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ORIGINAL ARTICLE

Do patients' information needs decrease over the course of radiotherapy?

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Abstract

Purpose We aimed to investigate if cancer patients' information needs decrease during radiotherapy and if so, which patient, consultation and radiation oncologist characteristics are associated with a decrease in information needs over time.

Methods In this longitudinal study, patients (n=104) completed a baseline questionnaire a week before the initial radiotherapy consultation, immediately following this initial consultation, and 1 week prior to the first follow-up visit, which took place on average 3–5 weeks after the initial visit. Besides information needs, measured by the Information Preference for Radiotherapy Patients scale, the questionnaire assessed patient, consultation and radiation oncologist characteristics.

Results Information needs decreased over time, but remained at a high level. Being religious, being male, having low health literacy and higher perceived involvement during the consultation were all statistically signifi-

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Conclusions Cancer patients' information needs decline between the initial consultation and the first follow-up visit, but remain high. It is therefore advised to investigate the patients' information needs at every radiotherapy visit and not rely on giving information just once. Furthermore, radiation oncologists should check if the information given at first consultation is understood and remembered. By those means, tailored information giving becomes possible.

Keywords Information needs · Radiotherapy · Cancer · Physician-patient interaction · Longitudinal study

Introduction

Since the 1980s attention has been drawn towards the information needs of cancer patients and their right to be fully informed. Until then, most physicians disclosed selected information only [1]. Numerous studies now show that cancer patients in general prefer to be fully informed [2].

About half of cancer patients receive radiotherapy during their treatment [3]. Radiation therapy is beneficial in the treatment of almost every solid cancer type. It is, however, difficult for patients to comprehend because it is not visible [4]. Furthermore, given the complexity and unpleasant side effects of the treatment and the importance that patients do understand procedures and follow-up advice, informing them well is essential. Information giving is likely to reduce patients' fears about treatment [5].

However, full information provision is not beneficial to all patients. Sometimes patients perceive that they are given too much information or details [6]. Quantitative studies report a minority of 5–36% of patients not wanting to know all details of their disease and treatment [7–11]. Denial [12, 13], difficulties in fully understanding information [13], not wanting to be involved in the medical decision-making [14, 15] or culture-determined attitudes [16, 17] may lead patients to prefer limited information. We found that among patients starting radiotherapy, a need for optimism was the most often mentioned reason to refrain from available information [18]. Furthermore, in this patient group, a lower information need was associated with being older and male, having lung or rectal cancer, more difficulty with understanding and a higher trait anxiety level [19].

Variation in information preferences may also result from the passing of time since diagnosis. It is imaginable that patients have a high information need at a first consultation; but how is this need at the follow-up visit? Does the patient need the same amount and kind of information? Studies addressing changes in information need over time showed that information needs generally remain high as patients move through different treatment stages [6, 20–22]. However, some patients prefer less information as time passes since their first diagnosis [22– 27]. The domains patients prefer to be informed about vary when treatment progresses [2, 28, 29]; for example, at diagnosis, individuals rank information about treatment as most important, while some months later, they want information about family risk [29].

Results from the studies so far cannot be directly extrapolated as only few of these studies specifically focused on patients receiving radiotherapy [20, 23, 26, 28] or included only specific patient groups [6, 21, 23, 27, 29]. Furthermore, the studies focusing on radiotherapy do all, except for one [28], solely involve breast cancer patients. Of the longitudinal studies performed [6, 20, 26, 28, 29], none focused on the relative short term, e.g. differences in information needs from consultation to consultation. Previous consultations could have left the patient with specific uncertainties and expectancies. A previous contact can influence the process of information giving at a follow-up contact [30]. One could expect information needs to decrease as many radiation oncologists strongly invest in information giving during the initial consultation. Furthermore, when patients undergo radiotherapy, their questions probably decrease as they get familiar with the procedure and are able to ask questions to other team members involved in the radiotherapy (e.g. radiotherapists). However, studies so far show mixed results; patient's information needs do not or only slightly decrease over the course of radiotherapy [20, 23, 26]. Therefore, we want to investigate the hypothesis that information needs decrease over time.

To tailor information, it is important to understand why and how factors might change information needs between adjacent consultations. A study by Butow et al. among cancer patients showed that lowered information needs at follow-up consultation depended on the radiation oncologist that had seen the patient. Patients' sociodemographic or clinical characteristics were not related to a change in information needs [25].

In earlier studies, preferences for less information differed depending on patients' age [31–33], gender [6, 9, 25], level of education [31, 34], anxiety levels and intellectual ability to understand medical information [13]. However, some studies showed no significant associations between information needs and gender [35] and level of education [36–38]. Therefore, these patient characteristics need to be considered to better understand change in information needs. Time between consultations may be important too, as recall of information could be related to changes in information needs. Finally, radiation oncologist characteristics, such as gender and experience, are relevant as these are known to influence doctors' behaviour of information needs between visits.

In the current prospective, longitudinal study, we therefore address two research questions: (1) do patients' information needs decrease during the course of radiotherapy and (2) if so, which patient, consultation and radiation oncologist characteristics are associated with a decrease in information need over time? With these results, we aim at gaining understanding of how patients' information needs change from visit to visit in order to be able to better tailor information giving.

Materials and methods

Study sample

Nine radiation oncologists and six trainees of the outpatient radiotherapy department of the Academic Medical Center in Amsterdam agreed to participate in the study. Their consecutive, new patients were selected. Exclusion criteria were: age <18 years, having undergone radiotherapy before, unable to read and write Dutch and presenting with cognitive problems or a brain tumour.

Procedures

Eligible patients were mailed a questionnaire before their first radiotherapy consultation. They were phoned some days later to invite for participation. Patients who gave informed consent were asked to complete a baseline questionnaire in the week before the initial consultation, a checklist immediately following this initial consultation and a follow-up questionnaire 1 week prior to the follow-up

visit. The initial visit with a radiation oncologist is generally structured around the following tasks: gathering information about patients' medical history, family and work situation and current physical functioning; conduct physical examination; explain treatment plan, procedures, side effects; and making recommendations. Between initial visit and start of radiation, the patient is prepared for radiotherapy through a simulation procedure guided by a radiotherapist. The radiation period can vary from a onetime radiation to 7 weeks of radiotherapy, 5 days a week. During radiotherapy, patients commonly see the radiation oncologist once a week to follow-up on treatment and address questions. A radiotherapist is present at every radiation session. In our study, most of the follow-up visits took place, on average, 3-5 weeks after the initial visit. This was due to the time necessary for planning and preparing the radiotherapy.

The study design is shown in Fig. 1. The study was approved by the ethical committee of the Academic Medical Center.

Measures

Information needs

We developed the Information Preferences of Radiotherapy Patients Questionnaire (IPRP) [19] which specifically assesses patients' need for information from their radiation oncologist about radiotherapy. This 35-item questionnaire consists of six domains: (1) disease (five items; α =0.93), (2) treatment (five items; α =0.79), (3) procedures (six items; α =0.89), (4) side effects (seven items; α =0.92), (5) prognosis (seven items; α =0.94) and (6) psychosocial aspects (four items; α =0.86). For all questions, response categories on a five-point scale ranged from 'I want to know nothing about it' to 'I want to know all about it'. A higher score reflects a higher information need. The questionnaire has high reliability on the total scale (α = 0.97) as well as subscales (α =0.84–0.94). Concurrent validity was found to be good as indicated by significantly positive associations with patients' general information preference, the amount of detail required and a monitoring coping style [19].

Predictors of information needs

- 1. Patient characteristics
 - (a) Sociodemographic and clinical variables

Age, gender, marital status, having children, employment status, ethnicity, native language and religion were assessed by self-report at baseline. Diagnosis and time of first diagnosis were assessed by medical record audits. Self-reported health status was assessed with one item of the EORTC-QLQ-C30 [41, 42] measuring global health.

(b) Level of health literacy and numeracy

The patients' level of understanding was assessed at baseline using (1) health literacy, i.e. the ability to perform basic reading and numerical tasks required to function in the health care environment (three items, Cronbach's α =0.63) [43]; (2) numeracy, i.e. understanding of quantitative information, using four questions covering the use of proportions and percentages (Cronbach's α =0.59) [44]; and (3) self-reported educational level.

(c) Level of anxiety and denial

The patients' level of anxiety and denial were assessed at baseline with extensively validated instruments: (1) the anxiety subscale of the Hospital Anxiety and Depression Scale [45]; (2) the subscale trait anxiety of the State-Trait Anxiety Inventory [46]; (3) the Fear of Cancer Scale [38]; and (4) the subscale avoidance from the Impact of Event Scale [47] assessing patient's preference for a denying coping style. These are extensively used and validated instruments.

2. Characteristics of the consultations

Time between initial and follow-up visit was assessed.



Fig. 1 Study design

Patients' satisfaction with the initial consultation overall, with information needs met, and with the behaviour of the radiation oncologist as trying to involve them during the consultation were assessed with three questions from the PSQ [48], immediately following the initial consultation. Response categories on a 100-mm visual analogue scale ranged from 'not satisfied at all' to 'very much satisfied' and 'not involved at all' to 'very much involved', respectively.

3. Characteristics of the consulted radiation oncologist Prior to inclusion of patients, radiation oncologists completed a short questionnaire assessing their gender and years of experience in medical practice.

Data analyses

Descriptive statistics were used to characterise the study sample. We compared the individuals who completed both measurements with the total sample with Pearson Chisquare, Mann–Whitney and independent t tests as appropriate. Reliability was determined by calculating Cronbach's α 's.

To assess if patients' information needs decrease during the course of radiotherapy, total subscale scores were calculated, as well as a total IPRP score (range 1-5). The number of items in the subscales of the IPRP varies; therefore, mean percentage scores were calculated in order to compare subscale scores. Responses to the IPRP appeared to be highly skewed, both on the total scale and on most subscales (5/6). The IPRP total scale was thus cubically transformed to obtain an approximately normal distribution. The IPRP subscales were too heavily skewed to be transformed. They were dichotomized, with average responses below 4 labelled as a lower information need and average responses of 4 and above indicating high information preference. Paired t tests for within-subjects design (for the transformed total scale) and Wilcoxon signed-rank tests (for the subscales) were carried out to determine change in information need between baseline and follow-up.

A change in information need was also described by a medium-sized difference, a difference of a half standard deviation [49], on the total scale and the subscales of the IPRP. Whether there were differences in the pattern of changes across the domains was tested with Chi-square tests.

To determine which patient, consultation and radiation oncologist characteristics were associated with a decrease in information need over time, predictors of a decrease in information needs (versus increase and stable) were explored using bivariate logistic regression analyses for the transformed total IPRP scale and subscales separately. All analyses were carried out with SPSS version 16.0. A pvalue of 0.05 (two sided) was considered significant.

Results

Sample characteristics

Of 293 eligible radiotherapy patients, 159 (54%) agreed to participate. Five participants had too many missing values on the IPRP at baseline and were excluded from further analyses. Of the remaining 154 patients, 104 (68%) also completed the IPRP at follow-up. Those who completed the IPRP on both baseline and follow-up did not differ significantly in age (p=0.75), gender (p=0.86) and IPRP total score at baseline (p=0.69) from those who only completed the IPRP at baseline.

Table 1 shows the sociodemographic and clinical characteristics of the 104 respondents available for analyses. Mean time between initial and follow-up visit was 34 days (SD=22). There was an outlier with 179 days between initial and follow-up visit. She had had her initial consultation before she underwent surgery and chemotherapy and started radiotherapy only after the chemotherapy was completed.

Decrease in information need over time?

Overall, patients' information need declined significantly from initial to follow-up visit for all domains except psychosocial issues (see Table 2). More specifically, information needs of 26-37% of the patients declined (i.e. decreased more than one half standard deviation) on the different domains, while 10-24% of patients had increased information needs over time and 39-62% of patients did not change (see Table 3). Domain preferences stayed roughly the same, with the highest need for information about side effects at both baseline and follow-up (see Table 2). The pattern of change of the domain psychosocial issues differed significantly (p < 0.05) from the other domains, with significantly more patients who changed in their needs between consultations.

Explaining a decrease in information need over time

There were no characteristics associated with the IPRP total score (information needs in general) (data not shown).

- 1. Patient characteristics
 - (a) Sociodemographic and clinical characteristics Being male was significantly associated with a decrease in information need about procedures (*p*= 0.01, exp *b*=0.28, 95%CI=0.10–0.76). Being religious was significantly associated with a decrease in information need about procedures (*p*=0.02, exp *b*=2.83, 95%CI=1.16–6.91) and expected side effects (*p*=0.03, exp *b*=2.87, 95%CI=1.13–7.29).

Table 1	Sociodemographic	characteristics	of the respondents	(n=104)
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	Mean (range)	SD
Age (in years)	62.6 (28-86)	12.6
	Ν	%
Gender		
Male	62	60
Female	42	40
Marital status		
Married/steady relation	78	75
No partner	25	24
Children		
No children	19	18
Children living at home	17	16
Grown-up children	67	64
Level of education ^a		
Low	74	71
High	27	26
Employment		
Yes	44	42
No	59	57
Ethnicity		
Dutch	99	95
Other	4	4
Native language		
Dutch	97	93
Other	6	6
Religion		
Yes	47	45
No	56	54
Diagnosis		
Breast	19	18
Urological ^b	30	29
Gynaecological ^c	7	7
Rectum	14	14
Esophagus	11	11
Lung	7	7
Gastrointestinal ^d	6	6
Other ^e	8	8
	Mean (range)	SD
Time between consultations (in days)	33.9 (12–179)	22.6
	Median, 26	
Duration of initial consultation (in minutes)	46.8 (17–99)	16.5
Duration of follow-up visit (in minutes)	10.6 (3-58)	7.7

Due to missing data, not all percentages add to 100%

^a Low: no education, primary school or lower professional education. High: high school, college or university

^b Urological: bladder, bile duct, prostate, testis and kidney

^c Gynaecological: cervix and uterus

^dGastrointestinal: anus, colon, stomach, pancreas

^e Other: skin, non-Hodgkin

lymphoma, other

No other sociodemographic and clinical characteristics were related to a decrease in information need over time (Table 4).

(b) Level of health literacy and numeracy

Lower health literacy was significantly associated with a decreased need for information about treatment (p=0.05, exp b=1.75, 95%CI=1.01–3.05). Neither numeracy nor education level was related to decreased information needs.

(c) Level of anxiety and denial Neither health-related anxiety, trait anxiety, fear of cancer nor a denying coping style were related to a decrease in information need.

2. Characteristics of the consultations

Patients' mean score on satisfaction with the initial consultation overall is 89.6 (SD=10.1), with information needs met 89.7 (SD=9.9), and with the behaviour of the radiation oncologist as trying to involve them during the consultation 82.1 (SD=15.4). The more individuals were satisfied with the degree to which the radiation oncologist tried to actively involve them, the more their information needs about psychosocial issues decreased (p=0.002, exp b=0.94, 95%CI=0.90–0.98). Time between consultations, satisfaction with the information provided and overall satisfaction were not related to a decrease in information need.

3. Characteristics of the consulted radiation oncologist The gender of the radiation oncologist and years of experience in clinical practice were unrelated to a decrease in information need.

Discussion

Since extensive information provision may not necessarily be beneficial to all patients, we should preferably move toward patient-tailored care which takes such individual variation into account [50]. With our study, we aim at gaining understanding of how patients' information needs may change from visit to visit in order to be able to better tailor information giving. To our knowledge, this study is among the first to quantitatively investigate in the radiotherapy setting information needs over time and which characteristics are related to a possible change in needs.

The most important finding of our study is that although information needs decrease over time, they remain high for most patients. A first explanation for such a high information need might be that patients have difficulties recalling information given at the initial consultation and therefore would like to have most information repeated at the follow-up visit. Studies on recall indicate that as much

Table 2 Information need over time (n=104)

Information need	n	Mean at baseline	Mean at follow-up	t	p value	
IPRP total score	84	4.22 (0.76)	4.06 (0.80)	3.09	<0.01*	
Information domain				Ζ		
Disease	102	4.08 (0.99)	3.96 (0.96)	-2.02	0.04*	
Treatment	97	4.14 (0.79)	3.98 (0.85)	-2.80	< 0.01*	
Procedure	101	4.38 (0.76)	4.14 (0.93)	-3.46	< 0.01*	
Side effects	100	4.44 (0.75)	4.28 (0.80)	-2.19	0.03*	
Prognosis	99	4.37 (0.88)	4.18 (1.04)	-2.34	0.02*	
Psychosocial	100	3.50 (1.08)	3.42 (1.14)	-1.25	0.21	

A higher score reflects a higher need for information. Scores on total scale and domains range from 1-5. The table shows the non-transformed data. For the IPRP total scores, the analysis was performed using transformed scores

IPRP Information Preferences of Radiotherapy Patients Questionnaire

*Significant at p<0.05 level

as 50% of information may be forgotten [51-54]. This supports the recommendation by Bensing et al. [30] that researchers should not look at the communication process as an isolated event, but rather as an ongoing process. Furthermore, future studies might incorporate recall of the information given at the initial consultation as this could possibly explain the high need for information at follow-up. A second explanation for a remaining high information need among patients could be that the initial consultation left the patient with unmet information needs at the followup visit. This could have been caused by suboptimal communication by the radiation oncologist, e.g. by not explicitly checking the patients' information needs. On the other hand, patients may not have wanted to bother their doctor with their questions. This emphasises the importance of all team members involved in radiotherapy to work together in eliciting patients' information needs. A third explanation could be that seeking information is part of the patients' coping process, i.e. it is their way to gain control [55]. If so, patients will want information, regardless of the amount of information provided by the radiation oncologist and others. However, physicians' attempts to meet patients' needs in this respect will positively affect their relationship. Clearly, all these explanations are hypotheses which need further study to be confirmed.

An alternative methodological explanation for the levels of information need remaining high is the scale's wording. It is possible that we partly measured a generalised preference or trait (the individual variation in information needs) rather than a current need or state (how much the patient presently wants to know). Since a monitoring coping style is a trait, we investigated in post hoc analyses the association between information needs measured with the IPRP and the person's monitoring coping style. We found a medium association between information needs and a monitoring coping style, both at baseline and follow-up (0.38 and 0.45 respectively), representing a limited part of the variance (14 versus 22%). These results suggest that we may have partly measured a generalised information preference rather than a current need. Obviously, needs

Information need	Total score $(n=84)$	Disease	Treatment	Procedure	Side effects	Prognosis	Psychosocial
information need		N=102	N=97	N=101	N=100	N=99	N=100
	n (%)	n (%)	n (%)	n (%)	n (%)	n (%)	n (%)
Decrease ^a	29 (35)	31 (30)	33 (34)	29 (29)	26 (26)	27 (27)	37 (37)
Stable ^b	46 (55)	55 (54)	50 (52)	62 (61)	60 (60)	61 (62)	39 (39)
Increase ^c	9 (11)	16 (16)	14 (14)	10 (10)	14 (14)	11 (11)	24 (24)

Table 3 Change of one half SD in information need between baseline and follow-up (n=104)

Percentages are based on difference scores between baseline and follow-up (sum score follow-up – sum score baseline). Scores on total scale and domains range from 1-5. Numbers do not add to 104 because of missing values

^a Decrease in the sum score of the scale of one half SD or more

^b Stable means that a change in the sum score of the scale is less than one half SD

^c Increase in the sum score of the scale of one half SD or more

Table 4 Significant predictors of decrease in information need	(n=10))4))
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	IPRP scale	р	Exp b	95%CI for exp b
Patient characteristics				
Demographic and clinical variables				
Gender	Procedures	0.01	0.28	0.10-0.76
Religion: yes versus no	Procedures	0.02	2.83	1.16-6.91
	Side effects	0.03	2.87	1.13-7.29
Level of intellectual ability				
Health literacy	Treatment	0.05	1.75	1.01-3.05
Level of anxiety and denial				
-	_	_	-	-
Characteristics of the consultations				
Patient satisfaction with involvement at intake	Psychosocial issues	< 0.01	0.94	0.90-0.98
Characteristics of the consulted radiation oncologist at intake				
_	_	—	_	_

All shown predictors are significant at p < 0.05 level. Bivariate logistic regression analyses in which information need is dichotomized (decrease versus stable/increase)

CI confidence interval, IPRP Information Preferences of Radiotherapy Patients Questionnaire, Exp b exponent of the B coefficient, which is an odds ratio

are always related to personality. At the same time, we may have to reconsider the wording of the time frame when revising the IPRP eventually.

The decrease in information needs in patients with low health literacy is noteworthy; they already had lower information needs at the initial consultation [19] and now also show a greater decrease in information need over time. The association between low health literacy and decreased information needs may suggest that (at least part of) the information needs of low literate patients were met during the initial consultation. As we only globally investigated if information needs were met, this needs further study. However, this association may also mean that the communication at the initial consultation does not stimulate these individuals to get better informed at the follow-up visit, i.e. as if they have given up the effort. Low literate patients may feel ashamed when they consider their intellectual capacities as insufficient to comprehend medical information [56] or may be afraid of consuming too much of their physicians time when asking for additional explanations [13]. The few studies which examined the association between health literacy and the exchange of information during consultations suggest that low literacy patients ask fewer questions and receive less information during interactions with their physicians [57, 58]. Radiation oncologists may adapt their communication to the patient's lower information need. From the literature, it is known that physicians may perceive a patient with low knowledge as incompetent or possibly uninterested, which leads to less information giving [59]. Rather than providing less information, low literate patients probably deserve extra attention to ensure their understanding and thus support their adaptation to the treatment process. An alternative explanation for remaining high information needs among high literate patients might be that they wanted more information than what is standard given; even large amounts of information could just not have satisfied them. However, all these explanations are highly speculative and need further investigation.

We also found information needs to decrease more in men than in women. As men had lower information needs to begin with [19], their information need could have been already fulfilled for the most part at the intake consultation. Future research should take into account the amount of information that was actually given during the consultation. We find the significant association between religion and decreasing information needs harder to explain. Maybe the support of patient's religious practice may reduce the impact of the disease [60] through a cognitive process of resignation or surrender to God's will.

Interestingly, individuals who were satisfied with the degree to which the radiation oncologist tried to actively involve them in the initial consultation showed a decrease in information needs about psychosocial issues at followup. These patients possibly feel that their psychosocial (information) needs are met by the radiation oncologist and therefore have less psychosocial information needs at follow-up. This finding may be of clinical importance because early investment of the radiation oncologist in psychosocial topics, such as contact with fellow-sufferers, other sources for psychosocial support and financial consequences of the disease, could thus satisfy the need for additional psychosocial information.

Some limitations of this study should be noted. Overall, individuals had high scores at the Information Preferences of Radiotherapy Patients Questionnaire at baseline. So, a ceiling effect was present, making it impossible for most individuals to score higher at follow-up. Moreover, the ceiling effects lead to low variance in the data. As a consequence, it is more difficult to find significant associations. On the other hand, we performed several separate logistic regression analyses which could have led to a multiple testing bias leading to an increased chance of finding significant results. Second, in our study, we asked about information needs in relation to the consultation with the radiation oncologist. However, these information needs in part could have been met through other sources like internet, family or other health professionals. Third, the overall response rate was relatively low, which is most likely due to the fact that patients just received their cancer diagnosis and did not have the attention or energy to fill out an extensive questionnaire. Furthermore, this was part of a larger study, in which consultations with the radiation oncologist were videotaped. Some patients did not want that and therefore did not take part in the study.

In summary, this study showed that information needs decrease over time. However, they remain at a high level, and for a majority of patients, their information needs did not change. Being male, being religious, having low health literacy and satisfaction with the degree of involvement during the consultation were all associated to a decrease in some, but certainly not all domains of information needs. Overall, there were no clear outstanding characteristics that explain a decrease in information need. Although we thoroughly investigated a variety of factors which are assumed to be associated with changes in information needs over time, we are still not able to fully explain patterns in such needs. As a consequence, radiation oncologists cannot assume that at the follow-up visit, the same type of patients, for example older and male patients have low information needs as compared to the initial consultation.

Future studies might use a qualitative approach to gain more insight in how information needs develop from visit to visit. Also, in view of the fact that oncology care involves many health professionals' attention should be paid to the role of the whole team on informing the patient. In addition, future studies should measure in more detail if information needs are met.

Currently, radiation oncologists invest much effort in information giving at the initial consultation. Our results suggest that it is also necessary to shortly explore the patients' information needs at every visit and not rely on giving information once. Patients are known to be less anxious when information is spread out [61]. Furthermore, radiation oncologists should check if the information given at first consultation is well understood and remembered. By those means, tailored information giving becomes possible.

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Conflicts of interest The authors have no conflict of interest to be reported.

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