

# Hard Copy Durable Patient Cancer Education Materials: Do They Still Matter?

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**Abstract** Traditional hard copy information materials are still present in our cancer clinics. While their actual impact on patient care often goes un-assessed, it is important to understand their role in today's electronic age where information can easily be obtained from various sources. It has remained the practice in our melanoma clinic to provide an information booklet to all of our new patients. The purpose of this study was to evaluate how useful this booklet was, as well as determine the current resources our patients use to gather cancer information. All patients referred to the clinic in the previous 3 years were pooled from our prospective, IRB-approved, melanoma sentinel node database. Of these 205 patients, a valid email address was listed for 147. A ten-question survey was emailed to all of these patients, who were not told ahead of time that their experience with the booklet would be studied. Seventy-seven of the 147 (52 %) patients polled responded. Fifty-eight (75 %) remembered receiving the booklet at their initial consultation. Forty-four (76 %) of those patients rated it as extremely or very useful, and no patients reported the booklet as not useful at all. Eighty-eight percent of respondents found the information to be clear and helpful. Sixty-four percent remembered the provider reviewing the

material with them, and nearly all of these patients found that helpful. When asked to rank the importance of the various resources for obtaining cancer information, providers were ranked as most important, followed by the information booklet and Internet information sites. Internet blogs and friends and family were rated as the least important sources of information. Even in the current electronic age, our results indicate that information shared by providers, including the hard copy education booklet, was the most important source of information for our newly referred melanoma patients.

**Keywords** Melanoma · Hard copy education materials · Cancer education

## Introduction

The number of newly diagnosed cases of cancer in the USA continues to rise despite our best preventative measures [1]. A diagnosis of cancer may be difficult for a patient to understand, leave many questions to be answered, make it challenging to process subsequently provided information, and invoke feelings of anxiety, fear, and anger [2]. Knowledge surrounding the diagnosis can create a sense of control as well as alleviate anxiety [3]. Furthermore, the perceived provision of adequate information has been shown to decrease the level of decisional conflict the patient experiences [4]. In order to fulfill this educational need, there are many modalities that can be used. These include, but are not limited to, verbal instruction, audiovisual aids, hard copy written materials, computer programs, as well as Internet and blog sites.

Multiple older studies, performed before the widespread use of the Internet, demonstrated print materials to be effective in increasing patient satisfaction and reducing anxiety, while improving knowledge, understanding, and recall [5–7]. Prior

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studies have also shown computer-assisted learning to be an effective tool in patient education [8]. However, these focused primarily on education programs as opposed to independent patient use of the Internet and many are not cancer specific [9–11]. Few studies provide a direct comparison between educational modalities.

In today's electronic age, patients increasingly rely on websites, blogs, and videos for information. In a survey conducted by the U.S. Census Bureau in 2013, 74.4 % of households in the USA reported Internet use [12]. Additionally, a survey conducted in 2012 reported that 59 % of U.S. adults had looked online for health information over the prior year [13].

Traditional hard copy information materials are still present in our cancer clinics, and it has remained the practice in our melanoma clinic to provide an information booklet to all of our new patients. Given the ease of Internet access and the current trend in its usage, we sought to examine whether these hard copy durable educational materials are still of value to our patients.

## Methods

All patients with newly diagnosed clinically node-negative melanoma referred for consideration of surgical management to a single surgeon (JV) at Oregon Health & Science University in Portland, Oregon, over the previous 3 years were pooled from our prospective, IRB-approved, melanoma sentinel node database. Of these 205 patients, a valid email address was listed for 147. A ten-question survey was emailed to all of these patients. Table 1 shows the complete questionnaire. It was designed to be simple, completed fairly quickly, and effectively evaluate our patients' experience with the melanoma booklet. Thus, the survey consisted of four yes/no questions, three Likert scale questions, and three free text questions. The survey was designed and run through SurveyMonkey (Palo Alto, CA), an online development cloud-based company.

The booklet that we use is an industry booklet, developed and distributed by Merck. As such, we have no control of its content. The booklet primarily focuses on explaining the diagnosis and staging of melanoma and was chosen for its readability, concise explanations, and accompanying illustrations. We received no support or compensation from the company for this study.

None of the surveyed patients had prior knowledge that their experience with the booklet would be studied, but had consented to be contacted for research purposes. Following the initial email, a reminder was emailed 1 week later. The second email specifically stated not to complete the survey if it had already been done. In order to further prevent duplicate answers, the survey was set up so that it could only be completed once from a given computer. There was no incentive for

completing the survey, and all of the respondents remained anonymous.

## Results

Of the 147 patients with a valid email address, 77 (52.4 %) responded to the survey. Table 1 shows the complete survey and answer data.

Fifty-eight (75.3 %) of these patients remembered receiving the booklet at their initial consultation, the majority of

**Table 1** Ten-question patient survey

Question	Number (%)
At your initial surgical visit did you receive a melanoma information booklet	
Yes	58 (78.4)
No	16 (21.6)
If no, do you feel an information booklet would have been useful	
Yes	18 (90)
No	2 (10)
Do you remember the surgeon going over the booklet with you	
Yes	47 (63.5)
No	27 (36.5)
If yes, did you find that helpful	
Yes	46 (95.8)
No	2 (4.2)
How useful was the information provided in the booklet	
Extremely useful	15 (26.8)
Very useful	29 (51.8)
Useful	9 (16.1)
Somewhat useful	3 (5.4)
Not at all useful	0 (0)
If it was useful, what particular aspects did you like	Free text See manuscript
What particular aspects of the booklet did you not like or find unhelpful	Free text See manuscript
The information in the booklet was:	
Too simple	3 (6)
Clear, but not helpful	2 (4)
Clear and helpful	44 (88)
Unclear or too complicated	1 (2)
Rank, 1–6, the following resources that you may have used to get information about melanoma (1 = most important, 6 = least important)	See Table 2
Please provide any comments that you have regarding getting information on melanoma	Free text See manuscript

which (75.9 %) rated it as extremely or very useful. No patients reported that the booklet was not useful at all. Eighty-eight percent of respondents found the information provided to be clear and helpful, while only one patient felt it was unclear or too complicated. Sixty-four percent remembered the provider reviewing the material with them, and nearly all of these patients (95.8 %) found that helpful.

As shown in Table 2, when asked to rank the importance of the various resources for obtaining cancer information, providers were ranked as the most important, followed by the information booklet and Internet information sites. Internet blogs and friends and family were rated as the least important sources of information.

In reviewing responses to the open-ended questions, several themes came to the forefront. In response to the query “if it (the booklet) was useful, what particular aspects did you like?”, 29.5 % of respondents felt that the booklet was instrumental in helping them better understand the staging system of melanoma and 31.8 % responded that it better helped them understand the disease or was useful in providing general/basic information about melanoma. When asked specifically what particular aspects of the booklet they did not like or found unhelpful, 68 % of respondents reported that they did not find any aspect of the booklet met these criteria. One patient responded that they felt the information provided was too general, while two patients reported the booklet was either too technical or provided too much information.

When given the opportunity to provide general feedback, the majority of respondents commented on their overall experience and what they found most helpful during the new patient intake process. In keeping with the response to question 9, in which 81.8 % ranked their treating physician as the best source of information, one third of patients reiterated their appreciation for and the utility of their treating physician in providing information. Four patients commented specifically on their experience using the Internet as a resource. Of these, one raised questions about the reliability of sources, stating, “the problem with info is not availability but reliability.” Two other respondents raised concern about “horror stories” and “worst-case scenarios” being presented on the web. Another

respondent to comment on the Internet felt very comfortable using MEDLINE, PubMed, and CINAHL for information. This individual also found the information booklet too simple and ranked the Internet more useful than the booklet.

### Discussion

Our study looked at the utility of hard copy durable patient education material in melanoma patients and revealed that the vast majority of respondents (78.6 %) found this resource to be either very or extremely useful. This is consistent with multiple prior studies, performed before the widespread use of the Internet, which demonstrated the efficacy of patient handouts in providing information about diagnosis and disease [5–7]. However, there is a scarcity of more current studies to support the use of these materials. Given the prevalence of Internet use and the accompanying increase in availability of cancer education web sites, this was somewhat of a surprise. Our results suggest that in newly diagnosed melanoma patients, hard copy educational materials are still a valuable resource.

While we have shown durable hard copy resources to be important, they cannot replace the educational role of the primary treating physician, but rather function as an adjunct. As expected, and in keeping with prior studies, communication between patients and their physician was shown to be highly valued [14]. Eighty-two percent of respondents in this study identified their health-care provider as the most important source of information. Furthermore, 64 % remembered the provider reviewing the booklet with them and nearly all of these patients found that helpful. In light of this, it is clear that the primary treating physician’s advocacy for the use of the melanoma information booklet had a positive impact on how it was received. Additionally, given the efficacy of the melanoma booklet and the benefit of physician/patient interaction shown in our study, this approach may serve as a model for providing patients with the information they need.

Although the educational value of the treating physician is clear, many patients sought out additional resources. Ninety-seven percent of respondents ranked Internet pages in the top

**Table 2** Rank, 1–6, the following resources that you may have used to get information about melanoma (1 = most important, 6 = least important) (N, %)

Rank	1	2	3	4	5	6	Total
Surgeon (JV), other healthcare providers	60 (81.8)	8 (10.8)	2 (2.7)	1 (1.4)	1 (1.4)	2 (2.7)	74
Information booklet	6 (8.1)	38 (51.4)	20 (27)	5 (6.8)	2 (2.7)	3 (4.1)	74
Internet information pages	5 (6.8)	22 (29.8)	34 (46)	11 (14.9)	0 (0)	2 (2.7)	74
Internet blogs	1 (1.4)	1 (1.4)	6 (8.1)	32 (43.2)	23 (31.1)	11 (14.9)	74
Friends and family	2 (2.7)	3 (4.05)	8 (10.8)	16 (21.6)	35 (47.3)	10 (13.5)	74
Other	0 (0)	2 (2.7)	4 (5.4)	9 (12.2)	13 (17.6)	46 (62.2)	74

three resources they used for information. Given the propensity of patients to seek out additional resources and concerns expressed about the reliability of the Internet, it is important for the treating physician to direct their patients to other relevant and accurate information sources.

The significance of health literacy and the importance of educational materials being comprehensible has been well documented [3, 15, 16]. Several agencies suggest that educational resources should be aimed at a sixth- to eighth-grade reading level [15, 17]. Our respondents almost universally found the melanoma booklet (which was aimed at a sixth-grade reading level) to be clear and helpful (88 %), while only 2 % found it unclear or too complicated, further helping to explain why it was well received.

While demonstrating the relevance of hard copy patient educational materials, this study has some limitations. Because the survey was completely anonymous, we were not able to correlate feedback with patient gender, age, disease stage, or outcomes. Additionally, given the small sample size and various disease stages, the specific results of this study may not be generalizable to other cancer populations. By choosing to use an electronic survey, and by contacting our patients via email, one might expect that we selected a more tech savvy population. In doing this, we may have excluded patients with lower literacy levels, making the information booklet seem more clear and readable than it actually was. Conversely, by limiting the survey to patients with access to the Internet, we may have *underestimated* the educational benefit of the booklet.

Despite these limitations, our study suggests that hard copy cancer educational materials still have importance in this electronic age. It will therefore remain our practice to provide this informational booklet to all of our newly diagnosed melanoma patients. Further, based on our results, we will be more diligent and consistent in reviewing the booklet with the patient during the initial visit.

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