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Cancer Information Seeking Preferences Among Health Professionals Serving American Indians in Minnesota, North Dakota, and Wisconsin

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Background

The primary purpose of this project was to identify by means of a phone survey the cancer information resources used by health professionals in tribal health departments or Indian Health Service clinics serving American Indian communities in Wisconsin, Minnesota, and North Dakota. Spirit of EAGLES (SOE) initiated the project to evaluate the use of *Cancer Information Resources for Native Americans*, a notebook published by the University of Wisconsin Comprehensive Cancer Center (UWCCC) in 1999, and later broadened it to include cancer information sources used by this group of health professionals.

Methods

SOE staff drafted the specific survey questions with the assistance of the UWCCC Survey Research Shared Service. The survey consisted of fourteen questions, formatted as yes/no items or using Likert scaling. The SOE program director identified an initial pool of 31 health professionals serving facilities visited through the SOE program between January 2001 and December 2003. Two of the original 31 potential respondents declined to participate, each suggesting a colleague they thought would be more appropriate to the survey's focus on cancer. These two health professionals were notified by letter, and added to the pool, bringing it to a total of 33 potential respondents. Twenty-five (76%) of the potential respondents participated in the survey.

Results

Survey respondents were asked to describe their job by choosing one or more of the following professional functions: administrative, clinical, and/or educational. Sixteen respondents stated their position included an administrative function, thirteen a clinical function, and nine an educational function. A majority of the respondents (14/25 or 56%) had between ten and twenty years experience in their present professional position, and an additional five respondents had between five and ten years experience.

Respondents were asked the relative difficulty of finding cancer information for their professional use on a scale of one (least difficult) to five (most difficult). Eight respondents reported little difficulty in finding cancer information, one reported a great deal of difficulty, and the remainder fell between; the mean was 2.36. Respondents were also asked how often clients requested information about cancer. Their response to the five options given was roughly bimodal: daily (2), weekly (8), monthly (4), rarely (9), and not at all (1).

Respondents were asked if they ever sought information on eight broad cancer topics. The topics and response rate were: prevention (96%), trends and statistics (88%), specific cancers (88%), screening (88%), resources/resource providers (80%), treatment (64%), diagnosis (56%), and clinical trials or studies (24%).

When locating cancer information for their professional use, respondents used websites (92%), local medical personnel (80%), brochures/booklets (72%), media sources (40%), local libraries (24%), and "other" sources. When referring clients to sources of cancer information, respondents used brochures/booklets (91%), local medical personnel (91%), websites (57%), media sources (24%), local libraries (10%), and "other" sources.

The set of responses to the "other" sources option were classified into broad groups for reporting purposes. When seeking cancer information for themselves, respondents used books, medical journals, and other publications (32%) and other medical personnel (20%). When referring clients to sources of cancer information, respondents used other medical personnel (10%) and 1-800 numbers (10%).

As a follow-up, respondents were asked to select which one cancer information source they preferred to use most in both circumstances. Websites was the respondents' preferred source for themselves, while brochures/booklets were preferred for clients.

Respondents were asked whether they sought information from five particular cancer-focused organizations for themselves and for clients. The five organizations, and the percentage of respondents who used them for themselves were: the American Cancer Society (72%), National Cancer Institute (72%), Spirit of EAGLES (72%), Native Circle (64%), and the Cancer Information Service (24%). When referring others, the respondents used the American Cancer Society (91%), National Cancer Institute (48%), Native Circle (33%), Spirit of EAGLES (33%), and the Cancer Information Service (29%).

When asked about "other" organizations used as a cancer information resource for themselves, respondents reported specific cancer centers (24%), state health department programs (20%), the Indian Health Service (12%), and the Centers for Disease Control and Prevention (12%). Respondents also cited several "other" organizations to whom they refer clients; with specific cancer centers (10%) reported most often.

Finally, respondents were asked about a UWCCC resource notebook, *Cancer Information Resources for Native Americans* distributed to their facility. Nine of the twenty-five (36%) respondents were familiar with the notebook, and two of twenty-five (8%) had used it.

Fourteen respondents made post-interview comments when asked for additional comments at the conclusion of the survey. Among the comments, the following three were specific to cancer information: 1) more cancer resources were generally necessary, 2) there are not enough American Indian-specific cancer resources, and 3) the application of this research would be useful in identifying cancer information needs for American Indian communities.

Discussion

The following three points were most noteworthy in the survey results: 1) there is a low level of interest in the topic of cancer clinical trials, 2) there is a low level of familiarity with the UWCCC notebook, and 3) there was a distinction between what cancer information resources the respondents use for themselves versus those to which they refer clients. Over 90% of respondents use websites for themselves, and nearly 70% said they use websites the most. When referring clients to cancer information, over 90% of respondents use brochures/booklets and local medical personnel, and almost 50% used brochures/booklets the most.

In addition, there was a high degree of respondent interest in the survey, as evidenced by the number of post interview comments and the volume of information volunteered when questions included an "other" category.

While this survey had several interesting findings, it is important to recognize its limitations. First, the respondents were selected for participation in the survey; second, they represent a very specific group of health professionals; and third, the small number of respondents (25) limits the applicability of the findings.

Conclusion

Both health professionals serving American Indian communities and their clients would benefit from greater availability and ease of access to American Indian-specific cancer information. A website containing resources and links for the health professional, as well as downloadable brochures for clients, would aid in meeting the primary resource preferences identified in this survey.

Editor's note: A more detailed version of this report may be obtained by contacting Rick Strickland, Spirit of EAGLES: American Indian and Alaskan Native Leadership Initiative on Cancer Control and Outreach, WARF 370, 610 N. Walnut St., Madison, Wisconsin 53726; e-mail strickla@uwccc.wisc.edu; telephone (608) 262-0072.

