

An Ovarian Cancer Diagnosis-Seeking Process: Unraveling the Diagnostic Delay Problem

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Purpose/Objectives: To propose a conceptualization that identifies when diagnostic delays occur and suggests a delay-reduction strategy for the diagnosis of ovarian cancer.

Data Sources: Findings and extrapolations from published national and international research studies, research reviews, books, Internet sources, and a family-functioning research project.

Data Synthesis: Three phases of diagnosis seeking were identified. Self-care was characterized by self-diagnosis, self-interpretation of symptoms, and self-management. Primary provider care was characterized by misdiagnosis and ineffective symptom management. Specialist care was characterized by specialized examinations, tests, and definitive diagnoses. Diagnostic delays were associated with extended periods of self-care and the misinterpretation of symptoms in primary care.

Conclusions: Periods of opportunity for early diagnosis occurred in the early symptom stages, when self- and primary care were dominant.

Implications for Nursing: Women must be taught to self-monitor for early ovarian cancer symptoms. Primary care providers should be urged to attend frequent state-of-the-science updates that regard early symptoms as manifestations of ovarian cancer.

Delays in the diagnosis of ovarian cancer are a problem of international scope. Misperceptions about and misdiagnoses of the malignancy continue to contribute to late-stage tumor diagnosis for approximately 70%–75% of women with ovarian cancer (“NIH Consensus Conference,” 1995; Tait, 1999). The situation has been described as simply unacceptable in a society with modern technologies (Wikborn, Pettersson, & Moberg, 1996). Limited research support is available for developing and testing secondary screening strategies to address diagnostic delay. Delays in diagnosis result in the minimization or loss of the opportunity to attain a survival rate of approximately 90% for women with the malignancy (Almadrones, Gordon, & Fitch, 2002).

Significant advancements regarding ovarian cancer have been made in recent decades, particularly in the identification of individual risk factors and protective behaviors. The human genome has been mapped, a number of genetic mutations have been discovered, and personal and intergenerational genetic links have been identified more precisely. Blood, tissue, and molecular indicators, which might serve as gauges of future malignancy development, continue to be under intense study and clinical testing. As a result of the advancements, new regimens of chemopharmacology have been developed and now are available for treatment. Clinical assessments using family histories of cancer and individual risk factors have improved predictions of risk potential.

Key Points . . .

- For most women, early-stage ovarian cancer generates a characteristic cluster of symptoms that occurs primarily in the gastrointestinal system.
- Early symptoms are not recognized during the self-care phase as potential indicators of ovarian malignancy activation.
- Primary healthcare providers misdiagnose early symptoms of ovarian cancer 70%–75% of the time.
- The self-monitoring of symptoms is one delay-reduction strategy.

Current treatment goals focus on controlling the disease, increasing survival, and improving quality of life. Current prevention activities focus on women obtaining yearly bimanual pelvic examinations, including specialized tests, as needed, for localized and systemic disease detection; identifying individual risk factors and protective behaviors; and mapping the cancer history of families. However, none of these actions individually or collectively has proven to be effective in identifying early ovarian cancer development.

Basic research has focused on the discovery of primary prevention tests for asymptomatic women. At the same time, the development of clinically based secondary screening approaches to reduce delays in diagnosis has received less emphasis. The development of more precise knowledge regarding the early diagnosis-seeking process, the identification of delays embedded in the process, and the clarification of the structures and circumstances that support their continuance is needed.

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The purpose of this article is to offer an original conceptualization of diagnosis seeking that pinpoints when delays in diagnosis occur and suggests a delay-reduction strategy. The conceptualization is comprehensive and identifies specific time points when vulnerability to delays begins as well as some of the circumstances associated with such occurrences. The conceptualization encompasses the experiences of women and their families during the cancer illness process and identifies how early symptoms are self-managed and interpreted by individuals and providers in managed healthcare systems. A delay-reduction strategy is proposed that women and healthcare providers of various educational and cultural backgrounds readily can use.

Prevalence of Ovarian Cancer

Ovarian cancer is the fourth most common reproductive malignancy, and an estimated 16,210 deaths will occur as a result of the disease in 2005 in the United States (Jemal et al., 2005). Ovarian cancer comprises 4% of all cancers in women worldwide (Parkin, 1998), and approximately 100,000 women die annually as a result of the disease, with an international trend showing increases in death rates among women older than age 65 and decreases in younger women (Adami, Bergstrom, Persson, & Sparen, 1990; Ewertz & Kjaer, 1988; Hartge, Whittemore, Itnyre, McGowan, & Cramer, 1994; Oriel, Hartenbach, & Remington, 1999; dos Santos Silva & Swerdlow, 1995). The changes are thought to be the result of longer life expectancies for all women and the use of birth control pills by younger women.

Postmenopausal Caucasian women, particularly those in Northern Europe and North America, are more likely to contract the disease. Scandinavian countries report the highest incidence rate, 15 cases for every 100,000 women, whereas North America and Western Europe have intermediate rates of 3 cases per 100,000 women (Parkin, Pisani, & Ferlay, 1993). The cancer burden is rising among women in many countries in which sophisticated diagnostic technologies and specialist care are not available (Wilson, Tobin, & Young, 2004). Variations in ovarian cancer incidence, mortality, and survival rates exist among countries because of other influences on individual and social risk factors (Pecorelli, Favalli, Zigliani, & Odicino, 2003).

Data Sources

Data sources used to develop the conceptualization of the ovarian cancer diagnosis-seeking process consisted of findings and extrapolations from national and international research studies, research reviews, books, and Internet sources. In addition, a significant contribution came from the findings of a family-functioning research project that investigated the impact of an ovarian cancer diagnosis on selected aspects of family functioning, from prediagnosis through diagnosis and treatment.

Family-Functioning Project

Data from the family-functioning project provided ongoing accounts of the cancer journeys of families as they unfolded throughout the first postdiagnostic year of members' illnesses. The mixed-method design, methodology, and analysis of data have been reported in detail elsewhere (Koldjeski, Kirkpatrick,

Everett, Brown, & Swanson, 2004; Koldjeski, Kirkpatrick, Swanson, Everett, & Brown, 2003). Demographic data and questionnaire responses were obtained from family members, who responded as a unit about early symptoms, socioemotional responses to the illness, coping strategies, needs, and illness beliefs. Qualitative data regarding the lived experiences of families were obtained as the illness process unfolded in daily living.

Family profile: Eighteen families participated for a full year. Five visitations were made to each family. A total of 50 family members participated, and 90 interviews were collected. Sixteen families (89%) were Caucasian, and two (11%) were African American. Twelve of the women diagnosed with ovarian cancer (67%) were married and living with spouses, four (22%) were widows, and two (11%) were single and lived with their parents. The average age of those with the disease was 58 years and ranged from 28–73 years. Fifteen women (83%) had maternal relatives who had been diagnosed with breast, colon, or ovarian cancers, whereas four (22%) identified fathers or uncles who had been diagnosed with colon or other types of cancers.

Relevant findings: Many research studies have reported accounts of early symptoms, but the symptoms have not been used as major clinical indicators of early malignancy activation (Eltabbakh, Yadav, & Morgan, 1999; Flam, Einhorn, & Sjøvall, 1988; Goff, Mandel, Melancon, & Muntz, 2004; Goff, Mandel, Muntz, & Melancon, 2000; Olson et al., 2001; Ranney & Ahmad, 1979; Smith & Anderson, 1985; Vine, Ness, Calingaert, Schildkraut, & Berchuck, 2001; Wikborn et al., 1996). Conceptualizing the array of early symptoms as a cluster unified the symptom phenomenon because, alone, each symptom traditionally was associated with a number of common illnesses. Recognition that the symptoms of early ovarian cancer occurred primarily in the gastrointestinal system and occasionally in the urinary system, rather than in the reproductive system, indicated that the malignancy had effects that were not located at organ sites. The primary symptom phenomenon is described on the Web sites of the National Ovarian Cancer Coalition (2004), the Mayo Clinic (2004), and the University of Texas M.D. Anderson Cancer Center (2002).

Four problems and concerns emerged from the data provided by families in the family-functioning project: the need to recount fragmented and disconnected experiences in an effort to give them wholeness; difficulty obtaining information about the illness, tests, treatments, and side effects; difficulty obtaining needed assistance and resources; and efforts to establish positive family-healthcare provider relationships. Once treatments were under way, families perceived that the four concerns became the focus of medical care, with professional relationships and family concerns becoming a secondary focus.

Relevant Findings From the Literature

The time and range of diagnostic delays for ovarian cancer have been reported for quite some time in research from the United States and elsewhere. Reported delays have ranged from 2–52 weeks, with averages ranging from 3–36 weeks (Axtell, Asire, & Myers, 1976; Goff et al., 2000, 2004; Howard, 1998; Kjellgren, 1977; Koldjeski et al., 2003; Ranney & Ahmad, 1979; Schapira, Matchar, & Young, 1993). The studies found that neither patients nor initial healthcare providers perceived

early symptoms as indicative of a potential and serious health problem.

Goff et al. (2000) consolidated the many symptoms into the following categories: abdominal, gastrointestinal, pelvic, constitutional, urinary, and pain. The categorization imposed order on the wide array of symptoms by identifying the systems involved and problems experienced and was a significant contribution to medical diagnostic efforts. However, clinical assessments by nonmedical providers are limited because the categories do not facilitate the early recognition of a distinct symptom pattern that combines the common nonserious symptoms in a configuration that gives meaning to the symptoms as a group and indicates the early stages of the disease.

Several studies have examined the status of ovarian health education and knowledge of symptomatology among Canadian women and physicians (Fitch, Gray, DePetrillo, Franssen, & Howell, 1999; Fitch, Gray, & Franssen, 2001; Gray, Chart, Carroll, Fitch, & Cloutier-Fisher, 1999; Gray et al., 1999). Findings of the studies revealed the need for more up-to-date information about the illness, tests, and assessment guidelines to be incorporated into standard practice protocols. Goff et al. (2004) noted that a number of medical textbooks continue to indicate that the majority of women diagnosed with ovarian cancer do not have symptoms until the disease is advanced. Piver and Eltabbakh (1997) identified the misconception as well as many others that are widespread among women, healthcare professionals, and the general public.

The family cancer illness experience has been likened to a journey, with different phases, needs, and changes at various points for all members (Kristjanson & Ashcroft, 1994). Family participation in cancer care has been a concern of nursing for many years and often is exemplified by family members assisting with the care of ill loved ones (Breaden, 1997; Giacuinta, 1977; Gotay, 1984; Hilton, 1993; Odling, Danielson, Christensen, & Norberg, 1998). The shift of cancer illness management from hospitals to families, with the exception of emergencies and specialized procedures, now places families in a central position for the provision of cancer care. Family members initiate ideas, participate in actions involving the health and illness of members, and actively support prevention, treatment, and rehabilitation programs. In cases when families are not available, support networks and survivor groups may serve as "constructed families" to provide caring relationships and activate resources for needed services.

Theoretical Underpinnings

From the outset of the family-functioning project, the researchers assumed that families or a network of significant others were involved in the circumstances, actions, and decisions that women made when symptoms occurred, persisted, and intensified over time. A sociosystems approach from a healthy family-functioning perspective (Koldjeski, 1993) guided and informed searches for research and reports. The theoretical framework holds that when cancer occurs in a family, the family as a unit and all members in the system are affected in some measure (Delengowski, 1993). The system and its subsystems interconnect through roles, relationships, illness beliefs, goals, and genetic endowments. The factors blend to form an energy-generating whole that sustains

the family system and provides essential experiences for individual member support, development, growth, and goal seeking. As families live through a cancer illness experience (i.e., the cancer journey), they adapt, hopefully in ways that develop different perspectives and consider different life goals of members. As a result, the family as a unit is transformed by coping with a life-altering experience. The use of a systems perspective in family-functioning research is widespread as a formulation for theory and research; therefore, the new conceptualization involving diagnosis seeking had grounding from the outset (Feetham, 1991; Gillis, 1991).

Synthesis Building

Process

After recognizing that a new conceptualization was needed to encompass the dimensions of diagnostic delay in ovarian cancer, a synthesis-building process was selected. The purpose of the process was to address a problem that was characterized by known and unknown details with a paucity of reasons to explain their continued occurrence. A number of disparate findings had to be organized to form a logical sequence, show coherence, unify significant existing evidence, and generate new insights and directions. For this purpose, a quality synthesis was used to combine the research parts into a whole and stimulate the development of a creative formulation with distinctive features (Strike & Posner, 1983). The strategy effected a "problem shift" so that the situation could be viewed from a different angle (Blaikie, 1993) to stimulate the discovery of new knowledge.

A quality synthesis requires the use of multiple deliberate processes. Several processes were used, including analysis of state-of-the-science contributions, reflection, induction, deduction, trial and error, and abduction. Abduction as a deliberation process requires drawing away from existing positions to consider new ones that offer a fresh direction for explaining the phenomena of concern.

Ovarian Cancer Diagnosis-Seeking Process

The diagnosis-seeking process was embedded in family functioning to ground it at the empirical level as well as in an extension of a general health-seeking model to ground it at the theory level (Koldjeski et al., 2004). A problem shift was made from a focus on the symptom-disease-diagnostic delay to the phases of a journey in which the role of the healthcare provider was dominant. In each phase, family participation and individual actions were identified. Phases were arranged sequentially as they unfolded to interconnect individual experiences, family contributions, and healthcare providers. As the phases evolved, when and where diagnostic delays occurred in the cancer journey became evident. Descriptions of the progression of patients with cancer from one phase of care to another were enriched by accounts of families' experiences (DeMarco, Picard, & Agretelis, 2004; Miller & Nygren, 1978; Murtonen et al., 1998; Scannel, 1985; Thorne, 1985; Welch, 1981; Woods, Lewis, & Ellison, 1989).

Phases of the Diagnosis-Seeking Process

Three phases of care were identified and organized as the basis for the diagnosis-seeking process: self-care, primary

provider care, and specialist care. Illness processes, perceptions, policies guiding the practices of the managed care system, and the interpretation of symptoms by symptomatic women and their families, friends, and healthcare professionals interconnected the various phases. In each phase, the dominant care provider could have sought consultation and referrals from other providers; however, different perceptions and interpretations of symptoms influenced whether the actions were taken. Initially, the women in the project sought treatment from their primary care providers, and specialist care was not sought until the regimens of prescribed care proved ineffective. The construction of the three phases of the diagnosis-seeking process associated with ovarian cancer is shown in Figure 1.

Self-Care Phase

The self-diagnosis, self-interpretation, and self-management of early symptoms characterized the self-care phase, which began when women started to feel that “something” was not right. Lay diagnoses were based on symptoms, were not considered serious, and included ailments such as too much acid, a stomach virus, and indigestion. Treatments consisted

of over-the-counter remedies. Support by family members, friends, and relatives was provided for the lay diagnoses and self-treatment. The women continued their usual roles and responsibilities. The early gastrointestinal tract symptoms were uncomfortable but not debilitating and reinforced an interpretation that the ailments were temporary and not serious enough to seek medical care. Some unease was present, which women often handled by promising themselves that if the symptoms did not disappear soon, medical care would be sought. From a systems perspective, if abatement of symptoms occurred, a woman would not be involved in the subsequent phases. When the self-care phase continued beyond five to seven weeks, a point of vulnerability was reached. If primary provider care rather than specialist care was sought at that time, a strong possibility existed that a diagnostic delay would occur. In many of the anecdotal accounts reviewed, the window of opportunity for early diagnosis was missed because of an extended self-care phase.

Primary Provider Care Phase

This phase was activated when the symptoms experienced by the women persisted, intensified, increased in discomfort,

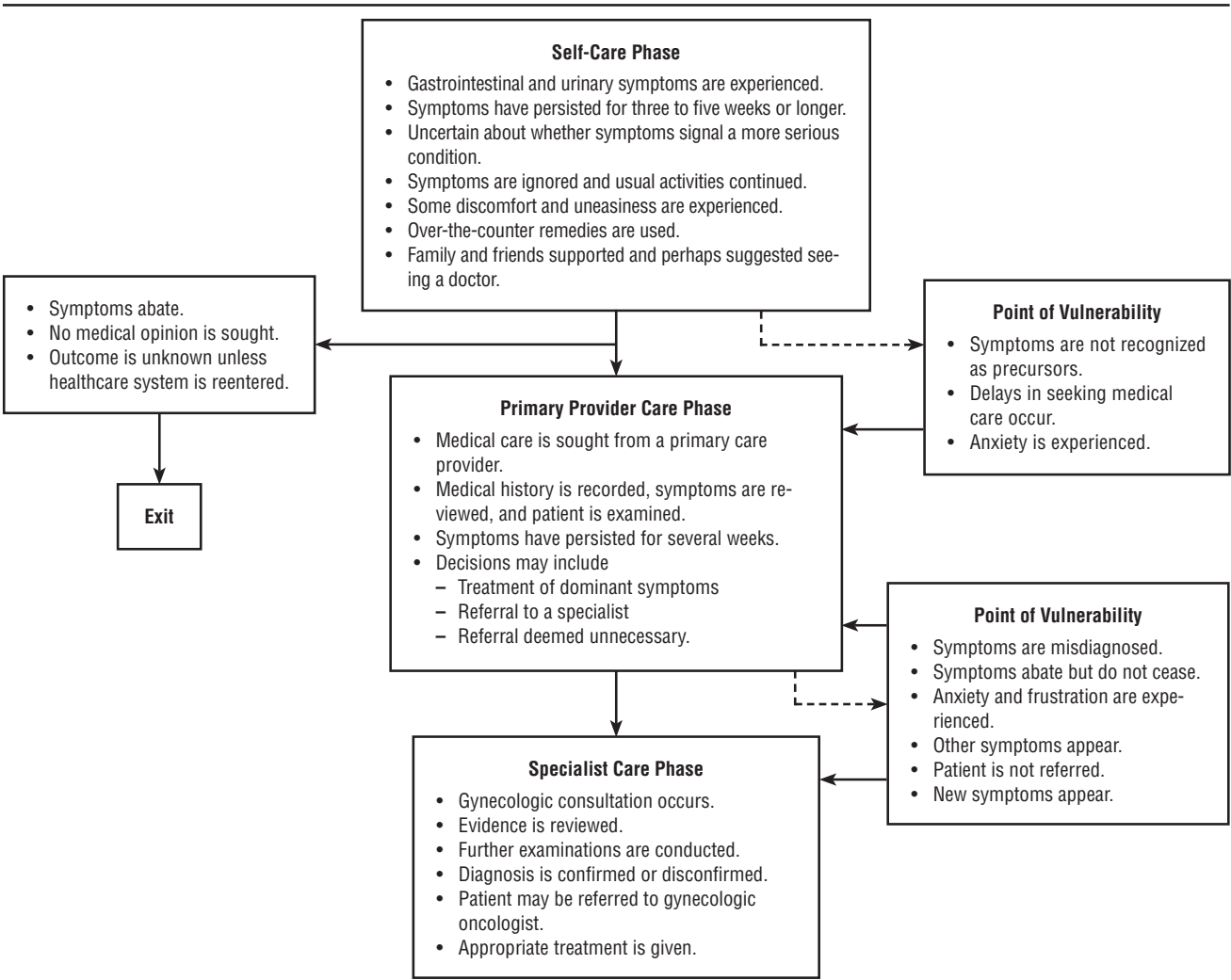


Figure 1. Phases of Diagnosis Seeking in Ovarian Cancer

and caused some pain. The earlier sense that “something is wrong” was replaced by “I have a problem.” The women usually sought medical care from a primary healthcare provider. One reason is because healthcare systems today are structured so that these professionals provide care for nonserious ailments and act as gatekeepers to specialist care. In this phase, standard examinations and tests did not show evidence that a serious problem existed but that the situation should be monitored. The diagnoses made by professional healthcare providers in the family-functioning project and reported by women in their anecdotal accounts did not differ to any extent from the self-diagnoses made earlier by the women. The diagnoses of healthcare providers were relabeled using standard medical terminology, and symptom management usually included prescriptive versions of over-the-counter remedies the women had used during the self-care phase.

At this juncture, a second point of vulnerability occurred. The women followed treatment regimens for several weeks and, when they proved ineffective, sought further consultation. Misinterpretation of clinical evidence resulted in misdiagnosis or discounting of symptoms. In this phase, approximately 75% of the women who presented with the characteristic symptom array continued to be misdiagnosed.

Specialist Care Phase

This phase began when symptoms neither abated nor disappeared over time and with treatment. The symptomatic women became convinced that they had a serious condition, and they wanted answers other than the ones they had received. Referral or self-referral to a gynecologic specialist occurred, at which time specialized examinations, tests, and clinical expertise became the basis for diagnosis. However, by the time women obtained care from a specialist, several weeks or months may have lapsed, and the malignancy may have developed to advanced stages. Once diagnosis was established, treatment was initiated promptly.

The construction of the diagnosis-seeking process related to ovarian cancer revealed that diagnostic delays are likely to occur in the self-care and primary provider care phases. The shift in conceptualization encouraged the development of a proposed diagnostic delay-reduction strategy. The conceptualization also sets the stage for field tests to determine whether early screening strategies would be effective in recognizing the characteristic cluster of symptoms now known to be associated with early malignancy activation of ovarian cancer.

Implications

The Institute of Medicine has emphasized that actualizing the potential of the United States for the prevention and early detection of cancer requires new strategies (Curry, Byers, & Hewitt, 2003). The strategies would require changing healthcare system policies and services, expanding practice standards, improving provider and consumer educational programs, and increasing public understanding of cancer prevention and early detection. According to Wilson et al. (2004), health education programs and prevention practices must be developed that are inexpensive, easily understood by women with diverse educational and cultural backgrounds, and able to be disseminated widely. These considerations were taken into account during the development of the new

conceptualization that describes where and when diagnostic delays occur in regard to ovarian cancer and the proposed reduction-type strategy.

Leadership in Prevention and Early Screening

Oncology nursing plays a key role in providing leadership in prevention and early screening strategies for ovarian cancer. The problem now is being addressed from several perspectives: molecular, genetic, blood, tissues, and radiologic. A nursing approach would use the knowledge and expertise of oncology nurses to expand standards of clinical assessments based on research evidence, apply varied interpretations to evaluate clinical phenomena, and give prompt referrals for medical specialist evaluation when needed.

Approaches need to be examined for emphasizing prevention and early screening by supporting innovative research projects, concentrating on prevention and early screening presentations and reports at conferences, and establishing recognition for innovations and contributions. Oncology nursing has a well-deserved reputation for excellence in cancer treatment and care and has the human and material resources to make a difference in preventive care by reducing diagnostic delays. For example, the breast self-examination model has been enormously successful in the identification of early growth activity. Such screening programs are not expected to be diagnostically decisive; rather, they alert women to seek prompt medical care, at which time expert judgment and sophisticated technologies may be used to augment the diagnostic process.

Ovarian Health Education

Ovarian health education programs tend to focus on the structures and functions of the ovaries in healthy women. Ovarian dysfunctions need to be considered in the context of other pelvic problems; however, special attention should be given to the two unique aspects of early-stage ovarian cancer: A number of common nondisease-specific symptoms are experienced as a cluster that persists and intensifies, and the cluster tends to occur primarily in the gastrointestinal and, to a lesser extent, urinary systems rather than the reproductive system. Symptom persistence for several weeks is an indication that gynecologic consultation is needed.

The roles of individual risk factors, family histories of cancer, and genetic factors need further emphasis in ovarian health education. Drapeau, Thouez, and Ghadirian (1995) observed that risk factors do not cause and protective behaviors do not prevent ovarian cancer development. Knowledge does not give women control of their ovarian destiny, which is a “chimerical illusion,” because few symptoms are subject to modification. However, such knowledge, when used as the basis for the development of specific delay-reduction strategies, is essential.

Focus on Women

Women, particularly postmenopausal women, need to become more knowledgeable about self-monitoring strategies for ovarian health until a test is developed that will be an effective and affordable primary prevention indicator. Clarification about the purpose and need for an annual standard bimanual pelvic examination for adult women is needed. Such examinations have proven to be effective in detecting anatomic and pelvic problems, local infections, and systemic diseases. However, specialized tests designed for the early detection of ovarian cancer, such as transvaginal sonography

and CA125, a tumor antigen test, have not shown sufficient effectiveness to recommend their use in preventive screening ("NIH Consensus Conference," 1995). To address diagnostic delay, women need approaches that are easy to use and sensitive enough to create an alert when the characteristic cluster of symptoms appears and persists for several weeks.

Women use self-care for many ailments that they perceive to be nonserious. However, teaching them not to rely on such efforts for too long if the characteristic symptom pattern fails to abate is important. Mapping the phases of diagnosis seeking showed that extended reliance on self-diagnosis sets the delay process in motion.

Focus on Primary Healthcare Providers

In managed healthcare systems, primary healthcare providers serve as generalists by caring for many common illnesses known to have effective standardized treatment protocols and act as gatekeepers to specialist care. State-of-the-science ovarian cancer health education is essential for such providers because they usually are the first professional providers women consult after self-care efforts fail.

Ovarian cancer education must stress that a different conceptualization regarding early symptom emergence needs to be used in addition to knowledge about personal and family risk factors. The recognition of a characteristic symptom cluster and its interpretation as a potential indicator of malignancy activation provide a rationale for initiating prompt referral to specialist care. In healthcare systems in which criteria for such referrals are maintained strictly, collaboration with other providers must occur to open a fast-track referral policy to specialist care because referrals are a critical factor for obtaining prompt diagnoses.

State-of-the-science ovarian health programs for primary healthcare providers should offer reeducation that emphasizes evidence that the malignancy has atypical manifestations that contribute to the misinterpretation of symptoms and misdiagnosis. Alternative formulations may encourage a higher level of awareness for clinical phenomena that vary from usual clinical paradigms.

Self-Monitoring as a Delay-Reduction Strategy

Of immediate value to women would be the inclusion of a self-monitoring plan as part of their preventive activities. Self-monitoring can be facilitated through the use of a diary-type tool (Koldjeski et al., 2004) that documents symptom experience. By using such a tool, women are given a role in early detection and become major players in the protection of their ovarian health. The purpose of this strategy is

to sensitize women to times when and places where their knowledge and observations serve as a first-line defense for reducing delays.

A checklist can consolidate aspects of family cancer history, personal risks, and menopausal status. The presence or absence of the frequently associated early occurring symptoms can be noted monthly to identify patterning if it occurs. The identification of patterning should be considered as an alert that prompt medical consultation should be sought. The goal of self-monitoring is not to teach women to become diagnosticians but rather to help them become effective monitors of this aspect of their reproductive health.

Conclusions

A conceptualization of the diagnosis-seeking process related to ovarian cancer has been formulated to identify the times and places in which diagnostic delays tend to occur during three phases of care: self-care, primary provider care, and specialist care. The conceptualization offers a different way of viewing the diagnosis-seeking process and facilitating the development of a delay-reduction strategy.

Delays in diagnosis are associated with the self-care and primary provider care phases. During self-care, a number of commonly occurring symptoms perceived as nonserious ailments contribute to their lack of recognition as potential indicators of an activated malignancy process. In the primary provider care phase, the characteristic cluster of symptoms often is not recognized or interpreted as a distinctive clinical indicator. Once specialist care is obtained, a diagnosis promptly can be made and treatment regimens begun.

Oncology nursing can expand its leadership in continuing education by focusing on state-of-the-science knowledge and supporting the development of screening approaches for early-stage ovarian cancer for women and primary healthcare professionals. A symptom self-monitoring approach is one diagnostic delay-reduction strategy; however, the development of others should be encouraged. Because of the rapid development of knowledge about ovarian cancer and its treatments, health education regarding the disease and clinical applications must be updated frequently. Nurses are in excellent positions and roles to provide leadership for the research and implementation of new strategies that address a major problem in the management of ovarian cancer.

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References

- Adami, H.O., Bergstrom, R., Persson, I., & Sparen, P. (1990). The incidence of ovarian cancer in Sweden, 1960–1984. *American Journal of Epidemiology*, 132, 446–452.
- Almadrones, L., Gordon, A.N., & Fitch, M.I. (2002). Perspectives on ovarian cancer: Treatment, interventions, and psychosocial concerns. In *Oncology Nursing Society 2002 Annual Congress and Symposia Highlights* (pp. 5–8). Wrightstown and Pittsburgh, PA: Medical Association Communications and the Oncology Nursing Society.
- Axtell, I.M., Asire, A.J., & Myers, M.H. (Eds.). (1976). *Cancer patient survival: Report Number 5* (DHEW Publication no. [NIH] 77–992). Bethesda, MD: U.S. Department of Health, Education, and Welfare, National Cancer Institute.
- Blaikie, N. (1993). *Approaches to social enquiry*. Cambridge, UK: Polity Press.
- Breaden, K. (1997). Cancer and beyond: The question of survivorship. *Journal of Advanced Nursing*, 26, 978–984.
- Curry, S.J., Byers, T., & Hewitt, M. (Eds.). (2003). *Fulfilling the potential for cancer prevention and early detection*. Washington, DC: National Academies Press.
- Delengowski, A.M. (1993). Effect of cancer on the family. In C.S. Fawcett (Ed.), *Family psychiatric nursing* (pp. 309–322). St. Louis, MO: Mosby.
- DeMarco, R.F., Picard, C., & Agretelis, J. (2004). Nurse experiences as cancer survivors: Part I—Personal. *Oncology Nursing Forum*, 31, 523–530.
- dos Santos Silva, I., & Swerdlow, A.J. (1995). Recent trends in incidence of

- and mortality from breast, ovarian and endometrial cancers in England and Wales and their relation to changing fertility and oral contraceptive use. *British Journal of Cancer*, 72, 485–492.
- Drapeau, A., Thoez, J.P., & Ghadirian, P. (1995). Homogeneity of the spatial distribution of cancers of the female reproductive tract in Quebec. *Social Science and Medicine*, 41, 949–955.
- Eltabbakh, G.H., Yadav, P.R., & Morgan, A. (1999). Clinical picture of women with early stage ovarian cancer. *Gynecologic Oncology*, 75, 476–479.
- Ewertz, M., & Kjaer, S.K. (1988). Ovarian cancer incidence and mortality in Denmark, 1943–1982. *International Journal of Cancer*, 42, 690–696.
- Feetham, S.L. (1991). Conceptual and methodological issues in research of families. In A. Whall & J.D. Fawcett (Eds.), *Family theory development in nursing: State of science and art* (pp. 55–68). Philadelphia: F.A. Davis.
- Fitch, M.I., Gray, R.E., DePetrillo, D., Franssen, E., & Howell, D. (1999). Canadian women's perspectives on ovarian cancer. *Cancer Prevention and Control*, 3, 52–60.
- Fitch, M.I., Gray, R.E., & Franssen, E. (2001). Perspectives on living with ovarian cancer: Older women's views. *Oncology Nursing Forum*, 28, 1433–1442.
- Flam, F., Einhorn, N., & Sjøvall, K. (1988). Symptomatology of ovarian cancer. *European Journal of Obstetrics, Gynecology and Reproductive Biology*, 27, 53–57.
- Giacquinta, B. (1977). Helping families face the crisis of cancer. *American Journal of Nursing*, 77, 1585–1588.
- Gillis, C.L. (1991). The family as a unit of analysis: Strategies for the nurse researcher. In A. Whall & J.D. Fawcett (Eds.), *Family theory development in nursing: State of the science and art* (pp. 197–208). Philadelphia: F.A. Davis.
- Goff, B.A., Mandel, L.S., Melancon, C.H., & Muntz, H.G. (2004). Frequency of symptoms of ovarian cancer in women presenting to primary care clinics. *JAMA*, 291, 2705–2712.
- Goff, B.A., Mandel, L.S., Muntz, H.G., & Melancon, C.H. (2000). Ovarian carcinoma diagnosis: Results of a national ovarian cancer survey. *Cancer*, 89, 2068–2075.
- Gotay, C.C. (1984). The experience of cancer during early and advanced stages: The views of patients and their mates. *Social Science and Medicine*, 18, 605–613.
- Gray, R.E., Chart, P., Carroll, J.C., Fitch, M.I., & Cloutier-Fisher, D. (1999). Family physicians' perspectives on ovarian cancer. *Cancer Prevention and Control*, 3, 61–67.
- Gray, R.E., Fitch, M., Saunders, P.R., Wilkinson, A., Ross, C.P., Franssen, E., et al. (1999). Complementary health practitioners' attitudes, practices and knowledge related to women's cancers. *Cancer Prevention and Control*, 3, 77–82.
- Hartge, P., Whittemore, A.S., Itnyre, J., McGowan, L., & Cramer, D. (1994). Rates and risks of ovarian cancer in subgroups of white women in the United States. The Collaborative Ovarian Cancer Group. *Obstetrics and Gynecology*, 84, 760–764.
- Hilton, B.A. (1993). Issues, problems, and challenges for families coping with breast cancer. *Seminars in Oncology Nursing*, 9, 88–100.
- Howard, B. (1998). Ovarian cancer: The diagnosis that doctors miss. *American Health for Women*, 17(2), 40–41, 44.
- Jemal, A., Murray, T., Ward, E., Samuels, A., Tiwari, R.C., Ghafoor, A., et al. (2005). Cancer statistics, 2005. *CA: A Cancer Journal for Clinicians*, 55, 10–30.
- Kjellgren, O. (1977). Ovarian cancer: A symposium. *Läkartidningen*, 74, 331.
- Koldjeski, D. (1993). Family mental health. In C.S. Fawcett (Ed.), *Family psychiatric nursing* (pp. 45–77). St. Louis, MO: Mosby.
- Koldjeski, D., Kirkpatrick, M.K., Everett, L., Brown, S., & Swanson, M. (2004). Health seeking related to ovarian cancer. *Cancer Nursing*, 27, 370–378.
- Koldjeski, D., Kirkpatrick, M.K., Swanson, M., Everett, L., & Brown, S. (2003). Ovarian cancer: Early symptom patterns. *Oncology Nursing Forum*, 30, 927–933.
- Kristjanson, L.J., & Ashcroft, T. (1994). The family's cancer journey: A literature review. *Cancer Nursing*, 17, 1–17.
- Mayo Clinic. (2004). *Ovarian cancer: Signs and symptoms*. Retrieved June 21, 2005, from <http://www.mayoclinic.com/invoke.cfm?objectid=EF55BD38-2667-4900-ACA0A74BD6F570D1&dsection=2>
- Miller, M.W., & Nygren, C. (1978). Living with cancer—Coping behaviors. *Cancer Nursing*, 1, 297–302.
- Murtonen, I., Kuisma, M., Paunonen, M., Lehti, K., Kiovuola, M., & White, M. (1998). Family dynamics of families with cancer in Finland. *Cancer Nursing*, 21, 252–258.
- National Ovarian Cancer Coalition. (2004). *Symptoms discovered for ovarian cancer*. Retrieved October 28, 2004, from <http://www.ovarian.org/press.asp?releaseID=281>
- NIH Consensus Conference. *Ovarian cancer screening, treatment, and follow-up. NIH Consensus Development Panel on Ovarian Cancer*. (1995). *JAMA*, 273, 491–497.
- Odling, G., Danielson, E., Christensen, S.B., & Norberg, A. (1998). Living with breast cancer: Care givers' perceptions in a surgical ward. *Cancer Nursing*, 21, 187–195.
- Olson, S.H., Mignone, L., Nakraseive, C., Caputo, T.A., Barakat, R.R., & Harlap, S. (2001). Symptoms of ovarian cancer. *Obstetrics and Gynecology*, 98, 212–217.
- Oriel, K.A., Hartenbach, E.M., & Remington, P.L. (1999). Trends in United States ovarian cancer mortality, 1979–1995. *Obstetrics and Gynecology*, 93, 30–33.
- Parkin, D.M. (1998). The global burden of cancer. *Seminars in Cancer Biology*, 8, 219–235.
- Parkin, D.M., Pisani, P., & Ferlay, J. (1993). Estimates of the worldwide incidence of eighteen major cancers in 1985. *International Journal of Cancer*, 54, 594–606.
- Pecorelli, S., Favalli, G., Zigliani, L., & Odicino, F. (2003). Cancer in women. *International Journal of Gynaecology and Obstetrics*, 82, 369–379.
- Piver, M.S., & Eltabbakh, G. (1997). *Myths and facts about ovarian cancer: What you need to know*. Huntington, NY: PRR.
- Ranney, B., & Ahmad, M.I. (1979). Early identification, differentiation and treatment of ovarian neoplasia. *International Journal of Gynaecology and Obstetrics*, 17, 209–218.
- Scannell, E.A. (1985). "I've seen cancer from both sides now": An oncology clinical nurse specialist shares her own cancer experience. *Cancer Nursing*, 8, 238–245.
- Schapira, M.M., Matchar, D.B., & Young, M.J. (1993). The effectiveness of ovarian cancer screening. A decision analysis model. *Annals of Internal Medicine*, 118, 838–843.
- 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.
- Strike, K., & Posner, E. (1983). Types of synthesis and their criteria. In S.A. Ward & L.J. Reed (Eds.), *Knowledge structure and use: Implications for synthesis and interpretation* (pp. 345–362). Philadelphia: Temple University Press.
- Tait, D.L. (1999). Ovarian cancer. In T. Stovall & F. Ling (Eds.), *Gynecology for the primary care physician* (pp. 211–215). Philadelphia: Current Medicine.
- Thorne, S. (1985). The family cancer experience. *Cancer Nursing*, 8, 285–291.
- University of Texas M.D. Anderson Cancer Center. (2002, September). *Family history aids ovarian cancer screening*. Retrieved June 21, 2005, from http://www.cancerwise.org/september_2002/display.cfm?id=B1503CFA-79DA-4503-A43C34176B4A1884&method=displayFull&color=green
- Vine, M.F., Ness, R.B., Calingaert, B., Schildkraut, J.M., & Berchuck, A. (2001). Types and duration of symptoms prior to diagnosis of invasive or borderline ovarian tumor. *Gynecologic Oncology*, 83, 466–471.
- Welch, D.A. (1981). Waiting, worry and the cancer experience. *Oncology Nursing Forum*, 8(2), 14–18.
- Wikborn, C., Pettersson, F., & Moberg, P.J. (1996). Delay in diagnosis of epithelial ovarian cancer. *International Journal of Gynecology and Obstetrics*, 52, 263–267.
- Wilson, C.M., Tobin, S., & Young, R.C. (2004). The exploding worldwide cancer burden: The impact of cancer on women. *International Journal of Gynecological Cancer*, 14, 1–11.
- Woods, N.F., Lewis, F.M., & Ellison, E.S. (1989). Living with cancer. Family experiences. *Cancer Nursing*, 12, 28–33.