

Year 2000 Oncology Nursing Society Research Priorities Survey

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Purpose/Objectives: To determine the Oncology Nursing Society's (ONS's) research priorities for 2001–2005 for oncology nursing across the entire scope of cancer care, including prevention, detection, treatment, and palliative care.

Design: A cross-sectional, mailed survey.

Sample: Stratified by the general member group (i.e., a random sample of 1,850 ONS members) and researcher group (i.e., census of 150 ONS researchers). 788 responded for an overall response rate of 39%.

Main Research Variables: 113 topics that were identified from the 1994 ONS Research Priority Survey questionnaire and earlier ONS Research Priority Surveys, with the addition of 20 new items to existing questionnaire categories and one new category area: health services research.

Findings: Top 20 research priorities were distributed across six of eight questionnaire categories, and the number of top 20 priorities within categories differs. Compared to the 1994 survey, 9 topics were common to both top 20 lists; 8 were new to the top 20, and 11 dropped out of the top 20. When the researcher group and adjusted total sample group top 20 priority ratings were compared, nine topics were common to both groups.

Conclusions: Examining research priorities affords different perspectives to guide practice, education, research, management, and administration.

Implications for Nursing: ONS Research Priority Survey results provide an important foundation for developing future research across the entire scope of oncology nursing.

Rapid advances in information and technology related to cancer prevention, detection, and care of people with cancer, as well as changes in the healthcare systems in which they are delivered, generate the need for periodic evaluation of research priorities. Determining what oncology nurses view as the most important issues for research is part of this process. In the past, oncology nursing research priorities have provided a basis for practice innovations, education of nurses, research initiatives and their funding, and health policy (McGuire & Ropka, 2000). The identification of research priorities helps direct resources to areas of greatest importance or need. Federal-funding agencies, such as the

Key Points . . .

- ▶ When comparing surveys, researchers should consider methodologic differences in sampling, design, and questionnaires.
- ▶ The top 20 research priorities for the total sample, in rank order, were pain, quality of life, early detection of cancer, prevention/risk education, neutropenia/immunosuppression, hospice/end of life, oncologic emergencies, suffering, fatigue, ethical issues, anorexia, access to cancer care, depression, stress-coping adaptation, nurse retention, hope, palliative care, decision making in advanced disease, family education, and cancer recurrence.
- ▶ Research priorities were rated differently by the total sample group compared to the researcher group.
- ▶ Some research priorities are important to address even though they were not ranked highly, such as genetic screening/testing, smoking, and special populations.

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National Institute for Nursing Research, National Cancer Institute, and Department of Defense; cancer-related organizations, such as the American Cancer Society and Oncology Nursing Society (ONS); and foundations, such as the ONS Foundation, utilize these identified priorities to target research funding.

ONS has conducted surveys of its members over the past 20 years to inform the process of setting research priorities for the organization. The Year 2000 ONS Research Priorities Survey is the sixth such survey conducted by ONS since 1981 (Funkhouser & Grant, 1989; Grant & Stromborg, 1981; McGuire, Frank-Stromborg, & Varricchio, 1985; Mooney, Ferrell, Nail, Benedict, & Haberman, 1991; Stetz, Haberman, Holcombe, & Jones, 1995). The four most recent ONS Research Priority Surveys are summarized in Table 1 to facilitate comparison of differences in sample design, response rate, and survey methods. Nursing organizations in other countries have followed ONS's lead and used similar approaches (Bakker & Fitch, 1998; Goldfrad, Vella, Bion, Rowan, & Black, 2000; Hinshaw, 1997; Moreno-Casbas, Martin-Arribas, Orts-Cortes, & Comet-Cortes, 2001; Rustoen & Schjolberg, 2000). Research priorities also have been established for other specialty areas of nursing, such as critical care and nursing administration (Lindquist et al.,

1993; Lynn, Layman, & Englehardt, 1998; Lynn, Layman, & Richard, 1999; Rudy, 1996; Sedlak, Ross, Arslanian, & Taggart, 1998; Wipke-Tevis, 2001).

The purpose of the Year 2000 ONS Research Priorities Survey was to gather information about the most important issues related to the health and health care of individuals affected by cancer that can be addressed by oncology nursing research. These issues are inclusive of the entire scope of cancer care—prevention, detection, treatment, and palliative care. This study focused on all aspects of cancer care rather than only oncology specialist care. Furthermore, it focused on the conduct of research to develop new knowledge and not research utilization or evidence-based practice. The stated timeframe for projecting current and future priorities was 2001–2005. Information from this survey will be used, along with other sources, to inform research priorities and plan future ONS research initiatives.

Methods

The charge to the Research Priorities Survey Project Team was to conduct a survey of the ONS membership for the purpose of determining ONS research priorities. The Project

Table 1. Prior Oncology Nursing Society Research Priority Survey Methods Compared to the Year 2000 Study

| Survey Year | Sample | Survey Details | Comments Regarding Comparison |
|---------------------------------|--|--|---|
| 1988 (Funkhouser & Grant, 1989) | Oncology Nursing Society (ONS) members who <ul style="list-style-type: none"> Previously identified research as their major focus <i>or</i> Participated as research faculty in ONS short courses <i>or</i> Functioned in ONS leadership positions | 213 returned/700 sent 30% response rate One-time mailing | <ul style="list-style-type: none"> Sample otherwise similar to year 2000 researcher group, but also included ONS leadership and short-course faculty; general membership not sampled Results not reported by sample subgroups |
| 1991 (Mooney et al., 1991) | “Convenience sample” (p. 1381) of ONS members who either <ul style="list-style-type: none"> Identified research as major focus in career <i>or</i> Held ONS leadership positions | 310 returned/429 sent 70% response rate One-time mailing | <ul style="list-style-type: none"> Sample similar to year 2000 researcher group, but also included ONS leadership; general membership not sampled Results not reported by sample subgroups |
| 1994 (Stetz et al., 1995) | 10% random sample of ONS members who identified patient care as primary functional area or ONS members who were <ul style="list-style-type: none"> ONS leadership <i>or</i> Members of Advanced Nursing Research Special Interest Group <i>or</i> Doctorally prepared | 789 returned/2,178 sent 36% response rate One-time mailing | <ul style="list-style-type: none"> Sample similar to year 2000 researcher group but broader and also included ONS leadership; similar to year 2000 general member group but restricted to patient care Results not reported by sample subgroups |
| 2000 | Two groups: <ul style="list-style-type: none"> General member group—random sample of ONS voting members Researcher group—census of all members who met researcher eligibility criteria | 788 returned/2,000 sent General member group: 685 returned/1,850 sent Researcher group: 103 returned/150 sent Total: 39% response rate General member group: 37% response rate Researcher group: 69% response rate Follow-up reminder postcard at one week and second mailing at three weeks | <ul style="list-style-type: none"> Overall sample adjusted for oversampling of researchers Results reported by overall sample adjusted and researcher group |

Team was comprised of seven volunteer members, specifically recruited to represent practice, administration, education, and health policy. The ONS Director of Research served as the ONS liaison. Two of the team members were involved in conducting the 1994 survey. The functions of the team included revising the existing questionnaire by adding new items and reorganizing its format; determining survey methodology, data acquisition, data analysis, and interpretation of the findings; and generating a manuscript. The work of the team was carried out through telephone conference calls and other means of electronic communication between August 1999 and spring 2001. A cross-sectional mail survey was conducted between May and August 2000.

Sample

At the time that the sample of 2,000 ONS members was drawn, July 2000 membership statistics obtained from ONS reported 28,764 total members. Of the 27,186 voting members, 26,546 were active members, 555 were senior members, and 85 were physically challenged members. The sample was limited to ONS voting members, who by ONS policy are comprised of the active, senior, and physically challenged membership categories.

The sample was stratified into two separate groups of the ONS membership: the general ONS membership, designated as the general member group, and ONS members who also were researchers, called the researcher group. Membership of these two groups did not overlap. The rationale for stratifying according to these two groups and then oversampling the researcher group was to tap the researchers, a particularly important group for determining research priorities, who might otherwise be missed by random sampling because of its small size. All members who met the researcher study definition were included in this stratum of the sample.

The researcher group ($n = 150$) consisted of all ONS members who were identified as researchers. Thus, this was a census of the researcher group and not a sample. Because re-

searchers are not directly identified in the ONS membership database, the Project Team devised sampling eligibility criteria to identify the researcher group by using membership information collected by ONS as part of initial membership or annual renewal applications. Eligibility criteria included (a) highest nursing degree reported as "doctorate" or highest non-nursing degree reported as "doctorate," (b) functional area reported as "researcher" or primary position reported as "researcher," or (c) member of the Advanced Nursing Research Special Interest Group who is an independent investigator.

The general member group ($n = 1,850$) represented the general ONS membership excluding researchers. This was a random sample of ONS voting members minus those designated as researchers according to the researcher group eligibility criteria.

Questionnaire

The Project Team developed the Year 2000 ONS Research Priorities Survey questionnaire after reviewing the five previous ONS research priority survey reports and the research priority surveys of other organizations (Bakker & Fitch, 1998; Lindquist et al., 1993). Review of the 1994 questionnaire led to refining questionnaire categories and items; adding one new category (i.e., health services research) and 20 new items that were interspersed throughout categories; regrouping items for better placement; and relabeling categories for improved readability. The Year 2000 ONS Research Priorities Survey questionnaire consisted of 113 topics divided into eight categories: (a) cancer symptom management (30 topics), (b) behavioral and psychosocial aspects of cancer care (13 topics), (c) cancer care delivery systems (14 topics), (d) cancer continuum of care (17 topics), (e) cancer health behaviors (6 topics), (f) special cancer populations (17 topics), (g) cancer decision making (9 topics), and (h) cancer health services research (7 topics).

Respondents were asked to rate each of the 113 topics as extremely important, very important, moderately important, a little important, and not at all important in reference to the following question: "What are the most important issues related to health and health care for individuals affected by cancer that can be addressed by oncology nursing research?" In addition, an open-ended question was included that asked respondents to "identify other important areas for oncology nursing research. Include those that are 'cutting edge' or 'visionary.'"

Procedures

Survey procedures followed the Tailored Design Method recommended by Dillman (2000), one of the foremost authorities in survey research. The Tailored Design Method "is the development of survey procedures that create respondent trust and perceptions of increased rewards and reduced costs for being a respondent, which take into account features of the survey situation and have as their goal the overall reduction of survey error" (Dillman, p. 27). The technique is intended to reduce survey error in coverage, sampling, measurement, and nonresponse (Dillman). Measurement error in written surveys is a major concern because it is largely controlled by good questionnaire design. The design controls whether questions are overlooked, responses are biased, and people are motivated to respond. The questionnaire should be respondent-

Table 2. Respondent Demographics

| Characteristic | Year 2000 Oncology Nursing Society Research Priorities Survey Respondents | | Oncology Nursing Society Membership (as of 7/1/2000) | |
|------------------------------|---|----|--|-----|
| | n | % | n | % |
| Gender (n = 760) | | | | |
| Female | 733 | 96 | 25,945 | 97 |
| Male | 27 | 4 | 802 | 3 |
| Age (years) (n = 764) | | | | |
| 20-29 | 104 | 14 | 2,373 | 9 |
| 30-39 | 167 | 22 | 7,046 | 27 |
| 40-49 | 314 | 41 | 10,277 | 39 |
| 50-59 | 146 | 19 | 5,476 | 21 |
| 60+ | 33 | 4 | 1,001 | 4 |
| Ethnicity (n = 767) | | | | |
| Caucasian | 701 | 91 | 23,287 | 90 |
| Asian | 33 | 4 | 1,137 | 4 |
| African American | 15 | 2 | 700 | 3 |
| Hispanic | 15 | 2 | 537 | 2 |
| Native American | 3 | 1 | 110 | < 1 |
| Other | - | - | 220 | < 1 |

Table 3. Professional Characteristics of Respondents

| Characteristic | Year 2000 Oncology Nursing Society Research Priorities Survey Respondents | | Oncology Nursing Society Membership (as of 7/1/2000) | |
|---|---|----|--|-----|
| | n | % | n | % |
| Highest nursing degree (n = 764) | | | | |
| Diploma | 83 | 11 | 4,359 | 17 |
| Associate | 238 | 31 | 6,845 | 26 |
| Bachelor's | 258 | 34 | 10,193 | 39 |
| Master's | 95 | 12 | 4,298 | 17 |
| Doctorate | 92 | 12 | 334 | 1 |
| Highest non-nursing degree (n = 743) | | | | |
| None | 484 | 65 | 10,210 | 162 |
| Diploma | 18 | 2 | 749 | 5 |
| Associate | 85 | 11 | 1,021 | 6 |
| Bachelor's | 95 | 13 | 2,851 | 17 |
| Master's | 31 | 4 | 1,347 | 8 |
| Doctorate | 30 | 4 | 243 | 1 |
| Years in oncology nursing (n = 764) | | | | |
| 1-3 | 199 | 26 | 4,684 | 16 |
| 4-10 | 323 | 42 | 10,894 | 38 |
| 11-15 | 90 | 12 | 8,561 | 30 |
| 16-20 | 72 | 9 | 3,171 | 11 |
| 20+ | 80 | 10 | 1,287 | 5 |
| Primary functional area (n = 766) | | | | |
| Patient care | 503 | 66 | 19,171 | 72 |
| Research | 104 | 14 | 1,714 | 6 |
| Education | 73 | 10 | 1,798 | 7 |
| Administration | 56 | 7 | 2,390 | 9 |
| Other | 27 | 4 | 1,634 | 6 |
| Practice setting (n = 759) | | | | |
| Hospital | 317 | 42 | 12,393 | 50 |
| Outpatient/ambulatory care | 181 | 24 | 6,054 | 25 |
| Home/public health/hospice | 32 | 4 | 1,246 | 5 |
| Physician office | 71 | 9 | 2,822 | 11 |
| Cancer center | 61 | 8 | 1,406 | 6 |
| Other | 97 | 13 | 738 | 3 |
| Employment status (n = 763) | | | | |
| Full-time | 634 | 83 | 21,759 | 80 |
| Part-time | 114 | 15 | 4,701 | 17 |
| Unemployed | 8 | 1 | 362 | 1 |
| Retired | 7 | 1 | 287 | 1 |

Note. Because of rounding, not all percentages total 100.

friendly and attractive, should encourage reading words in the same order by all respondents, and should be guided by graphical layout features (Dillman).

The cover letter and questionnaire initially were mailed in May 2000. One week after the first mailing, a postcard was mailed to the entire sample to thank those who already responded and encourage responses from those who had not done so yet. In June 2000, approximately three weeks after the postcard mailing, a second mailing of 1,600 questionnaires was sent to all nonresponders.

An incentive was offered to participants in the survey—entry into a drawing for one of ten \$25 gift certificates for ONS publications of the recipient's choice. Ten gift certificates were distributed by ONS in May 2001. To further enhance participation, reminders about the research priorities survey were printed in the June issue of the *ONS News* and prominently placed on the ONS Online Web site.

The ONS National Office in Pittsburgh, PA, coordinated preparation of the sample; organized and distributed the mailing of cover letters, questionnaires, and reminder postcards; received completed questionnaires; and entered and verified study data in Survey Pro®. Working with the Project Team, biostatisticians in the Department of Health Evaluation Sciences in the School of Medicine at the University of Virginia in Charlottesville analyzed the data using SAS®.

Results

Response Rates

The targeted sample of 2,000 ONS members consisted of 1,850 individuals from the general member group and 150 members from the researcher group. Of the 2,000 ONS members who were sent the questionnaire, 788 responded for an overall response rate of 39%. This response rate is similar to the 1988 and 1994 ONS research priorities surveys (Funkhouser & Grant, 1989; Stetz et al., 1995). When the year 2000 survey was planned, the goal for overall response rate was 50%. As noted in Table 1, response rates in prior ONS research priority surveys varied with the different study samples and methods. When the response rate is stratified by the two groups, 685 of 1,850 (37%) in the general member group and 103 of 150 (69%) in the researcher group responded.

Description of Survey Respondents

Respondents were compared with the ONS membership at the time the study was conducted to determine how representative the respondents were. To facilitate these comparisons, the study respondents are described by characteristics and categories used by ONS to collect information about its members. ONS data, obtained by member self-report, are updated annually at the time of membership renewal. Membership data were provided by ONS from the July 2000 membership statistics to compare study participants to the ONS membership.

Personal characteristics of the respondents are summarized in Table 2 and include gender, age, and ethnicity. Respondents were representative of the ONS membership in terms of personal characteristics.

Professional characteristics of the respondents, such as highest nursing degree, highest non-nursing degree, years in oncology nursing, primary functional area, practice setting, and employment status, are summarized in Table 3. Respondents were representative of the ONS membership in terms of practice setting and employment status.

Respondents' professional characteristics differed from the ONS membership in the areas of highest nursing degree, years in oncology nursing, and primary functional area. A smaller proportion of survey respondents were diploma-prepared, and a larger proportion of survey respondents had associate degrees or doctorates listed as their highest degree as compared to the ONS membership. A larger proportion of the ONS membership was master's prepared. A larger proportion of survey respondents, compared to ONS members, worked in oncology nursing for

Table 4. Top 20 Research Priorities Determined by Mean Importance Ratings for Total Sample, Adjusted for Researcher Group Sampling

| Topic | Rank Order Among All Topics | Mean Importance Rating ^a (SD) |
|-------------------------------------|-----------------------------|--|
| Pain | 1 | 1.28 (0.555) |
| Quality of life | 2 | 1.28 (0.542) |
| Early detection of cancer | 3 | 1.32 (0.595) |
| Prevention/risk reduction | 4 | 1.55 (0.700) |
| Neutropenia/immunosuppression | 5 | 1.60 (0.551) |
| Hospice/end of life | 6 | 1.62 (0.768) |
| Oncologic emergencies | 7 | 1.63 (0.782) |
| Suffering | 8 | 1.65 (0.771) |
| Fatigue | 9 | 1.66 (0.757) |
| Ethical issues | 10 | 1.67 (0.802) |
| Anorexia | 11 | 1.67 (0.719) |
| Access to cancer care | 12 | 1.69 (0.748) |
| Depression | 13 | 1.69 (0.685) |
| Stress-coping adaptation | 14 | 1.70 (0.668) |
| Nurse retention | 15 | 1.70 (0.891) |
| Hope | 16 | 1.70 (0.737) |
| Palliative care | 17 | 1.71 (0.728) |
| Decision making in advanced disease | 18 | 1.72 (0.786) |
| Family education | 19 | 1.75 (0.708) |
| Cancer recurrence | 20 | 1.78 (0.756) |

^a Scored 1 (extremely important) to 5 (not at all important). N = 788

1–3 years or 20+ years, whereas a smaller proportion worked 11–15 years. A larger proportion of survey respondents, compared to ONS members, identified research as their primary functional area, whereas a smaller proportion of survey respondents identified patient care. These differences are likely explained by the sampling plan that oversampled researchers.

Top 20 Research Priorities

Mean importance ratings were calculated for each topic and then were adjusted to remove the effects of oversampling the researcher group. The adjustment was accomplished by poststratification weighting of cases (i.e., using weights inversely proportional to the sampling probability for each group). Topics then were listed in rank order from most important to least important. Mean importance ratings were plotted in descending order to determine how many topics to display as top priorities. A break was observed at 20, so the decision was made to report the top 20 for the year 2000 survey (see Table 4) rather than the top 10 as had been reported in prior surveys. Mean importance ratings of the top 20 all reflected high importance ratings, ranging from 1.28–1.78 when responses were coded on a scale of 1 (extremely important) to 5 (not at all important). Many of the mean importance ratings were quite close even though the rank of the topic was different.

Rank Order of Mean Importance Ratings

The overall mean and importance ratings of all 113 topics are shown in Table 5, with each topic displayed in its respec-

tive category on the questionnaire. Topics are listed in rank order within each questionnaire category so that the mean importance rankings can be examined within and across the eight categories. Although some variability in the mean importance ratings of topics is observed in all questionnaire categories, none of the topics have a mean rating lower than 2.91 on the five-point scale.

In Table 5, a boldfaced topic entry indicates a top 20 rank. The top 20 research priorities are distributed across all but two of the eight questionnaire categories; cancer health behaviors and special cancer populations did not contain top 20 topics. In addition, the number within the categories differs. The cancer continuum of care category had six topics in the top 20: early detection of cancer, prevention/risk reduction, hospice/end of life, oncologic emergencies, palliative care, and cancer recurrence. The behavioral/psychosocial aspects of cancer category had five topics in the top 20: quality of life, suffering, depression, stress-coping adaptation, and hope. The cancer symptom management category had four topics in the top 20: pain, neutropenia/immunosuppression, fatigue, and anorexia. In the cancer care delivery systems category, only two topics, nurse retention and family education, were in the top 20. Likewise, the cancer decision-making category included only two topics in the top 20: ethical issues and decision making in advanced disease. One topic in the cancer health services research category, access to cancer care, was in the top 20.

Comparison of Research Priorities Between 1994 and 2000

Table 6 compares the rank order of the top 20 topics identified in the year 2000 survey to those of the 1994 survey (Stetz et al., 1995). Considerable change is evident. Nine topics were ranked among the top 20 in both surveys: pain, quality of life, early detection, prevention/risk reduction, neutropenia/immunosuppression, fatigue, ethical issues, access to cancer care, and stress-coping adaptation. Although these topics are among the top 20 in both surveys, their rank may have been different in each survey.

Eight topics not identified among the top 20 in the 1994 survey were evaluated as part of the top 20 in the Year 2000 Research Priorities Survey. They were hospice/end of life, oncologic emergencies, suffering, anorexia, depression, hope, palliative care, and cancer recurrence. In addition, two topics that were not part of the 1994 questionnaire appear in the year 2000 top 20: decision making in advanced disease and family education.

Eleven topics are not in the top 20 of the Year 2000 Research Priorities Survey that were ranked in the top 20 of the 1994 Research Priorities Survey (Stetz et al., 1995). They were patient education, cost containment, advanced practice nursing, long-term effects of treatment, care delivery models (case management), acuity/patient classification system, staffing ratios and mix, women, AIDS/HIV, nausea, and stomatitis/mucositis.

Comparison of Researcher Group and Adjusted Total Sample Ranking of Year 2000 Top 20 Research Priorities

Table 7 displays the top 20 research priority topics and their mean importance ratings in rank order for the researcher group beside those for the adjusted total sample, which also are displayed in rank order. The unweighted data, with its in-

Table 5. Rank Order of Mean Importance Ratings^a Listed Within Questionnaire Categories for Total Survey Sample, Adjusted for Researcher Group Oversampling

| Topic Listed in Rank Order Within Each Questionnaire Category | Rank Order Among All Topics | Mean Importance Rating Among All Topics (SD) | Number of Respondents to Item |
|---|-----------------------------|--|-------------------------------|
| Cancer symptom management | | | |
| 1. Pain | 1 | 1.28 (0.555) | 781 |
| 2. Neutropenia/immunosuppression | 5 | 1.60 (0.752) | 777 |
| 3. Fatigue | 9 | 1.66 (0.757) | 781 |
| 4. Anorexia | 11 | 1.67 (0.719) | 785 |
| 5. Nausea | 26 | 1.82 (0.771) | 780 |
| 6. Stomatitis/mucositis | 29 | 1.83 (0.724) | 778 |
| 7. Vomiting | 33 | 1.85 (0.809) | 778 |
| 8. Dyspnea/shortness of breath | 34 | 1.85 (0.828) | 777 |
| 9. Extravasation | 41 | 1.88 (0.962) | 771 |
| 10. Bleeding | 45 | 1.91 (0.928) | 781 |
| 11. Neurologic impairment | 47 | 1.95 (0.758) | 777 |
| 12. Impaired cardiac function | 49 | 1.95 (0.938) | 777 |
| 13. Appetite | 54 | 1.97 (0.804) | 780 |
| 14. Fluid and electrolyte imbalance | 60 | 2.01 (0.864) | 779 |
| 15. Cognitive impairment | 70 | 2.10 (0.839) | 781 |
| 16. Diarrhea | 76 | 2.14 (0.797) | 778 |
| 17. Fever | 80 | 2.18 (0.883) | 780 |
| 18. Weight changes | 83 | 2.23 (0.823) | 767 |
| 19. Wounds | 84 | 2.26 (0.889) | 768 |
| 20. Insomnia/sleep difficulties | 94 | 2.34 (0.830) | 776 |
| 21. Altered mobility | 98 | 2.37 (0.865) | 783 |
| 22. Constipation | 101 | 2.41 (0.854) | 785 |
| 23. Sexual dysfunction | 102 | 2.42 (0.780) | 779 |
| 24. Cutaneous reactions | 107 | 2.72 (0.842) | 776 |
| 25. Hot flashes/sweats | 108 | 2.73 (0.830) | 780 |
| 26. Dry mouth | 109 | 2.78 (0.798) | 778 |
| 27. Skin changes | 110 | 2.81 (0.771) | 775 |
| 28. Alopecia | 111 | 2.82 (0.918) | 783 |
| 29. Urticaria | 112 | 2.84 (0.839) | 773 |
| 30. Cough | 113 | 2.91 (0.842) | 781 |
| Behavioral/psychosocial aspects of cancer | | | |
| 1. Quality of life | 2 | 1.28 (0.542) | 785 |
| 2. Suffering | 8 | 1.65 (0.771) | 774 |
| 3. Depression | 13 | 1.69 (0.685) | 783 |
| 4. Stress-coping adaptation | 14 | 1.70 (0.668) | 777 |
| 5. Hope | 16 | 1.70 (0.737) | 782 |
| 6. Family communications/relationships | 21 | 1.78 (0.714) | 781 |
| 7. Grief | 22 | 1.79 (0.736) | 780 |
| 8. Caregiver burden | 23 | 1.80 (0.742) | 780 |
| 9. Social support | 31 | 1.84 (0.760) | 785 |
| 10. Spiritual well-being | 39 | 1.86 (0.748) | 778 |
| 11. Anxiety | 42 | 1.88 (0.753) | 783 |
| 12. Counseling | 64 | 2.08 (0.783) | 784 |
| 13. Body image/sexuality | 75 | 2.13 (0.733) | 783 |
| Cancer care delivery systems | | | |
| 1. Nurse retention | 15 | 1.70 (0.891) | 780 |
| 2. Family education | 19 | 1.75 (0.708) | 777 |
| 3. Continuing education/professional development | 27 | 1.82 (0.839) | 777 |
| 4. Standards of care | 28 | 1.82 (0.841) | 779 |
| 5. Family caregiving | 36 | 1.86 (0.731) | 775 |
| 6. Occupational hazards | 38 | 1.86 (0.954) | 778 |
| 7. Nurse recruitment | 52 | 1.96 (0.948) | 778 |
| 8. Continuous quality improvement | 56 | 2.00 (0.892) | 771 |
| 9. Information systems in patient care | 82 | 2.22 (0.871) | 774 |
| 10. Advanced practice nursing | 87 | 2.30 (0.922) | 775 |
| 11. Acuity/patient classification system | 92 | 2.33 (1.029) | 773 |

(Continued on next page)

^aRated 1 (extremely important) to 5 (not at all important).

Note. Boldfaced topics indicate top 20 ranking.

n = 767–785

Table 5. Rank Order of Mean Importance Ratings^a Listed Within Questionnaire Categories for Total Survey Sample, Adjusted for Researcher Group Oversampling (Continued)

| Topic Listed in Rank Order Within Each Questionnaire Category | Rank Order Among All Topics | Mean Importance Rating Among All Topics (SD) | Number of Respondents to Item |
|---|-----------------------------|--|-------------------------------|
| 12. Sites of care delivery | 93 | 2.33 (0.930) | 777 |
| 13. Case management/care management | 95 | 2.34 (0.870) | 774 |
| 14. Leadership | 104 | 2.46 (0.933) | 776 |
| Cancer health services research | | | |
| 1. Access to cancer care | 12 | 1.69 (0.748) | 781 |
| 2. Disease management | 40 | 1.86 (0.760) | 781 |
| 3. Outcomes of cancer care | 51 | 1.96 (0.792) | 780 |
| 4. Effects on healthcare system restructuring | 65 | 2.08 (0.929) | 775 |
| 5. Care delivery systems | 71 | 2.11 (0.825) | 781 |
| 6. Evidence-based practice | 78 | 2.15 (0.869) | 774 |
| 7. Health policy | 96 | 2.35 (0.883) | 777 |
| Cancer continuum of care | | | |
| 1. Early detection of cancer | 3 | 1.32 (0.595) | 779 |
| 2. Prevention/risk reduction | 4 | 1.55 (0.700) | 777 |
| 3. Hospice/end of life | 6 | 1.61 (0.768) | 779 |
| 4. Oncologic emergencies | 7 | 1.63 (0.782) | 779 |
| 5. Palliative care | 17 | 1.71 (0.728) | 778 |
| 6. Cancer recurrence | 20 | 1.78 (0.756) | 778 |
| 7. Long-term effects of treatment | 24 | 1.80 (0.721) | 778 |
| 8. Screening | 32 | 1.85 (0.802) | 771 |
| 9. Active cancer treatment | 37 | 1.86 (0.774) | 777 |
| 10. Cancer as a chronic disease | 48 | 1.95 (0.807) | 777 |
| 11. Participation in clinical trials | 55 | 1.97 (0.806) | 776 |
| 12. Home care | 62 | 2.05 (0.799) | 777 |
| 13. Bereavement | 68 | 2.09 (0.832) | 777 |
| 14. Ambulatory care | 69 | 2.09 (0.817) | 778 |
| 15. Rehabilitation | 77 | 2.14 (0.775) | 772 |
| 16. Genetic counseling/testing | 79 | 2.17 (0.890) | 779 |
| 17. Impact of technology | 97 | 2.35 (0.872) | 774 |
| Cancer health behaviors | | | |
| 1. Public education | 25 | 1.81 (0.763) | 779 |
| 2. Diet and nutrition | 35 | 1.86 (0.754) | 781 |
| 3. Stress management | 50 | 1.95 (0.805) | 781 |
| 4. Exercise/physical activity | 61 | 2.04 (0.769) | 780 |
| 5. Sleep/rest | 67 | 2.09 (0.815) | 777 |
| 6. Substance abuse | 106 | 2.63 (1.000) | 780 |
| Special cancer populations | | | |
| 1. Children and adolescents | 46 | 1.94 (0.832) | 777 |
| 2. Children of parents with cancer | 59 | 2.01 (0.833) | 780 |
| 3. Cancer survivors | 66 | 2.08 (0.781) | 777 |
| 4. Women | 72 | 2.11 (0.845) | 770 |
| 5. Families | 73 | 2.12 (0.803) | 772 |
| 6. Socioeconomically disadvantaged | 74 | 2.13 (0.857) | 773 |
| 7. Elderly | 81 | 2.20 (0.802) | 771 |
| 8. Men | 85 | 2.28 (0.800) | 771 |
| 9. Minority | 86 | 2.28 (0.876) | 770 |
| 10. Multicultural | 88 | 2.30 (0.892) | 775 |
| 11. Illiterate | 89 | 2.31 (0.864) | 772 |
| 12. Rural/frontier | 90 | 2.32 (0.872) | 771 |
| 13. AIDS/HIV | 91 | 2.32 (0.912) | 775 |
| 14. Disabled | 99 | 2.39 (0.795) | 769 |
| 15. Mentally ill | 100 | 2.40 (0.869) | 773 |
| 16. Immigrant | 103 | 2.44 (0.890) | 770 |
| 17. Migrant | 105 | 2.50 (0.899) | 770 |
| Cancer decision making | | | |
| 1. Ethical issues | 10 | 1.67 (0.802) | 780 |

(Continued on next page)

^aRated 1 (extremely important) to 5 (not at all important).

Note. Boldfaced topics indicate top 20 ranking.

n = 767-785

Table 5. Rank Order of Mean Importance Ratings^a Listed Within Questionnaire Categories for Total Survey Sample, Adjusted for Researcher Group Oversampling (Continued)

| Topic Listed in Rank Order Within Each Questionnaire Category | Rank Order Among All Topics | Mean Importance Rating Among All Topics (SD) | Number of Respondents to Item |
|---|-----------------------------|--|-------------------------------|
| 2. Decision making in advanced disease | 18 | 1.72 (0.786) | 780 |
| 3. Advance directives | 30 | 1.83 (0.878) | 779 |
| 4. Treatment decisions | 43 | 1.89 (0.795) | 779 |
| 5. Informed consent | 44 | 1.90 (0.883) | 780 |
| 6. Nursing role in decision support | 53 | 1.97 (0.851) | 781 |
| 7. Family role in decision making | 57 | 2.00 (0.849) | 780 |
| 8. Compliance/adherence | 58 | 2.01 (0.817) | 780 |
| 9. Complementary/alternative therapies | 63 | 2.07 (0.902) | 783 |

^aRated 1 (extremely important) to 5 (not at all important).

Note. Boldfaced topics indicate top 20 ranking.

n = 767-785

tentional oversample of researchers, would be most directly comparable to the sample design used in the 1994 survey (Stetz et al., 1995). Stetz et al. included a researcher oversample but did not use postweighting to adjust the published results as the current survey's researchers did. However, the differences in the top 20 categories between the year 2000 weighted and unweighted results are small. The results are displayed in weighted form in Table 7 to keep the listed means consistent with those shown in the other tables.^a

Nine topics were rated in the top 20 by both groups: pain, quality of life, early detection, prevention/risk reduction, hospice/end of life, fatigue, access to cancer care, depression, and palliative care. Four topics were from the cancer continuum of care category, two each were from the cancer symptom management category and behavioral/psychosocial aspects of care category, and one was from the cancer health services research category.

Ten topics rated among the top 20 by the researcher group were not included in the top 20 of the adjusted total sample. They were evidence-based practice, outcomes of cancer care, caregiver burden, family caregiving, family communications/relationships, cognitive impairment, socioeconomically disadvantaged, advanced practice nursing, long-term effects of treatment, and health policy. Three of these topics were from the cancer health services research category, two were from the cancer care delivery systems category, and one each was from the cancer symptom management, behavioral/psychosocial aspects of cancer, special cancer populations, cancer continuum of care, cancer health behaviors, and special cancer populations categories.

Discussion

Trends and Clinical Practice

Comparisons to previous studies are limited by differences in sampling technique and size, response rates, demographics, and survey methodology, including questionnaires. Sampling approaches varied by type (e.g., convenience, random, combination) and the number and types of participants (e.g., researchers, ONS leaders, sample of all members, combination). Although the current sample included a larger number of researchers than in the past, the results were adjusted to remove

the impact of this oversampling, and rankings of the researcher group responses were considered separately.

Topics that remained among the top 20 from 1994 to 2000 are pain, quality of life, early detection, prevention/risk reduction, neutropenia/immunosuppression, fatigue, ethical issues, access to cancer care, and stress-coping adaptation. Because the top research topics are similar to previous surveys, it can be inferred that oncology nursing practice continues to focus on managing the effects of cancer and its treatment and promoting quality of life for patients and families. Although these are broad topics, the fact that they continue to be ranked highly indicates oncology nurses' appreciation for further research in these areas.

Changes in treatments and technology may have caused or at least played a role in the dramatic change in specific priorities. For example, AIDS was ranked 10 in 1991 and 18 in 1994, but fell to 91 in 2000. Because new treatments have decreased mortality and enhanced symptom control, less focus on HIV has resulted. The possibility also exists that this patient population may not be cared for by oncology nurses. Interest in ethical issues has increased dramatically, moving to the top 10 in 1994 and 2000 from 46 in 1988. Decision making, now rated in the top 20, was not even listed as a topic in previous surveys. The increased availability of complex and aggressive treatment modalities, improved survival, and an emphasis on maintaining quality of life throughout the cancer experience have resulted in the identified need for research in solving new ethical problems and assisting patients and families in complex decision making. Progress in medical technology may account for the rise in the ranking of oncologic emergencies that is now 7th, whereas it was not even in the top 20 in previous surveys.

Other noteworthy shifts in rank relate to clinical practice. Hospice/end of life increased in rank from 23 in 1988 to 6 in 2000. This is congruent with the recent national focus on end of life and the palliative care movement designed to improve care at this stage and is indicative of oncology nurses' emphasis on quality of life, which includes the end of life. Another change relates to economic influences and cost containment that had been ranked in the top 10 in 1988, 1991, and 1994, but dropped to 51 in 2000. This sizable decrease in priority on the topic of cost is not currently understood.

Advanced practice nursing as a topic was introduced and ranked 11 in the 1994 survey. Surprisingly, in the 2000 study,

^a Results for unweighted data are available from the authors.

Table 6. Comparison of Top 20 Research Priorities Between 1994 Survey and Year 2000 Adjusted Total Sample

| Topic Listed in Rank Order for Year 2000 Survey | 1994 Survey Rank Order by Priority Index (Weighted Sum) ^a |
|---|--|
| 1. Pain | 1 |
| 2. Quality of life | 3 |
| 3. Early detection | 9 detection |
| 4. Prevention/risk reduction | 2 prevention, 4 risk reduction/screening |
| 5. Neutropenia/immunosuppression | 6 |
| 6. Hospice/end of life | (27 hospice/terminal care) |
| 7. Oncologic emergencies | (31) |
| 8. Suffering | (28) |
| 9. Fatigue | 12 |
| 10. Ethical issues | 5 |
| 11. Anorexia | (59) |
| 12. Access to cancer care | 20 barriers to access |
| 13. Depression | (33) |
| 14. Stress-coping adaptation | 8 |
| 15. Nurse retention | (54 retention) |
| 16. Hope | (37) |
| 17. Palliative care | (36) |
| 18. Decision making in advanced disease | - |
| 19. Family education | - |
| 20. Cancer recurrence | (34 disease recurrence) |

^aResearch priorities in 1994 survey were displayed in two ways: (a) a priority index based on the summed priority rank scores for each item and (b) the number of first priority votes each item received (Stetz et al., 1995).

it was ranked 87 by the adjusted total sample, but was ranked 17 by the researcher group. This decrease in priority ranking by clinicians may represent intense concerns regarding advanced practice roles, titling, positions, and education among practitioners and the emphasis placed by ONS on needing to meet these concerns during the early 1990s. Whether the decrease indicates that many of these issues are resolved or they are merely artifacts related to the large proportion of survey respondents with diplomas or associate or bachelor's degrees is unclear. Learning what aspect of advanced practice nursing the researcher group believes should be studied would be of particular interest.

Topics now listed in the top 20 that were not rated as high in the 1994 survey are of interest. These include suffering (rated 8 in 2000 versus 28 in 1994), depression (rated 13 in 2000 versus 33 in 1994), and hope (rated 16 in 2000 versus 37 in 1994). These topics reflect the realities of the cancer experience and may reflect oncology nurses' desire to minimize the psychosocial ramifications of cancer and its treatment while also decreasing the impact of physical symptoms.

The year 2000 survey has given ONS clinicians a voice and opportunity to reflect and articulate what they see as significant clinical issues for patients and families. The results of this survey represent the research needs perceived by ONS members and update the research values of practitioners. The results may be a reflection of the prevalence of problems that individual nurses see in their professional practice. Nurses'

personal and professional experiences could affect how responding nurses rated the research priorities, whereas those with a broad professional exposure may have more global insight to clinical research issues.

Education Perspective

Implications of the survey results for nursing education need to be approached with caution because the survey specifically asks for research priorities and not educational needs. Whether the highest ranked topics are areas in which knowledge is lacking or nurses are so well educated on the topics that they are able to identify the research gaps is difficult to determine. Considering the topics listed in each of the eight categories may be useful when planning educational programs. Identifying the educational needs of oncology and advanced practice nurses alternatively has been obtained by surveying practicing nurses about issues or knowledge gaps in their nursing educational program and desired areas for continuing education.

These findings have been incorporated into the ONS blueprint of educational priorities. Based on a variety of sources including current nursing trends, evolving medical technology, and identified member needs, the blueprint is evaluated yearly and then used as the basis for educational projects within ONS. An important perspective of the blueprint is to include levels of evidence in all education programs (Ropka & Spencer-Cisek, 2001). This will enable nurses to respond more knowledgeably to future research priorities by heightening awareness of the type and level of evidence that supports various clinical interventions.

Management and Administrative Perspective

Several items that may be of particular interest to managers and administrators have decreased in importance in 2000 when compared to prior surveys: cost containment, advanced practice nursing, care delivery systems, acuity/patient classification, and staffing ratios and mix. Interestingly, some of these items seem to represent changes that have occurred in the global healthcare environment. For example, healthcare and nursing administrators are increasingly adept in the application of financial analyses. Utilization of patient acuity and classification systems has assumed less emphasis.

Today, the combination of a competitive employment market, payor limits on length of stay, and more complex, aggressive therapies present administrators with additional challenges in effectively managing care and treatment outcomes. Administrators have responded to this predicament with an intensified emphasis on evidence-based practice and the measurement of outcomes of nursing care, which is mirrored in the survey results in these topic areas. Standards of care (ranked 28), outcomes of cancer care (ranked 51), and evidence-based practice (ranked 78) reflect increasing importance of these topics to managers and administrators of cancer care services.

External bodies, such as the Joint Commission on the Accreditation of Healthcare Organizations (JCAHO), have pointed to specific clinical problems, such as pain management (ranked 1), as a priority for clinicians and institution leaders (JCAHO, 2001). Managers and administrators must demonstrate the establishment of formal pain management programs, as well as the outcomes of these programs. Research

Table 7. Top 20 Research Priorities: Total Sample and Researcher Group

| Year 2000 Total Sample, Adjusted for Researcher Group Sampling | | |
|--|-------------------|--|
| Topic | Rank ^a | Mean Importance Rating ^b (SD) |
| Pain ^c | 1 | 1.28 (0.555) |
| Quality of life ^c | 2 | 1.28 (0.542) |
| Early detection of cancer ^c | 3 | 1.32 (0.595) |
| Prevention/risk reduction ^c | 4 | 1.55 (0.700) |
| Neutropenia/immunosuppression | 5 | 1.60 (0.551) |
| Hospice/end of life ^c | 6 | 1.62 (0.768) |
| Oncologic emergencies | 7 | 1.63 (0.782) |
| Suffering | 8 | 1.65 (0.771) |
| Fatigue ^c | 9 | 1.66 (0.757) |
| Ethical issues | 10 | 1.67 (0.802) |
| Anorexia | 11 | 1.67 (0.719) |
| Access to cancer care ^c | 12 | 1.69 (0.748) |
| Depression ^c | 13 | 1.69 (0.685) |
| Stress-coping adaptation | 14 | 1.70 (0.668) |
| Nurse retention | 15 | 1.70 (0.891) |
| Hope | 16 | 1.70 (0.737) |
| Palliative care ^c | 17 | 1.71 (0.728) |
| Decision making in advanced disease | 18 | 1.72 (0.786) |
| Family education | 19 | 1.75 (0.708) |
| Cancer recurrence | 20 | 1.78 (0.756) |

| Year 2000 Researcher Group | | |
|--|------|--|
| Topic | Rank | Mean Importance Rating ^b (SD) |
| Evidence-based practice | 1 | 1.40 (0.616) |
| Pain ^c | 2 | 1.41 (0.678) |
| Quality of life ^c | 3 | 1.44 (0.589) |
| Outcomes of cancer care | 4 | 1.45 (0.638) |
| Caregiver burden | 5 | 1.58 (0.679) |
| Family caregiving | 6 | 1.59 (0.648) |
| Fatigue ^c | 7 | 1.60 (0.691) |
| Access to cancer care ^c | 8 | 1.61 (0.675) |
| Family communications/relationships | 9 | 1.63 (0.703) |
| Early detection of cancer ^c | 10 | 1.71 (0.715) |
| Cognitive impairment | 11 | 1.73 (0.703) |
| Family education ^c | 12 | 1.78 (0.766) |
| Prevention/risk reduction ^c | 13 | 1.80 (0.813) |
| Socioeconomically disadvantaged | 14 | 1.81 (0.852) |
| Depression ^c | 15 | 1.82 (0.697) |
| Palliative care ^c | 16 | 1.82 (0.780) |
| Advanced practice nursing | 17 | 1.84 (0.777) |
| Hospice/end of life ^c | 18 | 1.85 (0.792) |
| Long-term effects of treatment | 19 | 1.85 (0.740) |
| Health policy | 20 | 1.87 (0.825) |

^aRank order reflects rank of topic in total sample after adjustment for researcher group oversampling.

^bRated 1 (extremely important) to 5 (not at all important).

^cIndicates that this topic was among the top 20 in both groups.

N = 788

in this topic can identify the qualities and components of successful pain management programs.

The year 2000 research priorities identified through the survey will provide managers and administrators with an opportunity to support the conduct of research in priority areas. These data also will provide a framework for administrators and managers to use in exploring the issues of concern and importance for clinical caregivers.

Future Research Perspective

Researchers should investigate phenomena of immediate concern to clinicians (e.g., symptom management), as well as areas of emerging interest (e.g., prevention, early detection, evidence-based practice, caregiver burden). In the quest for creating new knowledge and armed with information about the changing demographics of the patient population, researchers have an obligation to investigate these areas to ensure that future nurses involved in cancer care are prepared to address individual and family needs.

Some topics that represent future trends in cancer care and research were rated low on the priority scale by the entire sample. Some of these items include genetic counseling/testing (rank 79 of 113), elderly populations (rank 81), and multicultural populations (rank 88). These items and others ranked low or not included on the list (e.g., smoking cessation) should be addressed by oncology nursing researchers. The fact that they were not rated highly on the 2000 priority survey should not exclude them from consideration for study and funding. ONS, the ONS Foundation, and other funders need to develop a mechanism to include topics that represent future trends even though they may not be rated high using survey methods.

Although the prevalence of problems that clinicians encounter in practice may influence the importance ranking of these items, clinicians perceived them as just that—problems that have not been addressed adequately. Research utilization and incorporation of results into practice are essential steps in validating the findings of studies related to pain, suffering, fatigue, and the like. Knowledge may be derived from research, but the application of knowledge influences the effects and impact of the research. Future surveys might include the opportunity for respondents to comment on the degree to which research has been applied successfully to clinical problems.

Researchers tended to rate items such as evidence-based practice, outcomes of cancer care, family issues, and health policy as more important than clinicians rated them; however, researchers and clinicians did prioritize many areas similarly, including pain, quality of life, early detection, prevention and risk reduction, and fatigue. Working together, practice can influence research priorities and research can influence practice outcomes.

Using the 2000 ONS Priorities Survey Results

In the past, the ONS Research Priorities Survey has been used by both ONS members and the ONS Foundation in the development of proposals to a wide variety of funding sources. When researchers are able to cite the focus of their proposed research as one included in the top ONS research priorities, additional support toward funding of the proposal is engendered. In 2000, the ONS Steering Council, ONS Board, and ONS Foundation Board approved a business plan


to use the 2000 ONS Research Priorities in conjunction with other information from ONS expert panels and sources to develop an ONS Research Agenda. The ONS Research Agenda will represent ONS's best concepts regarding the research that needs to be conducted, some of the mechanisms needed to achieve the answers, and the resources that are needed. The survey results reported here provide an important foundation for this document. The ONS Research Agenda will be a dynamic document that will represent not only the content of the research that needs to be conducted, but articulate what type of research may be appropriate for what type of content, at what level the research is appropriate, how to approach the search for the answers to questions

in a step-by-step program of research over time, and estimates of monetary and personnel resources needed to achieve these goals. The ONS Research Agenda will provide an objective, balanced way of deciding on funding priorities and will build on the 2000 ONS research priorities survey findings.

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