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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

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