# Measuring Oncology Nurses' Psychosocial Care Practices and Needs: Results of an Oncology Nursing Society Psychosocial Survey

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n estimated 30%–43% of patients with cancer experience psychological distress at some point along the care continuum (Zabora, BrintzenhofeSzoc, Curbow, Hooker, & Piantadosi, 2001). Psychological distress is comprised of physical, emotional, and psychological responses to the diagnosis and treatment of cancer. Additional factors that can contribute to distress include access to care, treatment and resources, ability to work, and being under- or uninsured, as well as the hidden costs associated with care and treatment. Healthcare providers have recognized the significance of distress and the need for change to more adequately address this aspect of cancer diagnosis and treatment (Fulcher & Gosselin-Acomb, 2007; Hawkes, Hughes, Hutchison, & Chambers, 2010; Holland & Alici, 2010; Jacobsen, 2009; Jacobsen & Ransom, 2007). As more people are diagnosed with cancer and become survivors, broader changes are needed for patients, their families, healthcare providers, and the communities in which care is delivered.

The Institute of Medicine ([IOM], 2008) released the report *Cancer Care for the Whole Patient: Meeting Psychosocial Health Needs*, which was developed at the request of the National Institutes of Health and outlined unmet psychosocial needs of patients with cancer and their families, the policy and workforce issues, and how psychosocial care should be delivered within the context of the healthcare system. The report comprised 10 broad recommendations (see Figure 1) that are considered key components of quality cancer care. IOM defined psychosocial health services as,

Psychological and social services and interventions that enable patients, their families, and health care providers to optimize biomedical health care and to manage the psychological/behavioral and social aspects of illness and its consequences so as to promote better health (IOM, 2008, p. 9).

An accompanying standard of care (see Figure 2) was developed to help guide a systematic, quality-driven

**Purpose/Objectives:** To develop and implement a survey of Oncology Nursing Society (ONS) members focused on their current practices and needs in relation to providing psychosocial care.

**Design:** Descriptive, cross-sectional.

Setting: Web-based survey of ONS members.

**Sample:** An invitation was e-mailed to 11,171 ONS members. Of those, 623 followed the link to the electronic survey and 64% of those (n = 401) completed the survey.

**Methods:** An ONS Psychosocial Project Team was convened in 2009. One of the team's goals was to develop a survey to assess members' needs. The final survey consisted of 24 items, including five items related to demographic characteristics. Response formats included Likert-type scale, yes and no, and open-ended questions.

**Main Research Variables:** Psychosocial care practices, education, and research.

**Findings:** Psychosocial concerns are assessed using a variety of methods. Nurse perceptions regarding primary responsibility for providing psychosocial services differ by group. Barriers to the provision of psychosocial care exist at the individual, institutional, and community levels.

**Conclusions:** Although nurses assess patients' psychosocial needs, multiple barriers still exist related to interdisciplinary communication; knowledge of the Institute of Medicine's recommendations; and resources at the individual, institutional, and community levels.

Implications for Nursing: The survey results were presented to the ONS Board of Directors, along with a three-year plan that included recommendations for future development of advocacy, practice, education, and research initiatives. Additional work is needed to effectively support RNs in their provision of psychosocial care to patients and families.

care approach that healthcare providers could begin to incorporate into their practice.

The Oncology Nursing Society (ONS), as a key stakeholder in the realm of nursing practice and a professional organization representing more than 35,000 RNs and other healthcare providers, has long been an advocate of psychosocial care. Publications and a variety of

- Develop a standard of care that provides patients with cancer with psychosocial health services.
- 2. Ensure that all patients with cancer receive psychosocial health care.
- Educate patients with cancer and their caregivers about psychosocial care and encourage its use.
- 4. Procure support from the National Cancer Institute (NCI), Centers for Medicare and Medicaid Services CMS), and the Agency for Healthcare Research and Quality (AHRQ) for the demonstration and evaluation of effective psychosocial care delivery.
- Procure support from group purchasers of healthcare coverage and health plans for evidence-based interventions.
- Establish quality oversight from NCI, CMS, and AHRQ to develop performance metrics.
- Develop workforce competencies to support practice that integrates psychosocial care and services.
- Create a standardized nomenclature to assist research and quality measurement.
- Prioritize research amongst sponsors by focusing on further development of assessment and screening instruments and determining effective interventions.
- Promote use of psychosocial services and monitor progress (NCI and the National Institutes of Health).

## Figure 1. Institute of Medicine Recommendations for Action Regarding Psychosocial Care

Note. Based on information from the Institute of Medicine, 2008.

educational media have been developed, funded, and used by ONS to assist members in supporting the organization's adopted position statement (ONS, 2011). The

ONS Foundation has prioritized psychosocial research in the ONS Research Agenda since 2001 and has funded several nurse-led psychosocial studies. The development of a psychosocial project team to further identify members' needs was another important step in achieving ONS's mission related to high-quality cancer care and promoting excellence in nursing practice.

#### Methods

# ONS Psychosocial Project Team

In 2008, the ONS Steering Council provided preliminary recommendations to the ONS Board of Directors based on the IOM report, recommending that an ONS Psychosocial Project Team be brought together to address three specific goals: (a) complete a survey of current practice and needs of

ONS members in relation to psychosocial care, (b) review and make recommendations for changes to the ONS position statement *Psychosocial Services for Patients with Cancer*, and (c) develop a three-year plan for addressing the psychosocial needs and issues of ONS members.

The project team, consisting of nine ONS members from across the United States who demonstrated interest and expertise in the area of psychosocial care and who were diverse in relation to role, position, educational background, and years of experience, was convened.

To meet their goals, the group conducted eight conference calls as well as focused subgroup discussions to facilitate the development, design, and implementation of the survey. E-mail was used to share documents, facilitate editorial changes, complete group multivoting, and gather feedback on working documents. Team members were provided the 10 recommendations from the IOM report, an IOM report brief, and information related to the psychosocial and family research priorities set forth by the 2008 ONS Research Priorities Survey Team.

## **Survey Development Process**

Team members developed a descriptive, cross-sectional survey. They worked in small groups to develop survey items based on the IOM recommendations. Work was accomplished via e-mail with a designated leader who then sent the final set of questions to the ONS project team

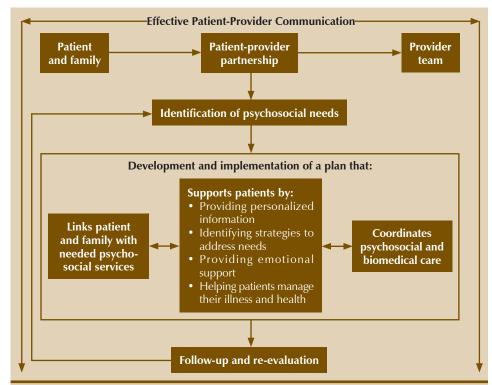


Figure 2. Institute of Medicine Model for the Delivery of Psychosocial Health Services

Note. From Cancer Care for the Whole Patient: Meeting Psychosocial Health Needs (p. 158), by Institute of Medicine, 2008, Washington, DC: National Academies Press. Copyright 2008 by National Academies Press. Reprinted with permission.

leader. Drafts of the survey were shared amongst the team. The final survey consisted of 24 items to elicit member responses regarding numerous aspects of psychosocial care, using findings and recommendations from the IOM report as an organizing framework. Demographic characteristics of respondents also were collected (9 items). Responses were coded using a Likert-type scale, in addition to yes-or-no questions and questions that allowed the respondent to provide a narrative response. The survey instrument was formatted and administered using the Zarca® electronic system. The electronic survey was piloted among project team members and an additional sample of 24 ONS members who previously had indicated interest in the topic and willingness to participate in the survey pilot testing. Feedback from the pilot was discussed amongst the team and incorporated into the final design. Based on user feedback, participants completed the survey in 15-60 minutes.

## **Sample**

The survey was launched on June 23, 2009, to a stratified random sample of 2,400 ONS members via an e-mail invitation to participate in the survey. The sampling strategy had the following groupings: advanced practice nurses (APNs) (clinical nurse specialists, n=580; nurse practitioners, n=600) and general membership (inpatient, n=610; outpatient, n=610). That strategy was employed because the team felt that the perspectives and experiences of APNs would be different from those of other groups of practicing nurses because of role and scope-of-practice differences. The initial sampling strategy was based on the tailored design method outlined by Dillman (2000) for less than or equal to a 10% sampling error, assuming a 10% response rate.

The invitation described the study purpose and potential uses of findings, and informed recipients that no information would be obtained by which any individual could be identified in any publication. The survey was to remain open for one week, but because of a low response rate, the survey was reopened for an additional six weeks, and an e-mail reminder was sent to members. Seventy-six individuals responded to the initial survey invitation and reminder. The project team determined that barriers to completion might have included the length and complexity of the survey; time to complete the survey based on e-mail address used (i.e., work versus home); and the short, one-week timeframe over a holiday weekend. Because of the small response, the survey was reduced from 34 items to 24 items and distributed in the shorter form on August 31, 2009, to an additional 9,000 randomly selected ONS members who met the criteria of working full or part time and having an e-mail address on file. Three hundred twenty-eight additional responses were obtained from the second sample.

**Table 1. Demographic Characteristics of Survey Sample Compared to ONS Membership** 

		ndents 401)	General ONS Members (N = 27,561)			
Characteristic	n	%	n	%		
Age (years)						
Younger than 40	47	14	7,139	26		
40–49	112	28	8,048	29		
50-59	189	48	9,398	34		
60 or older	46	12	2,425	9		
No response	7	2	551	2		
Highest nursing degree						
Diploma	29	7	2,949	11		
Associate	73	18	7,442	27		
Bachelor's	155	39	11,567	42		
Master's	122	31	4,907	18		
Doctorate (e.g., PhD, DNP, DNSc)	19	5	442	2		
No response	3	< 1	254	< 1		
Primary work setting						
Outpatient	222	55	15,047	55		
Inpatient	101	25	10,198	37		
Other	78	20	2,122	8		
Primary functional area						
Patient care	288	72	20,670	75		
Administration	34	9	2,149	8		
Education	34	9	1,653	6		
Research	27	7	1,654	6		
Other	18	5	1,378	5		

**ONS—Oncology Nursing Society** 

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

Note. ONS membership data collected in 2009.

The final common set of survey items included 24 questions. Five questions addressed the demographics and work settings of respondents. Three open-ended questions elicited additional information regarding the topic area. The other 16 questions were related to the psychosocial areas of practice, education, or research and included the following: nurse's awareness of selected psychosocial patient needs or issues (1 item), methods used to assess psychosocial needs (1 item), frequency of provision of psychosocial care provided in the five phases of the cancer care continuum (1 item), tools used in practice to help patients and families in obtaining information and problem solving (1 item), frequency of provision of specific aspects of psychosocial care (1 item), confidence in performing assessments and interventions (2 items), frequency of encountering selected problems in provision of psychosocial care (1 item), availability of selected services and resources (2 items), primary responsibility for provision of psychosocial care (1 item), familiarity with and application of the IOM report in one's practice setting (2 items), activities to enhance care provision (1 item), important areas for research and development (1 item), and workplace quality improvement or research activities

Table 2. Instruments and Approaches Used to Identify and Assess Patients' Psychosocial Needs

Instrument or Approach	n	%
Interview and discussion	335	84
Activities of Daily Living scale	111	28
Numeric, Likert-type, or visual analog scale to rate a specific problem	89	22
No specific measurement or assessment done	88	22
Symptom assessment scale (e.g., Edmonton, Memorial)	48	12
Depression scale (e.g., Beck, CES-D, Geriatric Depression Scale)	46	12
NCCN Distress Thermometer	37	9
Anxiety scale (e.g., HADS)	26	7
Social support scale	18	5
Caregiver Strain Index	10	3
Acculturation scale	8	2
Other	38	10

N = 401

CES-D—Center for Epidemiologic Studies—Depression Scale; HADS—Hospital Anxiety and Depression Scale; NCCN—National Comprehensive Cancer Network

*Note*. Participants could select more than one instrument or approach.

(1 item). Demographic and practice question results will be reported in the current article, and other findings in a future manuscript.

#### **Data Collection and Analysis**

The MagnetMail® system was used to track e-mail delivery, open rate, and the number of recipients who followed the survey link. After all responses were collected from both survey versions, the Zarca® system was used to export the data into two Excel® datasets, which were then imported for analysis into Predicted Analytics Software®, version 18.0, and merged into a single file. Recoding was conducted to remove duplicate responses and standardize response scales across survey versions. Standard descriptive statistics were used to identify frequencies of responses. For subgroup analysis, proportions were compared using Pearson's chi-square tests. Demographic characteristics of the respondents were compared to the ONS general membership at the time of the final survey. To assess whether respondents were substantially different from the general ONS membership, 95% confidence intervals were calculated, and proportions were observed for confidence interval overlap. All statistical tests performed were two-tailed, using an alpha of 0.05.

#### Results

#### Sample

The e-mail invitation to participate in the survey was successfully delivered to 11,171 members. Of those, 2,442 opened the e-mail (22%). Of those, 623 followed the link

to the electronic survey (26%), and 401 of these completed the survey (64% cooperation rate). The overall global response rate was 4%. Seventy-four percent of respondents had a bachelor's degree or higher as their basic nursing education (see Table 1). The majority worked in patient care in the outpatient setting, reflecting the overall ONS membership. Almost 60% were 50 years of age or older. Compared to the general ONS membership, the study sample had a higher proportion of individuals educated at the graduate level and older than 50 years.

#### **Methods Used in Psychosocial Assessment**

The most frequent approach reported for identifying and assessing patients' psychosocial needs was interview and discussion (84%) (see Table 2). Some reported use of the Activities of Daily Living scale (28%), and less than one-forth used numeric, Likert-type, or visual analog scales to rate specific problems (22%). Use of a valid and reliable depression scale was reported by 12% of participants, and other selected instruments, including the Distress Thermometer (Holland et al., 2010; National Comprehensive Cancer Network, 2011) were reported by less than 10%.

## **Tools Used to Support Patients and Families**

Booklets or pamphlets (90%), written guides for talking with providers (78%), individual counseling (75%), and use of support staff to help guide patients (74%) were the most frequent methods reported by respondents to help patients and families in making decisions, solving problems, and communicating effectively with providers (see Table 3).

#### **Availability of Psychosocial Care**

Availability of psychosocial services, resources, and providers varied considerably (see Table 4). General services that commonly were reported as somewhat or very available were education in how to find and

Table 3. Tools and Methods Used in Oncology Nurses' Practices to Help Patients and Families

Tool or Method	n	%
Booklets and pamphlets	360	90
Written guides for talking with providers	312	78
Individual counseling	302	75
Use of support staff to help guide patients and families	295	74
Internet resources (copying and providing materials to patients)	247	62
Referring patients to specific Internet sites	207	52
Support groups that offer training (e.g., self-advocacy)	240	60

N = 401

use community resources (89%), peer support groups (88%), financial aid (87%), assistance with activities of daily living at home, (e.g., home health aides) (86%), and appearance counselors (86%). General services reported as not at all available included child care assistance (56%), employment assistance (40%), legal aid (31%), and integrative or complementary therapies (30%). No awareness of availability was highest for legal aid (21%), child care assistance (18%), employment assistance (17%), and housing assistance (13%).

Healthcare providers most often perceived to be somewhat or very available were dietitians (91%), social workers (88%), and pastoral or spiritual care staff (87%). Psychiatrists and psychologists were reported to be somewhat or very available by 69% and 67% of respondents, respectively. Professionals reported as not at all available included sex therapists or counselors, patient navigators, and marriage or family therapists.

## Barriers to the Provision of Psychosocial Care

The most common barrier to the provision of psychosocial care in oncology nurses' practices was lack of time (see Table 5). Other prominent barriers included patients or families not wanting to address

Table 4. Availability of Services and Resources for Psychosocial Care								
	Ve	ry	Somewhat		Not at All		Do Not Know	
Variable	n	%	n	%	n	%	n	%
<b>General Services</b>								
Appearance counselors or services	236	59	106	27	46	12	9	2
Peer support groups	207	52	145	36	31	8	14	4
Assistance with activities of daily life (e.g., home health aids)	184	46	160	40	44	11	10	3
Education in how to find and use available community resources	167	42	189	47	27	7	16	4
Insurance information and assistance	148	37	171	43	43	11	33	8
Information regarding psychosocial self-care	137	34	196	49	34	9	31	8
Financial aid	132	33	214	54	29	7	24	6
Structured patient and caregiver education	131	33	165	41	73	18	28	7
Integrative or complementary therapies	115	29	148	37	121	30	13	3
Housing assistance	52	13	174	44	117	29	50	13
Legal aid	49	12	140	35	125	31	85	21
Employment assistance	29	7	142	36	159	40	68	17
Childcare assistance	10	3	90	23	224	56	73	18
Healthcare Providers								
Social workers	285	71	66	17	37	9	6	2
Chaplains, pastoral, or spiritual care staff	263	66	84	21	46	12	4	1
Dietitians	258	65	103	26	33	8	2	<1
Financial counselors or assistance	177	44	154	39	43	11	21	5
Complex case managers	165	41	138	35	72	18	23	6
Psychologist	121	30	149	37	103	26	22	6
Patient navigator (licensed professional staff)	112	28	87	22	162	41	35	9
Psychiatric consultation or liaison service	105	26	150	38	108	27	30	8
Psychiatrist	100	25	177	44	101	25	14	4
Marriage or family therapy pro- fessionals	89	22	133	33	129	32	43	11
Patient navigator (lay staff)	55	14	80	20	210	53	49	12
Sex therapist or counselor	27	7	93	23	206	52	70	18
N = 399								

Table 5. Barriers to Providing Psychosocial Care in Oncology Nurses' Practices							
	Often or Always		Some	times	Nev	Never	
Barrier	n	%	n	%	n	%	
Patients							
Patient and family do not want to address psychosocial issues.	131	33	216	54	52	13	
Patient and family have the mindset that psychosocial care is not as important as medical care.	129	32	186	47	81	20	
Patient and family are in crisis mode and unable to reach out for assistance.	127	32	212	53	57	14	
Patient and family are influenced by the stigma of psychosocial care and avoid these issues.	116	29	192	48	89	22	
Community at Large							
Lack of insurance coverage and/or the cost of psychosocial services	175	44	155	39	66	17	
Lack of patient and family access to psychosocial services	150	38	171	43	75	19	
Mindset of providers that psychosocial care is not as important as medical care	115	29	164	41	114	29	
Lack of privacy in the care setting to discuss psychosocial needs with the patient and family	114	29	123	31	160	40	
Healthcare Team and Setting							
Lack of time in the work setting to assess and address psychosocial needs and issues	229	57	131	33	37	9	
Lack of value and support for the provision of psychosocial care in the culture of the practice setting	168	42	131	33	96	24	
Difficulty obtaining referrals for psychosocial care	163	41	146	37	87	22	
Lack of personal energy to provide emotionally draining interventions	155	39	163	41	74	19	
Lack of clinical practice guidelines or protocols regarding provision of psychosocial care	151	38	125	31	118	30	
Lack of experience with assessment or screening tools for psychosocial distress	148	37	144	36	102	26	
Difficulty interpreting healthcare insurance benefits and/or processes for obtaining psychosocial care	136	34	138	35	116	29	
Lack of care team knowledge about psychosocial resources relevant to cancer care	138	35	156	39	101	25	
Lack of community resources to support patients' psychosocial needs	119	30	172	43	104	26	
Insufficient patient care team communications	102	26	172	43	119	30	
N = 399							

psychosocial issues, patients or families being in crisis mode and unable to reach out for assistance, and lack of insurance coverage for or cost of psychosocial services. More than 40% of respondents reported that lack of value and support for the provision of and difficulties obtaining referrals for psychosocial care were never a barrier.

# **Primary Responsibility for Psychosocial Care**

Respondents identified the staff nurse as having primary responsibility for providing psychosocial health services (35%), followed next by social workers (33%) (see Table 6). Less than 10% identified other healthcare providers as having primary responsibility for such care.

More effective coordination of psychosocial care and linking patients with services were two areas rated by respondents as important for research and development in psychosocial care for patients with cancer.

# **Institute of Medicine Report**

Only 27% of respondents indicated that they were somewhat or very familiar with the IOM report. Fifty-one percent of those surveyed indicated that they did not know whether their practice setting had communicated about or taken action related to the IOM report, and 36% said that the setting had not communicated or taken any action.

## **Subgroup Analyses**

Inpatient versus outpatient practice settings: Subgroup analysis of the ability to provide psychosocial care during each phase of the cancer care continuum demonstrated

**Table 6. Person Primarily Responsible** for Providing Psychosocial Health Services

N = 401

n	%
142	35
134	33
34	9
28	7
19	5
10	3
7	2
20	5
	142 134 34 28 19 10

significant differences between inpatient and outpatient settings. A significantly larger percentage of respondents from outpatient settings indicated that they were able to provide psychosocial care often or always during treatment and in cancer care transitions (p < 0.05), whereas a significantly larger percentage of respondents from inpatient settings indicated they were able to provide psychosocial care often or always during end of life (p < 0.001) (see Figure 3). To eliminate potentially confounding results from including respondents who worked primarily in academic or other types of settings, the analysis was completed based on respondents who primarily worked in an inpatient or outpatient area.

A difference existed in awareness of some patient needs in association with type of setting. A higher percentage of nurses in the outpatient setting were somewhat or very aware of financial issues (89%) compared to respondents who provided inpatient care (74%) ( $\chi^2 = 10.83$ , p = 0.001). More nurses in the outpatient setting also were aware of job-related stress (81% of outpatient, 71% of inpatient;  $\chi^2 = 3.91$ , p = 0.048), insurance issues (89% outpatient, 77% inpatient;  $\chi^2 = 7.76$ , p = 0.005), and transportation issues (91% outpatient, 80% inpatient;  $\chi^2 = 8.39$ , p = 0.004). In contrast, nurses in the inpatient setting were more aware of spiritual issues than nurses in the outpatient setting (80% inpatient, 67% outpatient;  $\chi^2 = 5.681$ , p = 0.017)

A number of significant differences existed between the inpatient and outpatient settings in terms of the availability of professional staff for psychosocial care. More respondents from outpatient settings indicated that appearance counselors were available (90% outpatient, 83% inpatient;  $\chi^2 = 5.09$ , p = 0.024). Respondents from inpatient settings reported more availability of pastoral care (inpatient 100%, outpatient 82%;  $\chi^2 = 20.99$ , p = 0), case managers (inpatient 96%, outpatient 70%;  $\chi^2 = 25.94$ , p = 0), dietitians (inpatient 100%, outpatient 88%;  $\chi^2 = 13.53$ , p = 0), psychiatrists (inpatient 88%, outpatient 68%;  $\chi^2 = 13.65$ , p = 0), and social workers (inpatient 98%, outpatient 88%;  $\chi^2 = 8.41$ , p = 0.004). No differences existed in the avail-

ability of other services reported between these two settings; however, significant differences were observed in the percentage of respondents who indicated that they did not know whether services were available or not. Respondents from outpatient settings were more likely to report the availability of financial aid (p = 0.000), housing assistance (p = 0.02), interpretation of benefit coverage for psychiatric services (p = 0.001), and assistance with insurance issues (p = 0.000) for patients compared to those from inpatient settings.

Setting also appeared to be associated with identification of primary responsibility for provision of psychosocial care. The staff nurse was identified as the person with that responsibility more often by individuals who worked primarily in the outpatient setting ( $\chi^2 = 23.25$ , p = 0.001).

Education: Highest nursing education level was associated with a higher awareness of some patient psychosocial issues. Education at the graduate level was associated with more reports of awareness of patient issues, such as job-related stress ( $\chi^2 = 5.28$ , p = 0.022), insurance issues  $(\chi^2 = 7.8, p = 0.005)$ , and spiritual issues  $(\chi^2 = 4.99, p = 0.005)$ 0.025). Education level also was associated with whom the nurse identified as the person responsible for provision of psychosocial care. Nurses educated at the undergraduate level tended to identify the staff nurse (44%) and physician (8%) as responsible for this aspect of care more often than those educated at the graduate level (23% and 2%, respectively). Respondents with a graduatelevel education identified the advanced practice nurse (23%) or behavioral health professional (11%) as those with primary responsibility for providing psychosocial services (p = 0.000).

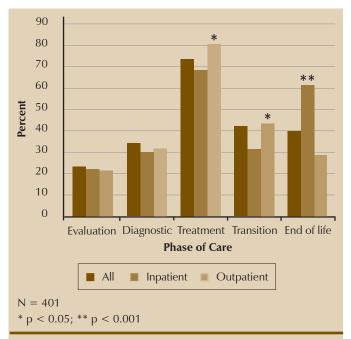


Figure 3. Frequency of Providing Psychosocial Care Often or Always Through Cancer Continuum

#### **Limitations**

The study had a low overall response rate (4%), but it was comparable to that typically seen when using e-mail to contact respondents. In a benchmarking study describing organizational member e-mail response behaviors, e-mails from nonprofit organizations had an average open rate of 16%, and only 2% of those followed internal links to additional content (Matheson, Ruben, & Ross, 2009). The open rate for the current survey was slightly higher (22%), and 26% of those followed the link to the survey.

## **Discussion**

Although oncology nurses' use of interview and discussion to identify and assess patients' psychosocial needs reveals the potential productivity of these nursepatient interactions, the depth of these contacts is unclear. With infrequent use or availability of standardized assessment tools and mostly passive approaches to providing psychosocial support, some concern arises that opportunities for in-depth psychosocial assessment and meaningful interventions may be missed. Survey results indicate nurses' perception that patients and families do not want to address psychosocial issues, are unable to reach out for assistance because they are overwhelmed by the cancer and its treatment, or are hesitant to admit to a need for psychosocial care because of the stigma it carries for many people. The expectation that patients and families in crisis will be able to identify their needs and actively request assistance on their own behalf may be unrealistic. Oncology nurses need to be prepared to assume a more proactive role throughout the continuum of care by learning more about assessment tools and incorporating them into practice.

A lack of privacy to discuss psychosocial issues with patients and families was never a problem, according to 40% of the nurses surveyed. In addition, 43% of respondents indicated that value placed on the provision of psychosocial care was never lacking within the culture of their practice setting. However, lack of time to assess and give attention to these patient concerns was rated high as a barrier to providing psychosocial care. These disconnects are evidence of a challenge and an opportunity for oncology nurses. Oncology nurses must recognize when patients and families are in crisis mode and be prepared to assist them with the elemental task of articulating their needs. To accomplish that goal, psychosocial care must be a recognized priority in terms of allocation of nursing time and institutional resources.

More than a third of participants responded that nurses have primary responsibility for providing psychosocial health services, and they also reported a need for more effective coordination to link patients with available services. Interestingly, staff nurses and APNs perceived theirs to be the primary group responsible for providing

psychosocial care. Differences also existed between inpatient and outpatient settings in terms of awareness of patient needs and ability to provide psychosocial care at different phases of the cancer illness trajectory. Although those differences may reflect patient and nurse priorities based on differing levels of care and patient needs, along with potential differences in care priorities among nurses, what is unclear is whether any global recognition exists of these differences, which would facilitate a more efficient focus of nursing efforts and coordination between nursing specialties and subgroups. Although strengths certainly exist in the recognition of the importance of patients' psychosocial needs in cancer care, areas of concern exist as well, as a majority of nurses report time as a barrier to addressing those needs, while also revealing what can be perceived as a lack of coordination or willingness to delegate these tasks to others, even to other nurses.

The challenge, given the reality of limited nurse time, is for oncology nurses to collaborate with interdisciplinary team members and community resources so a broader net of support can be cast to provide care. Most respondents stated that social workers, dietitians, and pastoral care personnel were very available in their practice setting. Use of the recently developed role of the patient navigator has not been widely implemented within the settings of the current survey's respondents, yet it might offer additional support in addressing psychosocial needs.

Respondents' perceptions that providers have the mindset that psychosocial care is not as important as medical care received almost the same score as patients and families having the mindset that psychosocial care is not as important as medical care. That raises the question of whether a particular mindset or perception on the part of providers regarding patient and family priorities may influence nurse's use of available assessment tools or resource offerings. Certainly, room for improvement exists in the area of assessment and the use of tools and instruments to identify psychosocial needs. Ambulatory centers, doctors' offices, inpatient care, and home health nurses can incorporate one or more of the assessment tools available to gauge distress and other symptoms that pertain to psychosocial problems. Incorporating those tools into the patient encounter normalizes the assessment, opens doors to discussion, and conveys to the patient and family that these feelings and needs are experienced by many people who journey through cancer diagnosis and treatment. Psychosocial care offers a leadership opportunity for nurses to initiate standardized psychosocial assessment and interventions, well-organized interdisciplinary collaboration, and follow-up, which will result in improved holistic cancer services for patients and families. The development of triage guidelines to support practice also is critical to success in clinical care environments where nurses note that time often is a barrier (Vitek, Rosenzweig, & Stollings, 2007).

The percent of nurses who did not know about available services in their practice setting was very low, demonstrating that nurses are aware of existing resources to help their patients. However, communication among the patient care team members was "sometimes" and "often" a problem in almost 70% of care settings. Communication, appropriate referrals among the healthcare providers, and follow-up regarding patient use of available psychosocial services and the benefit achieved are crucial to providing comprehensive care to help patients transition through all aspects of their cancer experience. Within the oncology care settings represented in the current survey, peer support groups, assistance with activities of daily living through home care services, information on psychosocial self-care, and finding community resources are very available more than 41% of the time. Appearance counselors are very available to patients in 59% of the settings. However, financial aid and insurance information and assistance are very available in only 33% and 37% of the settings, respectively. Connecting patients and families with available resources and advocating for additional resources are important care activities.

## **Conclusion**

The 2009 ONS Psychosocial Survey was successful in obtaining responses from a broad range of ONS members with diverse backgrounds and perspectives, including age, educational preparation, primary work setting, and professional responsibilities. The respondents were somewhat older and had higher levels of nursing education than the overall membership at the time; however, other characteristics were similar to the overall ONS membership at the time of the survey, suggesting that selection bias was minimal. The perspectives of researchers, administrators, educators, and nurses involved in direct pa-

tient care are represented, and patient care respondents, the largest group, represent inpatient and outpatient care settings. The broad-based survey results are an indication of the extent to which oncology nurses recognize, and are working toward meeting, the IOM (2008) recommendations regarding the psychological and social problems. Nevertheless, results also point to areas in which nursing provision of appropriate psychosocial health services can be better supported, improved, and strengthened, as well as highlighting some existing gaps in assessing and meeting the psychosocial needs of patients with cancer and their families, as identified in the IOM report.

The survey findings can be used to guide future ONS education initiatives through awareness of existing approaches, tools, and resources in inpatient and outpatient settings, as well as advocacy approaches to decrease barriers related to referrals and insurance coverage and to promote quality initiatives, which ultimately can improve the delivery of high-quality nursing care. These results and accompanying recommendations are provided in support of the ONS mission to promote excellence in oncology nursing and high-quality cancer care (ONS, 2008).

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## References

Dillman, D.A. (2000). Mail and Internet surveys: The tailored design method. New York, NY: John Wiley and Sons.

Fulcher, C.D., & Gosselin-Acomb, T.K. (2007). Distress assessment: Practice change through guideline implementation. *Clinical Journal of Oncology Nursing*, 11, 817–821. doi:10.1188/07.CJON.817-821

Hawkes, A.L., Hughes, K.L., Hutchison, S.D., & Chambers, S.K. (2010).
Feasibility of brief psychological distress screening by a community-based telephone helpline for cancer patients and carers. *BMC Cancer*, 10, 14. doi:10.1186/1471-2407-10-14

Holland, J.C., & Alici, Y. (2010). Mangement of distress in cancer patients. *Journal of Supportive Oncology*, 8(1), 4–12.

Holland, J.C., Andersen, B., Breitbart, W.S., Compas, B., Dudley, M.M., Fleishman, S., . . . Zevon, M.A. (2010). Distress management. *Journal of the National Comprehensive Cancer Network*, 8, 448–485.

Institute of Medicine. (2008). Cancer care for the whole patient: Meeting psychosocial health needs. Washington, DC: National Academies Press.

Jacobsen, P.B. (2009). Promoting evidence-based psychosocial care for cancer patients. Psycho-Oncology, 18, 6–13. doi:10.1002/pon.1468

Jacobsen, P.B., & Ransom, S. (2007). Implementation of NCCN distress management guidelines by member institutions. *Journal of the National Comprehensive Cancer Network*, 5, 99–103.

Matheson, K., Ruben, M., & Ross, H. (2009). 2009 e-Nonprofit benchmark study: An analysis of online messaging, fundraising, and advocacy metrics for nonprofit organizations. Retrieved from http://www.fresnoregfoundation.org/\_literature\_34547/2009\_Nonprofit\_Ebenchmarks\_Study

National Comprehensive Cancer Network. (2011). NCCN Clinical Practice Guidelines in Oncology: Distress management [v.1.2011]. Retrieved from http://www.nccn.org/professionals/physician\_gls/pdf/distress.pdf

Oncology Nursing Society. (2008). Psychosocial services for patients with cancer. Oncology Nursing Forum, 35, 337.

Oncology Nursing Society. (2011). ONS mission statement. Retrieved from http://www.ons.org/about

Vitek, L., Rosenzweig, M.Q., & Stollings, S. (2007). Distress in patients with cancer: Definition, assessment, and suggested interventions. Clinical Journal of Oncology Nursing, 11, 413–418. doi:10.1188/07 .CION.413-418

Zabora, J., BrintzenhofeSzoc, K., Curbow, B., Hooker, C., & Piantadosi, S. (2001). The prevalence of psychological distress by cancer site. *Psycho-Oncology*, 10, 19–28. doi:10.1002/1099-1611(200101/02)10:1<19::AID -PON501>3.0.CO;2-6