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Perception of burden experienced during diagnostic tests by melanoma patients with lymph node metastases

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Melanoma patients with lymph node metastases have to deal with diagnostic tests to exclude the presence of distant metastases; results of the tests could have major implications for their prognosis and treatment. There are, however, few studies concerning the patients' psychological issues and perception of diagnostic tests. The aim of this study was to describe the burden of diagnostic tests [radiograph, computed tomography (CT) and positron emission tomography (PET)] experienced by melanoma patients with lymph node metastases. Patients were asked to complete a questionnaire concerning satisfaction and burden experienced during the diagnostic tests. The levels of embarrassment, discomfort and anxiety for the different tests, as well as total scores for each burden were calculated. Logistic regression was used to examine factors associated with the degree of experienced burden. Fifty-nine of the 68 patients completed the questionnaire and the response rate was 87%. The overall mean scores on satisfaction and quality of life were high. More than half of the patients experienced no burden during PET, 65% no burden during computed tomography and 80% no burden during chest radiograph. Patients experienced significantly more discomfort during the PET scan than during the CT

Introduction

The incidence of melanoma is one of the most rapidly increasing types of cancer [1]. The incidence in The Netherlands in 2003 was 16.1 per 100 000; a rise of 41% compared to the incidence in 1992. Increased awareness and surveillance have resulted in earlier diagnosis of melanoma and, consequently, the melanoma patient is now diagnosed at an earlier stage of disease [2]. Nevertheless, some melanoma patients still present or recur with loco-regional metastases (American Joint Commission on Cancer stage III). When no distant metastases are detected, the standard of care for these patients is a surgical excision of the primary tumour and a lymph node dissection. Several imaging techniques, such as radiograph of the chest, computed tomography (CT), and positron emission tomography (PET), are available to detect distant metastases. Defining the additional value of these diagnostic tests requires an evaluation of the accuracy, the impact on treatment, and the costs of the tests. As the value of PET and spiral CT for melanoma

($P=0.003$). Less burden was experienced (in univariate analysis) by patients who were more satisfied. The overall experienced burden by patients is low and should therefore not interfere with primary choice for a diagnostic test based on accuracy, costs and percentage of patients upstaged. Attention should be paid in explaining the procedure and answering questions of the patients to reduce burden. *Melanoma Res* 19:36–41 © 2009 Wolters Kluwer Health | Lippincott Williams & Wilkins.

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Keywords: burden, computed tomography, diagnostic tests, fluorodeoxyglucose-positron emission tomography, melanoma, satisfaction

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patients clinically stage III is not clear, a prospective multicentre study in The Netherlands was undertaken. Additionally, burden experienced by the patients could be an important feature in defining the value of these diagnostic tests.

Considering the increased incidence of melanoma, there are only a few studies concerning the psychological issues and perception of diagnostic tests related to this disease, often with contradicting results. Studies have reported that newly diagnosed melanoma patients (stage I) exhibited the same psychological distress as other cancer patients, despite a good prognosis [3,4] Other studies, however, found that melanoma patients do not differ from the general public in terms of emotional well-being and even that their psychological functioning was superior to that of other dermatology patients [5]. Participants with a hereditary risk of melanoma in a melanoma prevention programme showed relatively low levels of psychological problems, whereas participants in public screening

revealed higher levels of problems [6,7] Considerable sex differences were found in this last study; women were more concerned, had higher levels of anxiety, tiredness and psychosomatic complaints [7]. A delay in diagnostics was also reported to be significantly more distressing for females than for males [8].

Some studies have shown anxiety-related reactions in patients undergoing MRI [9–11]. Patients who experience such feelings may disrupt the examination or move, which may cause a degradation of the images. Anxiety-related reactions may also influence patients' perception concerning their care [9]. Additionally, information about patients' preferences is necessary to be able to assist patients in making decisions about which tests to undergo, as patients may prefer an active role in test and treatment decision-making [12,13]. Patients with lymph node metastases have to deal with more diagnostic tests to prove or exclude the presence of distant metastases. The results of the tests could have major implications for prognosis and treatment. Therefore, the aim of this study was to describe and compare the perception, both satisfaction and burden, of the diagnostic tests (chest radiograph, CT and PET) of melanoma patients with lymph node metastases.

Patients and methods

From September 2004 to November 2006, patients with clinical stage III melanoma were included in a prospective study to determine the value of PET with the tracer fluorodeoxyglucose (FDG) and CT. If patients showed no distant metastases on CT and PET, they were questioned about different aspects related to the diagnostic tests. They received a questionnaire 2–6 weeks after lymph node dissection.

Diagnostic tests

Some patients had a standard chest radiograph taken before the other diagnostic tests. All patients underwent at least a multidetector spiral CT and PET to prove or exclude the presence of distant metastases.

Computed tomography

The examination was performed with a multidetector spiral CT with at least four detector rows. Patients had to drink 800 ml oral contrast in four portions before the CT examination. First, a chest CT was performed with intravenous contrast, followed by an abdomen CT. If the lymph node metastases were located in the neck, CT of the neck was performed with intravenous contrast. Total investigation time is 5–10 min. The CT results were examined by experienced radiologists.

Positron emission tomography

After a 6 h or overnight fasting period, patients were intravenously injected with 220–650 MBq and prehydrated with 500–1500 ml water. The interval between the

FDG injection and the PET scan was 60–90 min. When specially indicated, furosemide or bed rest was given. Patients were scanned from the midfemoral region until the skull (two-dimensional or three-dimensional acquisitions). Emission scan duration was 5 min per bed position, transmission imaging 3 min. The total duration of the procedure was approximately 2 h and 30 min including a scan time of approximately 1 h.

Questionnaire

Patients were asked to complete a self-administrated questionnaire. The following sociodemographic information was gathered: date of birth, sex, marital status, education and occupational status. Eleven questions assessed patients' satisfaction with care and with all the diagnostic tests combined. A high score corresponds with high satisfaction (see Table 2) [14]. For each diagnostic test (chest radiograph, CT scan and PET scan), the following questions were asked: (i) how much embarrassment, (ii) discomfort and (iii) anxiety did you experience during the test and (iv) would you recommend the test to a friend. These questions were also used in other studies (Westerterp *et al.*, 2007, in preparation) [9–11,15]. Questions concerning the burden had to be answered on a 5-point scale, with 1 indicating 'none', 2 'mild', 3 'moderate', 4 'severe' and 5 indicating 'extreme' and were followed by the question of why patients felt that way. Finally, patients were asked to rank the different diagnostic tests, questions were asked about the length of the tests, how they felt about having to travel to the hospital on two different days and whether they had come with their partner, family or friends. At the end of the questionnaire, we left space for patients' comments. The levels of embarrassment, discomfort and anxiety for the different tests, as well as total scores for each burden were calculated. Correlation was assessed between quality of life (QoL) as scored by the patient, and the preference for decision-maker. Differences in embarrassment, discomfort and anxiety during the tests were calculated (Wilcoxon for two groups and Friedman test for the three groups). Regression analysis was used to examine the factors, which affected the degree to which patients experienced burden. *P* values < 0.05 were considered statistically significant.

Results

Fifty-nine of 68 patients completed the questionnaire; the response rate was 87%. Male and female patients were almost equally represented. The median age of the included patients was 58.6 (range 29–85) years. Most of the patients were married (69%) or cohabiting and almost half had finished middle/higher secondary or middle vocational school. Almost a third of the patients had a full-time job or was retired (Table 1).

The overall scores on satisfaction and QoL were high (Table 2). Satisfaction with the amount of information

Table 1 Demographic characteristics of the patients

Characteristic		N	%
Sex	Male	33	55.9
	Female	26	44.1
Age	≤ 45 years	15	25.4
	46–64 years	29	49.2
	≥ 65 years	15	25.4
Marital status	Married	40	69.0
	No relationship, living alone	9	15.5
	Relationship, living alone	3	5.2
	Divorced or widower	6	11.3
Highest education	Primary school/Lower vocational school	20	33.9
	Middle/higher secondary or middle vocational school	28	47.5
	Higher vocational school/university	11	18.6
Occupation	Full-time job	18	30.5
	Part-time job	11	18.7
	Housekeeping	7	11.9
	Retired	17	28.8
	Unable to work	6	10.2

Table 2 Reported scores concerning the satisfaction of the patients, QoL and preference for decision-maker (part 2 of the questionnaire)

Satisfaction of patients	Mean ± SD
Possible range 0–5 Amount of information given	4.8 ± 0.6
Willingness and patience of doctors in answering your questions	4.7 ± 0.8
Answers to all your questions	4.6 ± 0.9
Explanation of the procedure and the reason for the test	4.6 ± 0.9
Time and attention given to you	4.4 ± 1.0
The support given	4.4 ± 1.1
The weight of your own opinion in decisions	4.3 ± 0.6
Quick help	4.1 ± 1.2
To make own decisions	3.5 ± 0.8
Possible range 0–10	
The amount of medical information you would like to have	8.9 ± 1.6
Overall satisfaction with diagnostic tests	8.0 ± 1.6
QoL	
How would you judge your QoL?	7.5 ± 1.5
Decision-maker	
Who would you prefer to make the decision: the doctor or you?	Only the doctor: 3 (5.1%) Predominantly the doctor: 12 (20.3%) The doctor and patient equally: 39 (66.1%) Predominately the patient: 5 (8.5%) Only the patient: 0

QoL, quality of life.

that was given to the patients received the highest score. Second was satisfaction concerning the doctors' willingness and patience to answer questions. Patients were highly satisfied if they felt that all their questions were answered and the procedure and reason for the test were explained. A mean score of 4.4 was reported concerning the satisfaction of patients with the amount of time and attention given to them and the satisfaction concerning the support given. Patients were also satisfied with the weight that was given to their opinion in the decision-making. The mean score for the satisfaction with quickness

of help was also relatively high. The lowest score was in the satisfaction with the amount of space patients were given to make their own decisions. A high mean score was reported for patients' satisfaction with the amount of information they received about their medical situation. The overall mean satisfaction with the course of the diagnostic tests was 8.0.

Most patients thought the decisions about their treatment had to be made by the doctor and the patient collaboratively, 20% preferred the doctor to be the predominant decision-maker, 9% preferred the patient to be the predominant decision-maker and only a few patients preferred the doctor to be the sole decision-maker. The mean QoL was 7.5; four patients judged their QoL lower than 6. In this study, there was a significant correlation between the reported QoL and the preference for decision-maker: the larger the doctor's role in making the decision, the higher the patient's QoL ($r = -0.38$; $P = 0.004$). Additionally, older age was associated with preference for the doctor to make the decision ($P = 0.01$).

Table 3 shows the amount of embarrassment, discomfort or anxiety patients felt during the diagnostic tests. Of the 40 patients who had a chest radiograph, 35 (87.5%) felt no embarrassment. Five patients (12.5%) felt mild-to-extreme embarrassed: two for being nude from the waist up, two because they were not sure what to do and one patient was anxious about the test results during the chest radiograph. No discomfort during the chest radiograph was reported by 36 patients (90%). Four patients (10%) felt mild-to-moderate discomfort during the chest radiograph; reasons that were mentioned were having to hold their breath for a longer time, being cold, feeling nervous or pain in the shoulder. Thirty-two patients

Table 3 Number of patients who felt none to extreme embarrassment, discomfort and anxiety during the chest radiograph, PET and CT scans

		Radiograph CT		FDG-PET
		N (%)	N (%)	N (%)
Embarrassment	None	35 (87.5)	38 (65.5)	36 (61.0)
	Mild	3 (7.5)	14 (24.1)	15 (25.4)
	Moderate	1 (2.5)	3 (5.2)	4 (6.8)
	Severe	1 (2.5)	1 (1.7)	2 (3.4)
	Extreme	–	2 (3.5)	2 (3.4)
Discomfort	None	36 (90.0)	38 (65.5)	25 (42.4)
	Mild	3 (7.5)	18 (31.0)	27 (45.8)
	Moderate	1 (2.5)	–	5 (5.8)
	Severe	–	1 (1.7)	–
	Extreme	–	1 (1.8)	2 (3.4)
Anxiety	None	32 (80.0)	40 (69.0)	38 (64.4)
	Mild	3 (7.5)	11 (19.0)	11 (18.6)
	Moderate	3 (7.5)	4 (6.9)	5 (8.5)
	Severe	2 (5.0)	1 (1.7)	4 (6.8)
	Extreme	–	2 (3.4)	1 (1.7)

CT, computed tomography; FDG, fluorodeoxyglucose; PET, positron emission tomography.

(80%) reported no anxiety during the chest radiograph. Eight patients (20%) reported anxiety about the results of the chest radiograph.

No embarrassment during the CT scan was reported by 38 patients (65.5%). Twenty patients were, however, mild-to-extreme embarrassed during the CT scan, mainly because they did not know what to do and they had trouble lying still. Discomfort during the CT scan was not reported by 38 patients (65.5%). Twenty patients experienced discomfort during the CT scan; again a larger percentage found it difficult to lay still and others felt cold. Forty patients (69%) experienced no anxiety during the CT scan; 18 (31%) experienced some kind of anxiety because they were anxious about the results or claustrophobic (extreme anxiety).

No embarrassment during the PET scan was reported by 36 patients (61%). Twenty-three patients (39%) were embarrassed during the PET scan, mainly because they did not know what to do or they had trouble lying still. Discomfort during the PET scan was not reported by 25 patients (42.2%). Thirty-four patients (58%), however, reported discomfort (trouble lying still, feeling cold and discomfort from having a full bladder). Thirty-eight patients (64.4%) felt no anxiety during the PET scan. Twenty-one patients (35%) were anxious during the PET scan; patients were anxious about the test results and felt claustrophobic.

Overall, more than half of the patients experienced no burden during the PET scan, more than 65% of the patients experienced no burden during the CT and more than 80% experienced no burden during the chest radiograph. Patients who experienced anxiety during one of the diagnostic tests, experienced anxiety during all tests (correlation CT and PET $P < 0.001$; CT and radiograph $P = 0.0006$; PET and radiograph $P = 0.003$). Patients who experienced discomfort during the PET scan experienced discomfort during the CT scan ($P = 0.001$). Additionally, patients who experienced embarrassment during the CT also felt embarrassed during the PET ($P < 0.0001$) and radiograph ($P = 0.01$).

Patients experienced significantly more discomfort during the PET scan than during the CT scan ($P = 0.003$). Despite this burden, all patients indicated that they would recommend the tests to a friend if they were advised to go for one. Less burden was experienced by patients who felt satisfied that the procedure was explained ($P < 0.001$), doctors were willing and patience ($P = 0.002$), questions were answered ($P = 0.011$), attention was given ($P = 0.006$), enough support was given ($P = 0.001$) and that enough medical information was given ($P = 0.018$). Additionally, patients who were more overall satisfied ($P = 0.006$) and patients who reported a

higher QoL ($P = 0.002$) also reported less burden in univariate analysis. Age ($P = 0.22$), sex ($P = 0.07$), marital status ($P = 0.83$) and education ($P = 0.67$) were not statistically significant associated with burden. In addition, time from lymph node dissection to filling in the questionnaire was not associated with the burden experienced ($P = 0.168$). In multivariate analysis, none of the variables was significantly associated with burden.

Most patients ranked the PET scan as most inconvenient, 25% thought there was no difference in inconvenience between the diagnostic tests. The length of the PET scan was experienced as rather long or very long by 51.7% of the patients, the CT scan by two patients. The fact that the tests could not be performed in 1 day was no problem to 48% of the patients, a small problem to 36% and nine patients reported it being very unpleasant. Having to travel to the hospital was no problem for 56% of the patients, a small problem for 37% and very unpleasant for 7%. Only three patients came to the test alone, the remaining came with their spouse (61.4%), with family members (26.3%) or with spouse and family members or a friend (7.0%).

Discussion

In the last 15 years, QoL has been identified as an important outcome for cancer patients. The amount of emotional distress the patient experiences is an important component of that QoL [16]. The psychosocial demands that confront cancer patients vary over the course of the illness; however, the time of diagnosis is described as particularly distressing [17–19]. Additionally, younger cancer patients face more difficulties when they receive a cancer diagnosis than older patients [20]. As the incidence of melanoma continues to increase and the age at which it is diagnosed continues to decrease, more and more younger patients will be referred to the oncology clinics [16].

In this study, more than half of the patients experienced no burden during the PET, more than 65% no burden during the CT and more than 80% no burden during the chest radiograph. Patients experienced significantly more discomfort during the PET scan compared to the CT scan ($P = 0.003$). Patients who were more satisfied, experienced less burden during the diagnostic tests (univariate analysis).

Patients in this study were very satisfied with various aspects concerning the diagnostic tests. Patients seem to be the most satisfied with the amount of information that was provided to them, the willingness and patience of the doctors to answer questions. A high score was reported when patients were satisfied with how quickly they were helped, despite the fact that a few patients mentioned that the time between the diagnostic tests and the

operation was long. Patients were least satisfied with the amount of space that was given to them to make their own decisions. Mainly, patients who scored low on this question felt that the doctor and patient had to make the decisions together. Additionally, we found a significant correlation between QoL and decision-maker: patients who left the decision entirely to the doctor or predominantly to the doctor reported a higher QoL in this study.

Several studies have been carried out to evaluate anxiety-related reactions associated with MRI [9,10,21]. A Canadian review reported that anxiety-related reactions occur in approximately 4–30% of the patients undergoing MRI, ranging from apprehension to severe reactions, which interfered with the performance of the test [10]. Criteria for diagnosis and categorization of the reactions and identification of patients at risk are scarce, although management strategies such as patient education, drug therapy and cognitive-behavioral intervention have been proposed [10]. A recent prospective study in patients at risk for colorectal cancer showed that patients preferred CT colonography above colonoscopy. This preference, however, decreased over time, and outcome considerations gradually replaced temporary experiences of inconvenience [15]. It is likely that future decisions will be based on the final opinion, as this opinion is formed after immediate experiences have tempered and when patients have returned to normal functioning. The researchers assumed that experience and preference are preferably measured after a certain time, as this may better reflect future behaviour than if experience and preference are measured under stressful circumstances [15]. In this study, we chose a 2–6 week interval after surgery and found no association between time since operation to questionnaire and burden. However, it remains unknown when opinions change and which interval should be used to optimally measure patient preference.

In this study most of the patients experienced discomfort, particularly during the PET scan. This is probably because of the fact that patients have to lay still for a longer period of time as during a CT scan. Future PET–CT scanners could correct this discomfort as they can scan a patient in less than 30 min, or even in 10 min if more FDG is injected. Furthermore, patients who felt they were not sufficiently informed about the procedure or were cold felt embarrassed and discomfort; burdens that probably could be avoided.

Several limitations to the study should be noted. First, it is not possible to determine whether the nonresponders were less satisfied or experienced more burdens from the diagnostic tests. Second, the questionnaires were only sent to a relatively small sample of patients who showed no distant metastases on PET and CT scans. It could be that patients who had distant metastases experienced

more burden from the diagnostic tests; future studies should compare these two groups. To our knowledge, however, this is the first study to investigate the patients' perceptions of the diagnostic tests FDG–PET, CT and chest radiograph, and, therefore, the results could be of great interest. The findings cannot be representative for all melanoma patients, but they do highlight salient issues in an area where research has been lacking.

In conclusion, although patients experience more discomfort during the PET scan, the overall levels of moderate-to-extreme embarrassment, discomfort and anxiety were low. The accuracy, costs and the percentage of patients upstaged will probably be the most important outcomes to determine the additional value of FDG–PET and CT, but it is reassuring to know that the overall burden of these diagnostic tests is low.

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