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Melanoma patients' disease-specific knowledge, information preference, and appreciation of educational YouTube videos for self-inspection

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Abstract

Background: Informing and educating melanoma patients is important for early detection of a recurrence or second primary. This study aimed to investigate Dutch melanoma patients' disease-specific knowledge, and their opinions on information provision and the value of e-Health videos.

Methods: All AJCC stage I–II melanoma patients in follow-up between March 2015 and March 2016 at a single melanoma center were invited to complete 19 online questions, addressing respondents' characteristics, knowledge on melanoma, and opinions on melanoma-specific information received and the educational YouTube videos.

Results: In total, 100 patients completed the survey (response = 52%); median age was 60 years and 51% were female. Breslow tumor thickness was unknown by 34% and incorrectly indicated by 19%, for presence of ulceration this was 33% and 11%, for mitosis 65% and 14%, and for AJCC stage 52% and 23%, respectively. Only 5% correctly reproduced all four tumor characteristics. Orally delivered information regarding warning signs, severity, treatment possibilities, and importance of self-inspection was clearest for patients, compared to information in the melanoma brochure. According to 77% of patients, YouTube videos regarding self-inspection of the skin and regional lymph nodes had additional value. Altogether, 63% preferred receiving information in multiple ways; 92% orally by their physician, 62% through videos, and 43% through brochures.

Conclusions: Patients' melanoma-specific knowledge appears to be limited. There is an urgent need for further improvement of providing information and patient education. In addition to oral and written information, e-Health videos seem to be a convenient supplemental and easy accessible method for patient education.

Keywords: Melanoma; Health knowledge; Information dissemination; Patient education; e-Health videos; Self-inspection

Introduction

Worldwide, the incidence of melanoma is still rising.[1] As a result of better staging, improved surgical techniques and the development of targeted drugs and immunotherapies, the ten-year relative survival is increasing.[2] Lower tumor stage at primary diagnosis and early detection of a recurrence are found to be prognostic factors for survival in melanoma patients.[3] Consequently, prevention of a primary melanoma and detection of primary melanomas, recurrences and second primaries have become an important issue in current healthcare systems.

Despite available prognostic systems, such as the American Joint Committee on Cancer (AJCC) staging system,

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the behavior of melanoma can be unpredictable, making it difficult for patients to get a grip on the disease. Therefore it is necessary for them to understand the basics of melanoma, the dissemination patterns, and how self-inspection should be carried out precisely.[4,5] Although melanoma patients are usually given oral and written disease-specific information, some patients indicate they have unmet information needs, and patient education for self-inspection is not always provided in follow-up.[5–7]

The reported rate of 70% patient-detected recurrences emphasizes the importance of patient education regarding self-inspection.[8] Skin self-examination (SSE) was already described in 1996 as a useful and inexpensive method for the early detection of a loco-regional recurrence or second primary.[9] Self-inspection is regarded as a crucial component of current follow-up. Detailed instructions about whole-body inspection as well as palpation of the scar area, in-transit route, and regional lymph nodes should be provided to patients and their relatives.[10]

In the present time in which the use of multimedia and e-Health technology is indispensable, the Internet and video-sharing sites like YouTube are commonly used sources for patients to obtain disease-specific information.[11] The use of videos for patient education has greatly increased since 1973, as this assures a standardized level of teaching and visual presentations may have a greater individual impact than oral or written information.[12] It appears that around 75% of patients acquire knowledge on their illness through web-based information searches, suggesting a platform like YouTube could be used for disseminating health-related information and as educational tool.[13–15]

The aims of this study were to examine: 1) Dutch melanoma patients' disease-specific knowledge, 2) opinions on oral and written information received and on the additional value of e-Health video-education for self-inspection, and 3) preferred information source.

Methods

Procedure and respondents

All AJCC stage I–II cutaneous melanoma patients in clinical follow-up at the UMCG between March 2015 and March 2016 were asked to participate. Patients were treated as recommended by the Dutch Melanoma Guideline.[16] According to this guideline, all patients received standardized oral and written information on melanoma and instructions on self-inspection during the first outpatient-clinic visit after diagnosis. Patients did not receive their pathological report. Additionally, they were informed about the Dutch Melanoma Patient Association.

An information letter was sent, explaining the goal of the study, with a hyperlink to the questionnaire, the web-links to two YouTube videos, and the melanoma brochure of the Dutch Cancer Society (DCS)[17] one week before the planned outpatient-clinic visit. Patients were asked to complete the online questionnaire after this outpatient-clinic visit, reading the brochure, and watching both YouTube videos. A reminder letter was sent after four weeks. The study was conducted in accordance with the Declaration of Helsinki, and approved by the central medical ethics committee (METc2015.031).

In collaboration with the DCS, a surgical oncologist, a psycho-oncological specialist, and a communication advisor of the University Medical Center Groningen (UMCG) developed two online instruction videos on self-inspection, in a format suitable for Dutch melanoma patients. The videos are available on YouTube: one explaining and visualizing self-inspection of the skin (5:06 min, https://www.youtube.com/watch?v=CYuBPSwuEU0) and another on self-inspection of the lymph node bearing areas (5:45 min, https://www.youtube.com/watch?v=vyE1o_tafiM). The purpose of these videos was to emphasize the necessity of self-inspection, to demonstrate how to perform self-inspection, and to increase patients' confidence in performing self-inspection.

Instrument

A self-developed 19-item, web-based questionnaire was created using SurveyMonkey® (supplementary file), addressing: respondent and tumor characteristics (10 questions), agreements and opinions on melanoma-specific information and education received (8 questions), and opinions on the value of video-education for self-inspection (1 question; 7 statements). To verify patients' responses, Breslow thickness, ulceration, mitosis, and AJCC stage were retrieved from pathological reports.

Statistical analysis

Frequencies and percentages were calculated. Differences between responders (complete and incomplete) and non-participants were tested using chi-square tests or t-tests, as appropriate, with a significance level of 5%. Statistical analyses were performed using IBM SPSS statistics version 22. Figures were made using GraphPad Prism 5.04.

Results

Of the 193 AJCC stage I–II melanoma patients approached, 124 started the survey, of which 14 did not complete the questionnaire and 10 did not watch the videos. Consequently, responses of 100 participants (response = 52%) were analyzed. Of these, 51% were female and 42% had completed high vocational education or university. Median age was 60 (range 20–86) years and median time since diagnosis 32.5 (range 3–209) months. Of the primary melanoma, 76% had been detected by the patients (n = 56; 22 male, 34 female) or relatives (n = 20; 13 male, 7 female), and 24% during a medical check-up by general practitioner or specialist (n = 24; 14

male, 10 female). Self-detection rate was significantly lower in male than in female patients ($p = 0.028$). The manner of detection (self; relative; physician) was not related to level of education or age. The trunk was more commonly affected in males (55%) and the lower limbs in females (45%, $p < 0.001$) (Table 1).

Those who did not complete the survey ($n = 24$) were significantly lower educated (elementary school or low vocational education) than those who did (high vocational education or university; $n = 100$; $p = 0.048$), no differences were found in gender, age, or time since diagnosis. Of the non-participants ($n = 69$), 55% were female and median age was 55 (range 18–89) years; level of education, and time since diagnosis were unknown. Respondents ($n = 124$) and non-participants did not differ significantly in gender or age.

Patients' melanoma specific knowledge

Of the 100 respondents, 34% replied not to know the Breslow thickness of their melanoma and 19% reported an incorrect Breslow thickness. Presence of ulceration was unknown for 33% and 11% answers were incorrect, presence of mitosis was unknown for 65% and 14% answered incorrectly, and AJCC stage was unknown for 52% and 23% answered incorrectly. Overall, only 5% correctly reproduced these four tumor characteristics (Table 1). No significant effect was found of gender, age, educational level, or time since diagnosis on correctly, not or incorrectly knowing these tumor characteristics.

Patients' opinions on information provision

Fifteen percent of patients stated not having received oral information on melanoma from their physician/nurse practitioner (NP) and 40% replied they did not receive the melanoma brochure before they were approached for this survey.

Of the respondents, 89% (totally) agreed that the orally provided information about warning signs of melanoma was clear, stage and severity was clear for 66%, and treatment possibilities for 93%. Regarding (total) agreement with clarity of information gained from the brochure percentages were 82%, 65% and 74%, respectively (Table 2). Regarding warning signs for a melanoma, 96% mentioned at least two aspects to be alert to: 77% mentioned a change in color, 81% changes in shape or size, and 66% physical changes (itching, bleeding, ulceration, raw surface). In total, 17% of patients indicated a wish for more information regarding melanoma. This was not associated with the number of unknown or incorrect tumor characteristics.

The physician/NP emphasized the importance of self-inspection for the detection of a recurrence, a second primary and nodular metastases according to 80%, 77% and 70%, respectively, while respectively 45%, 46% and 38% remembered this information from the brochure. Instructions on how to perform SSE were provided by the physician/NP according to 87%, and through the brochure according to 78%. As for lymph-node self-examination (LNSE), 69% could recall receiving oral instructions, and 64% remembered this information from the brochure (Table 2).

Respondents' appreciation of educational YouTube videos

The YouTube videos gave additional information to the oral and written instructions provided on SSE according to 77% of patients and 75% (totally) agreed the videos had additional value for LNSE. After watching both videos, 61% (totally) agreed to possess new information. The videos increased confidence in performing self-inspection according to 79%. Eighty-one percent would recommend the videos to other melanoma patients, and 58% would recommend their relatives to watch them. Overall, 53% (totally) disagreed that follow-up frequency could be decreased to once a year, with implementation of these videos (Fig. 1). This disagreement was significantly related to shorter time since diagnosis (mean difference 16 months, $p = 0.005$).

Information source preference

Of the patients, 63% preferred to receive patient education regarding self-inspection through more than one source. Summarized, 92% of all patients preferred their treating physician/NP to provide oral instructions, 43% preferred receiving instructions through a brochure, and 62% preferred the educational YouTube videos (Fig. 2). No effect was found of gender, age, educational level, or time since diagnosis on preferred information source.

Discussion

This study illustrates that the information currently provided to melanoma patients is insufficient. Two-thirds of patients prefer to receive information on melanoma and self-inspection in multiple ways, with the physician being the first source of preference, video transmission the second, and written information the third. Overall, e-Health education regarding self-inspection through YouTube seems to be considered a valuable supplement to instructions provided by the physician and the brochure, rather than as a substitute.

A small but significant percentage of patients (15%) indicated they did not receive oral information at all, and 40% stated not having received written information through a brochure, before study participation. This is worrying, as information should be provided to every patient according to the melanoma guideline as well as the Dutch law.[16,18] Possibly, some patients did not remember this information

Table 1
Characteristics of respondents and discrepancies between melanoma characteristics remembered by patients and melanoma characteristics according to the pathological report (n = 100).

Characteristics	According to patient (n)	According to pathological report (n)	Unknown + incorrect (n, %)
Gender			
Female	51		
Male	49		
Age (years)			
Median, range	60, 20–86		
≤60	49		
>60	51		
Level of education[a]			
High	42		
Intermediate	32		
Low	26		
Time since diagnosis (months)			
Median, range	32.5, 3–209		
Person detecting primary melanoma			
Patient	56		
GP	14		
Specialist	10		
Other; friend, family	20		
Primary melanoma site			
Lower extremity	29		
Upper extremity	14		
Trunk	38		
Head/neck	19		
Breslow thickness (mm)			34 + 19 (53.5%)
Median, range	1.3, 0.1–12.0	1.2, 0.4–8.0	
T1: <1.00	16	20	
T2: 1.00–2.00	33	59	
T3: 2.00–4.00	11	15	
T4: >4.00	6	5	
Unknown	34	–	
Missing	–	1	
Ulceration			33 + 11 (45.4%)
No	51	82	
Yes	16	15	
Unknown	33	–	
Missing	–	3	
Mitosis			65 + 14 (82.3%)
No	14	15	
Yes	21	81	
Unknown	65	–	
Missing	–	4	
AJCC Stage			52 + 23 (76.5%)
Ia	12	6	
Ib	12	67	
IIa	14	17	
IIb	10	4	
IIc	0	4	
Unknown	52	–	
Missing	–	2	
Unknown or incorrect			
1 tumor characteristic	14		
2 tumor characteristics	31		
3 tumor characteristics	26		
4 tumor characteristics	24		
All 4 known and correct	5		
Information on melanoma received before this study started? (yes)			
Oral (physician/NP)	85		
Written (melanoma brochure)	60		

Abbreviations GP; General practitioner, AJCC Stage; American Joint Committee on Cancer, NP; Nurse Practitioner.
Missing values were excluded for calculation of percentages.
[a] Highest level of education completed (high: high vocational education, university; intermediate: secondary vocational education, high school; low: elementary school, low vocational education).

Table 2
Patients' agreement on oral and written information received about melanoma and self-inspection (n = 100).

Question	Oral by physician (n)	Written in brochure (n)
Warning signs for melanoma clearly explained:		
Totally agree	60	55
Agree	27	19
Disagree	6	–
Totally disagree	5	16
Missing	2	10
Stage and severity (Breslow, ulceration, mitosis, AJCC stage) clearly explained:		
Totally agree	32	32
Agree	34	33
Disagree	15	11
Totally disagree	19	24
Treatment possibilities clearly explained:		
Totally agree	74	47
Agree	19	27
Disagree	2	8
Totally disagree	5	18
Information received? (yes)		
A recurrence can be detected by SSE	80	45
A second primary can be detected by SSE	77	46
Nodular metastases can be detected by LNSE	70	38
Instructions received for SSE (yes)	87	78
Instructions received for LNSE (yes)	69	64

Abbreviations: SSE; skin self-examination, LNSE; lymph node self-examination.

had been provided, being distracted by the message of having a malignancy. Nevertheless, providing adequate information and checking whether this is understood, must be the first issue to address.

Regarding specifics of their own melanoma, the vast majority of patients did not know one or more of their tumor characteristics (unknown: mitosis = 65%, AJCC stage = 52%, Breslow thickness = 34%, ulceration = 33%), or incorrectly remembered these characteristics (an additional 11–23%), suggesting that the oral information provided was lacking or unclear, or patients did not understand the relevance and forgot. These results emphasize the need

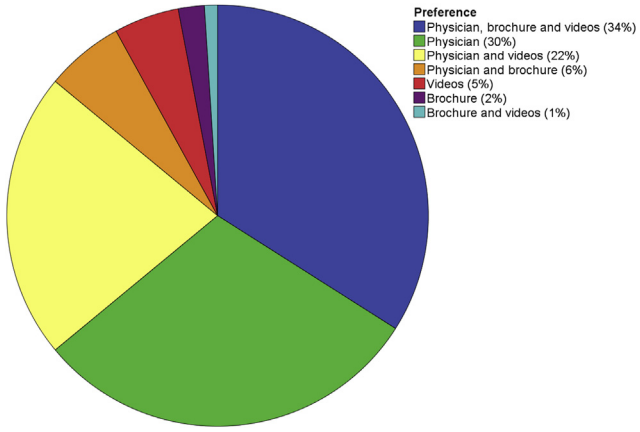

Figure 2. Preference of information source regarding patient education for self-inspection. Preferred information source (total): 1) physician: 92%, 2) videos: 62%, and 3) brochure: 43%.

for better quality, guidance, and greater consistency in providing information to patients. Remarkably, only 17% of patients expressed a wish for more information, and this was not associated with melanoma-specific knowledge. Dissatisfaction of melanoma patients regarding disease-specific information, and lack of patient education in follow-up have been reported before.[5,6] The ignorance of patients concerning their own melanoma, might be a result of the discrepancy between the information needs of cancer patients in general, and the perception of physicians on how to inform patients.[19] In the United States of America it has already been suggested to offer every patient an individualized 'survivorship care plan' to increase patients' knowledge, including specifics of their disease, treatment, and possible side-effects, that can be updated regularly.[20] Almost all patients were able to mention warning signs indicative of a melanoma, suggesting the lack of awareness on their own prognosis is a result of inadequate information provision or understanding. Providing an individualized report to all patients, as proposed before, could improve patients' understanding. Nevertheless, the presence of a certain level of 'patient denial' might also be a factor to take into account. In literature, denial of diagnosis in cancer patients is reported to be between 4 and 47%.[21]

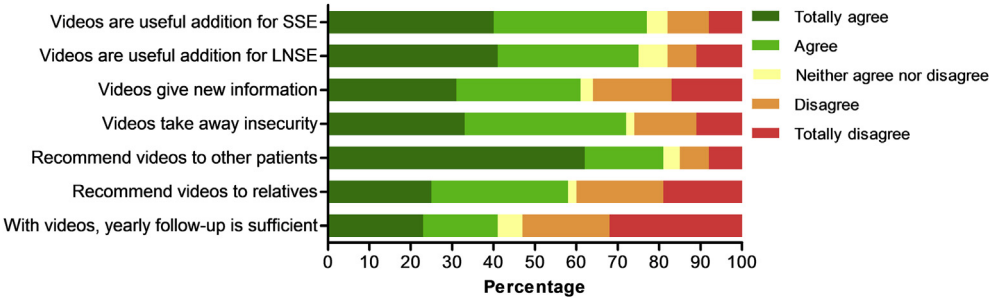

Figure 1. Additional value of e-Health instruction videos for skin self-examination (SSE) and lymph node self-examination (LNSE) on YouTube.

Information on warning signs, stage and severity, treatment options, detection of recurrent disease, and instructions for performing self-inspection was more clear to patients when received orally from the physician/NP, compared to the brochure. Apart from the necessity that medical specialists and nurse practitioners should further improve their skills to inform and educate patients, the present results underline the urgency that brochures should address these topics more explicitly as well, and that the currently used brochure on melanoma in the Netherlands might need a thorough revision. Besides, patients should be stimulated to read the brochure.

The finding that in more than three-quarter of patients the melanoma was self-detected by patient or partner/relative, emphasizes the importance of self-inspection. Male patients appear to detect a melanoma significantly less frequent than female patients. Possibly, female patients perform more thorough self-inspection, or because melanoma in male patients is significantly more often located on the trunk. The trunk, particularly the back, may be harder to inspect than the leg. Although self-inspection for the detection of a recurrence or second primary is currently recommended for all melanoma patients, around 80% of patients recalled receiving instructions.[22] Nevertheless, this is much higher than the 13% reported in a previous survey, emphasizing the importance to improve educational strategies.[23] This difference may be explained by the instructions patients received orally and in writing shortly before study participation. Although of equal importance, more patients reported to have received instructions on SSE, suggesting less focus on LNSE. Possibly, LNSE is more difficult to explain to patients, as nodal recurrences don't usually present visually, but have to be detected by palpation.

The majority of patients appreciated the e-Health videos on YouTube as useful additional educational source and would recommend other melanoma patients to watch the videos. This appreciation could possibly increase by combining these two videos into one compact video. The use of instructional videos for effective patient education has been described before, as they can be delivered through different forms of multimedia, without requiring a high level of literacy.[24] Although more than two-third of patients in the present study felt more secure in performing self-inspection after watching the videos, a possible downside might be induction of anxiety, as reported for melanoma prevention television advertisements, graphically illustrating undetected spread of melanoma.[25] However, the use of videos to reduce patients' anxiety, while increasing knowledge and confidence in performing self-inspection, has been described since 1988.[12,26] Furthermore, video education has been reported to improve melanoma-specific knowledge among medical students, as well as protocol adherence for medical procedures.[27,28] This demonstrates the potential of videos for educational purposes. A video-based intervention designed to increase skin-awareness, SSE, and timely patient' presentation to a physician with suspicious skin lesions, was found to result in higher prevalence of self-inspection than written materials only.[29] Even though the current study shows that videos are of additional value for many patients, more than half disagreed that the frequency of outpatient-clinic visits could be lowered with use of these videos, suggesting a persisting level of insecurity and need for professional reassurance, especially in patients with shorter time since diagnosis.

The response rate (52%) in the present study is comparable with other questionnaire surveys among cancer patients. Patients who did not finish the survey were lower educated that those who did, possibly due to a certain complexity of an online survey. Educational level is another factor healthcare workers should be aware of, to achieve adequate information provision. However, education was not related to knowledge. Although the Internet might be a difficult accessible source for some older patients, the possible effect of age on Internet use is expected to diminish in the near future.

This study indicates that two-thirds of patients prefer to receive instructions for self-inspection through various sources combined. This is in line with previous literature, reporting patients prefer multiple information sources for knowledge acquisition, emotional coping, and health protection.[23] Nevertheless, the medical specialist/NP was found to be the preferred information-source, followed by e-Health videos, and lastly written information. Apparently, patients prefer the personal attention and expertise of their physician, rather than having to read a brochure. Healthcare providers have been reported to be the key source of health information for cancer survivors before.[11]

Many methods of providing information and education to patients are currently offered in clinical practice, however oral and written are still the most commonly used. Patients with chronic illnesses are found to increasingly rely on Internet-based resources to search for information and to manage their conditions.[11] In 2005, 39% of melanoma patients used the Internet to obtain information, this percentage is likely to only keep on rising.[30] Several advantages of web-based information have been reported, such as better-informed patients, improved communication between patient and physician, and time efficiency due to increased basic knowledge.[31] Of great importance is the contribution of healthcare professionals and organizations to the quality of the provided information, as web-based sources may also contain misleading or incomplete information.[13,32,33] Video-sharing sites are popular for retrieving health-related information by patients.[11] However, patients need to be assisted in finding comprehensive and accurate web-based information, and ideally, educational videos should focus on disease-specific information as well. Unfortunately, there is little attention for development of interventions for effective dissemination of e-Health videos for healthcare communication and education.[13]

With nearly two-thirds of Americans being smartphone owners, and an increasing number of patients using the

internet to access health information, e-Health tools (digital resources that facilitate self–management and information) may be effective for individual information needs and lead to improved melanoma-specific knowledge and quality of self-inspection, also longer after completion of treatment.[34–36] For example, YouTube videos can be watched as many times a patient needs and give consistent conceptualization of performing self-inspection, in contrast to healthcare providers. To increase patients' awareness and disease-specific knowledge, e-Health videos could be implemented as standard part of patient education. As videos are found to be a valuable addition to the oral and written information provided, more attention should be given to the development and publicity of online educational videos or smartphone apps, in the current era of Internet and social media.

Conclusion

This study shows the importance of providing adequate information and education to melanoma patients, as patients' knowledge on melanoma, their own tumor characteristics in specific, appears to be insufficient. Healthcare providers in oncology should be stimulated to not only provide patients oral information, but also in writing, addressing all individual aspects of their disease. The majority of patients wish to receive information in multiple ways, with the treating physician being the preferred source, followed by educational videos. Provided that the quality is guaranteed and recognizable for patients, e-Health videos may additionally contribute to patients' melanoma-specific knowledge, provide information on melanoma prevention, and encourage self-inspection of the skin and regional lymph nodes, as part of a multimedia patient education library. If regulated nationally, every country could develop e-Health videos on melanoma and other topics. Better informed and educated patients can make sincere decisions, which could have positive effects on adherence to treatment, follow-up, and the performance of self-inspection.

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Appendix A. Supplementary data

Supplementary data related to this article can be found at http://dx.doi.org/10.1016/j.ejso.2017.06.008.

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