

Perceptions of Distress in Women With Ovarian Cancer

Judith DellaRipa, PhD, RN, FNP-BC, Annemarie Conlon, PhD, MBA, MSW, LCSW, Debra E. Lyon, PhD, RN, FAAN, Suzanne A. Ameringer, PhD, RN, Debra Lynch Kelly, PhD, RN, OCN[®], and Victoria Menzies, PhD, RN, PMHCNS-BC

The diagnosis of ovarian cancer is unexpected and devastating for women and their families. Diagnosis may be complicated and delayed with the initial symptoms attributed to nonspecific physical and emotional conditions, such as fatigue, gastrointestinal and genitourinary alterations, menstrual irregularities, depression, and stress (Goff, Mandel, Muntz, & Melancon, 2000). Only 15% of women are diagnosed at an early stage when ovarian cancer is most responsive to treatment; 61% are diagnosed when the cancer is distant or metastasized. The relative five-year survival rate for all stages of ovarian cancer is 46%. Ovarian cancer is the fifth-leading cause of cancer-related death among women, but it accounts for only 5% of all cancer diagnoses in women in the United States (American Cancer Society, 2014).

Background and Significance

Results of research have suggested that women with ovarian cancer experience distress at multiple time points in the disease trajectory (Cain et al., 1983; Dawson, 1993; Lobchuk & Bokhari, 2008; Matulonis et al., 2008; Norton et al., 2004, 2005; Portenoy, Kornblith, et al., 1994; Portenoy, Thaler, et al., 1994). Qualitative studies have reported women's perspectives related to ovarian cancer diagnoses (Ferrell et al., 2005; Ferrell, Smith, Cullinane, & Melancon, 2003a, 2003b; Fitch, Deane, Howell, & Gray, 2002; Ponto, Ellington, Mellon, & Beck, 2010; Power, Brown, & Ritvo, 2008; Reb, 2007; Schulman-Green et al., 2012), including the challenges of late diagnosis and the treatment regimen (Ferrell et al., 2003b), communication difficulties with healthcare providers (Fitch et al., 2002), and concerns about the effect of the diagnosis on their loved ones (Ferrell, Smith, Ervin, Itano, & Melancon, 2003). In a systematic literature review, Arden-Close, Gidron, and Moss-Morris (2008) examined psychological distress, specifically anxiety and depression, and concluded that emotional distress was a part of the experience for many women

Purpose/Objectives: To explore women's experience of distress by asking "What do women with ovarian cancer want their spouse or significant other, family, friends, and healthcare providers to know about their experience of distress during diagnosis and treatment?"

Research Approach: Modified Glaserian grounded theory.

Setting: An urban setting in the Mid-Atlantic region of the United States.

Participants: 12 women, aged 21–71 years, diagnosed with and treated for ovarian cancer.

Methodologic Approach: Constant comparative analysis of data obtained by audio recorded interviews.

Findings: Although individual experiences differed, abstraction and conceptualization of the data supported a theory of existential assault. Participants found that the diagnosis was shocking and came "out of the blue like lightning." Their responses included seeking the best physician and treatment available, described as "no stone left unturned." Information about the disease was welcomed and unwelcomed as they shared the experience of "knowing what I don't want to know and not knowing what I want to know," and then had the added experience of sharing that information with those in their social network. Interpersonal interactions were described as "watching you watching me—we are both afraid," and "talking yet not talking about death," resulting in relationship changes and the realization that "now I have to take care of me."

Conclusions: Participants experienced diagnosis with and treatment for ovarian cancer as an existential assault that, with the potential for an early death, affected the individual and her relationships.

Interpretation: Previous studies have suggested that women diagnosed with and treated for ovarian cancer experience distress. This study reports women's perceptions of their own distress.

Key Words: distress; ovarian cancer; grounded theory; perceptions

ONF, 42(3), 292–300. doi: 10.1188/15.ONF.292-300

with ovarian cancer, particularly younger women and women diagnosed at a later stage.

The diagnosis and treatment of ovarian cancer may initiate profound effects to physiological, psychological,