

Skin Cancer Risk Discussions in Melanoma-Affected Families

JENNIFER HAY, PHD, JAMIE OSTROFF, PHD, ALISA MARTIN, MD,
NICOLE SERLE, BA, SIREESHA SOMA, BA, URVI MUJUMDAR, MPH,
MARIANNE BERWICK, PHD

Abstract—*Background.* First-degree relatives (FDRs) of melanoma patients are at increased melanoma risk and thus represent an important target for prevention education. Family skin cancer risk discussions may be a useful education context. *Methods.* We assessed melanoma patients' (N = 115) self-reported family skin cancer risk discussions and changes in FDRs' prevention strategies. *Results.* Melanoma patients overwhelmingly (94%) reported risk discussions, primarily to communicate about melanoma prevention. These discussions occurred most frequently with patients' children (36%). Nearly half (46%) of household FDRs increased their melanoma prevention and control behaviors. *Conclusions.* This study attests to the potential to engage melanoma-affected families in prevention education. *J Cancer Educ.* 2005;20:240-246.

Melanoma is one of the most rapidly increasing cancers in the United States. The incidence rates for melanoma have increased 4% per year since the 1970s and include increases in both early and late-stage diagnoses.¹⁻⁴ Established risk factors for melanoma include strong, intermittent sun exposure,⁵ dysplastic nevi,⁶ cutaneous phenotype (red hair, blue eyes, poor tanning ability^{7,8}), and a family history of the disease.^{9,10} Fortunately, sun avoidance and sun protection with clothing, hats, and sunscreen are useful behavioral strategies for melanoma risk reduction¹¹ even if adopted in adulthood.¹² First-degree family relatives (FDRs) of melanoma patients have at least a two-fold increased risk of developing melanoma compared with the general population¹⁰ due to common family sun behavior and genetic factors.¹³⁻¹⁸ However, those with a family history of melanoma often do not engage in adequate sun protection and screening behaviors¹⁹⁻²⁴ because of lack of knowledge²⁵ and a lack of appreciation of their increased risk status.²⁶ As such, they represent a primary target for education about risk and prevention strategies.

A patient's initial melanoma diagnosis and treatment may represent an opportune time to deliver family-focused melanoma prevention education to families affected by this

disease.²⁷⁻³¹ Family discussions about skin cancer risk may be a naturally occurring context for such education, which could include information about shared melanoma risk factors and appropriate strategies to support sun protection and screening behaviors within multigenerational family systems. To date, the potential to use a family discussion framework to provide education to melanoma-affected families has not been examined.

To examine this potential, in this study, we documented (and describe in this article) the existence of naturally occurring family skin cancer risk discussions among recently diagnosed melanoma patients and family members. We also examined the relationship between melanoma patients' of skin cancer risk discussions and health beliefs. We included an assessment of health beliefs derived from Social Cognitive Theory^{32,33} and hypothesized that patients would be more likely to initiate family educational discussions if they had stronger beliefs about their own ability to prevent the development of recurrent or second primary disease (self-efficacy) and stronger beliefs that sun protection and skin cancer screening are efficacious measures to prevent and control this disease (response-efficacy). We also hypothesized that family skin cancer risk discussions would be more likely to occur in the context of patients' heightened risk perceptions and cancer worries, as these patients may be more motivated to warn family members about skin cancer risks or to garner social support. Finally, we examined patients' reports about household FDRs' changes in melanoma prevention and control behaviors. Results of this study will provide the basis for future family-focused melanoma educational interventions, which will help address an identified need for education and cancer risk reduction for cancer-affected families.³⁴⁻³⁷

Received from Department of Psychiatry and Behavioral Sciences, Department of Epidemiology and Biostatistics, Memorial Sloan-Kettering Cancer Center, New York, NY (JH, JO, UM); Long Island Jewish Hospital (AM); Weill Medical College of Cornell University (NS); Albert Einstein College of Medicine (SS); and University of New Mexico (MB).

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Address correspondence and reprint requests to: Jennifer Hay, Department of Psychiatry & Behavioral Sciences, Memorial Sloan-Kettering Cancer Center, 641 Lexington Ave., 7th Floor, New York, NY 10022; phone: (646) 888-0039; fax: (212) 888-2584; e-mail: <hayj@mskcc.org>.

MATERIALS AND METHODS

Sample

Melanoma patients were identified from the Genes, Environment, and Melanoma (GEM) study.³⁸ We recruited New Jersey GEM participants with a single primary melanoma diagnosed from January 2000 through June 2000 and diagnostic pathology information reported to the New Jersey Department of Health and Senior Services for this study.

Procedure

We conducted this cross-sectional, descriptive study by telephone interview. We sent letters of introduction to all eligible New Jersey GEM participants who had completed study items for GEM and who agreed to further research contact. The letter requested their participation in a 25- to 45-minute individual interview assessing thoughts and feelings about family skin cancer prevention. A trained research interviewer (AM) subsequently contacted these patients by telephone to request participation and conduct the interview. A total of 148 individuals were eligible for this study. Of these, 115 completed the telephone interview (response rate = 78%). The remainder (22%) could not be reached after 5 telephone attempts (N = 20), refused participation (N = 10), or had died (N = 3). This study was approved by the Institutional Review Boards of Memorial Sloan-Kettering Cancer Center and the New Jersey Department of Health and Senior Services.

Measures

We assessed sociodemographic characteristics including age, race, and gender, amount of time since diagnosis, as well as the presence/absence of a previous melanoma diagnosis in a FDR. To assess family skin cancer risk communication, we first examined the existence of family skin cancer risk discussions through the following question: "We would like to learn a bit about whether you have talked to an immediate family member (spouse, child, parent, or sibling) about skin cancer risk (including your risk, or their risk) since you were diagnosed with melanoma. Have you ever talked to your family about skin cancer risk?" Subsequent questions included (1) frequency of skin cancer risk discussions, (2) motivations for such discussions and motivations for not having these discussions, (3) with which family members these discussions occurred, and (4) who initiated these discussions. Although spouses do not necessarily share genetic susceptibility or common sun exposure histories with patients, we thought it valuable at this descriptive phase of the research to include discussions that potentially occur frequently within the married couple.^{29,30} Assessment of motivations for skin cancer risk discussions were based on the breast cancer literature³⁹ and included the following (with binary responses, eg, yes/no): to give family members information

about their own skin cancer risk, to get social support, to encourage sun protection, to encourage skin cancer screening, and to get personal medical advice. Motivations for not having discussions included the following (with binary responses, eg, yes/ no): not wanting to burden/upset family members, family tends not to discuss health matters in detail, preferences to avoid advice-giving, or they did not see a good reason to do so. Open-ended items were also included to evaluate additional motivations for having or avoiding risk discussions. We also assessed, in an open-ended fashion, the content of these discussions. We used established measures to assess self-efficacy and response-efficacy for melanoma prevention and control behaviors,³³ cancer worry⁴⁰ and perceived risk for developing melanoma in the future.^{41,42}

We also assessed patient-reported changes in melanoma prevention and control behaviors in household FDRs because family report of health behavior is most reliable for those who actually live in the household.⁴³ Descriptive and inferential statistics were calculated in SPSS for Windows Version 11.5 (SPSS, Inc, Chicago).

RESULTS

Participants (N = 115) were recently diagnosed melanoma patients who ranged in age from 20 to 90 years (mean = 60), with most participants aged 40 or older (age 20-29, 2%; age 30-39, 9%; age 40-49, 19%; age 50-59, 18%; 60-69, 16%; 70-79, 23%; 80-90, 13%). About half (55%) were women, and they were predominantly (96%) White. They were interviewed 9 to 30 months after their diagnosis (mean = 19 months). Twelve percent reported a positive first-degree history of melanomas.

Most (94%) melanoma patients surveyed reported that they had engaged in discussions about skin cancer risk with at least 1 family member since they were diagnosed with melanoma. Additionally, of the melanoma patients who reported any family discussions, most engaged in multiple discussion occasions, with 21% reporting 1 or 2 discussions, 27% reporting 3 to 5 discussions, and 45% reporting 5 or more discussions (7% had missing data on this question). Those participants who were interviewed sooner after their diagnosis reported that they had engaged in fewer discussions than those participants interviewed later ($F_{2,90} = 7.09$, $P = .001$), with post hoc least significant difference (LSD) tests indicating that those who engaged in 1 or 2 discussions had been diagnosed more recently than those who engaged in 3 to 5 or 5 or more discussions. Participants primarily (67%) initiated these discussions, or they were initiated mutually with family members (19%). These discussions were frequently centered around family members' risk (94%) and less often around patients' own risk of melanoma recurrence (51%). Of all the family members engaged in skin cancer risk discussions, 36% were participants' adult children, and the primary rationale for engaging in these discussions was to provide information and encouragement for family members

to perform melanoma primary prevention behaviors (see Table 1).

Next, we examined the relationship between skin cancer risk discussions and health beliefs in a series of 1-way analysis of variance tests using frequency of skin cancer risk discussion as the 3-level covariate (1-2 vs. 3-5 vs. > 5 discussions) and each health belief as the continuous dependent variable. For self-efficacy, 6 items were combined into a total score for self-efficacy (alpha reliability = .57) as were 6 items for response efficacy (alpha reliability = .68). For cancer worry, the 4 items were combined into a total score (alpha reliability = .71). For perceived risk, the 2 items, perceived future melanoma risk compared to (1) others the same age/sex and (2) other melanoma patients the same age/sex, were moderately correlated ($r = 0.53, P < .001$), so they were maintained as separate perceived risk variables. Analyses on perceived risk are based on reduced sample size because 1 participant did not respond to the question concerning perceived melanoma risk compared to others their age/sex, and 8 participants did not respond to the question concerning perceived melanoma risk compared to other melanoma patients their age/sex. Melanoma patients who engaged in more skin cancer risk discussions had higher self-efficacy, confidence that they could perform melanoma prevention and control behaviors, and response efficacy, stronger beliefs that sun protection and skin cancer screening are efficacious measures to minimize recurrence, than those who engaged in less frequent discussions. Post hoc LSD indicated, in each of these analyses, that those who engaged in more than 5 discussions had higher efficacy beliefs than those who reported only 1 or

2 discussions (see Figure 1). There was a curvilinear relationship between frequency of skin cancer risk discussions and melanoma worry, with higher levels of worry reported among those that reported both fewer (1-2) and frequent (> 5) skin cancer risk discussions and lower levels of worry reported among those reporting a moderate number (3-5) of skin cancer risk discussions with their family. In this analysis, post hoc LSD indicated significant differences in cancer worry among those reporting a moderate number (3-5) of risk discussions and the other two groups. Frequency of risk discussions was not related to perceived risk for developing recurrent or second primary disease. Inclusion of time since diagnosis as a covariate (analyses of covariance) in these analyses did not change the results.

We next examined the content of skin cancer risk discussions among family members of melanoma patients. Open-ended responses were recorded verbatim by the telephone interviewer. On initial examination of the responses, a preliminary coding scheme was developed by the primary investigator (JH) to capture all aspects of responses provided: (1) sun protection, (2) sunscreen use, (3) genetics/family history, (4) avoidance of tanning salons, (5) patient's personal cancer experience, and (6) other. Responses generally involved multiple categories and were coded independently (AM and SS) into 1 or more of the 6 categories. Discrepancies were discussed in a meeting that included the coders and the primary investigator until consensus was reached. The content of these discussions was consistent with the reported prevention focus of the discussions, with half or more of those participants who reported family risk discussions; including sunscreen use or sun protection, and more than a third who addressed physician screening for skin cancer. Of note, almost a third commented on increased familial or genetic risks of melanoma with their family members, and this included those who brought up shared family risk factors including mole number, light hair/skin color, as well as more general statements about their family being at greater genetic risk. Very few (5%) mentioned skin self-examination in their discussions (see Table 2).

Finally, we requested information about whether household family members had made changes in their sun protection or skin cancer screening behaviors. Of participants, 40% reported that they live with at least 1 FDR who were mostly (67%) the participants' children. Of 82 household family members mentioned, participants reported that nearly half (46%) had increased their melanoma prevention and control behaviors since the patient's melanoma diagnosis. Again, open-ended responses were recorded verbatim by the telephone interviewer. On examination of the responses, a coding scheme was developed by the primary investigator (JH) to capture all aspects of responses provided: (1) family member has increased the sun protection factor of sunscreen used, (2) family member has increased the frequency of sunscreen use, (3) family member has increased the area of sunscreen coverage, (4) family member is now wearing sunscreen, (5) family member has decreased sun exposure, (6) family member now avoids peak sun hours, (7) family member now wears protective clothing in the sun, and (8) family

Table 1. Why Did Patients Initiate Skin Cancer Risk Discussions?

Rationale (N=108, 94% of participants)	N	%
For skin cancer risk discussions*†		
To give family member info about their own risk	102	94
To encourage family to engage in sun protection	100	93
To encourage family to seek skin cancer screening	89	82
To get social support	31	29
To get medical advice	25	23
Concern about something on family member's face	3	3
Advice for a relative to avoid tanning salon	1	1
Recent melanoma death in niece prompted family discussion	1	1
For avoidance of risk discussion† (N = 7, 6% of participants)		
Didn't want to burden or upset	1	14
Family doesn't discuss health matters	3	43
I don't like to give advice	2	29
I saw no reason to do so	2	29

*Of the 212 family members that were engaged in skin cancer risk discussions by study participants, 76 (36%) were participants' children, 46 (22%) were participants' siblings, 37 (17%) were participants' spouses, 23 (11%) were participants' parents, and 30 (14%) were other relatives.

†Percentages are not mutually exclusive.

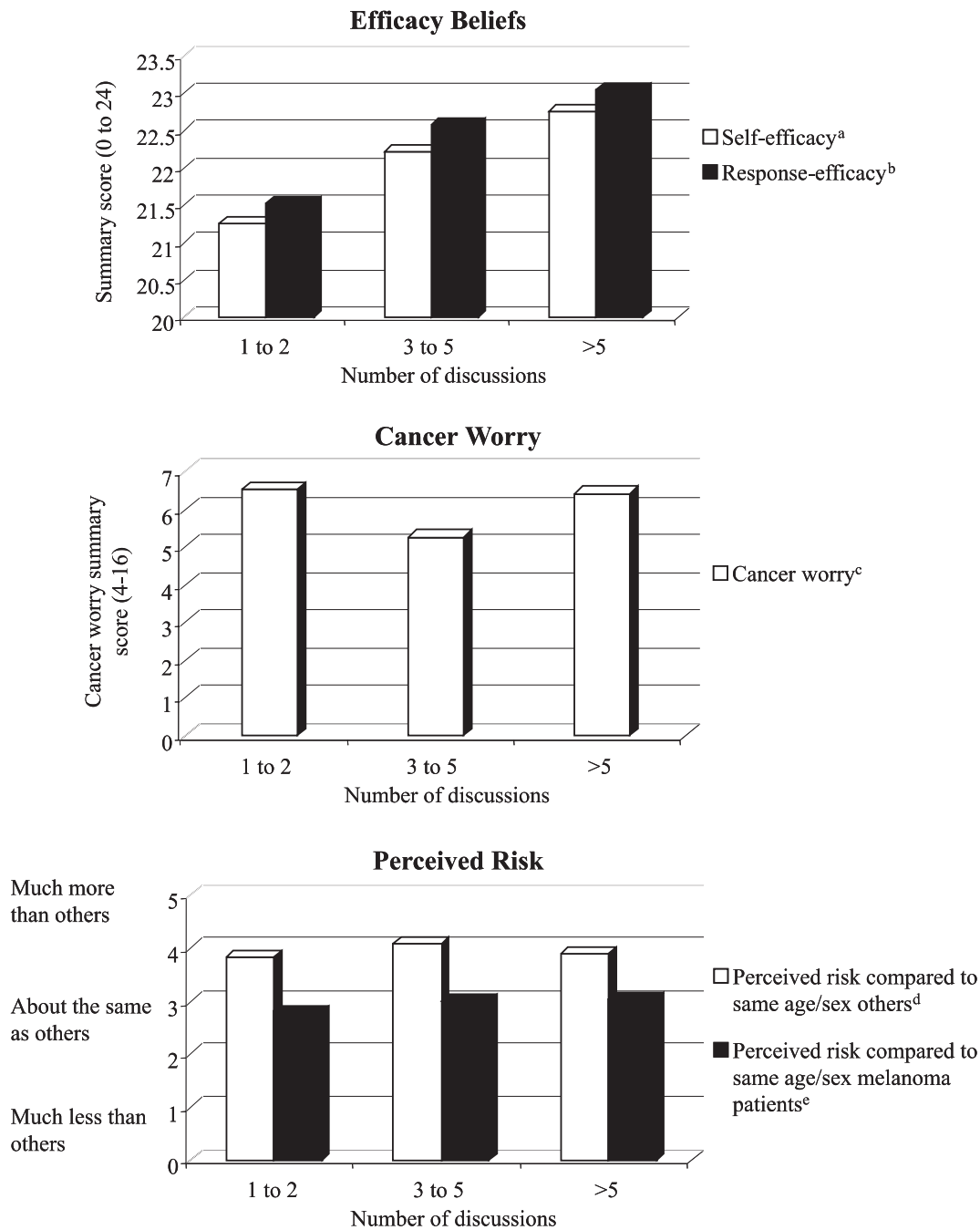


FIGURE 1. Relationship between skin cancer discussions and health beliefs. ^aF(2,98) = 4.45, *p* = .014*, ^bF(2,98) = 4.88, *p* = .010**, ^cF(2,98) = 3.52, *p* = .033*, ^dF(2,97) = 0.31, *p* = .730, ns, ^eF(2,91) = 0.33, *p* = .720, ns.

member has pursued physician skin examination. Responses contained one or more of the aforementioned categories and were subsequently coded independently (AM and SS) into 1 or more of the 8 categories. Discrepancies were discussed between the coders and the primary investigator (JH) until consensus was reached. The nature of these changes were consistent with the reported discussion topics raised and with the changes noted by participants predominantly focused around sun protection (initiation of sunscreen use, increased frequency of use, decreased sun exposure, increased use of protective clothing when outdoors, see Table 2).

DISCUSSION

In this article, we examined skin cancer risk discussions among newly diagnosed melanoma patients and their family members. In this study, we found skin cancer risk discussions to be remarkably prevalent, with 94% of surveyed melanoma patients reporting that they have had at least 1 or 2 discussions about skin cancer risk with family members since they were diagnosed. These high rates of family risk discussion exceed those reported for patients undergoing Mohs micrographic surgery for skin cancer in which 65% reported

TABLE 2. Content of Risk Discussions and FDRs' Prevention and Control Behaviors*

Content	N	%
Skin cancer risk discussion (N = 108 participants)		
Sunscreen use	63	58
Sun protection	54	50
Physician examination	41	38
Genetics/family history	31	29
Something else	14	13
Participant's cancer experience	11	110
Non-specified screening	10	9
Avoiding tanning salons	6	6
Skin self-examination	4	5
Participant-reported changes in household FDRs' melanoma prevention and control behaviors (N = 38 household FDRs)		
Now wearing sunscreen	17	45
Wear protective clothing	15	40
Decreased sun exposure	14	37
Increased the frequency of sunscreen	13	34
Had physician skin examination	12	32
Avoid midday sun (10 am to 4 pm)	2	8
Increased the SPF of sunscreen	2	5
Increased the area of sunscreen coverage	1	3

*FDR indicates first-degree relative. Percentages are not mutually exclusive.

spontaneously encouraging sunscreen use in their family members²⁷ and are consistent with rates and motives reported for breast cancer risk discussions in high-risk families.^{39,44,45} The primary reported goal for these discussions involved family member skin cancer risk reduction rather than social support or communication of the patients' cancer experiences. This primary theme was reflected in other aspects of risk discussions. First, one third of the family members engaged in discussion were the participants' children—perhaps reflecting patients' desires to pass on risk and prevention information to those for whom a great number of years remain to reduce risk for themselves as well as participants' grandchildren. Second, the topics discussed involved the importance of behavioral risk reduction of melanoma, with half or more of those who engaged in discussion including information about the importance of sunscreen use and sun protection strategies and more than a third on physician screening. Of note, there were many discussions that included references to shared family risk factors for melanoma including mole number, hair or skin color, or shared genetic susceptibility. Third, participants who engaged in more frequent skin cancer risk discussions felt more confident in their ability to prevent disease recurrence and more certain that sun protection and screening could prevent and control this disease. Clearly, family risk identification and melanoma prevention are important goals for these patients.

We also examined melanoma patients' awareness of household family members' changes in sun protection or skin cancer screening behaviors since the melanoma patient

was diagnosed. Half of all reported household FDRs were described by the melanoma patient as having enhanced their melanoma prevention and control efforts since the patient's diagnosis. Two thirds of these FDRs were the patients' children. Although these changes were certainly not universal, they point to a significant response in the household—in the *absence* of an established educational or clinical risk-reduction intervention for family members of melanoma patients.

We think it is important to highlight some consistent emphases in the content of risk discussions and reported behavioral changes among FDRs. The most frequently reported content of risk discussions involved the use of sunscreen, sun protection, and physician skin examination, which are all useful risk reduction strategies. Similarly, the most frequent participant-reported changes in household FDRs' behaviors included increased use of sunscreen and protective clothing and decreased sun exposure. Because increased sunscreen use may lead to increased sun exposure, this finding identifies a potentially important area for intervention with melanoma patients and their family member, who may be counseled to prioritize sun protection and avoidance.⁴⁶ Melanoma patients reported that they discussed the importance of skin self-examination infrequently, and none reported that household FDRs initiated this behavior since the patient's diagnosis. These results indicate fruitful areas for intervention with families.

Additionally, those participants who reported few (1-2) or many (> 5) discussions reported higher levels of cancer worry than those who reported a moderate number of discussions (3-5). Because worry could both encourage and inhibit discussions, a greater understanding of these issues can be more definitively answered in prospective studies that examine cancer worries as precursors, as well as outcomes, of skin cancer risk discussions.

We note limitations of this study. First, participants' self-reports could be biased by memory limitations or socially desirable responding. Second, the sample was drawn from a population-based epidemiological study; thus, the high rates of family skin cancer risk communication may not be fully generalizable to all primary melanoma patients. Third, for the changes reported in household FDRs' behaviors, we did not substantiate this information with family members themselves.

In conclusion, we provide evidence that naturally occurring family skin cancer risk discussions are prevalent and frequent in melanoma-affected families and that these discussions are largely focused around primary prevention with the patients' children. Recently, the need to target cancer patients' family members in cancer education has been identified as an important unmet need.³⁴⁻³⁷ Indeed, discussions within families affected by hereditary breast cancer are associated with a range of positive outcomes including increased cancer knowledge and screening utilization and improved family adjustment and decision making.⁴⁷⁻⁵² Family discussions may also be a valuable route to primary melanoma prevention because family members integrate important family-specific social and cultural norms into their discussions

and strategies for mutual support for risk reduction. Melanoma prevention education within a family framework facilitated by nurses, physicians, and health educators will usefully combine family-specific discussions of genetic risk, early detection strategies, and lifestyle behavior change and will be enhanced by participation and goal setting by multigenerational family members who may be able to provide consistent support to each other in changing—and maintaining—melanoma risk reduction.

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AMERICAN ASSOCIATION FOR CANCER EDUCATION

The American Association for Cancer Education was founded in 1947 as the Cancer Coordinators, an association of cancer educators from US medical and dental schools that met annually to discuss problems and methods of mutual interest. The American Association for Cancer Education was incorporated under its present name in 1966. The object of the Association is to foster cancer education by individuals of any country responsible for or whose duties include cancer education or training within medical, dental, osteopathic, nursing, and public health schools, and other schools, institutions, or organizations within which formally organized cancer teaching and training programs are conducted. It provides a forum for those concerned with the education of groups who attempt to advance the cause of early cancer detection, promote individualized multimodality therapy, or develop programs of rehabilitation for cancer patients. This includes faculties of schools of medicine, dentistry, osteopathy, education, nursing, public health, and social work; projects for the training of paramedical personnel; and educational programs for the general public, populations at special risks, and patients.

Membership in this Association is open to all individuals engaged in any phase of education in this field. Applications for membership are made to the Secretary of the American Association for Cancer Education on the prescribed form. Applicants must submit a summary of their involvement in cancer education. The officers of the Association are the President, President-Elect, Vice President,

Secretary, and Treasurer. The above officers, the immediate Past President, and six appointed members constitute the Executive Council of the Association. Standing committees also operate within the Association. They are the Advisory, By-Laws, Editorial, Finance, Local Arrangements, Membership, Nominating, and Program Committees.

There are sections of the Association through which members may conduct projects in conjunction with fellow members having similar interests and expertise. These are Communication in Cancer Care, Cancer Prevention Education, Cancer Education Evaluation & Methods, Postgraduate and Continuing Cancer Education, International Cancer Education, Oral Cancer Education, Palliative Cancer Education, Psychosocial Cancer Education, Public & Patient Cancer Education, and Predoctoral Cancer Education.

The Association holds an annual meeting in the fall of each year. Members are urged to submit abstracts and present data on new and innovative techniques in cancer education for students of the health professions, practicing health professionals, cancer patients, and the general public. Members also present data on evaluation of cancer education-related materials such as films, slide-cassette presentations, texts, and computer-based education programs.

At the annual meeting the Association honors an outstanding cancer educator with its Margaret Hay Edwards Achievement Medal and recognizes contributions to the field of cancer in general through the annual Harvey Lectureship, which was begun in 1951