

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

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

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.

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.

Dixie Koldjeski, RN, PhD, FAAN, is a distinguished professor emerita in the School of Nursing at East Carolina University in Greenville, NC, and president and director of Health Education Seminars and Consultation, Inc., in Morehead City, NC. Mary K. Kirkpatrick, RN, EdD, is a professor, Melvin Swanson, PhD, is a statistician, Lou Everett, RN, EdD, is a professor, and Sylvia Brown, RN, EdD, is a professor, all in the School of Nursing at East Carolina University. Research for the family-functioning project was funded by a grant from the ONS Foundation and the East Carolina University School of Nursing Research Initiative. (Submitted June 2004. Accepted for publication December 15, 2004.)

Digital Object Identifier: 10.1188/05.ONF.1036-1042

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.