Beyond the Skin Examination:
Public Awareness as a Melanoma Prevention Method

By

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Abstract

Background: Melanoma incidence is increasing in the US, with 62,190 Americans projected to be diagnosed with some form of the skin cancer in 2006. Despite its increasing incidence and the assumption that early intervention can lead to a cure, no preventive method is supported by definitive evidence, and mortality rates remain relatively stable. Most funding has been devoted to education campaigns advocating sun avoidance and sunscreen use (primary prevention) and regular skin examinations (secondary prevention), especially among populations considered to be at highest risk. Recently campaigns encouraging patient awareness and early detection have gained attention as a tertiary prevention method.

Objective: This research project will review current methods used in melanoma prevention and propose an education-oriented approach to decreasing morbidity and mortality from melanoma.

Methods: The most recent melanoma literature will be reviewed systematically, with an emphasis on prevention methods currently being employed. A manuscript will be drafted of our proposed research project, a 40-question survey evaluating pre-disease awareness in newly diagnosed melanoma patients.

Conclusion: There is insufficient evidence to support or disprove any particular melanoma prevention modality currently being used. Based on available information, we believe greater improvement in melanoma statistics will be realized if prevention methods are broader and include greater emphasis on public education campaigns so that patients are aware of what skin lesions warrant
medical evaluation. Still, we concede that more research is needed. First, future studies should ascertain the genetic and environmental etiology of melanoma. Next, epidemiologic investigations should better establish which populations have the highest rates of mortality, focusing on the histological classification of high-risk lesions in addition to the demographic characteristics of high-risk patients. Lastly, current prevention plans should be evaluated on a large-population scale with future works addressing the associated costs and estimated effects on both the morbidity and mortality of melanoma.
What You Know May Save You: Pre-Disease Awareness and Delay in Seeking Evaluation for Malignant Melanoma

Crystal Brooks MPH, Nancy Thomas MD, PhD, and Karyn Stitzenburg MD, MPH

Context: Melanoma incidence is increasing in the United States, with 62,190 Americans projected to be diagnosed with some form of the skin cancer in 2006. Despite its increasing incidence and the assumption that early intervention can lead to cure, no preventive method has been proven effective definitively, and mortality rates remain relatively stable.

Objective: The project objective is to develop a research protocol evaluating the relationship between a patient's pre-disease awareness and his delay in seeking medical evaluation of a suspicious skin lesion.

Proposed Design and Setting: We developed a 40-question survey to be administered to newly diagnosed melanoma patients seeking treatment at the University of North Carolina healthcare system clinics over a one-year period.

Main Outcome Measure: The association between (pre-diagnosis) melanoma awareness and time elapsed in seeking medical evaluation of a suspicious skin lesion using simple correlation coefficients (Student’s t-test).

Results: To be determined

Conclusion: We propose that those melanoma patients with greater disease awareness prior to their diagnosis will have a shorter elapsed time between their recognizing a suspicious skin lesion and seeking medical evaluation of that lesion. We believe these data will lend greater support to public health efforts that emphasize the importance of patient awareness and their seeking prompt medical attention when suspicious lesions arise.

INTRODUCTION

While skin cancer screening is encouraged by dermatologic organizations, current research does not indicate screening has improved mortality rates.\textsuperscript{1,2} Though improvements in 5-year survival have been reported, the increase in the number of biopsies performed appear to have produced an artifact of exaggerated malignant melanoma incidence, suggesting over-diagnosis of thin, non-malignant tumors in screened populations.\textsuperscript{1-3} Many believe these data reveal the inadequacy of skin cancer screening protocols while others focus on the benefit of identifying any melanoma early. This scientific debate demonstrates the need for greater
evaluation of skin cancer screening as well as more research of other early
detection models that may be more effective than those currently employed.

The visual manifestation of most melanoma tumors make them unique in the
ability to be detected at an early stage. Still, among patients with invasive
disease, there is a significant lag between symptom / sign presentation and
seeking medical evaluation. Reduction in diagnostic delay has been adopted as
a national strategy by the British government to improve cancer morbidity and
mortality rates, a country with a slightly lower melanoma incidence than that
found in the United States. Various organizational strategies have been
employed to minimize delay between the first evaluation of symptoms and
diagnosis. However, addressing only organizational factors related to delay
overlooks associated patient contributions. Cancer research literature
demonstrates that one of the primary factors associated with diagnostic delay is
the patient’s failure to recognize symptoms as problems related to malignancy.
One promising preventive approach, therefore, is to increase patient awareness of
dermatologic changes in order to decrease delays in seeking medical attention.

The diagnostic course of melanoma involves (1) lesion appearance, (2)
recognition of abnormality / development of concern regarding the lesion, (3)
seeking medical attention and (4) diagnosis. Secondary prevention through
clinical screening and regular skin self examinations has not been supported
because of the costs, both temporal and financial, to the healthcare system. As
early detection may provide a strong opportunity for mortality reduction, global
education campaigns for the general public and physicians alike are being
recommemded to increase awareness and recognition of cutaneous melanoma.\textsuperscript{9-11}

Because patients have a principal role not just in detecting their cancer but seeking treatment as well, it is important to identify those factors that affect patients' health behavior. In our study, we will survey patients undergoing treatment for cutaneous melanoma in a university-hospital subspecialty clinic to assess the relationship between the patient's prior awareness of melanoma and his/her likelihood of seeking medical attention for the skin lesion of concern.

\textbf{METHODS}

\textit{Sample}

Our sample will be comprised of 80 patients of various ages undergoing treatment for cutaneous invasive melanoma at a university hospital-based clinic. Patients will be notified of the study by their treating physician and asked about their willingness to participate by clinic staff during a telephoned appointment reminder. Exclusion criteria are prior diagnosis of melanoma and diagnosis of melanoma more than 3 months prior to study enrollment. We further limited our study sample by excluding those patients with in-situ lesions. Questionnaires were self-administered and written in English. No translation of the text was available. The research protocol was reviewed and approved by the Institutional Review Board of the University of North Carolina.

\textit{Development and administration of survey instrument}

A 40-item survey instrument was developed to determine delay and pre-diagnostic awareness based on questions used in previously published studies
assessing melanoma awareness and knowledge.\textsuperscript{5,12} This questionnaire will be piloted on 15 participants. Those questions that are frequently misinterpreted by subjects will be modified or eliminated. Participants in the pilot will be excluded from final analysis.

We defined patient-associated medical delay as the time between the respondent becoming concerned about his or her lesion and the first physician’s evaluation of that mark. Using power analysis, we previously determined the sample size needed to detect a 3 month difference of delay between those with high or low-disease awareness and the expected delay of approximately 169 days in general melanoma populations. Time period estimates were based on those used in previously published reports.\textsuperscript{13,14} The minimal sample size needed was calculated at 38 patients, but to account for any drop-outs (i.e. refusal to complete survey, incomplete surveys), we will use a sample size of 80 patients to ensure our minimum is met.

The survey asks respondents about various aspects of their melanoma healthcare experience, including (1) patient’s prior awareness of disease (knowledge of disease definitions and characteristics, their awareness of risk factors, social familiarity with disease), (2) patient’s skin awareness before diagnosis (including use of self-examination of skin), (3) patient’s usual healthcare pattern, and (4) details of the medical evaluation for the suspicious skin mark. Pre-melanoma awareness is rated on a scale of 0 – 30 with 0 indicating no prior disease awareness and 30 indicating strong awareness of melanoma prior to diagnosis. To ensure the association between pre-disease awareness and health
seeking behavior is not confounded by unfamiliarity with the healthcare system, we included an assessment of health literacy, using three questions adapted from the Short Test of Functional Health Literacy in Adults (S-TOHFLA) that address difficulty learning of medical disorders, confidence with medical forms, and requirement for assistance when reading health-related materials. Following completion of the questionnaire, research staff will access medical records to obtain Breslow depth and Clark length.

**Variables**

The primary outcome of interest is the reported time period between the date when the patient became concerned about his/her skin mark and the date of visiting a physician for evaluation of the lesion. The principal independent variable is the patient’s pre-melanoma awareness. Breslow depth is an additional outcome variable with analysis of its correlation to both medical delay as well as pre-disease awareness.

**Statistical analysis**

After dichotomizing awareness scores (low awareness: score < X; high-awareness: score >= X), we compared medical delay in low vs. high-awareness patients using the Student’s t-test. We also performed multivariate analysis of individual patient awareness components to determine their associations with medical delay and Breslow depth. Clark length is included only if needed at a later date for comparison to previously published data. We adjusted for other factors (usual pattern of healthcare, including usual dermatologic care, skin awareness, and assistance in detection) to indicate whether or not our association
was modified by any of these covariates. STATA software version 9.0 will be used for statistical analysis. 

RESULTS

In Table 1, characteristics of our sample will be presented as proportions of the total number of study respondents. First, we will determine if there is a correlate between awareness score and patient-associated medical delay.

Additionally, we will evaluate the range of awareness scores and determine if scores vary based on demographic information (including distance from evaluating physician), with data presented in Table 2.

To finish, we will establish the distribution of pre-disease awareness in our study population (i.e. is the number of highly aware greater than, less than, or equal to
those who are less aware) and compare our rates to those published in past research studies.

**Table 2: Analysis of association between low versus high disease awareness and potential predictors of pre-diagnosis disease awareness**

<table>
<thead>
<tr>
<th>Characteristics</th>
<th>Low Disease Awareness n= x</th>
<th>High Disease Awareness n= y</th>
<th>P-value*</th>
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<tr>
<td>Median Breslow tumor thickness (mm)</td>
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<td>Sex (%)</td>
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<td>Mean age (yrs)</td>
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<td>High School Graduate (%)</td>
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<td>Mean Health Literacy Score</td>
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<td>% Marginal Literacy</td>
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<td>% Inadequate Literacy</td>
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<td>Social familiarity with Melanoma (%)</td>
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<td>Health Insurance (%)</td>
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*p value for student’s t-test comparing means of the two disease awareness groups

**DISCUSSION**

A study evaluating melanoma awareness and skin self examinations conducted in the mid 1990s found the American public was poorly informed about the specific characteristics of melanoma, although globally aware of skin cancer.5 This lack of knowledge would promote complacency regarding dermatologic changes and create a false sense of security as patients negate the severity of their illness. In addition, if oblivious to the potential for cure at earlier stages of disease (as has been proposed throughout melanoma literature), patients
are missing a crucial opportunity to avoid morbidity and mortality because of this lack of awareness.

In this investigation, we chose to focus on pre-disease awareness and patients’ seeking medical attention because subsequent stages of melanoma care are dependent on these factors. We believe our study will demonstrate that those patients who have greater awareness of melanoma have a shorter period of patient associated medical delay. Literature on melanoma awareness and health-seeking behavior is limited, but previous studies have drawn similar conclusions to our premise.\(^1\)\(^2\) We expanded on published data by investigating other features that may correlate to both disease awareness and delay in seeking medical attention. Our study included an assessment of health literacy while also addressing other potential confounders such as usual healthcare utilization patterns and social familiarity with melanoma. In addition, we limited our study sample to those patients with invasive melanoma, excluding those with in situ disease, to determine whether pre-disease awareness would have an effect on those cancer types more closely associated with mortality.

Melanoma research is hampered by the qualitative nature of analysis required to establish potential risk factors and health seeking behavior prior to diagnosis. Retrospective surveys completed by patients are prone to “social desirability biases”, recall bias and respondents’ memory deficiencies.\(^1\)\(^7\) Prospective analyses may eliminate some of the error introduced by memory deficits and minimize social desirability biases by evaluating behavior before the diagnosis is made. However, prospective studies would be difficult to implement especially in
countries with a relatively low melanoma incidence because the population followed (even if chosen from a larger population of those at greatest risk) would yield a small sample of malignant melanoma cases and require a very long follow-up. In addition, it may be hard to qualify or quantify changes in lesion characteristics, precluding our ability to assess the point when preventive intervention is most efficacious. Lastly, prospective studies would require respondents to document health behaviors (i.e. performance of self or clinical skin examinations, disease knowledge or exposure) which may maintain biases introduced by survey utilization. Overall, the requirements of prospective studies may prove cost-prohibitive to implementation.

We used a number of different measures to counter problems encountered in previous investigations. We adapted our study instrument from previously published works to increase validity of the questions used. We attempted to control for recall bias by limiting study participation to those diagnosed with melanoma within 3 months of study entry. However, we acknowledge that a known melanoma diagnosis still may influence how participants thought about and reported their disease awareness and reasons for seeking medical care. Additionally, our small sample size as well as population homogeneity (primarily white North Carolinians) affect generalizability and may bias our association because of unaccounted shared confounding factors. Lastly, our study was focused on one particular aspect of the healthcare experience; therefore, broad generalizations about the conclusive association between patient awareness and
medical delay would be unwarranted, especially because of the cross-sectional study design.

Still, we believe the probable similarity of our results to previously reported data is important in determining a patient-related component to the diagnostic framework of melanoma. The next step is to better define the association between medical delay and diagnostic features of melanoma such as Breslow depth. If decreased delay is associated with diminished Breslow depth, there will be stronger support for the implementation of educational campaigns to increase public awareness of melanoma so that people know which features are suggestive of malignancy and know to act quickly when suspicious lesions arise. Both of which may decrease patient-related medical delay and ultimately postponement of diagnosis.

We recognize that the jump from patient associated factors to diagnosis misses a number of key factors that may affect the overall outcome. Even if it is found that patient's lack of awareness increases delay in initially seeking medical evaluation, this does not wholly explain delay in diagnosis or the more distal outcome of Breslow depth. Blum et al found that "substantial" disease awareness did not preclude diagnostic delay and melanoma treatment, supporting our idea of a multi-factorial etiology of delay. Investigating all of these potential correlates extend beyond the scope of what can be done in a succinct questionnaire. Optimally, our study will be one in a series of research investigating various fundamental factors that may lead to delay in diagnosis of melanoma. Used collectively, these studies should describe more adequately the
melanoma diagnostic process and demonstrate points of intervention that will decrease delay in diagnosis.
REFERENCES


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**Introduction**

**An Overview**

In 1996, melanoma incidence rates were reported to be 1800% of what they were in the 1930s.\(^1\) Authors suggested this increase in incidence was not an artifact of increased surveillance or better cancer-counting methods but an important increase in disease prevalence secondary to changes in environmental and social conditions.\(^1\) Ten years later, melanoma is cited as the fifth most common malignancy in the United States, with an incidence increasing at a rate faster than that of any other cancer.\(^2\) Between 2005 and 2006, the number of new cases is expected to increase from an estimated 59,580 to 62,190, though mortality is projected to remain stable with an approximated increase of only 200 deaths attributable to melanoma.\(^2,3\) However, because much of the data are based on the prevalence of thin or in-situ melanoma, which may never progress to malignant disease, the significance of some of these statistics becomes less certain.

**Melanoma Classification**

Melanomas are categorized into four subtypes based on clinical and pathologic determinants. The most common subtype is superficial spreading melanoma (SSM), which accounts for 70% of all diagnosed melanomas.\(^4\) Superficial spreading melanomas are characterized by a period of lateral (radial) growth that predates more invasive, vertical growth by anywhere from 1 – 5 years.\(^4\) The vertical growth phase marks the period of greatest malignant
potential for superficial spreading melanomas since the tumor is most likely to metastasize to dermal lymphatics and blood vessels during this stage.\textsuperscript{4}

The second most common melanoma is the nodular subtype, comprising 15 – 30\% of diagnosed cases.\textsuperscript{4} Clinically, these lesions usually present as discrete, darkly pigmented nodules; they account for a large proportion of amelanotic melanomas.\textsuperscript{4} Nodular melanoma typically demonstrates vertical growth only, making identification of these lesions more difficult\textsuperscript{4} and the risk of morbidity and mortality greater.

The lesser known subtypes of melanoma, each representing approximately 5\% of the total, are acral lentiginous melanoma and lentigo maligna melanoma.\textsuperscript{4} Despite the lower incidence of acral lentiginous melanoma, it is the most common subtype among dark-skinned individuals and presents in inconspicuous areas such as the palms, soles, and nail beds.\textsuperscript{4} Lentigo maligna melanoma, on the other hand, usually develops from in-situ melanoma on sun-damaged areas of the head and neck.\textsuperscript{4}

\textit{Diagnosis and Staging}

Although the presence of melanoma may be suggested by visual inspection by a trained healthcare professional, confirmation is required by biopsy and histological assessment. Excisional biopsy with non-diseased skin margins is the standard, both diagnostically and therapeutically.\textsuperscript{4} Incisional biopsies are only employed when a complete excision is impractical or melanoma suspicion is low.\textsuperscript{4}
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Shave biopsies are contraindicated because they do not provide enough tissue for diagnosis and prohibit accurate depth measurement.\(^4\)

In 2002, the American Joint Committee on Cancer revised its staging system for cutaneous melanoma from the 1997 version, making the following changes:

- T-stage was to be defined by tumor thickness (mm), the distance from epidermal granular layer to tumor base at its thickest points (Breslow Depth), as well as the presence of ulceration. In addition, cut-off points for each stage were modified.

- Micro- and macrosatellites, in-transit, and nodal metastases were used to represent lymphatic dissemination, and number of positive nodes were used to define nodal disease.

- Lastly, serum LDH, representing hepatic involvement, was used to categorize stage IV disease.\(^4,5\)

Accurate melanoma staging requires not just histological analysis but a thorough clinical examination as well, with particular focus given to the skin, lymph nodes, liver and spleen. Additionally, a complete review of systems should be performed to implicate or exclude metastatic disease.\(^4\)

Treatment

Excision is the standard of care for melanoma treatment. In situ melanomas should be excised with a margin of non-diseased skin of 0.5 cm; melanomas < 2mm require a 1 cm margin; and melanomas equal to or thicker than 2 mm require a 2 cm border.\(^4\) No significant benefit has been demonstrated with deeper
or wider excisions although UK guidelines do vary slightly. Lymph node
dissection is reserved for patients who exhibit clinically evident lymph node
involvement in discreet drainage areas. Adjuvant therapy is recommended
primarily for individuals with stage III cancers and includes melanoma vaccines
and high dose interferon alfa-2b, which has not been proven to improve disease
free intervals or overall survival. Palliative and “survival prolonging therapy”
are both still under investigation.

Risk Factors

Despite recent alarming statistics on the increasing incidence of melanoma in
younger populations, the median age at diagnosis remains 53 years and incidence
is extremely rare in children. Although the etiology of melanoma is poorly
understood, many believe disease development is multifactorial with both primary
host and environmental risk factors associated with incidence.

One of the more broadly researched host factors is family history of
melanoma, commonly defined as two or more first degree relatives with a history
of melanoma. Some studies indicate that those with a family history of melanoma
are more likely to present at a younger age with thinner melanomas and greater
likelihood of multiple primary melanomas. Beyond representing a hereditary
marker of disease, this trend may correlate with increased awareness and
screening on the part of those who have social familiarity with melanoma. Still,
some susceptibility genes have been identified in groups of high-risk families
which lend support to a hereditary disease pathway as well as genetic etiology.
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Skin type is another risk factor that has been investigated frequently and reliably associated with melanoma development. Reports consistently indicate that fair-skinned persons and those with a propensity for freckling are more likely to develop melanoma than those with a darker complexion. However, this assessment has persistent measurement difficulties with recent studies suggesting that an individual’s ability to tan, rather than the color of unexposed skin, serves as a better risk factor for melanoma. There is also strong epidemiologic evidence supporting the number of nevi as a melanoma risk marker. However, distinguishing between nevi types and the potential effects of each has been difficult.

Most research indicates that sun and ultraviolet radiation exposure are the environmental risks that have the greatest influence on melanoma incidence. However, the studies are plagued by the difficulty of assessing the validity of retrospective recall of sun exposure by study participants. Sunburn incidence proves problematic not just because of recall bias, but also because it is a result of both host susceptibility and sun exposure patterns (i.e. recreational, occupational). In addition, analysis of the significance of lifestyle habits that may affect ultraviolet radiation exposure, such as tanning bed use, have yielded mixed results with some studies citing no association with melanoma incidence. Still, collective data indicate that ultraviolet exposure is important in all stages of melanoma development.

Despite the difficulty in measuring melanoma risk factors, most researchers agree that the epidemiologic evidence is sufficient to establish the most important
markers and exposures for melanoma development. And on this etiologic framework, most current prevention recommendations and intervention protocols are based. The American Academy of Dermatology describes melanoma as a completely curable disease when detected early but potentially fatal if allowed to progress and metastasize to extra-dermal anatomic sites. This distinction, coupled with rising incidence, highlights the medical community’s resolution to develop appropriate and effective prevention strategies on a primary, secondary, and tertiary level.

**An Introduction to Prevention**

Prevention is the act of stopping an incident from occurring. In public health and medicine, prevention is categorized into three levels: primary, secondary, and tertiary. Primary prevention prevents disease from occurring by eliminating its causes. Secondary prevention detects asymptomatic disease at a point when treatment precludes progression. And lastly, tertiary prevention comprises initiatives that prevent further progression or minimize morbidity after disease presentation. Screening is a secondary prevention protocol that detects asymptomatic disease while many early detection interventions are more closely aligned to tertiary prevention principles. Screening may be used as a step in the diagnostic process but, in itself, usually does not confer disease presence. The debate on whether or not to screen individuals for disease is controversial as definitive guidelines for when screening should be employed have not been determined; however, most scholars agree that the following considerations be made when determining whether or not a screening test be used.
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- Estimated prevalence should be high in the population being screened to ensure adequate positive predictive value of the test and that the screening is cost-effective. In addition, prevalence should be high enough and/or disease severity significant enough to produce a considerable burden of suffering on society.

- The quality of screening test must be satisfactory with either high specificity, high sensitivity, or optimally, both.

- Effective treatment for the disease detected by screening must exist. Screening is not to be used in isolation and instead requires follow up by the physician for all abnormal results and subsequent treatments. In addition, treatment of early disease must be superior to treatment of disease at a later state during the usual disease course.

- For widespread implementation, cost must be considered with the screening test proven to be cost-effective.

The ideal screening test is inexpensive, administered easily, has minimal associated risk or discomfort for the patient, and produces valid, reliable, and reproducible results.9,10

**Melanoma Screening**

The American Cancer Society recommends all adults receive a baseline skin examination from a physician with subsequent clinical examinations performed at the physician’s discretion depending on an individual’s risk of disease.11 The American Medical Association, likewise, recommends physician consult on
individual frequency of clinical skin examinations but concludes that skin self-
examinations should be performed on a monthly basis. Supporters argue that (1) examination requires only a couple of minutes when performed by a qualified observer, (2) is safe, (3) is acceptable to the public, (4) is reliable and (5) identifies disease in areas poorly viewed by the examinee. However, the literature varies in its support of examination.

First, who is classified as a qualified observer is not clear and often does not correlate to who treats the majority of American patients. Forty-percent of annual office visits are made to a family practitioner or internist. Yet studies indicate that dermatologists are not only more likely to detect melanoma but also have shorter diagnostic delays than general practitioners. If screening is most advantageous when performed by a "qualified observer", research will have to determine what the measure of quality will be. Chen et al compared dermatologists’ and primary care physicians’ accuracy in detecting melanoma and concluded that data were insufficient to support either a gatekeeper system of PCPs or direct access to dermatologists. As expected, dermatologists generally had greater sensitivity than PCPs, but both groups had sensitivity of less than 50% in some reports.

The physical safety of skin examinations is clear since assessment is non-invasive; however, physical safety does not directly correlate with benign practice. Screening may not only increase anxiety among the worried well, but also may lower specificity and increase false positive results in order to not miss melanoma cases. Most screened lesions referred for biopsy are categorized
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later as false positive. Also, there is some debate on screening’s benefit since biopsy often is unable to distinguish between benign melanocytic nevi and early melanoma in addition to reported difficulties in assessing atypical/dysplastic nevi. Misdiagnosis of melanoma is another potential harm associated with screening and biopsy; also a diagnosis of thin melanoma, even with optimal prognosis, may contribute to discrimination when applying for insurance or to unnecessary utilization of the healthcare system for additional biopsies and other expensive procedures.

Meta-analyses do indicate that the percentage of thin melanomas diagnosed is higher in populations that undergo screening than in those provided standard care. However, the clinical relevance of this increased detection is uncertain since many of these would not evolve to invasive disease and contribute to overall melanoma mortality. Further, no randomized trials or case-control studies have evaluated skin cancer screening and its effects on mortality rates. Improvements in 5-year melanoma survival rates with decreased tumor thickness are often used as support for screening programs to identify thinner lesions. However, the increase in 5-year survival minimally correlates with changes in cancer mortality. This may be a result of improved treatment prolonging the life expectancy of the same number of cancer patients, effective treatment increasing survival period (with resultant decrease in mortality rate) or lead time bias. Ultimately, data indicate that physicians are unable to infer the “effectiveness of early diagnosis or treatment from temporal changes in 5-year survival” and that this measure does not represent decreased disease prevalence and therefore can
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not be used as proof of improved interventions in prevention or therapy.\textsuperscript{16} Both the Institute of Medicine and the United States Preventive Services Task Force recommend that clinicians and patients “remain alert” to skin marks suggestive of malignancy (i.e. lesions with ill-defined borders, color variation, and increase in diameter).\textsuperscript{11,17} Yet neither has found sufficient evidence to support routine screening by primary care providers or self-examination by patients.

\textit{Alternative Prevention Approaches}

Heightened awareness of disease signs and symptoms has been shown to be effective in other cancer models, specifically breast cancer. Breast awareness is a public health model that encourages women to “think in terms of ‘what is normal for them’”, highlighting the importance of passive acknowledgment of bodily changes as opposed to active seeking of disease signs or symptoms.\textsuperscript{18} This preventive method also imparts a degree of empowerment to women in fighting breast cancer which may have benefits that extend beyond specific morbidity and mortality related to breast malignancy.\textsuperscript{19}

Both breast cancer and melanoma are assumed to have a period during disease progression in which intervention can have a positive effect on mortality and morbidity, making both prime targets for educational campaigns that encourage body awareness and assertive health seeking behavior when changes are noted. The increased knowledge of the general public regarding breast cancer has contributed to heightened vigilance for lumps and, undoubtedly, anxiety and overestimation of one’s risk. However, increased pre-disease awareness has done
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much to improve mortality rates. Additionally, increased awareness has not eliminated the need for other screening modalities such as mammography nor has it impeded the development of new preventive methods. Instead, it has expanded the preventive resources offered to populations at risk for breast cancer. Likewise, a similar expansion of prevention modalities may prove effective in melanoma.

Methods

Literature Search

We began by searching MEDLINE to identify articles relevant to the melanoma diagnostic course and, specifically, those discussing patient related factors that affect accessing the healthcare system. We used Medical Subject Headings (MeSH) as search terms when available or when key words were appropriate. We combined terms for our health outcome of choice (broadly defined as “melanoma”), “incidence” “mortality”, “survival rates”, “patient awareness”, “health knowledge”, “patient beliefs”, “educational campaigns”, “disease awareness”, “interference in lifestyle / daily activities”, “health seeking behavior” and “access to care”. We limited our electronic searches to “human” and “English language” and employed “a snowball technique”, using the resources found to identify additional relevant sources. Because the available research was limited in our topic of interest, we did not restrict our search to specific article types and included editorials, case-series, cross-sectional studies,
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randomized control trials, and meta-analyses in our assessment. In addition, we included studies and reports of foreign populations to expand available data.

Conceptual Framework

We began our investigation with a comprehensive framework (shown in Figure 1) detailing fundamental, intermediate, and proximate factors correlated to our outcome of interest: presence of melanoma.

Figure 1: Conceptual Framework

We defined the outline components in the following manner:

- Fundamental contributors are broad - based macro level factors that serve as the foundation for all other contributors in the development of a particular health outcome. We divided our fundamental factors into the four broad categories noted above.
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- The intermediate division is defined as intermediary because these factors serve as a link between a specific aspect of the etiologic base and factors that influence a system’s action within the diagnostic process.

- Proximate contributions are those factors that are most closely related to the occurrence of a particular health outcome.

- Completing our framework, we determined the factors we considered to be the most pertinent aspects of disease outcome: (1) diagnosis of melanoma, (2) time between period of initial concern regarding mark and melanoma diagnosis (which we further sub-categorized as medical delay and diagnostic delay), (3) melanoma characteristics (Breslow depth and Clark length), and (4) mortality rates.

The framework employed was adapted from a conceptual outline used to describe the correlation between social determinants of health and environmental health promotion.20

Much of the initial research we found focused on the debate between the appropriateness of screening and whether there was a need for alternative prevention methods. Though somewhat limited, much of the alternative prevention literature focused on disease awareness and knowledge and its effect on various aspects of melanoma outcome. We felt that determining the correlation of pre-disease awareness not to the distal outcome of melanoma presence but to the intermediate outcome of patient delay in seeking medical attention would contribute to a better, and more concise, understanding of the diagnostic process.
For this reason, we decided to limit our focus to patient-associated fundamental factors and established a list of intermediate factors from which we chose prior awareness of disease as our variable of interest. Subsequently, we further narrowed our assessment of proximate factors to those individual and population-level factors that could influence a patient’s ability to access the healthcare system. Relevant concepts are listed in our framework at each factor level but this list is by no means comprehensive. We limited inclusion of potential contributors to those with the greatest likelihood of available literature and to those in which we had the greatest interest. Lastly, in our framework, we broadened our distal outcome category beyond disease presence because we wanted to assess the outcome process which, similar to its contributing factors, is multi-faceted. Still, our primary outcome of interest is patient-associated medical delay which we define as the period between the point when the patient becomes concerned about his / her skin mark and his / her visiting a physician for evaluation of the lesion.

**Instrument Development**

We concluded a survey would be an adequate method of assessing both patient prior awareness of disease and delay in seeking medical attention following concern of the suspicious lesion (shown in Appendix). We reviewed the medical literature for dermatologic questionnaires pertinent to melanoma to develop the questions that would be used in our survey. Few published models were found, but we did locate the Public Health Survey developed at Yale
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University from which we adapted many of our questions. We also reviewed articles to see how questions were phrased in interviews and telephone surveys for better validation of the question format we used. Additionally, we searched for health literacy assessment tools. The REALM was felt to be a good assessment tool with an estimated completion time of 7 minutes, but we wanted to use a device that did not require the assistance of an interviewer as this staff was not included in our original research plan. The Short Test of Functional Health Literacy in Adults (S-TOHFLA) proved similarly problematic as an interviewer was required. Chew et al adapted a 3-question tool to assess health literacy which yielded adequate sensitivity in their analysis, but demonstrated poor efficacy in identifying those with moderate to minimal health illiteracy. Another potential limitation to our use of this assessment tool is that it only has been evaluated in this study and its results not confirmed by outside parties.

Instrument Validation

We intentionally modeled our questions from those used in previous works to increase the validity of our survey. Still, we believe further validation of the survey via a trial administration will be required to ensure that our patient population is able to understand and complete the questionnaire with minimal difficulty. A trial administration also will allow us to estimate the required completion time more accurately. We propose a trial administration, employing 15 – 20 patients who will be asked to complete the questionnaire in the presence of research staff. The researcher will be able to address any questions the patient
has at that time, and difficulties will be noted for survey modification. The survey will be changed based on which questions elicit the most concern from pilot respondents.

**Sample size calculation**

\[ \alpha = 0.05 \]

Power = 0.80

\[ \beta = 0.20 \]

\[ n = \text{sample size} \]

\[ n = \left[ \frac{z_{\alpha} + z_{\beta}}{\Delta} \right]^2 = \left[ \frac{1.96 + 1.28}{169 / 90} \right]^2 = 37.01 = 38 \text{ patients} \]

**Discussion**

Even with an extensive history of signs and symptoms, many melanoma patients still delay evaluation of suspicious skin lesions.\(^{22}\) There are a number of reasons for this delay, and lack of awareness of melanoma by both the general public and physicians within the United States is a very likely contributor. Self-detection of suspicious lesions is the most commonly reported mode of melanoma detection,\(^{22}\) which implies patient knowledge of suggestive disease signs is of considerable importance. Therefore, promoting disease awareness and patient pro-activity may prove to be an effective method of tertiary prevention, significantly impacting mortality rates of invasive melanoma.

Prospective studies of current prevention methods, both screening and patient awareness / early detection initiatives are needed to provide more definitive proof
Addendum 17

of their benefit. One such study of screening protocols was being conducted in Queensland, Australia, the country with the greatest incidence of melanoma in the world.\textsuperscript{23} The prospective randomized trial was to investigate the effectiveness of a multi-component community-based early detection intervention that included thorough skin self-examinations (TSSEs), whole body examination by primary care physicians, and specialized screening clinics.\textsuperscript{23} The completed results were to be published in 2015,\textsuperscript{23} but investigators encountered funding difficulties which required changes to the study design. This, in turn, decreased the sample size and, subsequently, the generalizability of reported results.\textsuperscript{24} Still, preliminary unpublished data indicate 16,383 full body skin examinations were performed, resulting in 2,302 referrals for suspicious lesions of which 222 were thought to be melanoma.\textsuperscript{25} Of those lesions biopsied, thirty-three were diagnosed as melanoma with an overall specificity of 86.1\% for detecting melanoma and positive predictive value of 2.5\%\textsuperscript{25} It was also reported that those with thinner melanomas were more likely to have a clinical skin examination within the past 3 years when compared to those with thicker melanomas.

These data substantiate past case series reports of similar results with the additional benefit of greater reliability and generalizability secondary to the study's larger sample size. Yet, how detection of these thin melanomas affects mortality rates still is to be determined. Two studies, both of significant sample size, conducted in a country with high melanoma incidence (Australia) and over a long period (30-year longitudinal follow-up at Duke University) determined that those with thin melanomas had low rates of recurrence and longer periods of
Most research agrees that tumor thickness, positive nodal status, primary tumor ulceration, and disease recurrence are all associated with greater mortality, yet tumor thickness (> 6mm) carries a 5-year survival rate above 50%, suggesting this characteristic alone does not always lead to poor outcome. Furthermore, whether tumor thickness is (a) the result of aggressive growth over a short period of time or (b) the result of longer period of development (i.e. delayed diagnosis) has not been determined. This distinction is important in establishing prevention guidelines as the former is the type more amenable to intervention.

In order to support any intervention method, we must assume that melanoma is a curable disease if found early for all types, or at the very least, the more malignant forms. These considerations demonstrate the importance of determining melanoma’s etiologic framework prior to developing and evaluating possible prevention interventions. For example, the biologic process of melanoma must be delineated more clearly. One of the primary guidelines in the establishment of prevention protocols is that early detection decrease the morbidity and mortality associated with disease. This intervention must not just increase lead time bias with a false lengthening of survival (an argument that arises from the use of 5-year survival rates as an outcome measure) but intervene in a stage of disease that causes a change in mortality rate. There have been tremendous advances in the genetic study of melanoma, contributing to a better understanding of the biologic and molecular components of melanoma. Still, few melanoma have been attributed to particular germline mutations in identified
genes, and thus more studies are required to assess the interaction between host/environmental factors and genetic susceptibility.\(^8\)

Additionally, melanoma should be qualified by histological type in SEER data so that we may better assess those types that carry the greatest mortality risk. Specific classifications can be further evaluated by determining medical delay, patient-related correlations, and other diagnostic features associated with each. A better schematic of the etiologic framework and the accompanying malignant interval associated with disease development (defined as the time period required for the development of a malignant lesion) will allow for development of interventions that better target those exposures that can be modified in a time period to reduce both morbidity and mortality. We may also better determine which patient populations carry a greater mortality risk so that specific prevention modules be specifically targeted to them.

Furthermore, if protocols are developed to determine the efficacy of education campaigns, investigators still must define those factors that are most important and of which participants should be aware. As discussed previously, there is a general consensus of what factors are most commonly associated with melanoma incidence, but these conclusions are based on qualitative data with definitions of exposures that vary by study group and results that are hampered by dependency on patient recall. Optimally, those factors that consistently have been correlated to melanoma incidence should be defined in a specific manner employed by all researchers. In turn, patients with these factors should be followed prospectively and compared to the general population to determine better the odds ratios
associated with each possible exposure. This type of study would allow for the establishment of particular exposure guidelines and lesion characteristics from which the education module can be developed. By doing so, we would be able to refine what constitutes high risk groups and ultimately develop better prevention recommendations whether they be on a primary (avoidance of disease), secondary or tertiary (detection of early disease) level.

After establishing risk factors, signs/symptoms, and points of intervention, we next consider how best to implement an effective program based on these data. Currently, no method has been researched with sufficient results to earn universal support of its implementation. Again, we propose a step-wise analysis of the diagnostic process of melanoma, and ideally, intervention research would follow these etiologic investigations. However, we will discuss proposed intervention methods at this time for completeness’ sake.

The first step in establishing prevention protocol is determining who will be responsible for implementing the proposed activities: the patient, the general practitioner, the dermatologist, etc. Specialists in skin would appear to be the best choice for a first-line defense against melanoma. However, utilizing dermatologists in a global prevention plan presents some difficulties. Previous reports indicate that dermatologists’ care varies from practice to practice with some dermatologists not performing annual full-body skin examinations on all patients or even on all new patients. One suggested intervention would require that a standard be set for all practicing dermatologists, perhaps requiring initial skin examinations of all patients and more frequent exams for those with greater
perceived risk. Still, one must consider that access to dermatologists often is limited and not offered to a broad segment of the population. According to the National Ambulatory Medical Care Survey: 2002 Summary, dermatology care accounted for less than 4% of annual medical office visits. 31 Primary care physicians, on the other hand, interact with larger numbers of the American public and may serve as an appropriate group to whom public health initiatives can be targeted. 24 In 2002, fifty-five percent of all office visits were to general/family practice, internal medicine, or pediatric practices. 31 Yet, passing the baton of patient education and annual examinations to primary care physicians still may prove problematic.

During office visits, primary care clinicians often must address acute care issues as well as a number of USPTF-supported activities. These primary duties coupled to limited blocks of time may serve as a barrier for this group providing skin cancer prevention. 24, 32 When evaluating the diagnostic process of melanoma patients, some reports reveal longer diagnostic delays in melanoma patients evaluated by primary care physicians as well as greater tumor depth. 12 The reason for this inequality probably is multi-fold, including (1) lower incidence of melanoma in general practice (compared to dermatology clinics), (2) subsequent difficulty in retaining melanoma pattern recognition, and (3) inadequate training of general practitioners. 12 Most primary care clinicians believe they receive limited training in melanoma detection, which correlates to a higher degree of insecurity in their skin examination skills and subsequently leads to a decreased likelihood of reviewing any portion of the skin during the clinic
Despite these factors, some studies indicate that primary care physicians are actively participating in skin cancer prevention. One survey reported 60% of PCPs performed routine skin examinations with their high risk patients\(^\text{34}\), and a second of family practice and internal medicine doctors reported similar incidence of clinical skin examinations with use being strongly correlated to the perceived importance of screening by physicians.\(^\text{35}\) One Connecticut survey of general practitioners differed in the reported incidence of clinic skin exams with less than half of the respondents indicating they “often perform” clinical full skin examinations; however, of those that noted suspicious lesions, most made a referral to a dermatologist.\(^\text{33}\)

Ultimately, because of broader access to the general public and ability to refer to dermatologists when appropriate, primary care physicians still may be the best option in screening which patients warrant greater attention. Limiting skin surveillance programs to a targeted population that is at greatest risk for melanoma development is a proposed modification to the current skin examination recommendations. Targeted screening within high-risk populations could maximize the number of melanoma lesions detected which is of greatest importance in those countries where malignant melanoma incidence is low, like the United States.\(^\text{36}\) Targeted screening programs by primary care clinicians has been suggested previously, but some researchers countered that this method would increase physician workload (which is already stretched thin in many clinical practices) and negatively affect the public economically as well as psychologically by increasing unnecessary testing, procedures, and patient
anxiety. Additionally, to have a significant impact on mortality and implement ethical public health interventions, we still must determine who is at greatest risk of poor melanoma outcome.

On the other hand, patients are employed in almost all facets of prevention protocols. In primary prevention efforts such as reduction of sun/UV exposure, patients are asked to change behavior in order to decrease risk. Many believe that this method alone will not adequately address melanoma mortality as these measures have not produced a decrease in melanoma incidence, and even when effective may require 20+ years of follow-up before changes in incidence or mortality are recognized. This delay in benefit is primarily the result of this method’s requirement of behavior modification by the targeted population. While sun-awareness campaigns do increase public knowledge of the potential risk of skin cancer development, they do not produce individual behavioral changes.

In secondary prevention, patients (and physicians) are encouraged to look for suspicious marks in order to detect cancerous lesions early. In a survey of 1,000 participants from a 43-state sample, approximately 46% said they closely examined themselves for signs of skin cancer or melanoma, most commonly, looking for things that weren’t there before (34.2%) and changes in moles (21.7%). Of those who practice self skin examinations, a smaller number have a delay in diagnosis when compared to their counterparts who do not, with shorter diagnostic delays correlating to thinner melanomas in one Connecticut case control study of 650 melanoma patients. As mentioned previously, these thinner
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melanomas are associated with better individual outcomes, but global implications on mortality and morbidity are uncertain.

For many, the greatest debate exists between whether to employ a “look and see” intervention as recommended by Brown University dermatologist Martin Weinstock, M.D., or to use one of “awareness, see and take action”. In discussing public health approaches to early detection, Weinstock proposes an intervention that encourages the public to inspect the skin for possible melanoma lesions (look) and identify those lesions at an early, curable stage (see). 24 For such an intervention program to be successful, however, the public and healthcare professionals must be encouraged to perform skin examinations and be educated to know for what they are looking. In 2000, British researchers determined that general public skin examination campaigns would not be cost-effective because of the low incidence of disease among the population. 37 With an estimated incidence in the United States of 62,190 cases in 2006 2, a similar conclusion may be drawn. Of those who would benefit from this type of intervention, Weinstock notes that monthly TSSEs are “associated with a substantial reduction of melanoma mortality risk” 24; yet these data are not substantiated by many other published reports of melanoma mortality rates.

Despite the low predictive measures of almost all of the currently recommended prevention protocol, we still believe interventions are needed to decrease melanoma incidence. The American Academy of Dermatology has sponsored annual skin cancer programs since 1985, and the effort was evaluated approximately 10 years later to determine its impact on melanoma diagnosis. 42
Researchers contacted 96% of all persons (4,458) with suspected melanoma at screening and acquired the final pathologic diagnosis of 72 percent. The three-hundred and sixty-four participants were diagnosed with melanoma with a positive predictive value of 17%. The majority of those lesions found were thin with a median thickness of 0.33mm with advanced disease only representing 8.3% of the total. Perhaps, this diagnostic discrepancy indicates that the program is operating appropriately with disease being identified in an early stage when a favorable prognosis is more likely. Conversely, the lack of advanced disease may indicate the program’s inability in recruiting those at greatest risk for having lesions with the greatest malignant potential. Measuring which is true is difficult and requires more extensive analysis of who is and is not being screened.

Ultimately, the true efficacy of the AADA’s project still is unknown. Those who were not believed to have “suspicious lesions” were not biopsied to ensure no melanoma existed, making calculation of specificity and negative predictive value impossible. In addition, participants were not followed prospectively to see if they modified risky behavior, maintained annual skin examinations, or eventually developed melanoma. Nonetheless, despite a low proportion of diagnosed cases and potential limitations to the evaluation of the program, the American Academy of Dermatology as well as physicians participating in the screening still believe the project is beneficial. The project is not just an opportunity for clinical full-body skin examination but, more importantly, is a platform from which information about melanoma, sun protection, and early detection can be distributed.
We believe continued educational campaigns will prove beneficial in the future. The public should be made aware of what melanoma is, educated to what the most common presenting signs and symptoms are, and encouraged to seek medical attention if suspicious lesions of similar appearance arise. Education campaigns, targeted to the general public, should re-identify the ABCDs of melanoma (asymmetry, irregular border, color variegation, diameter > 6mm) with additional emphasis on the importance of recognizing new lesions or changes to existing moles / marks; both of which are cited as a strong, if not the strongest, pre-diagnostic predictor of melanoma in recent publications. ²⁴, ³²

This information can be conveyed in public service announcements in various media outlets (television, radio, newspaper ads) as well as waiting room pamphlets available in all medical facilities. Education campaigns also should target physicians and other health professionals via brochures, luncheons, and seminars during medical conferences for which participants can earn Continuing Medical Education credit. These projects should be analyzed to determine both costs and effectiveness. We would employ a prospective cohort study design with a random nationwide sample of (1) individuals exposed to our education campaigns and (2) those individuals who are not likely to be aware of our intervention. Differences between the populations would be noted with the following characteristics evaluated: presence of disease awareness, melanoma-risk behavior, incidence of melanoma and relevant characteristics (type, depth, diagnostic delay), and mortality rates. As a sub-analysis, we would survey the
exposed group at various follow-up points to determine if there were any changes in awareness and/or behavior.

Because we are not looking, will we not detect melanoma? We do not think this is the case as other preventive methods exist outside of screening that may prove to be just as beneficial and cost-effective. Patient education has increased the public’s seeking medical attention for a variety of diseases. Therefore, a similar focus on patient knowledge of melanoma and awareness of relevant dermatologic changes should prove similarly helpful in addressing melanoma incidence. While we specifically do not encourage “looking for” melanoma, we do support global awareness so that suspicious lesions are noted, patients seek care more quickly, and the medical community be able to evaluate and diagnose melanoma earlier.

ACKNOWLEDGMENTS

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REFERENCES


Appendix 1

Questions 1 – 6: Disease Knowledge

We would like to learn how much you knew about melanoma one year prior to your recent skin biopsy.

1. **Before your recent skin biopsy**, did you know what melanoma was?
   - Yes
   - No

2. **Before your recent skin biopsy**, what characteristics did you believe were related to melanoma? *Please check all that you believed were true.*
   - Dark / varied color
   - Large size
   - Abnormal shape
   - Change in shape, color or size of a mark or mole
   - Hair growing in mole
   - Bleeding
   - Elevation of mark
   - Itching
   - Multiple development of new moles
   - Scab that doesn’t heal
   - Other (please specify): ________________________________
   - I did not know of any characteristics related to melanoma.

3. **Before your recent skin biopsy**, were you able to identify any risk factors for melanoma?
   - Yes – *If you answer yes, go to Question 4.*
   - No – *If you answer no, go to Question 5.*

4. **Before your skin biopsy**, what risk factors did you believe were associated with melanoma? *Please check all factors that you believe apply.*
   - Light / fair skin color
   - Moles
   - History of recreational sun exposure
   - Freckles
   - Red hair and blue eyes
   - Brown hair and brown eyes
   - Personal history of melanoma
   - Personal history of diabetes
   - Presence of moles and freckles
   - Tanning beds
   - History of severe sunburn occurring early in life
   - Family history of melanoma

5. **Before your recent skin biopsy**, did you know what a melanoma looked like?
   - Yes
   - No
6. At the time you first became concerned about the mark on your skin, what made you think it might be melanoma? *Please check all that apply.*
- Dark / varied color
- Large size
- Abnormal shape
- Change in shape, color or size of a mark or mole
- Hair growing in mole
- Bleeding
- Elevation of mark
- Itching
- Multiple developments of new moles
- Scab that doesn’t heal
- Other (please specify): ________________________________
- None of the above.

Questions 7 – 9: Skin Awareness
*We are trying to evaluate how much you thought about your skin, one year prior to your recent skin biopsy.*

7. **Before your recent skin biopsy**, about which of the following aspects of your skin did you think? *Please check all that apply.*
- Cosmetic changes in my skin (e.g., wrinkles, hair loss)
- Other changes in my skin like change in moles, appearance of new moles.
- Abnormal marks that were already on my skin.
- Other (please specify)
- I did not think about my skin before the biopsy.

8. **Before your recent skin biopsy**, did you check your skin?
- Yes  *If you answer yes, please go to question 10.*
- No  *If you answer no, please go to question 11.*

9. When you checked your skin, what did you do?
- I looked at a particular mark.
- I casually checked my skin
- I did a deliberate skin examination.
- None of these.
Questions 10 – 13: Mark Appearance / Mole History
We would like for you to tell us more about your noticing the mark or mole that was biopsied.

For questions 10 and 11, please give us the following dates (month/year):

10. First time you noticed the mark.

11. First time you became concerned about it.

12. Did another person tell you about the mark / mole before you noticed it?
   ☐ Yes
   ☐ No

13. If you answered yes to Question 12, please indicate who also noticed the mark.
   ☐ My spouse
   ☐ Other family member
   ☐ Friend, acquaintance
   ☐ Physician
   ☐ Other (please specify):

Questions 14 – 20: Accessing the Healthcare System
We would like you to tell us more about what happened after you became concerned about your skin mark.

14. After becoming concerned about the mark, did you see a healthcare professional (doctor, nurse practitioner, physician assistant) about the mark?
   ☐ Yes
   ☐ No

15. Who was the first health professional you saw about the mark? (Please give us his/her name)

16. What type of health professional is the doctor named in Question 15?
   ☐ Family Practice physician
   ☐ Internist
   ☐ Obstetrician – Gynecologist
   ☐ Dermatologist
   ☐ Surgeon
   ☐ Other (please specify):
17. Where is this health professional located? *(Please give us the city and state of the medical office where you went)*

18. When did this healthcare professional first look at the mark? *(Month / Year)*

19. Did more than 6 months pass from the time you noticed the mark to the time you saw a physician?
   - Yes
   - No

20. If more than 6 months passed between your noticing the mark and you seeing a physician, please tell us why.

Questions 21: Social familiarity
*We would like to know if others in your family have had melanoma.*

21. Has someone close to you had melanoma?
   - Yes
   - No

Questions 22 – 25: Usual Pattern of Healthcare
*We would like to know how often you saw a doctor before having your recent skin biopsy.*

22. Do you at least have one doctor whom you see at least once a year?
   - Yes
   - No

23. **Before your recent skin biopsy,** how often did you have a general medical check-up even though you did not feel ill or perceive any serious illness? Please list **number of visits per year:**

   ————
24. In the two years before your biopsy, how often did you visit your doctor?
   □ More often than usual—*If you answer “more”, please answer question 25.*
   □ Less often than usual—*If you answer “less”, please answer question 25.*
   □ Same as usual

25. If the number of times you visited the doctor was more or less than usual, why do you believe it changed?

__________________________________________________________________________________________

__________________________________________________________________________________________

__________________________________________________________________________________________

26. Has there been a change in the frequency of skin exams (by you or a doctor)?
   □ Yes
   □ No

27. If yes, how have they changed?
   □ Increase
   □ Decrease

28. If yes, at what age, did the change of skin exam frequency occur?

__________________________________________________________________________________________

29. Why do you believe these changes occurred?

__________________________________________________________________________________________

__________________________________________________________________________________________

__________________________________________________________________________________________

30. Had any doctor examined your skin within 3 years before your diagnosis?
   □ Yes
   □ No
Questions 31 – 33: Health Literacy

*We want to ask you a couple of questions about how familiar you are with the healthcare system.*

31. How often do you have someone help you read hospital materials?
   - Never
   - Occasionally
   - Sometimes
   - Often
   - Always

32. How confident are you filling out medical forms by yourself?
   - Never
   - Occasionally
   - Sometimes
   - Often
   - Always

33. How often do you have problems learning about your medical condition because of difficulty understanding written information?
   - Never
   - Occasionally
   - Sometimes
   - Often
   - Always

Questions 34 – 40: General Demographics

*This is the final section of the questionnaire. We would like to ask you some questions about general information like insurance, income, education level, and race.*

34. Sex:
   - Female
   - Male

35. Race:
   - White
   - Black
   - Hispanic / Latino
   - Asian / Pacific Islander
   - Other: __________________________

36. What is your age (in years)? __________
37. Marital Status:
- Married
- Single
- Widowed
- Divorced

38. Household Income:
- Less than $25,000
- $25,000 - $49,999
- $50,000 - $74,999
- More than $75,000

39. Did you graduate from high school?
- Yes
- No

40. During the past 5 years, have you had medical insurance that covers office visits?
- Yes
- No
Appendix I

Questions 1 – 6: Disease Knowledge

We would like to learn how much you knew about melanoma one year prior to your recent skin biopsy.

1. **Before your recent skin biopsy**, did you know what melanoma was?
   - Yes
   - No

2. **Before your recent skin biopsy**, what characteristics did you believe were related to melanoma? *Please check all that you believed were true.*
   - Dark / varied color
   - Large size
   - Abnormal shape
   - Change in shape, color or size of a mark or mole
   - Hair growing in mole
   - Bleeding
   - Elevation of mark
   - Itching
   - Multiple development of new moles
   - Scab that doesn't heal
   - Other (please specify): ____________________________
   - I did not know of any characteristics related to melanoma.

3. **Before your recent skin biopsy**, were you able to identify any risk factors for melanoma?
   - Yes – *If you answer yes, go to Question 4.*
   - No – *If you answer no, go to Question 5.*

4. **Before your skin biopsy**, what risk factors did you believe were associated with melanoma? *Please check all factors that you believe apply.*
   - Light / fair skin color
   - Moles
   - History of recreational sun exposure
   - Freckles
   - Red hair and blue eyes
   - Brown hair and brown eyes
   - Personal history of melanoma
   - Personal history of diabetes
   - Presence of moles and freckles
   - Tanning beds
   - History of severe sunburn occurring early in life
   - Family history of melanoma

5. **Before your recent skin biopsy**, did you know what a melanoma looked like?
   - Yes
   - No
6. At the time you first became concerned about the mark on your skin, what made you think it might be melanoma?” Please check all that apply.

☐ Dark / varied color
☐ Large size
☐ Abnormal shape
☐ Change in shape, color or size of a mark or mole
☐ Hair growing in mole
☐ Bleeding
☐ Elevation of mark
☐ Itching
☐ Multiple developments of new moles
☐ Scab that doesn’t heal
☐ Other (please specify): ____________________

☐ None of the above.

Questions 7 – 9: Skin Awareness

We are trying to evaluate how much you thought about your skin, one year prior to your recent skin biopsy.

7. Before your recent skin biopsy, about which of the following aspects of your skin did you think? Please check all that apply.

☐ Cosmetic changes in my skin (e.g., wrinkles, hair loss)
☐ Other changes in my skin like change in moles, appearance of new moles.
☐ Abnormal marks that were already on my skin.
☐ Other (please specify)

☐ I did not think about my skin before the biopsy.

8. Before your recent skin biopsy, did you check your skin?

☐ Yes  If you answer yes, please go to question 10.
☐ No  If you answer no, please go to question 11.

9. When you checked your skin, what did you do?

☐ I looked at a particular mark.
☐ I casually checked my skin
☐ I did a deliberate skin examination.
☐ None of these.
Appendix 3

Questions 10 – 13: Mark Appearance / Mole History
We would like for you to tell us more about your noticing the mark or mole that was biopsied.

For questions 10 and 11, please give us the following dates (month/year):
10. First time you noticed the mark.
__________________________

11. First time you became concerned about it.
__________________________

12. Did another person tell you about the mark / mole before you noticed it?
□ Yes
□ No

13. If you answered yes to Question 12, please indicate who also noticed the mark.
□ My spouse
□ Other family member
□ Friend, acquaintance
□ Physician
□ Other (please specify): ______________________________

Questions 14 – 20: Accessing the Healthcare System
We would like you to tell us more about what happened after you became concerned about your skin mark.

14. After becoming concerned about the mark, did you see a healthcare professional (doctor, nurse practitioner, physician assistant) about the mark?
□ Yes
□ No

15. Who was the first health professional you saw about the mark? (Please give us his/her name)
______________________________________________

16. What type of health professional is the doctor named in Question 15?
□ Family Practice physician
□ Internist
□ Obstetrician – Gynecologist
□ Dermatologist
□ Surgeon
□ Other (please specify): ____________________________
Appendix 4

17. Where is this health professional located? *(Please give us the city and state of the medical office where you went)*

18. When did this healthcare professional first look at the mark? *(Month / Year)*

19. Did more than 6 months pass from the time you noticed the mark to the time you saw a physician?
   - Yes
   - No

20. If more than 6 months passed between your noticing the mark and you seeing a physician, please tell us why.

Questions 21: Social familiarity
*We would like to know if others in your family have had melanoma.*

21. Has someone close to you had melanoma?
   - Yes
   - No

Questions 22 – 25: Usual Pattern of Healthcare
*We would like to know how often you saw a doctor before having your recent skin biopsy.*

22. Do you at least have one doctor whom you see at least once a year?
   - Yes
   - No

23. **Before your recent skin biopsy**, how often did you have a general medical check-up even though you did not feel ill or perceive any serious illness? Please list **number of visits per year**: 
24. In the two years before your biopsy, how often did you visit your doctor?
   - More often than usual—If you answer “more”, please answer question 25.
   - Less often than usual—If you answer “less”, please answer question 25.
   - Same as usual

25. If the number of times you visited the doctor was more or less than usual, why do you believe it changed?

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Questions 26 – 30: Usual pattern of dermatologic care

We would like to get an idea about how often you sought care specifically for your skin at least one year prior to your recent biopsy.

26. Has there been a change in the frequency of skin exams (by you or a doctor)?
   - Yes
   - No

27. If yes, how have they changed?
   - Increase
   - Decrease

28. If yes, at what age, did the change of skin exam frequency occur?
   _____________

29. Why do you believe these changes occurred?

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Questions 31 – 33: Health Literacy
We want to ask you a couple of questions about how familiar you are with the healthcare system.

31. How often do you have someone help you read hospital materials?
   - Never
   - Occasionally
   - Sometimes
   - Often
   - Always

32. How confident are you filling out medical forms by yourself?
   - Never
   - Occasionally
   - Sometimes
   - Often
   - Always

33. How often do you have problems learning about your medical condition because of difficulty understanding written information?
   - Never
   - Occasionally
   - Sometimes
   - Often
   - Always

Questions 34 – 40: General Demographics
This is the final section of the questionnaire. We would like to ask you some questions about general information like insurance, income, education level, and race.

34. Sex:
   - Female
   - Male

35. Race:
   - White
   - Black
   - Hispanic / Latino
   - Asian / Pacific Islander
   - Other: ____________________________

36. What is your age (in years)? __________
37. Marital Status:
☐ Married
☐ Single
☐ Widowed
☐ Divorced

38. Household Income:
☐ Less than $25,000
☐ $25,000 - $49,999
☐ $50,000 - $74,999
☐ More than $75,000

39. Did you graduate from high school?
☐ Yes
☐ No

40. During the past 5 years, have you had medical insurance that covers office visits?
☐ Yes
☐ No