;66:411–421.
- Oerlemans S, Husson O, Mols F, *et al.* Perceived information provision and satisfaction among lymphoma and multiple myeloma survivors results from a Dutch population-based study. *Ann Hematol* 2012;91:1587–1595.
- Husson O, Denollet J, Oerlemans S, Mols F. Satisfaction with information provision in cancer patients and the moderating effect of type D personality. *Psycho-Oncology* 2013;22:2124–2132.

as insufficient, suggesting room for improvement. The finding that unmet informational needs were associated with both negative and positive impacts of cancer highlights the importance of a personalized care approach for TC survivors.

- 25. Nicolaije KA, Husson O, Ezendam NP, et al. Endometrial cancer survivors are unsatisfied with received information about diagnosis, treatment and follow-up: a study from the population-based PROFILES registry. Patient Educ Couns 2012;88:427–435.
- Pinquart M, Frohlich C, Silbereisen RK. Cancer patients' perceptions of positive and negative illness-related changes. *J Health Psychol* 2007;**12**:907–921.
- Schroevers MJ, Kraaij V, Garnefski N. Cancer patients' experience of positive and negative changes due to the illness: relationships with psychological well-being, coping, and goal reengagement. *Psycho-Oncology* 2011;20:165–172.
- Rowlands IJ, Lee C, Janda M, et al. Predicting positive and negative impacts of cancer among long-term endometrial cancer survivors. Psycho-Oncology 2013;22:1963–1971.
- Cacioppo JT, Berntson GG. Relationship between attitudes and evaluative space: a critical review with emphasis on the separatability of positive and negative substrates. *Psychol Bull* 1994;115:401–423.
- Miller SM. Monitoring versus blunting styles of coping with cancer influence the information patients want and need about their disease. Implications for cancer screening and management. *Cancer* 1995;**76**:167–177.
- Carver CS, Connor-Smith JK. Personality and coping. Annu Rev Psychol 2010;61:679–704.
- 32. Seok JH, Choi WJ, Lee YS, *et al.* Relationship between negative mental adjustment to cancer and distress in thyroid cancer patients. *Yonsei Med J* 2013;**54**:658–664.
- Connor-Smith JK, Flachsbart C. Relations between personality and coping: a meta-analysis. *J Pers Soc Psychol* 2007;93:1080–1107.
- de Ridder D, Geenen R, Kuijer R, van Middendorp H. Psychological adjustment to chronic disease. *Lancet* 2008;**372**:246–255.
- van Mossel C, Leitz L, Scott S, *et al.* Information needs across the colorectal cancer care continuum: scoping the literature. *Eur J Cancer Care (Engl)* 2012;21:296–320.
- 36. Jenkins V, Solis-Trapala I, Langridge C, Catt S, Talbot DC, Fallowfield LJ. What oncologists believe they said and what patients believe they heard: an analysis of phase I trial discussions. J Clin Oncol 2011;29:61–68.
- Husson O, Haak HR, Oranje WA, Mols F, Reemst PH, van de Poll-Franse LV. Healthrelated quality of life among thyroid cancer survivors: a systematic review. *Clin Endocrinol* (*Oxf*) 2011;**75**:544–554.