

# Perspectives on the Impact of Ovarian Cancer: Women's Views of Quality of Life

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**Purpose/Objectives:** To describe quality-of-life (QOL) concerns particular to women with ovarian cancer and to examine whether subgroups of patients with ovarian cancer have significantly different QOL concerns.

**Design:** Mailed survey.

**Sample:** Readership of an ovarian cancer newsletter.

**Methods:** A total of 1,383 surveys were received in response to the survey's inclusion in the November 2002 issue of *Conversations! The International Newsletter for Those Fighting Ovarian Cancer*, a monthly newsletter circulated to 3,300 women with ovarian cancer (response rate = 42%). Women were asked to complete the 45-item City of Hope QOL Ovarian Cancer Tool (QOL-OVCA) and a short demographic questionnaire.

**Main Research Variables:** Patients' QOL-OVCA scores were compared across six independent variables, including disease status, age at diagnosis, stage at diagnosis, marital status, household income, and use of alternative therapy, controlling for survival time.

**Findings:** Ovarian cancer survivors reported significant QOL concerns across dimensions of physical, psychological, social, and spiritual well-being.

**Conclusions:** Patients with ovarian cancer experience particular QOL concerns requiring support. Future research is needed to describe the needs of survivors in more diverse populations and to develop and test interventions that can address these QOL concerns.

**Implications for Nursing:** Women with ovarian cancer experience QOL concerns common to other patients with cancer and some that are particular to ovarian cancer. Nurses should assess for and aggressively address these QOL concerns.

Ovarian cancer is the leading cause of gynecologic cancer death in the western world, with an incidence of approximately 14 cases for every 100,000 women (Ries et al., 2005). A total of 22,220 new cases of ovarian cancer are estimated for 2005, making it the seventh most common cancer diagnosed in American women (Ries et al.). The management of newly diagnosed patients generally is dependent on the extent of disease defined during surgical staging and cytoreduction. Standard initial therapy subsequent to surgical resection and staging most often is five to six courses of systemic chemotherapy with a platinum and taxane regimen (Piccart et al., 2000). This treatment approach results in a complete clinical response to therapy in 70%–80% of patients with advanced-stage disease with amelioration of most presenting symptoms. Recent literature has supported the addition of systemic chemotherapy to surgical management in a spectrum of patients with early-stage ovarian cancer (Trimbos et al., 2003).

## Key Points . . .

- ▶ Ovarian cancer survivors report significant concerns related to pain and other symptoms.
- ▶ Fears of recurrence and of dying are prevalent in ovarian cancer survivors.
- ▶ Quality of life is influenced by patient factors, including age, stage of disease, and disease status.

Despite the often-seen dramatic clinical response to treatment, the disease will recur in 60%–85% of patients diagnosed with advanced disease. Unfortunately, no proven curative therapy exists for this group of patients, and the optimal treatment approach for those with residual disease or those who relapse after initial therapy remains unknown. A growing number of new chemotherapeutic agents active in recurrent advanced ovarian cancer have been successful at providing a clinical response or stabilization of disease and thus are allowing recurrent ovarian cancer to be treated as a chronic disease. Because of these advances in therapeutic modalities, the number of ovarian cancer survivors for whom primary goals are to maximize disease-free survival and maintain quality of life (QOL) is growing.

As such, survivorship issues are becoming increasingly important, warranting further inquiry into the effects and benefits of long-term treatment on QOL. A growing body of literature supports the notion that the effects of treatment and QOL concerns in survivors of ovarian cancer are similar to other cancer survivors but also include issues specific to ovarian cancer

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(Ersek, Ferrell, Dow, & Melancon, 1997; Ferrell, Smith, Cullinane, & Melancon, 2003b; Ferrell, Smith, Ervin, Itano, & Melancon, 2003), including significant psychosocial concerns (Howell, Fitch, & Deane, 2003; Swenson, MacLeod, Williams, Miller, & Champion, 2003). This includes significant levels of distress, as well as impairment in functioning in the physical, psychological, social, and spiritual QOL domains. The current investigation sought to identify and provide quantitative data relating to physical, psychological, social, and spiritual well-being associated with the diagnosis of ovarian cancer using a disease-specific QOL tool adapted from the City of Hope four-dimensional QOL instrument (Ferrell, Dow, & Grant, 1995). The QOL tool was modified in a previous study of ovarian cancer survivors (Ersek et al.) and using qualitative data from more than 20,000 pieces of correspondence written by women with ovarian cancer (Ferrell et al., 2003a, 2003b; Ferrell, Smith, Ervin, et al.; Ferrell, Smith, Juarez, & Melancon, 2003). Thus, the City of Hope QOL Ovarian Cancer Tool (QOL-OVCA) focuses on the specific needs identified by the ovarian cancer survivor.

The following study questions were examined: (a) What are the prediagnosis symptoms experienced by women with ovarian cancer? (b) What are the greatest problems or fears of women with ovarian cancer? (c) What alternative therapies do women with ovarian cancer use? (d) Does overall QOL differ according to stage at diagnosis and treatment modality? (e) Does social well-being differ by socioeconomic characteristics? (f) What is the effect of platinum-containing treatment on physical QOL, and specifically on symptoms of neuropathy? (g) Does a difference exist in physical, psychological, or social QOL in women on or off treatment? (h) Do demographic and clinical characteristics significantly explain overall QOL?

## Theoretical Framework

The conceptual framework that guided this research was the model of QOL in cancer survivorship. The model depicts QOL as encompassing dimensions of physical, psychological, social, and spiritual well-being. The model has evolved from 1987 to the present during research at the City of Hope National Medical Center (Dow, Ferrell, Leigh, Ly, & Gulasekaram, 1996; Ferrell, Dow, Leigh, Ly, & Gulasekaram, 1995).

## Methods

### Subjects

A total of 3,300 surveys along with postage-paid envelopes were mailed to recipients of the November 2002 issue of the monthly newsletter *Conversations! The International Newsletter for Those Fighting Ovarian Cancer*. Surveys were returned by mail, coded, entered into ASCII files, and audited for accuracy. Surveys that were returned by family members or from patients with nonovarian gynecologic disease, low malignant potential, or benign ovarian tumors were excluded from analysis. The usable response rate was 42%. The study was approved by the City of Hope Institutional Review Board for the Protection of Human Subjects.

### Instruments

Women were asked to complete the QOL-OVCA, which includes 45 items scored from 0 (poor) to 10 (best) QOL

outcome. QOL items were recoded so that high values corresponded to high QOL. QOL-OVCA subscale and total scale internal consistency reliability coefficients and corrected item-total correlations were computed and are shown in Table 1. Despite the high coefficient alphas that compared favorably to the generic QOL tool, data from this large sample suggested that items related to the childbearing segment of the life cycle (changes in menstrual cycle and interference with fertility) should be removed from future versions of the tool along with the item on survivorship guilt, which perhaps was not well understood by the respondents. Those items had item-total correlations of less than 0.20. Correlation coefficients among the four subscale scores ranged from  $r = 0.16-0.71$ , indicating less than 50% overlap in variance between scores. Correlation coefficients between the four subscale scores and the overall QOL score were moderate to high ( $r = 0.53-0.93$ ). Measures of validity of the generic patient version include content validity with the Functional Assessment of Cancer Therapy instrument ( $r = 0.78$ ), and factor analysis (Dow et al., 1996). The instrument has demonstrated construct validity by discriminating between known groups. The OVCA version subscale scores are significantly and positively correlated with a single QOL item at the moderate level. Significant differences existed in overall QOL and subscale scores with regard to years of survival, with zero- to three-year survivors having significantly lower QOL than those who had survived six years or more. The 45 QOL items were factor analyzed using principal axis factoring with a varimax rotation. A four-factor solution was identified, confirming the multidimensional QOL model theorized by the investigators.

## Data Analysis and Statistical Methods

Any missing data were handled by creating a “missing” variable and by coding any survey that did not have answers for more than half of the items on any of the QOL subscales or the total scale as missing. Respondents whose surveys were classified as missing ( $n = 63$ ) were compared to the remainder of the sample with respect to age, cohabitation status, employment status, income, personal and familial predisposition toward cancer, disease status, elapsed survival time, and overall risk for cancer. None of these associations showed any statistical significance. Therefore, the cases were considered unbiased and were removed from the dataset, rather than inputting missing values.

Data were analyzed using SPSS® 11.5 for Windows (SPSS Inc., Chicago, IL). Descriptive statistics were computed, frequency distributions of explanatory variables of interest were examined, and categories were collapsed as needed. Descriptive statistics were used to answer study questions a–c. Analysis of covariance was used to test for differences between groups in answering study questions d–g, controlling for number of

**Table 1. Internal Consistency Reliability Coefficient Alphas**

| Subscale                 | Generic Patient Version | Ovarian Cancer Version |
|--------------------------|-------------------------|------------------------|
| Physical well-being      | 0.77                    | 0.80                   |
| Psychological well-being | 0.89                    | 0.91                   |
| Social well-being        | 0.81                    | 0.78                   |
| Spiritual well-being     | 0.71                    | 0.70                   |
| Overall quality of life  | 0.93                    | 0.92                   |

years since diagnosis. Research question d used overall QOL as the dependent variable and separately examined differences between the four major disease stages at diagnosis (I–IV), participation in alternative therapies (yes or no), risk factors (having at least one of three risk factors or not), and current disease status classified into three categories (newly diagnosed and under treatment, no evidence of recurrence, and recurrent disease under treatment or not). In addition, differences between age groups (45 or younger, 46–59, and 60 or older), marital status (married or cohabitating versus other), employment status (employed or not), and income (less than or more than \$50,000) were examined.

Research question e used social well-being as the dependent variable and compared indicators of socioeconomic status, including education, income, and employment status. Research question f used the single item regarding symptoms of neuropathy and the physical QOL subscale score as two dependent variables, and four categories of chemotherapy as the independent variable (cisplatin only, paclitaxel only, both, or neither). Research question g used the physical, psychological, and spiritual QOL subscale scores as three dependent variables and current treatment status of the respondent (on or off treatment). Research question h used selected demographic and clinical characteristics in a hierarchical logistic regression to explain membership in two extreme overall QOL groups (high QOL, ranging from 7–10 versus low QOL, ranging from 1–5). The covariate of number of years since diagnosis was tested in step one of this model.

## Results

From November 2002–February 2003, a total of 1,446 surveys were returned. Of those, 1,383 were usable for an effective response rate of 42%, providing 95% confidence in an error of the estimate of average QOL subscale and scale scores for the target population at  $\pm 0.056$ .

### Demographic and Clinical Characteristics of the Sample

Mean age at diagnosis was 53 years and at the time of the survey was 57 years, slightly less than the national averages. A vast majority of responses were from Caucasian women (95%), a finding similar to other support groups. Minority groups represented included Asian, African American, Hispanic/Latino, Middle Eastern, and Native American. Most of the women were married and living with their spouses (71%). Twenty percent had children still living at home. The majority of respondents had completed college (40%) or had graduate training (32%).

Specifics of each patient's disease and treatment are delineated in Table 2. About one-third of the women had been diagnosed within two to three years (31%); however, 21% of respondents were newly diagnosed (less than one year), 23% had been diagnosed four to five years earlier, and 24% were survivors of six years or more. The majority of patients had advanced disease at diagnosis (75% in stages III and IV). Despite this, half of the sample had no evidence of disease at the time of the survey. Four percent had been recently diagnosed and were in treatment at the time of the survey, and 35% had recurrent disease. Most women had undergone a total abdominal hysterectomy with bilateral salpingo-oophorectomy, whereas 4% had undergone an attempt at fertility preservation with a unilateral oophorectomy. Almost

**Table 2. Clinical Characteristics**

| Variable                                     | n     | %  |
|----------------------------------------------|-------|----|
| <b>Years since diagnosis</b>                 |       |    |
| $\bar{X} = 4.1$                              | –     | –  |
| SD = 3.3                                     | –     | –  |
| Range = 0–22                                 | –     | –  |
| ≤ 1                                          | 286   | 21 |
| 2–3                                          | 423   | 31 |
| 4–5                                          | 315   | 23 |
| ≥ 6                                          | 329   | 24 |
| Missing                                      | 30    | 2  |
| <b>Stage at diagnosis</b>                    |       |    |
| I                                            | 170   | 12 |
| II                                           | 136   | 10 |
| III                                          | 883   | 64 |
| IV                                           | 158   | 11 |
| Missing                                      | 36    | 3  |
| <b>Type of ovarian cancer</b>                |       |    |
| Adenocarcinoma                               | 354   | 40 |
| Epithelial                                   | 443   | 50 |
| • Serous                                     | 356   | 50 |
| • Mucinous                                   | 38    | 5  |
| • Endometrioid                               | 115   | 16 |
| • Clear cell                                 | 95    | 13 |
| Adenocarcinoma or epithelial                 | 82    | 9  |
| Other                                        | 110   | 15 |
| <b>Family members with ovarian cancer</b>    |       |    |
| Yes                                          | 286   | 21 |
| <b>Initial surgery</b>                       |       |    |
| Unilateral salpingo-oophorectomy             | 48    | 4  |
| Bilateral salpingo-oophorectomy (BSO)        | 121   | 9  |
| Total hysterectomy and BSO                   | 1,115 | 87 |
| <b>Chemotherapy</b>                          |       |    |
| Yes                                          | 1,347 | 98 |
| • Paclitaxel                                 | 1,223 | 88 |
| • Cisplatin                                  | 494   | 36 |
| • Carboplatin                                | 1,154 | 84 |
| • Topotecan                                  | 227   | 16 |
| • Gemcitabine                                | 223   | 16 |
| • Liposomal doxorubicin                      | 139   | 10 |
| • Etoposide                                  | 72    | 5  |
| • Other                                      | 360   | 26 |
| No                                           | 30    | 2  |
| <b>Current disease status</b>                |       |    |
| Newly diagnosed and under treatment          | 60    | 4  |
| Treatment completed and no recurrence noted  | 674   | 49 |
| Cancer has recurred (under treatment or not) | 481   | 35 |
| Missing                                      | 168   | 12 |

N = 1,383

Note. Not all patients had initial surgery or received chemotherapy. Because of rounding, not all percentages total 100.

all (98%) had received adjuvant chemotherapy, and few (9%) had received radiation therapy.

Given the growing understanding of the risks associated with hereditary disease among the public, the authors asked women to report whether they had a family history of breast or ovarian cancer and whether they had undergone genetic testing themselves. Only 8% reported that family members had undergone genetic testing. Although 21% had a family member with ovarian cancer and 46% reported a family history of breast cancer, only 14% had undergone genetic testing. These figures of family history of cancer are higher than population statistics.



## Prediagnosis Symptoms, Greatest Problems or Fears, and Alternative Therapies

As documented in the literature (Ersek et al., 1997; Ferrell, Smith, Ervin, et al., 2003), the vast majority of women described distinct prediagnosis symptoms (see Table 3). To understand what the greatest concerns were of the group as a whole, the authors added an open-ended question, “What is your biggest problem or fear right now?” One hundred and two different concerns were given, the 10 most common of which are listed in Table 4. The growing interest on the part of cancer survivors about complementary and alternative therapies was seen in the considerable number (32%) of women who were using complementary therapy. A total of 68 different complementary therapies were identified; of those, the most common were osteopathy (17%), acupuncture (13%), teas or herbs (11%), dietary (8%), and massage (7%).

### Quality of Life

As described previously, the QOL-OVCA included 45 items scored from 0 (poor) to 10 (best QOL outcome). QOL domain scores and overall score according to survival categories are shown in Table 5. Mean scores for the QOL domains were physical (7.19), psychological (5.38), social (6.23), and spiritual well-being (6.54). The mean total QOL score was 6.14. The issues detracting most from these women’s QOL were distress of initial diagnosis (1.46), distress of treatment (2.58), family distress (2.91), fear of recurrence (3.08), uncertainty (3.69), concern that relatives will be diagnosed with cancer (3.82), fear of a second cancer (4.20), fear of future diagnostic tests (4.55), sexuality (4.56), and fear of dying (4.86). Of note is that these are psychological, social, and spiritual, not physical, issues.

### Difference in Overall Quality of Life According to Selected Demographic or Clinical Characteristics

Descriptive statistics and adjusted QOL means for selected demographic and clinical characteristics are shown in Table 6. A significant difference existed in overall QOL according to disease stage at diagnosis after controlling for survival time ( $F [3,1318] = 7.83, p < 0.001$ ). QOL was significantly higher for those diagnosed at stages I or II (adjusted [adj]  $\bar{X} = 6.5$  and  $6.4$ , respectively) than for those diagnosed at stages III and IV (adj  $\bar{X} = 6.1$  and  $5.9$ , respectively). After controlling for survival time, no significant difference existed in overall QOL between those using alternative therapies and those not using

**Table 3. Symptoms Prior to Diagnosis**

| Symptom                            | n     | %  |
|------------------------------------|-------|----|
| <b>Experienced symptoms</b>        | 1,178 | 87 |
| Bloating                           | 924   | 67 |
| Fatigue                            | 622   | 45 |
| Abdominal pain                     | 579   | 42 |
| Other <sup>a</sup>                 | 400   | 29 |
| Urinary frequency                  | 394   | 29 |
| Constipation                       | 325   | 24 |
| Back pain                          | 282   | 20 |
| Decreased appetite                 | 278   | 20 |
| Vaginal bleeding                   | 175   | 13 |
| <b>Did not experience symptoms</b> | 170   | 13 |

<sup>a</sup> Most common “other” symptoms were bowel changes or diarrhea, pelvic pain, severe indigestion, excessive gas, and painful intercourse.

**Table 4. Ten Most Frequently Mentioned Concerns**

| Concern                                           | n   | %  |
|---------------------------------------------------|-----|----|
| Recurrence                                        | 774 | 56 |
| Death or dying                                    | 122 | 9  |
| Getting cancer under control or being cancer free | 60  | 4  |
| Managing treatment side effects                   | 42  | 3  |
| Running out of drugs or options for treatment     | 36  | 3  |
| Severe pain or neuropathy                         | 22  | 2  |
| Husband or family being left alone                | 21  | 2  |
| Financial or employment issues                    | 20  | 2  |
| Quality-of-life issues                            | 16  | 1  |
| Future chemotherapy radiation                     | 14  | 1  |

them. Women with at least one of three risk factors (Jewish heritage, family history of ovarian cancer, or family history of breast cancer) were classified as higher risk and compared with lower-risk women. The lower-risk group had significantly higher QOL (adj  $\bar{X} = 6.2$ ) compared with higher-risk women (adj  $\bar{X} = 6.1$ ), after controlling for survival time ( $F [1,1350] = 4.63, p = 0.032$ ). After controlling for survival time, women with no evidence of recurrence had a significantly higher QOL score (adj  $\bar{X} = 6.5$ ) than recently diagnosed women under treatment (adj  $\bar{X} = 5.9$ ) or women experiencing a recurrence (regardless of whether under treatment) (adj  $\bar{X} = 5.6$ ).

Younger women (45 years of age or less) had a significantly lower QOL score (adj  $\bar{X} = 5.6$ ) compared to middle aged or older women (adj  $\bar{X} = 6.0$  and  $6.4$ , respectively), after controlling for survival time ( $F [1,1349] = 23.21, p < 0.001$ ). Married or cohabitating women had significantly higher QOL scores (adj  $\bar{X} = 6.2$ ) than did women without partners (adj  $\bar{X} = 6.0$ ) after controlling for survival time ( $F [1,1347] = 4.37, p = 0.037$ ). Women with annual incomes above \$50,000 had significantly higher QOL scores (adj  $\bar{X} = 6.2$ ) than did women with lower incomes (adj  $\bar{X} = 6.0$ ) after controlling for survival time ( $F [1,1234] = 9.76, p = 0.002$ ). Finally, employed women had significantly higher QOL scores (adj  $\bar{X} = 6.3$ ) than did unemployed women (adj  $\bar{X} = 6.0$ ) after controlling for survival time ( $F [1,1334] = 12.72, p < 0.001$ ).

### Difference in Social Quality of Life According to Socioeconomic Variables

Women with annual incomes higher than \$50,000 had significantly higher social QOL scores (adj  $\bar{X} = 6.4$ ) than did women with lower incomes (adj  $\bar{X} = 5.9$ ) after controlling for survival time ( $F [1,1234] = 19.82, p < 0.001$ ). Employed women had significantly higher social QOL scores (adj  $\bar{X} = 6.4$ ) than did unemployed women (adj  $\bar{X} = 6.1$ ) after controlling for survival time ( $F [1,1334] = 14.53, p < 0.001$ ). After controlling for survival time, no significant difference existed in social QOL by education level.

### Effect of Platinum-Containing Treatment on Physical Quality of Life

Women were classified as taking no platinum-containing treatments ( $n = 74$ ), cisplatin only ( $n = 74$ ), paclitaxel only ( $n = 791$ ), or both cisplatin and paclitaxel ( $n = 409$ ). Women who took paclitaxel only had a significantly higher physical QOL score (adj  $\bar{X} = 7.3$ ) than did those who took both drugs (adj  $\bar{X} = 6.9$ ) after controlling for survival time ( $F [3,1343] = 4.84, p = 0.002$ ). In terms of neuropathic symptoms, however,

**Table 5. Quality of Life by Survival Time Since Diagnosis**

| Subscale                             | Zero to One Years<br>(n = 286) |      | Two to Three Years<br>(n = 423) |      | Four to Five Years<br>(n = 315) |      | Six Years or More<br>(n = 329) |      | Total<br>(N = 1,353) |      |
|--------------------------------------|--------------------------------|------|---------------------------------|------|---------------------------------|------|--------------------------------|------|----------------------|------|
|                                      | $\bar{X}$                      | SD   | $\bar{X}$                       | SD   | $\bar{X}$                       | SD   | $\bar{X}$                      | SD   | $\bar{X}$            | SD   |
| Physical well-being                  | 7.31                           | 1.61 | 7.09                            | 1.71 | 7.03                            | 1.81 | 7.35                           | 1.69 | 7.19                 | 1.71 |
| Psychological well-being             | 5.12                           | 1.68 | 5.24                            | 1.72 | 5.43                            | 1.60 | 5.73                           | 1.73 | 5.38                 | 1.70 |
| Social well-being <sup>a</sup>       | 6.15                           | 1.72 | 6.07                            | 1.76 | 6.22                            | 1.80 | 6.53                           | 1.80 | 6.23                 | 1.78 |
| Spiritual well-being                 | 6.58                           | 1.66 | 6.51                            | 1.79 | 6.43                            | 1.78 | 6.64                           | 1.80 | 6.54                 | 1.76 |
| Overall quality of life <sup>b</sup> | 6.05                           | 1.32 | 6.02                            | 1.40 | 6.10                            | 1.34 | 6.39                           | 1.43 | 6.14                 | 1.38 |

<sup>a</sup> Two to three years significantly lower quality of life than six years or more

<sup>b</sup> Zero to three years significantly lower quality of life than six years or more

women who were not exposed to platinum-containing treatments had significantly higher QOL (adj  $\bar{X}$  = 8.4) compared to the other three groups (adj  $\bar{X}$  = 6.2–6.8) after controlling for survival time (F[3,1333] = 11.35, p < 0.001). Descriptive statistics are shown in Table 7. Of note is that the covariate

was not significant in these analyses, explaining why the observed and adjusted means were nearly identical.

**Difference in Physical, Psychological, or Spiritual Quality of Life Based on Current Treatment Status**

A total of 451 women were on treatment when they completed the survey. The multivariate main effect for treatment status was significant (F[3,1319] = 40.99, p < 0.001). For each subscale, women on active treatment had significantly lower physical, psychological, and spiritual QOL than those not on treatment (see Table 8).

**Table 6. Differences in Overall Quality of Life by Selected Demographic or Clinical Characteristics**

| Characteristic                 | n     | $\bar{X}$ | SD   | Adj $\bar{X}$ | F     | p       |
|--------------------------------|-------|-----------|------|---------------|-------|---------|
| <b>Stage<sup>a</sup></b>       |       |           |      |               | 7.83  | < 0.001 |
| I                              | 169   | 6.52      | 1.27 | 6.50          |       |         |
| II                             | 136   | 6.43      | 1.30 | 6.40          |       |         |
| III                            | 864   | 6.05      | 1.37 | 6.06          |       |         |
| IV                             | 154   | 5.91      | 1.47 | 5.92          |       |         |
| Total                          | 1,323 | 6.13      | 1.37 | –             |       |         |
| <b>Risk</b>                    |       |           |      |               | 4.63  | 0.032   |
| High                           | 785   | 6.07      | 1.39 | 6.07          |       |         |
| Low                            | 568   | 6.22      | 1.37 | 6.23          |       |         |
| Total                          | 1,353 | 6.14      | 1.38 | –             |       |         |
| <b>Status<sup>b</sup></b>      |       |           |      |               | 63.45 | < 0.001 |
| Recently diagnosed             | 60    | 5.77      | 1.32 | 5.88          |       |         |
| No evidence of cancer          | 663   | 6.54      | 1.31 | 6.53          |       |         |
| Recurrence                     | 470   | 5.65      | 1.32 | 5.65          |       |         |
| Total                          | 1,193 | 6.15      | 1.38 | –             |       |         |
| <b>Age<sup>c</sup> (years)</b> |       |           |      |               | 23.21 | < 0.001 |
| ≤ 45                           | 134   | 5.63      | 1.38 | 5.65          |       |         |
| 46–59                          | 658   | 5.99      | 1.33 | 6.00          |       |         |
| ≥ 60                           | 561   | 6.42      | 1.37 | 6.41          |       |         |
| Total                          | 1,353 | 6.14      | 1.38 | –             |       |         |
| <b>Marital status</b>          |       |           |      |               | 4.37  | 0.037   |
| Not married or cohabitating    | 358   | 6.01      | 1.51 | 6.01          |       |         |
| Married or cohabitating        | 992   | 6.15      | 1.33 | 6.18          |       |         |
| Total                          | 1,350 | 6.14      | 1.38 | –             |       |         |
| <b>Income</b>                  |       |           |      |               | 9.75  | 0.002   |
| < \$50,000                     | 551   | 5.98      | 1.44 | 5.97          |       |         |
| > \$50,000                     | 686   | 6.21      | 1.30 | 6.21          |       |         |
| Total                          | 1,237 | 6.10      | 1.37 | –             |       |         |
| <b>Employment</b>              |       |           |      |               | 12.72 | < 0.001 |
| Employed                       | 552   | 6.29      | 1.25 | 6.29          |       |         |
| Unemployed                     | 785   | 6.02      | 1.46 | 6.02          |       |         |
| Total                          | 1,337 | 6.13      | 1.38 | –             |       |         |

Adj—adjusted

<sup>a</sup> Quality of life is significantly higher for those diagnosed at stage I or II than for those diagnosed at stage III or IV.

<sup>b</sup> Quality of life is significantly higher for those with no evidence of cancer than for the newly diagnosed or those with recurrence.

<sup>c</sup> Quality of life is significantly different among all three age groups.

**Effect of Demographic and Clinical Characteristics on Quality of Life**

Ten independent variables were examined to determine whether they explained levels of QOL using a hierarchical logistic regression in which survival time was entered first, followed by demographic and other clinical characteristics. The total QOL score was used to create high and low QOL groups. Twenty-three percent of the women were classified as having low QOL (scoring 1–5), and 24% were classified as having high QOL (scoring 7–10). Survival time (odds ratio [OR] = 1.1) was significantly positively associated with high

**Table 7. Effect of Treatment on Physical Quality of Life in General and Symptoms of Neuropathy in Particular**

| Symptom                                     | n     | $\bar{X}$ | SD   | Adj $\bar{X}$ | F     | p       |
|---------------------------------------------|-------|-----------|------|---------------|-------|---------|
| <b>Physical quality of life<sup>a</sup></b> |       |           |      |               | 4.84  | 0.002   |
| No platinum                                 | 74    | 7.51      | 1.55 | 7.46          |       |         |
| Cisplatin only                              | 74    | 7.33      | 1.85 | 7.15          |       |         |
| Paclitaxel only                             | 791   | 7.26      | 1.69 | 7.30          |       |         |
| Cisplatin and paclitaxel                    | 409   | 6.95      | 1.75 | 6.92          |       |         |
| Total                                       | 1,348 | 7.18      | 1.72 | –             |       |         |
| <b>Neuropathy symptoms<sup>b</sup></b>      |       |           |      |               | 11.35 | < 0.001 |
| No platinum                                 | 74    | 8.45      | 2.48 | 8.44          |       |         |
| Cisplatin only                              | 74    | 6.85      | 3.26 | 6.83          |       |         |
| Paclitaxel only                             | 784   | 6.83      | 3.11 | 6.83          |       |         |
| Cisplatin and paclitaxel                    | 406   | 6.24      | 3.12 | 6.24          |       |         |
| Total                                       | 1,338 | 6.74      | –    | –             |       |         |

Adj—adjusted

<sup>a</sup> Physical quality of life is significantly higher for those receiving paclitaxel only than for those receiving both paclitaxel and cisplatin.

<sup>b</sup> Neuropathy symptoms are significantly less troublesome for those who had no platinum-containing drugs compared to all other groups and for those who had paclitaxel only compared to those who had both paclitaxel and cisplatin.

**Table 8. Difference in Physical, Psychological, and Spiritual Well-Being Based on Treatment Status**

| Subscale                        | n     | $\bar{X}$ | SD   | Adj $\bar{X}$ | F      | p       |
|---------------------------------|-------|-----------|------|---------------|--------|---------|
| <b>Physical well-being</b>      |       |           |      |               | 118.11 | < 0.001 |
| On                              | 451   | 6.51      | 1.66 | 6.51          |        |         |
| Off                             | 873   | 7.55      | 1.63 | 7.55          |        |         |
| Total                           | 1,324 | 7.20      | 1.71 | –             |        |         |
| <b>Psychological well-being</b> |       |           |      |               | 43.84  | < 0.001 |
| On                              | 451   | 4.93      | 1.63 | 4.96          |        |         |
| Off                             | 873   | 5.62      | 1.70 | 5.60          |        |         |
| Total                           | 1,324 | 5.38      | 1.17 | –             |        |         |
| <b>Spiritual well-being</b>     |       |           |      |               | 13.24  | < 0.001 |
| On                              | 451   | 6.29      | 1.69 | 6.29          |        |         |
| Off                             | 873   | 6.66      | 1.79 | 6.66          |        |         |
| Total                           | 1,324 | 6.53      | 1.76 | –             |        |         |

Adj—adjusted

QOL ( $\chi^2(1) = 10.97, p = 0.001$ ) but did not improve on the correct prediction of QOL classification (56.6%). The entire equation significantly explained QOL groups ( $\chi^2(14) = 172.79, p < 0.001$ ), correctly predicting the QOL classification of 76% of the women. Age group, employment status, income, and disease status were the four significant explanatory variables (see Table 9), overshadowing survival time. High QOL is associated with being 60 years of age or older (OR = 62.9), being employed (OR = 2.8), having an income of more than \$50,000 per year (OR = 2.1), and having no current evidence of cancer (OR = 24.2). Low QOL is associated with being age 45 or younger (OR = 0.03) and having a recurrence (OR = 0.09).

## Discussion

Study findings are limited in application to the total population of ovarian cancer survivors because of the sample bias. Women who were readers of the newsletter and responded to the survey were predominantly Caucasian and had a higher

**Table 9. Influence of Demographic and Clinical Characteristics on Overall Quality of Life**

| Characteristic                 | Wald  | df | p       | Odds Ratio | 95% Confidence Interval |        |
|--------------------------------|-------|----|---------|------------|-------------------------|--------|
|                                |       |    |         |            | Lower                   | Upper  |
| <b>Survival time</b>           | 1.05  | 1  | 0.305   | 1.04       | 0.97                    | 1.11   |
| <b>Married or cohabitating</b> | 2.34  | 1  | 0.126   | 1.47       | 0.90                    | 2.40   |
| <b>Age group</b>               | 48.67 | 2  | < 0.001 |            |                         |        |
| Age > 60                       | 47.83 | 1  | < 0.001 | 62.87      | 19.44                   | 203.27 |
| Age ≤ 45                       | 20.86 | 1  | < 0.001 | 0.03       | 0.01                    | 0.13   |
| <b>Education</b>               | 1.96  | 3  | 0.58    |            |                         |        |
| < High school                  | 0.45  | 1  | 0.501   | 1.67       | 0.37                    | 7.51   |
| High school graduate           | 1.18  | 1  | 0.278   | 1.38       | 0.77                    | 2.47   |
| College                        | 1.51  | 1  | 0.22    | 1.37       | 0.83                    | 2.27   |
| <b>Employed</b>                | 16.59 | 1  | < 0.001 | 2.75       | 1.69                    | 4.47   |
| <b>Income &gt; \$50,000</b>    | 9.55  | 1  | 0.002   | 2.08       | 1.31                    | 3.30   |
| <b>Disease status</b>          | 59.97 | 2  | < 0.001 |            |                         |        |
| No evidence of cancer          | 28.13 | 1  | < 0.001 | 24.22      | 7.46                    | 78.65  |
| Recurrence                     | 16.25 | 1  | < 0.001 | 0.09       | 0.03                    | 0.29   |
| <b>Stage</b>                   | 3.73  | 1  | 0.054   | 0.76       | 0.58                    | 1.00   |
| <b>Alternative therapy</b>     | 0.18  | 1  | 0.673   | 1.11       | 0.69                    | 1.78   |
| <b>High-risk group</b>         | 0.48  | 1  | 0.49    | 0.86       | 0.56                    | 1.32   |

incidence of family breast and ovarian cancer. However, the authors believe the findings are relevant to the population and identify the need for future research in a larger and more diverse sample of ovarian cancer survivors. The findings also indicate important areas for nursing intervention in clinical practice.

Newer therapeutic modalities have changed the overall trajectory of disease in ovarian cancer (Markman, 2002; Markman & Bookman, 2000). Most patients with advanced ovarian cancer achieve a complete clinical remission after cytoreductive surgery and combination chemotherapy. Unfortunately, a large number of these patients will experience disease recurrence. Although second-line treatments are not curative, they may provide an improvement in QOL, provide palliation, and perhaps extend survival (Markman & Bookman; Michael & Tannock, 1998). Because survival time for this disease has been so short until recently, little opportunity has existed to study or intervene to improve QOL among these patients. As treatment has become more effective, however, more and more patients are experiencing extended survival, and now is the opportune time to begin to identify ways that patients maximize their QOL. Measuring the impact of treatment on QOL in this group of patients will be critical in assessing the ultimate utility of therapy (Markman; Michael & Tannock; Wenzel, Schmidinger, Locker, Jakesz, & Steger, 2002).

As such, the ability to measure QOL considerations has become more crucial, and assisting nurses in identifying and supporting women with the disease is essential. This study was undertaken to confirm data collected from correspondence (N = 21,806) describing the spontaneous reflections of the myriad of QOL issues facing patients with ovarian cancer and to ascribe demographic information to individual QOL assessment (Ferrell et al., 2003a, 2003b; Ferrell, Smith, Ervin, et al., 2003; Ferrell, Smith, Juarez, et al., 2003).

Women included were in various stages of survivorship, providing unique insights into the QOL issues faced throughout the trajectory of disease. Patients with a new diagnosis of ovarian cancer demonstrated significant distress in global QOL, most significant in the domains of physical, psychological, and social well-being. These data suggest that perhaps interventions aimed at addressing these concerns could improve the overall QOL of newly diagnosed women. As expected, patients with no evidence of disease scored significantly higher in overall QOL than those with recurrent disease; however, uncertainty still was present in this group as was the fear of recurrence. Patients with recurrent disease demonstrated the poorest QOL scores, suggesting that interventions to improve QOL are drastically needed.

The past decade also has contributed to the understanding of the genetic basis of cancer, including the increased risk of ovarian cancer in patients found to have a *BRCA1* or *BRCA2* mutation (Ford, Easton, Bishop, Narod, & Goldgar, 1994). Knowledge of high-risk status may contribute to perceptions of QOL, specifically with regard to the meaning of illness and in the context of family (Robson et al., 2003). The current survey also provided the ability to assess the incidence of genetic testing performed in a population of patients with ovarian cancer and its effect on QOL subscales. Striking in this group of patients was the number of women with a family history of breast (46%) or ovarian cancer (21%) and the few (14%) who had undergone genetic counseling or testing. Issues of

family distress and concern for relatives seen in women with ovarian cancer may be addressed in part by more aggressive referral for genetic counseling.

Future research is needed to develop and test interventions to improve QOL in ovarian cancer survivors. Understanding the needs of women throughout the trajectory of disease is of

paramount importance to nurses who, through a better understanding of the impact of treatment and disease, can better assist patients throughout diagnosis, treatment, and survivorship.

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