# ARTICLES

# **Ovarian Cancer: Early Symptom Patterns**

Dixie Koldjeski, PhD, FAAN, Mary K. Kirkpatrick, EdD, Melvin Swanson, PhD, Lou Everett, EdD, and Sylvia Brown, EdD

Purpose/Objectives: To examine early symptom and diagnostic-seeking experiences of women newly diagnosed with ovarian cancer.

Design: Longitudinal descriptive.

Setting: Homes of families.

Sample: Purposive; 19 families were obtained by referrals.

Methods: Interviews and questionnaires; descriptive analysis. Main Research Variables: Early symptoms and delays in diagnosis.

**Findings:** Families were 88% Caucasian and 12% African American. Almost two-thirds had annual incomes of \$25,000 or more. The ages of the patients with cancer ranged from 28–73 years ( $\overline{x} = 56$  years). Delay between initial symptoms and diagnosis was  $\overline{x} = 14$  weeks. Early symptoms experienced by 95% of women were abdominal bloating, vague abdominal pain and "spots," indigestion problems, fatigue, and urinary problems.

**Conclusions:** Women usually experience a cluster of symptoms, unrecognized and discounted, which delays diagnosis.

**Implications for Nursing:** Pelvic assessments should be reformulated to conceptualize early symptoms, risk factors, and family cancer history as a dynamic, interconnected whole to guide and interpret ovarian health.

varian cancer is depicted as a reproductive malignancy that presents few, if any, early symptoms. When diagnosis occurs, the cancer is usually in the late stages of development. Early undifferentiated symptoms long have been reported; however, their clinical significance has been largely unrecognized as a diagnostic indicator. The research reported in this article was part of a large study that examined selected aspects of the lived experiences of families that had members recently diagnosed with ovarian cancer. One aspect was information about the presence of prediagnostic symptoms. The purpose of this article is to report this early symptom experience in the context of the diagnosisseeking process and examine its significance.

Ovarian cancer occurs most frequently in women aged 55 and older. The incidence is highest among Caucasian women in North America and northern Europe. The next most vulnerable group is African Americans, followed by Asian Americans. Native Americans have the lowest incidence (Daly & Obrams, 1998). This malignancy accounts for an estimated 14,300 deaths and 25,400 new cases each year (Jemal et al., 2003). The high mortality rate results, in large part, from delays in diagnosis. When the diagnosis is made in stage I, 90% of patients can be cured with therapies that

## Key Points . . .

- Healthcare professionals must conceptualize their assessment framework to use early symptom data as early warning signals.
- Gynecologic examinations must routinely include early symptoms.
- ► Women can be taught to self-monitor their ovarian health.

currently are available (Bast, Fishman, Smith, & Skates, 2003).

Primary prevention approaches for ovarian cancer in asymptomatic women have focused on the use of the CA125 blood test, transvaginal sonography, and bimanual pelvic examinations (American Cancer Society, 2001; National Cancer Institute, 2001; National Institutes of Health, 1994). As yet, neither blood nor sonographic approaches have been found to be sensitive or cost-effective enough to serve as standards in primary prevention programs.

Chemoprevention approaches and selected surgical interventions have not been recommended as primary prevention strategies (Barnes, Grizzle, Grubbs, & Partridge, 2002). Secondary prevention approaches focus on early detection and diagnosis. Strategies include the identification and minimization of risk factors, development of protective factors, bimanual pelvic examinations, and specialized consultation as needed. Ovarian health education and self-monitoring of reproductive structures and functions by women are key activities in early detection. Grimes (1993) noted that aggressive screening was essential. Jennings-Dozier and Mahon (2000) have cited this area as the next frontier in oncology nursing leadership and service.

Digital Object Identifier: 10.1188/03.ONF.927-933

ONCOLOGY NURSING FORUM - VOL 30, NO 6, 2003

Dixie Koldjeski, PhD, FAAN, is a distinguished professor emeritus and Mary K. Kirkpatrick, EdD, Melvin Swanson, PhD, Lou Everett, EdD, and Sylvia Brown, EdD, are professors, all in the School of Nursing at East Carolina University in Greenville, NC. This research was funded by the ONS Foundation and the East Carolina University School of Nursing Research Initiative. (Submitted February 2002. Accepted for publication March 1, 2003.)

# Theoretical Perspectives on Ovarian Cancer

Several theories have proposed why normal ovarian cells become malignant. The incessant ovulation hypothesis holds that risk increases as the number of ovulations increases because ruptured follicles are exposed repeatedly to estrogen baths (Casagrande et al., 1979; Fathalla, 1971). Reviews of research suggest that this relationship may be a weak indicator of ovarian cancer risk (Hankinson et al., 1995; Parazzini, LaVecchia, Negri, & Gentile, 1989; Polychronopoulou et al., 1993; Purdie et al., 1995). Over the years, however, other studies have reported support for the hypothesis (Cancer and Steroid Hormone Study, 1987; Risch, Weiss, Lyon, Daling, & Liff, 1983; Schildkraut, Bastos, & Berchuck, 1997; Whittemore, Harris, & Intyre, 1992).

Another theory is the contaminant hypothesis, which holds that materials such as talc move through the vaginal-uterusfallopian tube route and activate malignant cell changes in the ovaries (Cook, Kamb, & Weiss, 1997; Cramer, Welch, Scully, & Wojciechowski, 1982; Harlow, Cramer, Bell, & Welch, 1992). Supporting and nonsupporting research evidence has been reported.

Genetic factors involved in the etiology of ovarian cancer are linked to the *BRCA1* and *BRCA2* tumor-suppressor genes that have had their protective functions suppressed or destroyed by mutations (Amos & Struewing, 1993; Easton, Bishop, Ford, & Crockford, 1993; Tait, 1998). Defects are suspected when a history of ovarian, breast, or colon cancers is present among siblings and first- and second-generation family members. In particular, women with first- and seconddegree relatives with ovarian cancer and a *BRCA1* mutation are considered to have an increased risk of developing the malignancy (Tait).

## **Clinical Perspectives**

Multiple risk factors related to ovarian cancer have been identified (see Figure 1) and widely disseminated to the public (Mellody, 1999; National Cancer Institute, 2001, 2002; Ovarian Cancer Alliance Canada, 1998). Amos and Struewing (1993) identified two risk factors—being age 55 or older and having close family relatives with colon or breast cancers as conferring a 3.6-fold increase in risk. Williams (1992) cited family history as the most important risk factor. Stratton, Pharoah, Smith, Easton, and Ponder (1998) estimated that risk increases 1.8%–4.7% when a woman has one first-degree relative with this malignancy. A risk of 7%–10% exists when two first-degree relatives have the malignancy (Kerlikowski, Brown, & Grady, 1992).

Protective factors include having a family history free of cancers, using oral contraceptives, using non-talc-based femi-

Age 55 or older Caucasian race Ashkenazi Jewish descent Early onset of menses No children Family history of breast, colon, or ovarian cancer Mineral-based feminine hygiene products Use of fertility drugs No breastfeeding history

Figure 1. Risk Factors for Ovarian Cancer

nine hygiene products, being multiparous, and breastfeeding. Preemptive tubal and uterine surgery may be considered for women at very high risk. Cancer-related checkups at periodic intervals should include bimanual pelvic, blood, urine, stool, and abdominal examinations; Pap test; family history of cancer; and identification of risk factors. Annual pelvic examinations are recommended for women experiencing abdominal, pelvic, and constitutional symptoms (American Cancer Society, 2001; American College of Obstetricians and Gynecologists, 1989). These primary prevention approaches for ovarian cancer have had limited success in reducing delays in diagnoses of ovarian cancer.

# Literature Review

In 1985, Dugan described a bleak outlook for ovarian cancer recovery because early symptoms of pain, abdominal or pelvic fullness, ascites, abnormal uterine bleeding, and urinary complaints were not considered relevant to the disease. Brucks (1992) reported that women ignored the undifferentiated symptoms and professionals excluded them from the diagnostic process. The lack of recognition of the importance of these early precursors was a factor in labeling ovarian cancer as a "silent killer" (Dillon, 1994; Shurpin, 1997). Healy (1997) called it a "hidden killer," and Hall (1997) compared the diagnostic process to "stalking a stealthy killer."

In 1994, Ivey encouraged women older than 40 to report any abnormal pain or swelling, abdominal discomfort after meals, and changes in urinary frequency or weight. Hartenbach (1998) recommended that the undifferentiated symptoms often reported needed to be used in the diagnostic process. Haley (2000) reported that such symptoms signaled the need for prompt follow-up. In 2000, Martin stated that, contrary to what is heard and read, ovarian cancer does present early signs and symptoms most of the time and labeled it a "whispering disease" because the symptoms do not speak loud enough to be heard. O'Rourke and Mahon (2003), in a comprehensive look at the early detection of ovarian cancer, noted that prognosis continues to be poor, although tests identifying the symptoms of early-stage malignancy are emerging.

Seven research reports were reviewed that focused on early symptom experiences usually identified after a diagnosis of ovarian cancer was made. Ranney and Ahmad (1979) examined case reports and found that 91% of the patients with ovarian neoplasia reported early symptoms of irregular uterine bleeding, pelvic pain, abdominal fullness, lower back and leg aches, urinary frequency, and lower abdominal "lumps." Sargis (1983) examined four research projects and found that all of them reported symptoms of abdominal swelling and discomfort, gastrointestinal and urinary abnormalities, and weight loss. In 1985, Smith and Anderson evaluated 85 ovarian cancer cases listed in a midwestern state cancer registry and found documentation for early-stage symptoms of abdominal swelling, fatigue, abdominal pain, urinary problems, and indigestion.

In Sweden, Flam, Einhorn, and Sjövall (1988) reviewed 362 cases of women diagnosed with ovarian cancer and found that in stages I and II, abdominal swelling, back pain, gastrointestinal problems, vaginal bleeding, and fatigue frequently were reported. Wikborn, Pettersson, and Moberg (1996) reviewed the records of 160 women diagnosed with ovarian cancer and found early reports of bladder symptoms, pain, and abdominal swelling. In 1997, Igoe surveyed 50 women diagnosed with ovarian cancer and found that, prior to diagnosis, more than two-thirds experienced symptoms of fatigue, abdominal swelling, bloating, indigestion, and pelvic pressure and more than one-half experienced abdominal and back pain, bloating, and constipation. Goff, Mandel, Muntz, and Melancon (2000) surveyed 1,500 women to obtain their early symptom experiences. Ninety-five percent reported an increase in abdominal size, bloating, pelvic and back pain, fatigue, indigestion, and urinary problems. Five percent of the respondents reported no symptoms.

The time lapse between symptom evolvement and diagnosis long has been a concern in ovarian cancer management. In 1977, Kjellgren reported that among women who consulted a physician, approximately 75% showed a delay ranging from three to six months. Ranney and Ahmad (1979) reported that delays ranged from two weeks to 10 months. Smith and Anderson (1985) found a delay of approximately three months between symptom evolvement and diagnosis among the cases they investigated in a state registry. Flam et al. (1988) reported that almost three-fourths of the subjects they investigated had three-month delays. Wikborn et al. (1996) and Goff et al. (2000) reported delays ranging from seven weeks to one year. Delays in diagnosis related to perceptions held by women that the symptoms were not serious. Discounting of early symptom evidence, resulting in part from a lack of symptom specificity, was a factor when professional care was sought. Misdiagnoses were frequent.

Since the 1970s, the presence of ovarian cancer symptoms has been well documented but generally not used in the diagnostic process because the significance has not been recognized. Delays in diagnosis related primarily to two factors: the failure of women to seek medical care even when symptoms persisted and multiplied and the discounting or misdiagnosis of this clinical data by professionals. The evidence is clear that an identifiable array of early symptoms usually occurs in ovarian cancer development and, if recognized and used in the diagnostic process, has the potential to increase early diagnosis and treatment.

## Methods

## Context

The context for this research was the Family Functioning Research Project, which examined the impact of a diagnosis of ovarian cancer on aspects of family functioning. The prediagnostic symptom experience and diagnostic-seeking process were a part of this inquiry. The university institutional review board for protection of human subjects approved the project.

Recruited families were provided with information about the project by clinic nurses and physicians in regional oncology clinics. Permissions were obtained to refer their interest to the research project director; once these were received, researchers initiated an appointment for family visitation and orientation. The purpose of the research was emphasized as that of discovering knowledge about the experiences of families during the first year after diagnosis of a family member and not one of providing clinical care. Each participating family member signed an informed consent. Families could withdraw from the project at any time without jeopardizing healthcare treatments, benefits, and services. Referral to the primary medical provider was made if needed.

## Design

A longitudinal descriptive design consisting of qualitative and quantitative measures guided data collection during five family visitations in the homes of families during a period of 12 months. Visitations were scheduled by appointment, with the first conducted two to three weeks after diagnosis. Subsequent visits occurred at six weeks and 3, 6, and 12 months.

## Sample

Twenty families were referred from regional cancer clinics from 1998–2000. Nineteen consented to have a home visitation to learn about the project and to complete the demographic and research questionnaires. All families resided in the southeastern United States. After the first visitation, a purposive sample of 18 families consented to participate in the yearlong study. The representativeness of the sample is not known because it was purposive. Families who were willing to participate *as units* in interviews and to complete questionnaires, had a member diagnosed with ovarian cancer in the previous two to three weeks, and accepted responsibility for notifying members to attend visitation sessions met the inclusion criteria for the study. No family withdrew from the study. Researchers made 91 visitations involving 50 different family members.

#### Instrumentation

A 13-item demographic questionnaire was used to obtain information about each family. An ovarian symptom checklist, developed by the researchers from a content analysis of ovarian symptom research, was used to record early symptoms. Congruent validity (Brewer & Hunter, 1989), a strategy to determine whether different measurements address a similar set of phenomena, was used to check symptom similarity between the constructed checklist and the Memorial Symptom Assessment Scale, a patient-rated instrument that measures a core of common cancer symptoms collected from patients with many kinds of cancer (Portenoy et al., 1994). Nine symptoms on the constructed checklist were among the high- and low-prevalence physical symptoms (69%), and four symptoms (31%) were not listed in either group. This showed a high level of core symptom similarity as well as ovarian cancer symptom specificity. Provision was made in the checklist for the option of "other" on the premise that additional symptom specificity might emerge.

### **Data Collection**

Data were collected through two activities: an open-ended interview and questionnaire completion. At the beginning of a visit, an interviewer asked family members to focus on experiences of daily living. Family members chose the topics for discussion. Questionnaires about select aspects of family functioning were completed, with family members acting as a unit to reach consensual responses to questions. The early symptom and diagnostic process information was collected during the first home visitation.

Family members and the interviewer convened in a living area. The interviewer reiterated that the purpose of the research was to obtain ongoing accounts of the family's experience as it coped with the impact of the patient's ovarian cancer. The interviewer participated only when asked for general information. Field notes were collected because families had declined, when informed consents were signed, to have sessions recorded. Open-ended sessions averaged an hour. Once discussions ended, family members convened around a table to complete the questionnaires, a process that took approximately 45 minutes. The same interviewers met with the same families throughout the year.

## **Data Analysis**

For demographic and symptom checklist data, descriptive statistics were used to obtain frequencies and percentages. Comparisons of symptoms by kind and frequency with those reported in other studies were used to ascertain similarity and time occurrence in the diagnostic-seeking process.

# Findings

## Sample Characteristics

Selected demographic characteristics of the 19 families that participated in the initial home visitation indicated that 17 (89%) were Caucasian. Forty-one family members (82%) had completed high school and two or more years of college. Twelve families (63%) reported incomes higher than \$25,000 (see Table 1).

## **Characteristics of Women With Ovarian Cancer**

Twelve (63%) of the women with cancer were married and living with spouses. Five (26%) were widows and had relatives living nearby. The age range of the women with cancer was 28–73 years ( $\overline{X} = 57.5$  years). Fifteen (79%) women identified maternal relatives with breast, colon, or ovarian cancers, and four women (22%) had fathers or uncles with cancer. The women with ovarian cancer were primarily Caucasian, middle class, and well educated (see Table 2).

## Early Symptom Experiences

The prediagnostic symptom experiences of family members were extensive and associated with gastrointestinal, urinary, and reproductive systems and what Goff et al. (2000) called "constitutional factors." The seven most frequently experienced symptoms were bloating, vague abdominal pain, indigestion problems, fatigue, painful spots in the abdomen, lumps in the abdomen, and urinary problems (see Table 3). Collectively, they were labeled as the primary symptom cluster. Eleven low-occurrence symptoms were classified as the secondary symptom cluster.

### **Table 1. Selected Demographics**

Variable	n	%
Race (N = 19 families)		
Caucasian	17	89
African American	2	11
Income (N = 19 families)		
> \$25,000	12	63
< \$25,000	7	39
Education (N = 50 family members)		
9-11 years	9	18
12–14 years	35	70
15+ years	6	12

## Table 2. Characteristics of Women With Ovarian Cancer and Family History of Cancer

Variable	n	%
Marital status		
Married	12	63
Widowed	5	26
Sinale	2	11
Age (vears)		
20–39	2	11
40-59	7	37
60–79	10	53
Family cancer history		
Mother or grandmother	8	42
Aunt	3	16
Sister	2	11
Niece	1	5
Daughter	1	5
Father	3	16
Uncle (fraternal)	1	5

N = 19

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

## Time Lapse Between Symptom Development and Diagnosis

The time lapse between symptom development and diagnosis for women in the study families ranged from 2–52 weeks  $(\overline{X} = 14)$  (see Table 4). This period of delay is consistent with reports in the literature. Delays in seeking medical care were related primarily to the women's, family members', and

## Table 3. Prediagnostic Symptoms

Verbatim Descriptions	n	%
Primary cluster		
Bloating	16	84
Vague abdominal pain	13	68
Indigestion problems	12	63
Fatigue	11	58
Painful spots in abdomen	10	53
Lumps in abdomen	10	53
Urinary problems	8	42
Secondary cluster		
Nausea	5	26
Pain in chest, coughing, shortness of breath	5	26
Abdominal fullness	4	21
Constipation	4	21
Fluid in abdomen	4	21
Pain in lower abdomen	3	16
Weight loss	3	16
Bleeding or spotting (vaginal)	2	11
Fluid in lungs	2	11
Weight gain	2	11
Bleeding during intercourse	1	5
Back pain	1	5
Elevated temperature	1	5
Insomnia	1	5
Leg cramps	1	5
Flu-like virus	1	5
No symptoms	1	5

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

N = 19

ONCOLOGY NURSING FORUM - VOL 30, NO 6, 2003

### Table 4. Weeks Between Symptom Onset and Diagnosis

Number of Weeks	n	%
2	2	11
3–6	5	26
7–12	7	37
24–52	2	11
Unsure	3	16

N = 19

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

friends' perceptions that the symptoms were not serious. When medical care was sought, misdiagnoses frequently occurred. Approximately one-third of the women in the study were diagnosed in stages I and II.

## Symptom Dispersion

In Table 5, symptom dispersion is shown by kind and stage. The pattern is consistent with the international classification system (Beahrs & Henson, 1993; Creasman, 1990; DiSaia & Creasman, 1989), which is based on the histologic processes by which ovarian cancer cells migrate and colonize throughout abdominal, pulmonary, urinary, and reproductive structures. When symptom occurrence was cross-referenced with the stage of cancer development, the lack of specificity of early symptoms in stages I and II became evident and showed a basis for diagnostic difficulties.

## Discussion

The symptoms of early ovarian cancer identified by women in the study families are consistent with findings reported in studies from several countries. The malignancy almost always produces a number of vague and nondisease-specific symptoms that are discounted or unrecognized as having a relationship to ovarian dysfunction. Piver and Eltabbakh (1997) have suggested that prevailing perceptions and myths that the malignancy has no early symptoms contribute to diagnostic delays.

The results of this study further confirm that early symptoms do occur with developing ovarian cancer but usually are not identified as such until the diagnosis is made. An advancement based on study findings was the patterning of symptoms into

Table 5.	Symptom	Dispersion	by	Stage	of	Cancer
----------	---------	------------	----	-------	----	--------

Symptoms	Stage I n = 4 (21%)	Stage II n = 2 (10%)	Stage III n = 10 (53%)	Stage IV n = 3 (16%)
Bloating	Х	Х	Х	Х
Indigestion problems	Х		Х	
Fatigue	Х	Х	Х	Х
Lumps in abdomen	Х	Х	Х	
Vague pain in abdomen		Х	Х	Х
Urinary problems		Х	Х	
Painful lumps in abdomen		Х	Х	Х
Abdominal fullness			Х	Х
Nausea				Х
Shortness of breath				Х
Fluid in abdomen				Х
Weight gain				Х

N = 19

primary and secondary clusters by frequency of occurrence. The cross-referencing of stages of malignancy development at time of diagnosis and types of symptom evolvement showed that in stages I and II, the symptom pattern had a *dominant primary cluster* consisting of gastrointestinal symptoms of bloating and indigestion problems, painful spots in the abdomen, and fatigue. Urinary problems and pressure on the bladder were experienced less frequently. In stages III and IV, symptoms spread into other systems and organs. Symptoms included fluid in the abdomen and chest, breathing difficulties, pain in abdomen and back, and lower gastrointestinal tract problems.

The finding that most early symptoms were concentrated in the gastrointestinal system and produced painful spots on or near ovarian sites provides a reasonable explanation of why misdiagnoses and diagnostic delays occur. In the early stages of this malignancy, the presence of defined tumor evidence from which to make a diagnosis is difficult because of the lack of differentiation and vagueness of the early symptom pattern. This finding suggests a need for a different perspective that will interconnect key pieces of clinical knowledge in a paradigm that uses rather then discounts early symptom evidence.

Formulation of a different perspective has to link risk factors, family cancer history, and symptom evidence into an interconnected and interactive whole. Each area provides a distinct piece of evidence that is essential to establishing a different perspective. Conceptualization of interconnecting relationships among the three data sets enables women and clinicians to arrive at answers that, in turn, point to a course of action.

Bast et al. (2003) noted that a requirement for early detection of ovarian cancer is that, prior to metastasis development, an interval of sufficient length must exist to permit screening at annual and semiannual intervals. This examination time frame does not fit the diagnostic-seeking experiences of women in the study families because ovarian cancer development seems to have a timeline of its own that is influenced by vulnerabilities and other unknown factors. Further, periodic pelvic examinations have not yet proven to be an effective strategy for early identification of the malignancy. Presently, early secondary prevention strategies have to be ongoing and encompass key domains of knowledge in ways that are different than the traditional identification of risks and watchful surveillance.

# Implications for Nursing

## **Clinical Nursing**

The research evidence about early ovarian symptoms and continued long delays in the diagnosis of ovarian cancer supports the need for a more unified formulation of key domains of knowledge to provide a different perspective by which to strengthen assessments. This goal is related directly to increasing the percentage of women who are diagnosed in the early stages, thus increasing dramatically the effectiveness of treatment and lengthening survivability.

Nurses provide many routine health assessments and much reproductive health education to women. In routine pelvic assessments, information is collected about reproductive functions and practices, individual risk factors, the cancer history of families, and any other aspects that seem important to decisions about reproductive health. The presence or absence of the characteristic array of early and vague symptoms traditionally has not been an area of inquiry. Further, each area of health information usually is considered as a disparate data set rather than as an interconnected and interactive whole. Assessments can be strengthened by use of a formulation of risk factors, family cancer history, and early symptom information by conceptualizing their interrelationship in the following ways.

- Risk factors are an individual vulnerability.
- Family cancer history identifies inherited collective vulnerabilities.
- Early, vague, and nondisease-specific symptoms signify that individual and family vulnerabilities are under assault.
- The presence of such symptoms serves as a "canary-in-themine" signal that life-threatening processes have become active.

Specifically, individual risk factors, the cancer history of close relatives, and symptoms associated with early ovarian cancer are arranged in a format to emphasize their presence or absence. For assessment purposes, the presence or absence of each is the focus, rather than the relative contribution. Knowledge of individual risk factors or family cancer history does not in and of itself serve as an indicator that a dynamic change process is under way and generating multisystem symptoms. The presence of the characteristic symptom cluster serves as the sensitive indicator that individual and family vulnerabilities are under attack. This interconnected whole provides an Apgar scale-like picture that alerts women and clinicians to a need for ovarian health to be investigated promptly by specialists and specialized examinations.

This formulation points to a strategy that has women selfmonitor their ovarian health. This secondary prevention strategy, if used routinely by women on a monthly basis, has the potential to reduce diagnostic delay time.

Several routes disseminate state-of-the-art evidence-based knowledge about ovarian cancer. One is including content and assessment experiences in basic and advanced nursing education curricula. Another is through continuing education for healthcare professionals. Targeted groups, particularly women, need healthcare information programs that present knowledge and demonstrations of how to self-monitor ovarian health as an integral part of reproductive functions. The profession has a role in helping the media to provide up-to-date information to the public, which would help dispel myths about the disease and present research-based advancements.

#### Research

In 2001, Given noted that a solid science base about breast cancer exists but gaps are present in other areas of oncology nursing science. The science base for ovarian cancer nursing has these gaps, and nursing care depends in large part on extrapolations from breast cancer research and disease management. Oncology nurses help in this area by providing leadership to use and disseminate up-to-date nursing research.

Ovarian cancer nursing would be advanced by the support of several research initiatives. First, a need exists for a comprehensive review of the science base to identify knowledge gaps and needed extensions as well as areas of new knowledge. This base would serve as a point of reference for clinicians to evaluate areas in which continuing education is needed and to provide leadership to effect changes in standard models of assessment. The specialty would have a firm grasp of the knowledge base being used to guide and inform nursing practice.

Next, the "killer" image of ovarian cancer depicted by many nurse authors needs to be reexamined in the light of up-to-date research, current statistical trends, and treatment successes. Content in information updates needs to move from a repetitive focus on anatomy and physiology of the reproductive system, highly specialized examinations, late-stage treatments, palliative nursing care, and treatment-induced symptom management. Nursing care has many other aspects, particularly in the areas of prevention, family dynamics, and the socioemotional impact of the illness, that need exploration because very little research supports family interventions and strategies.

A critical need exists for oncology nurses to support the development of pilot tests to investigate the usefulness of nursing interventions such as incorporation of the assessment approach proposed in this research. Such tests would serve as a basis for support of larger trials and rationalize the need for funding.

Lastly, the majority of ovarian cancer research focuses on individual variables. Cancer is a family affair. It is a chronic disease, and the family is the environment in which a great deal of caring, healing, and dying takes place. The quality of life for family members who participate in these activities is a major concern. Additionally, little is known about the characteristics of healing and helping families. Research initiatives that focus on families *as units* would provide such knowledge to help families more effectively assist the members with cancer and actualize the hopes and dreams of other members.

# Conclusion

The science bases about early symptom experiences in ovarian cancer and delays in diagnosis have been advanced by this research through a formulation of the clinical assessment structure to unify early symptoms, individual risk factors, and family history to provide a different clinical perspective. The assessment formulation can be integrated easily into current models of pelvic examinations and has the potential for signaling that system and functional changes are under way. State-ofthe-science continuing education for women, nurse clinicians, and educators is an integral part of health education and, for professionals, ensures that evidence-based nursing is taught and used in clinical practice. In their role as key primary care providers, nurses expand their leadership by serving as expert clinicians to the women and general public they serve.

Author Contact: Dixie Koldjeski, PhD, FAAN, can be reached at polishkay@aol.com, with copy to editor at rose\_mary@earthlink.net.

# References

American Cancer Society. (2001). News and views. CA: A Cancer Journal for Clinicians, 51, 10.

American College of Obstetricians and Gynecologists. (1989). Task force report on routine cancer screening [ACOG Committee Opinion No. 68]. Washington, DC: Author.

Amos, C.I., & Struewing, J.P. (1993). Genetic epidemiology of epithelial

ovarian cancer. Cancer, 71(Suppl. 2), 566-572.

- Barnes, M.N., Grizzle, W.E., Grubbs, C.J., & Partridge, E.E. (2002). Paradigms for primary prevention of ovarian carcinoma. CA: A Cancer Journal for Clinicians, 52, 216–225.
- Bast, R.C., Fishman, D., Smith, D., & Skates, S. (2003). Early detection of ovarian cancer. Retrieved February 4, 2003, from http://spores.nci

ONCOLOGY NURSING FORUM – VOL 30, NO 6, 2003

.nih.gov/ovarian/ovarian\_docs/21-ov-mda.html

- Beahrs, O.H., & Henson, D.E. (1993). Handbook for staging of cancer. Philadelphia: Lippincott.
- Brewer, J., & Hunter, A. (1989). Multimethod research: A synthesis of styles. Newbury Park, CA: Sage.
- Brucks, J.A. (1992). Ovarian cancer: The most lethal gynecologic malignancy. Nursing Clinics of North America, 27, 835–845.
- Cancer and Steroid Hormone Study of the Centers for Disease Control and the National Institute of Child Health and Human Development. (1987). The reduction in risk of ovarian cancer associated with oral-contraceptive use. *New England Journal of Medicine*, *316*, 650–655.
- Casagrande, J.T., Louie, E.W., Pike, M.C., Roy, S., Ross, R.K., & Henderson, B.E. (1979). "Incessant ovulation" and ovarian cancer. *Lancet*, 2, 170–173.
- Cook, L.S., Kamb, M.L., & Weiss, N.S. (1997). Perineal powder exposure and the risk of ovarian cancer. *American Journal of Epidemiology*, 145, 459–465.
- Cramer, D.W., Welch, W.R., Scully, R.E., & Wojciechowski, C.A. (1982). Ovarian cancer and talc: A case-control study. *Cancer*, 50, 372–376.
- Creasman, W.T. (1990). New gynecologic cancer staging. *Obstetrics and Gynecology*, 75, 287–288.
- Daly, M., & Obrams, G.I. (1998). Epidemiology and risk assessment for ovarian cancer. Seminars in Oncology, 25, 255–264.
- Dillon, P. (1994). Ovarian cancer—Confronting the "silent killer." Nursing, 24(5), 66–69.
- DiSaia, P.T., & Creasman, W.T. (1989). Advanced epithelial cancer. In P.T. DiSaia & W.T. Creasman (Eds.), *Clinical gynecologic oncology* (3rd ed., pp. 325–416). St. Louis, MO: Mosby.
- Dugan, K.K. (1985). The bleak outlook on ovarian cancer. American Journal of Nursing, 85, 144–147.
- Easton, D.F., Bishop, D.T., Ford, D., & Crockford, G.P. (1993). Genetic linkage analysis in familial breast and ovarian cancer: Results from 214 families. *American Journal of Human Genetics*, 52, 678–701.
- Fathalla, M.F. (1971). Incessant ovulation—A factor in ovarian neoplasia? Lancet, 2, 163.
- Flam, F., Einhorn, N., & Sjövall, K. (1988). Symptomatology of ovarian cancer. European Journal of Obstetrics, Gynecology, and Reproductive Biology, 27, 53–57.
- Given, B. (2001). Into the millennium: Open the door and let the future in for cancer nursing research. *Oncology Nursing Forum*, 28, 647–654.
- Goff, B.A., Mandel, L., Muntz, H.G., & Melancon, C.H. (2000). Ovarian carcinoma diagnosis. *Cancer*, 89, 2068–2075.
- Grimes, D.A. (1993). Primary prevention of ovarian cancer. JAMA, 270, 2855–2856.
- Haley, S. (2000). Knowledge essential to ovarian cancer care. *Nursing Times*, 96(5), 41–42.
- Hall, L.L. (1997). Ovarian cancer: Stalking a stealthy killer. University of Alabama (UAB) Magazine, 17(2), 14–15.
- Hankinson, S.E., Colditz, G.A., Hunter, D.J., Willett, W.C., Stampfer, M.J., Rosner, B., et al. (1995). A prospective study of reproductive factors and risk of epithelial ovarian cancer. *Cancer*, *76*, 284–290.
- Harlow, B.L., Cramer, D.W., Bell, D.A., & Welch, W.R. (1992). Perineal exposure to talc and ovarian cancer risk. *Obstetrics and Gynecology*, 80, 19–26.
- Hartenbach, E. (1998). Pelvic masses in women: Deriving a diagnosis from obscure symptoms. *Consultant*, 38, 161–165, 169–170.
- Healy, M. (1997). Hidden killer. Nursing Times, 93(40), 31-32.
- Igoe, B.A. (1997). Symptoms attributed to ovarian cancer by women with the disease. *Nurse Practitioner*, 22(7), 122, 127–128, 130 passim.
- Ivey, C.L. (1994). When your patient has ovarian cancer. RN, 57(11), 26-32.
- Jemal, A., Murray, T., Samuels, A., Ghafoor, A., Ward, E., & Thun, M. (2003). Cancer statistics, 2003. CA: A Cancer Journal for Clinicians, 53, 5–26.
- Jennings-Dozier, K., & Mahon, S.M. (2000). Introduction: Cancer prevention and early detection—From thought to revolution. *Oncology Nursing Forum*, 27(Suppl. 9), 3–4.
- Kerlikowski, K., Brown, J.S., & Grady, D.G. (1992). Should women with familiar ovarian cancer undergo prophylactic oophorectomy? *Obstetrics* and Gynecology, 80, 701–707.

- Kjellgren, O. (1977). Ovarian cancer: A symposium. *Lakartidingen*, 74, 331. Martin, V.R. (2000). Listen for the "whispering disease." *Nursing*, 30(Suppl. 4), 6–7.
- Mellody, P. (1999). Negotiating optimal ovarian cancer care. Journal of Care Management, November, 7–12.
- National Cancer Institute. (2001). *Prevention of ovarian cancer*. Retrieved March 21, 2001, from http://www.cancer.gov/cancerinfo/pdq/prevention/ ovarian/healthprofessional
- National Cancer Institute. (2002). *Screening for ovarian cancer*. Retrieved March 4, 2002, from http://www.cancer.gov/cancerinfo/pdq/screening/ ovarian/healthprofessional
- National Institutes of Health. (1994). Ovarian cancer: Screening, treatment, and followup [NIH consensus statement]. Retrieved October 13, 2000, from http://text.nlm.nih.gov/nih/cdc/www/96yxt.html
- O'Rourke, J., & Mahon, S.M. (2003). A comprehensive look at early detection of ovarian cancer. *Clinical Journal of Oncology Nursing*, 7, 41–47.
- Ovarian Cancer Alliance Canada. (1998). *Information about ovarian cancer* [Brochure]. Vancouver, British Columbia, Canada: Author.
- Parazzini, F., LaVecchia, C., Negri, E., & Gentile, A. (1989). Menstrual factors and the risk of epithelial ovarian cancer. *Journal of Clinical Epidemi*ology, 42, 443–448.
- Piver, M.S., & Eltabbakh, G. (1997). Myths and facts about ovarian cancer. Melville, NY: PRR.
- Polychronopoulou, A., Tzonou, A., Hsieh, C.C., Kaprinis, G., Rebelakos, A., Toupadaki, N., et al. (1993). Reproductive variables, tobacco, ethanol, coffee and somatometry as risk factors for ovarian cancer. *International Journal of Cancer*, 55, 402–407.
- Portenoy, R.K., Thaler, H.T., Kornblith, A.B., Lepore, J.M., Friedlander-Klar, H., Kiyasu, E., et al. (1994). The Memorial Symptom Assessment Scale: An instrument for the evaluation of symptom prevalence, characteristics and distress. *European Journal of Cancer*, 30A, 1326–1336.
- Purdie, D., Green, A., Bain, C., Siskind, V., Ward, B., Hacker, N., et al. (1995). Reproductive and other factors and risk of epithelial ovarian cancer: An Australian case-control study. *International Journal of Cancer*, 62, 678–684.
- Ranney, B., & Ahmad, M.I. (1979). Early identification, differentiation and treatment of ovarian neoplasia. *International Journal of Gynaecology and Obstetrics*, 17, 209–218.
- Risch, H.A., Weiss, N.S., Lyon, J.L., Daling, J.R., & Liff, J.M. (1983). Events of reproductive life and the incidence of epithelial ovarian cancer. *American Journal of Epidemiology*, 117, 128–139.
- Sargis, N.M. (1983). Detecting ovarian cancer: A challenge for nursing assessment. Oncology Nursing Forum, 10(2), 48–52.
- Schildkraut, J.M., Bastos, E., & Berchuck, A. (1997). Relationship between lifetime ovulatory cycles and overexpression of mutant p53 in epithelial ovarian cancer. *Journal of the National Cancer Institute*, 89, 932–938.
- Shurpin, K.M. (1997). Clinical snapshot: Ovarian cancer. American Journal of Nursing, 97(4), 34–35.
- Smith, E.M., & Anderson, B. (1985). The effects of symptoms and delay in seeking diagnosis on stage of disease at diagnosis among women with cancers of the ovary. *Cancer*, 56, 2727–2732.
- Stratton, J.F., Pharoah, P., Smith, S.K., Easton, D., & Ponder, B.A. (1998). A systematic review and meta-analysis of family history and risk of ovarian cancer. *British Journal of Obstetrics and Gynecology*, 105, 493–499.
- Tait, D.L. (1998). Ovarian cancer. In E.A. Blechman & K.D. Brownell (Eds.), *Behavioral medicine and women* (pp. 211–215). New York: Guilford Press.
- Whittemore, A.S., Harris, R., & Intyre, J. (1992). Characteristics relating to ovarian cancer risk: Collaborative analysis of 12 US case-control studies. II. Invasive epithelial ovarian cancers in white women. *American Journal* of Epidemiology, 136, 1184–203.
- Wikborn, C., Pettersson, F., & Moberg, P.J. (1996). Delay in diagnosis of epithelial ovarian cancer. *International Journal of Gynaecology and Obstetrics*, 52, 263–267.
- Williams, L. (1992). Ovarian cancer screening. The search for cost-effective methods. *Postgraduate Medicine*, 92(8), 63–66, 72.

ONCOLOGY NURSING FORUM - VOL 30, NO 6, 2003