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WWW mesothelioma information: Surfing on unreliable waters. A cross-sectional study into the content and quality of online informational resources for mesothelioma patients

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ABSTRACT

Objective: Malignant Mesothelioma (MM) is a rare asbestos related disease mostly diagnosed in low-skilled patients. The decision-making process for MM treatment is complicated, making an adequate provision of information necessary. The objective of this study is to assess the content and quality of online informational resources available for Dutch MM patients.
Methods: The first 100 hits of a Google search were studied using the JAMA benchmarks, the Modified Information Score (MIS) and the International Patient Decision Aid Standard Scoring (IPDAS).
Results: A total of 37 sources were included. Six of the 37 resources were published by hospitals. On average, the informational resources scored 37 points on the MIS (scale 0–100). The resources from a (bio)medical sources scored the best on this scale. However, on the domain of use of language, these resources scored the worst.
Conclusions: The current level of medical content and quality of online informational resources for patient with MM is below average and cannot be used as decision-aids for patients.
Practice implications: The criteria used in this article could be used for future improvements of online informational resources for patients, both online, offline and through health education in the care path.
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1. Introduction

Malignant Mesothelioma (MM) is a malignancy of the pleura, strongly related to exposure to asbestos [1]. In 2013 in the Netherlands alone, a total of 570 new cases of mesothelioma were diagnosed [2]. MM is mostly diagnosed in low-skilled patients with a professional exposure to asbestos, such as ship- and construction workers [3].

Due to the biologically aggressive nature, the diffuse spread and the relatively late stage of disease diagnoses [4], a curative treatment for MM is quite rare. Chemotherapy, surgery and radiation [4] are part of the current treatment possibilities in the Netherlands. In addition, new, experimental therapies such as immunotherapy are being investigated [5]. Currently, there is no international consensus amongst professionals about the optimal treatment for mesothelioma patients [4]. In contrast to for example the United States, a surgical treatment of mesothelioma is not part of the standard treatment in the Netherlands. The decision-making process revolved around the treatment of MM is therefore complicated, making an adequate provision of information and guidance for patients even more necessary.

Patients with MM have access to a variety of resources about their disease and treatment possibilities. With the rise of the worldwide web, a vast amount of information is now digitally accessible [6]. From previous research in other areas, such as oncological diseases, it was concluded that patients are influenced by online information resources during the decision making process [7–9]. Research by McMullan et al. [10] reported that on average, 53% of Americans and 23% of Europeans use the internet for health related purposes. When asked which purposes in particular, the authors found two particular occasions: 1) to determine the need for professional help previous to the clinical encounter and 2) to reassure themselves, or gather more detailed information after the clinical encounter [10].

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However, the online available information is generally not regulated or evaluated; therefore, resources vary in quality and through that, in usability [11,12]. Previous research into informational resources in research areas such as heart- and vascular disease [13] and breast cancer [14] have shown that the quality of online information resources is inadequate and insufficient when it comes to domains such as risk description of the treatment and the discussion of alternative treatments [15].

The quality of online informational resources focused on patients with MM in the Dutch context has not been assessed or described as of yet. This study aims to assess and evaluate the content and quality of online information resources for patients with mesothelioma. Insight into the quality of this information can be a jumping board for further improvements in provision of information about the difficult decisions involved in the treatment of mesothelioma patients.

2. Methods

2.1. Online search strategy

On the 12th of September 2015 the term 'mesothelioom' (the Dutch translation of 'mesothelioma') was entered in the Google search engine (www.google.nl).

2.2. Inclusion- and exclusion criteria

The inclusion and exclusion process consisted of two phases. The first phase consisted of the inclusion of the first hundred hits of the Google search. These were websites or online documents (PowerPoint, PDF, etc.) only. Videos and other informational resources were excluded. In the second phase, informational resources were excluded if they were considered to be non-relevant on the basis of the following two criteria: 1) the informational resource was too short (less than 10 lines of text), 2) the informational resource is written from a non-medical context (personal blog etc.).

2.3. Quality measures

The quality and content of informational resources was evaluated through a total of four scoring systems. Firstly, the source of publication of each resource was considered, through which a division was made into hospitals (academic and non-academic), the government, commercial sources (e.g. insurance companies) or other resources (e.g. patient organizations). Secondly, using the JAMA Benchmarks [16], the quality of the medical content was assessed. The JAMA Benchmarks consist of four quality measures; display of authorship of the medical content, display of attribution or references, display of currency and disclosure of ownership. For each of these domains, the presence in the informational resource was assessed (see Appendix A). Thirdly, a modified version of the Information Score (MIS) was used to score the medical content of the resources on four weighted, mesothelioma-specific domains: Disease Description, Treatment Options, Surgical Options, and Symptom Control (see Appendix C for further description of these domains). The MIS was based on the information score as developed by Soot et al. [13] for the assessment of the ability of websites to educate patients about vascular diseases. In order to make the score mesothelioma-specific, we omitted the domains of Recovery Expectations and Disease and Surgical Complications from the original score [13], and replaced this with the domain of Symptom Control, to reflect the often incurable nature of MM [17]. Similar to the original score, in our MIS, the largest weight was given to the domain of Disease Description. The modification and scoring was executed by three medical specialist (LM, RC, NJ), all three closely involved with the care for mesothelioma patients. Scoring was performed on a scale from 0 to 10 for each of the domains, with 0 being no mention of the domain in the informational resource at all, and 10 being the most complete discussion of the domain as could expected. The score for each of the domains reflected the proportion of information presented in the informational resource relative to two previously discussed extremes on the scale. In addition, weights were added to each of the domains, based on their relative importance and in parallel to the score as developed by Soot et al. [13]. As such, the MIS allows for scoring on a scale from 0 to 100 (see also Appendix C).

Lastly, the International Patient Decision-Aid standard **S**coring (IPDAS) instrument [18] was used to assess to what extent the informational resources were useful as decision-aids in the decision-making process. The IPDAS score looks at a total of twelve domains and delivers a dichotomous score for each domain (present/not present) (see Appendix B). As part of these domains, we have looked at the presence of an online decision-aid tool, as well as the level of difficulty of language use. Scoring was executed by the same three medical specialist that performed the coring for the MIS (LM, RC, NJ). In case of disagreement, issues were resolved in a general discussion and when necessary, a fourth reviewer (SST) was asked to join the discussion.

3. Results

3.1. Outcome search strategy

The term 'mesothelioom' in the Google search engine resulted in over 36,000 hits with Dutch-language informational resources. Within the first 100 hits of the Google search, there were no videos or other multimedia found (see Fig. 1). Four resources could not be opened or were removed. Of the remaining 96 informational resources, 25 were excluded in phase 2; 22 because they could not meet the inclusion criterion of a minimum of 10 lines of text. Twenty-four resources were excluded because they contained a non-medical content. The last nine resources discussed another subject than pleural mesothelioma. Finally, 4 articles were excluded: two could no longer be opened due to construction of the website, and two sets of sites were found to be copies hosted under different domain names. This left us with a total of 37 information resources which were actually assessed on quality and content (see Fig. 2).

3.2. Source of publication

Of the 37 informational resources, 5 resources were of an unknown source of publication. Six informational resources were published by hospitals. Three were published by commercial resources (insurance companies and asbestos removal companies). The remaining 23 resources were from very variable resources, ranging from victim organizations to medical guidelines and online encyclopaedias (Wikipedia) (Table 1).

3.3. JAMA benchmarks

In Table 2, the results of the JAMA Benchmarks are depicted. Of the 16 resources that displayed a last date of update, only four were recently updated (in the last year).

3.4. Modified information score (MIS)

In Table 3 the results of the MIS are depicted. Overall, the 37 informational resources assessed scored an average of 36.7 points on the scale form 0–100. On average, the resources scored the

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