

# Role and Gender Differences in Cancer-Related Distress: A Comparison of Survivor and Caregiver Self-Reports

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**Purpose/Objectives:** To examine role and gender differences on measures of psychological distress as a consequence of dealing with cancer.

**Design:** Cross-sectional, descriptive, quantitative analyses of retrospective survey data.

**Setting:** A large, nonprofit, volunteer-based cancer organization. The sample was recruited through an online cancer survivor's network (61%), a rural event (24%), and hospital registries (15%).

**Sample:** Convenience sample of 135 cancer survivors matched to their family caregivers (N = 270).

**Methods:** Dyads (i.e., survivors and family caregivers) completed matched questionnaires requesting demographic and medical information and measures of cancer-related distress.

**Main Research Variables:** Role (i.e., survivor or caregiver), gender, and psychological distress.

**Findings:** Caregiver means on overall psychological distress were significantly higher than those shown for survivors. Caregiver scores were significantly higher on distress for diagnosis and fear of cancer recurrence. Females scored higher than male caregivers on cancer-related anxiety, future uncertainties, fear of recurrence, and future diagnostic tests. Gender differences were not found for survivor distress.

**Conclusions:** Results suggest a need for gender-specific, dyad-tailored cancer support services.

**Implications for Nursing:** As expert caregivers, nurses can provide valuable assistance with the caregiving process that may decrease distress during the family's cancer experience and adaptation period.

## Key Points . . .

- Lay caregivers experience the distress of a family member's cancer diagnosis as much as survivors.
- Because survivors' needs come first, family caregivers may not report their own distress.
- Female caregivers are particularly anxious about the possibility of future negative events.
- Professional nurses specializing in oncology are key in assisting cancer survivors and their family members successfully navigate and adapt to a cancer diagnosis.

Measures of psychological distress among informal caregivers generally are equal or surpass those of the family members for whom care is provided (Blanchard, Albrecht, & Ruckdeschel, 1997; Fang & Manne, 2001; Given et al., 1993; Kornblith, Herr, Ofman, Sher, & Holland, 1994). Overall, the results of most investigations have shown that patients' and their matched relatives' psychosocial status often are correlated highly (Baider & De-Nour, 1988; Cassileth et al., 1985; Epping-Jordan et al., 1999; Kurtz, Kurtz, Given, & Given, 1996); however, the effect of role based on gender has received little attention in the literature (Northouse et al., 1998).

The majority of the research on caregiving focuses on Alzheimer's disease. Relatively few studies have focused on cancer caregiving, but of those that have, the bulk of the research suggests that women generally report more distress than men (Baider, Koch, Esacson, & De-Nour, 1998; Hagedoorn, Buunk, Kuijer, Wobbles, & Sanderman, 2000; Lutzky & Knight, 1994; Morse & Fife, 1998). For example, in the few studies comparing the psychological distress of patients

A diagnosis of cancer is a psychological blow that can produce cognitive and emotional crises and persistent distress to survivors (Akechi, Okamura, Nishiwaki, & Uchitomi, 2001; Baum & Posluszny, 2001; Manne, Glassman, & DuHamel, 2001; Zabora, Brintzenhofesoc, Curbow, Hooker, & Piantadosi, 2001). However, cancer and how it is experienced are not limited to individual survivors; family caregivers also are affected (Fang & Manne, 2001; Ferrell, Grant, Borneman, Juarez, & terVeer, 1999; Matthews, Baker, & Spillers, 2003; Northouse, Templin, Mood, & Oberst, 1998). Because family caregivers often are key in providing support to cancer survivors (Fang & Manne), defining caregivers' reactions in the context of those of survivors' and elucidating the particular circumstances associated with major stress have important implications for survivors' and their family's well-being (Cassileth et al., 1985). The purpose of the current study was to examine role and gender differences on measures of psychological distress as a consequence of dealing with a cancer experience.

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with prostate cancer and their spouses, wives were more distressed than their husbands (Cliff & MacDonagh, 2000). Carlson, Ottenbreit, St Pierre, and Bultz (2001) found that female partners possessed a more accurate understanding of their husband's experience with prostate cancer than male partners had of their wife's breast cancer experiences. These results suggest that survivor and caregiver perceptions of the cancer experience may be influenced by gender. However, Zabora et al. (2001) found no evidence of gender differences on measures of distress among patients across a variety of cancer types.

Much of what is known about cancer and psychological distress is based on measures of depression or generalized affect (Baider et al., 1998; Gallagher, Wrabetz, Lovett, Del Maestro, & Rose, 1989; Given et al., 1993), although awareness has increased regarding the necessity to explore a broader range of psychological outcomes, such as anxiety (Raveis, Karus, & Pretter, 1999), fear (Clipp & George, 1992), uncertainty (Northouse et al., 1998), distress specific to a cancer diagnosis (Fang & Manne, 2001), treatment (Gotay, 1984), and recurrence (Blanchard et al., 1997), among cancer survivors and the impact on informal caregivers. In their comprehensive review of strategies to assist distressed caregivers, Northouse and Peters-Golden (1993) discussed the results of several studies indicating that threat associated with a cancer diagnosis is widespread. According to the results of these studies, fear of cancer and metastasis were the two primary concerns shared by cancer survivors and their caregivers.

Standard measures of distress capture global, generalized negative affect, but they may not measure negative affect specific to the cancer experience. Moreover, standard measures of distress often contain phrases that may be gender specific. If surveys ask more questions about types of distress typical of women (e.g., feeling blue) than about those typical of men (e.g., urges to injure someone), women may falsely appear more distressed (Nolen-Hoeksema, 1987) or men may falsely appear less distressed. Results from several studies were among the handful of empirical research efforts located that examined measures of distress specific to the cancer experience (Ferrell et al., 1999; Ferrell, Grant, Chan, Ahn, & Ferrell, 1995; Ferrell, Hassey-Dow, Leigh, Ly, & Gulasekaram, 1995). Empirical results from these studies indicated that cancer survivors and their family caregivers consistently reported worse outcomes for fear, anxiety, and distress resulting from initial cancer diagnosis, treatment, further diagnostic tests, recurrence, and uncertainty about the future than other quality-of-life measures. However, items focusing on specific cancer distress-related nodal points (i.e., diagnosis, treatment, or post-treatment diagnostics) were not the focus of these investigations nor were role and gender differences on cancer-related distress items compared.

In short, relatively little research has been conducted to investigate role and gender effects on cancer-related psychological distress among long-term survivors and their families. Most of the extant research on caregiving for adult patients with cancer has focused on samples comprised primarily of spouses. The extent of family members' (i.e., other than spouses) reactions to various dimensions of distress is unknown. Moreover, the results of several studies show inconsistent gender effects based on role and often focus primarily on survivors of breast cancer rather than different types of cancer, thereby limiting

generalizability (Carlson et al., 2001; Northouse et al., 1998; Zabora et al., 2001). Additionally, measures of depression and generalized distress often have been used that may not be sensitive enough to measure cancer-related distress. Based on the literature, role and gender were expected to affect appraisals of psychological distress in the current study. Specifically, the researcher hypothesized that (a) caregivers would report overall levels of cancer-related psychological distress that equaled or surpassed those shown for cancer survivors, (b) depending on role, fluctuations in appraisals of psychological distress would occur at different recalled nodal points (i.e., diagnosis, treatment, and future diagnostics) in the disease trajectory, and (c) regardless of role (i.e., survivor or caregiver), women would show greater cancer-related distress at diagnosis, during treatment, on recurrence, and about future uncertainties and have greater emotional response (e.g., anxiety, worry, fear) to the illness than men.

## Methods

### Sample

The current study focused on a subsample of 135 survivor-caregiver dyads who were determined to be matched pairs (i.e., the caregiver was a member of the survivor's immediate family, distant relative, partner, or friend). This cross-sectional pilot study was a part of a longitudinal, national quality-of-life study for cancer survivors and their family caregivers and was approved through Emory University's institutional review board. A total of 756 adult volunteers agreed to participate in the pilot study; of the 579 who returned questionnaires (77% return rate), 39 were omitted because the respondents failed to meet inclusion criteria (i.e., cancer survivor or nominated family caregiver of cancer survivor, English-speaking, and older than 18 years of age) or their questionnaires were grossly incomplete, resulting in a final sample size of 540 (71% response rate). The sample was recruited by a large, nonprofit, volunteer-based cancer organization located in the southeastern United States through an online cancer survivor's network (61%), a rural event for cancer survivors and family caregivers celebrating survivorship (24%), and hospital registries in Georgia (15%). Cancer survivors recruited from hospital registries and the online source were asked to name their primary caregiver who later was asked to participate. Caregivers accompanied cancer survivors attending the rural event.

Matching was determined by a combination of factors, including recruitment method, precoded questionnaires, and a series of interlocking questions that appeared on cancer survivor and caregiver questionnaires. For example, both sets of respondents were queried regarding relationships, gender, age, health status, cancer type, and time since diagnosis. Items that made statistical and logical sense from each member of the dyad's perspectives were determined as matched pairs. All participants received a letter of informed consent explaining the purpose of the study, the risks and benefits associated with the study, their rights as participants, and contact sources. Confidentiality was protected at all phases of the research study, and results were reported in aggregate form.

### Measures

In the current study, a cancer survivor was defined as any living person diagnosed with cancer (National Coalition for

Cancer Survivorship, 1986). Family caregivers were nominated by the survivors and defined in the questionnaires as unpaid, nonprofessional care providers who were members of the immediate family, distant relatives, or close friends (Houts, Nezu, Nezu, & Bucher, 1996). Caregiver distress was defined broadly to include anxiety, worry, fears, and other measures of negative affect related specifically to cancer diagnosis, treatment, or recurrence (Knight, Lutzky, & Macofsky-Urban, 1993).

Measures of caregiver and survivor distress were drawn from the **Quality of Life–Family (QOL-F)** and **Quality of Life–Cancer Survivor (QOL-CS)** tools (Ferrell, Hassey-Dow, & Grant, 1995; Padilla, Ferrell, Grant, & Rhiner, 1990). Selected items asked survivors and caregivers to appraise the level of distress associated with the initial cancer diagnosis, treatment modality, cancer-related anxiety, fear of cancer recurrence, worries about future diagnostic tests, uncertainty about the future of their loved one, and the impact of the illness on the family. Scores on these items have been consistently lower in previous administrations of the tools for patients with cancer and their caregivers (Ferrell et al., 1999; Ferrell, Hassey-Dow, Leigh, et al., 1995). Respondents were asked to read each question and circle a number to indicate the degree to which they agreed or disagreed with the statement according to word anchors on each end of the scale. Following instructions from Ferrell et al. (1999), all data were coded from 0 (best outcome) to 10 (worst outcome). Items reflecting cancer-related distress were summed and averaged for aggregate distress scores.

Previous psychometric analyses for QOL-CS have shown good test-retest reliability ( $r = 0.89$ ) and internal consistency (Cronbach's  $\alpha = 0.93$ ) for agreement between items and total scale scores (Ferrell, Hassey-Dow, Leigh, et al., 1995). Psychometric analysis of QOL-F also has shown adequate test-retest reliability ( $r = 0.68$ ), internal consistency ( $\alpha = 0.84$ ), and content validity (Ferrell, Grant, et al., 1995). In the current study, Cronbach's  $\alpha$  for the seven aggregated measures of distress indicated that the items were internally consistent for both caregiver ( $\alpha = 0.80$ ) and survivor ( $\alpha = 0.85$ ) distress subscales.

Sociodemographic variables for survivors and caregivers included age, education, gender, marital status, ethnic background, annual income level, cancer diagnosis, and years since diagnosis. Relationship variables queried respondents about their dyadic status. For example, survivors were asked whether their caregiver was their husband, wife, or other relative or friend. Caregivers also were asked if the person for whom they provided care was their husband, wife, or other friend or relative. Asking similar questions from both perspectives provided a check that the caregiver shared the same relationship as indicated by the survivor and vice versa.

## Procedures

Survivor-caregiver dyads completed similar questionnaires. Each questionnaire contained complete definitions of the terms “family” (i.e., relatives and close friends as well as immediate family members), “caregiving” (i.e., providing consistent help, such as physical care, emotional support, and transportation), and other nebulous terms to ensure equal understanding among participants. Caregiver items queried respondents about their experiences as family caregivers rather than eliciting their opinions regarding survivors' experiences.

Online participants were invited to join the study through a message posted on a Web site for cancer survivors. Interested participants called a toll-free number to talk to a member of the research team who obtained contact information. Online and hospital registry volunteers were sent questionnaires accompanied by a letter explaining the study and detailing informed consent. A self-addressed, prestamped envelope was included. Survivor questionnaires were sent in separate envelopes prior to mailing the caregiver questionnaires. Rural respondents who attended a meeting celebrating survivorship completed their questionnaires on site and returned the documents to the research team in person. Survivors and caregivers were asked to sit at different tables and complete their questionnaires without conferring with each other. Members of the research team monitored the process to ensure compliance with the request and answer respondents' questions. Return of the questionnaires implied informed consent.

## Results

On average, the majority of cancer survivors and their family caregivers tended to be white, married, and of similar age (see Table 1). Most reported that they had attended college and earned middle-range annual incomes. Caregivers tended to be men more often than women, and most reported that the person for whom they provided care was their wife or partner. Correspondingly, the majority of cancer survivors were female and their caregivers were more likely to be their husbands or partners; however, other relationships such as parents or siblings were present. Breast cancer was reported more often as the most recent diagnosis, followed by colorectal, non-Hodgkin's lymphoma, prostate, lung, and other cancer sites. Thirty-four percent of survivors reported less than two years had passed since their diagnosis, 31% were reportedly two to five years postdiagnosis, and 35% reported being more than five years postdiagnosis. About half of the subjects' tumors had been detected in the early stages of disease, and only 10% of the survivors reported a recurrence of the initial or any other type of cancer.

## Preliminary Analyses

No statistically significant differences were shown for age or marital or employment status for caregivers or survivors based on data collection sources. However, significant group differences were found among data collection sources for caregiver gender ( $\chi^2[1, N = 135] = 7.73, p < 0.005$ ), survivor income ( $\chi^2[3, N = 129] = 33.56, p < 0.001$ ), and survivor educational level ( $\chi^2[3, N = 131] = 8.87, p < 0.03$ ). A greater proportion of male caregivers participated online than did female caregivers, and survivors who participated online reported higher incomes and educational levels than survivors from other collection sources.

Analysis of variance did not show significant differences on any item of psychological distress depending on recruitment method among caregivers (Bonferri adjustment applied,  $\alpha = 0.05/7$  tests,  $p < 0.007$ ). Significant differences based on recruitment method were found among survivors for distress at diagnosis ( $F[2, 124] = 5.86, p < 0.004$ ), and uncertainty about the future ( $F[2, 131] = 5.11, p < 0.007$ ). Post hoc tests (Student Newman Keuls) showed that rural ( $\bar{X} = 6.74$ ) survivors were less distressed at diagnosis than survivors from online ( $\bar{X} = 8.57$ ) or registry ( $\bar{X} = 7.47$ ) sources. Rural ( $\bar{X} =$

**Table 1. Sociodemographic and Medical Characteristics**

| Characteristic                             | Survivors |    | Caregivers |    |
|--------------------------------------------|-----------|----|------------|----|
|                                            | n         | %  | n          | %  |
| <b>Age (years)</b>                         |           |    |            |    |
| Median                                     | 55        |    | 56         |    |
| $\bar{X}$                                  | 54.96     |    | 55.20      |    |
| SD                                         | 11.3      |    | 11.6       |    |
| Range                                      | 26–86     |    | 19–82      |    |
| <b>Years since most recent diagnosis</b>   |           |    |            |    |
| Median                                     | 4         |    |            |    |
| $\bar{X}$                                  | 4.90      |    |            |    |
| SD                                         | 3.57      |    |            |    |
| Range                                      | 1–17      |    |            |    |
| <b>Gender</b>                              |           |    |            |    |
| Female                                     | 96        | 71 | 64         | 47 |
| Male                                       | 39        | 29 | 71         | 53 |
| <b>Income (\$)</b>                         |           |    |            |    |
| ≤ 20,000                                   | 17        | 13 | 8          | 6  |
| 20,001–40,000                              | 27        | 21 | 34         | 28 |
| 40,001–75,000                              | 39        | 30 | 38         | 31 |
| > 75,000                                   | 46        | 36 | 43         | 35 |
| <b>Education</b>                           |           |    |            |    |
| High school (or less)                      | 27        | 21 | 41         | 33 |
| College attendance                         | 38        | 29 | 24         | 19 |
| College graduate                           | 34        | 26 | 29         | 23 |
| Graduate degree                            | 32        | 24 | 32         | 25 |
| <b>Ethnicity</b>                           |           |    |            |    |
| White                                      | 118       | 90 | 116        | 92 |
| Black                                      | 7         | 5  | 7          | 5  |
| Latino                                     | 4         | 3  | 2          | 2  |
| Other                                      | 2         | 2  | 1          | 1  |
| <b>Marital status</b>                      |           |    |            |    |
| Never married                              | 13        | 10 | 7          | 5  |
| Married                                    | 99        | 75 | 104        | 80 |
| Cohabiting                                 | 7         | 5  | 8          | 6  |
| Divorced                                   | 7         | 5  | 3          | 2  |
| Widowed                                    | 6         | 5  | 8          | 6  |
| <b>Relationship</b>                        |           |    |            |    |
| Husband                                    | 32        | 24 | 60         | 44 |
| Wife                                       | 60        | 44 | 32         | 24 |
| Friend                                     | 7         | 5  | 7          | 5  |
| Mother                                     | 9         | 7  | 9          | 7  |
| Father                                     | –         | –  | 1          | 1  |
| Brother                                    | 1         | 1  | –          | –  |
| Sister                                     | 6         | 4  | 7          | 5  |
| Aunt                                       | 1         | 1  | –          | –  |
| Child                                      | 10        | 7  | 9          | 7  |
| Niece                                      | –         | –  | 1          | 1  |
| Other                                      | 9         | 7  | 9          | 7  |
| <b>Cancer site (most recent diagnosis)</b> |           |    |            |    |
| Breast                                     | 53        | 39 |            |    |
| Colon or rectal                            | 11        | 8  |            |    |
| Kidney                                     | 6         | 4  |            |    |
| Lung                                       | 10        | 7  |            |    |
| Melanoma                                   | 1         | 1  |            |    |
| Non-Hodgkin's lymphoma                     | 11        | 8  |            |    |
| Ovarian                                    | 6         | 4  |            |    |
| Prostate                                   | 10        | 7  |            |    |
| Uterine                                    | 2         | 2  |            |    |
| Other                                      | 25        | 19 |            |    |
| <b>Cancer stage</b>                        |           |    |            |    |
| Early                                      | 63        | 47 |            |    |
| Middle                                     | 41        | 30 |            |    |
| Advanced                                   | 31        | 23 |            |    |

Note. N values vary from 123–135 for survivor-caregiver dyads. Because of rounding, percentages may not total 100.

3.30) survivors also felt more certain about their futures than survivors from online ( $\bar{X}$  = 5.02) or registry ( $\bar{X}$  = 5.90) sources.

Gender differences between caregivers and survivors on sociodemographic measures also were examined. No statistically significant gender differences were found among caregivers based on educational level, annual income, or ethnicity. Caregivers differed by gender on employment ( $C^2[1, N = 128] = 4.22, p < 0.04$ ) and marital status ( $C^2[1, N = 130] = 7.99, p < 0.005$ ). More men were employed outside the home; they also were more likely to be married to the person for whom they provided care. Gender differences were not found among cancer survivors on any socioeconomic variable. No statistically significant gender differences were found among survivors based on disease stage ( $C^2[2, N = 13] = 0.81, p = 0.668$ ) nor were gender differences found among caregivers based on stage of cancer during caregiving ( $C^2[2, N = 135] = 4.49, p = 0.106$ ).

### Primary Analysis

Individual distress items were aggregated for a measure of overall distress. Scores obtained by caregivers who provided care to spouses ( $\bar{X}$  = 6.20, SD = 1.89) were essentially identical to scores attained by caregivers who provided care to other family members ( $\bar{X}$  = 6.51, SD = 2.03) on overall caregiver distress ( $F[1, 133] = 0.682, p = 0.410$ ). Similarly, no significant differences were shown between the scores obtained by survivors who received care from spouses ( $\bar{X}$  = 5.82, SD = 2.25) or other family members ( $\bar{X}$  = 5.64, SD = 2.32) on survivor distress ( $F[1, 133] = 0.161, p = 0.689$ ). Therefore, caregiver relationship scores for the categories “spouses” and “other relatives” were pooled and treated as a single group in subsequent analyses. Survivor relationship scores also were combined.

A significant association was found between aggregated distress scores for caregivers and survivors ( $r = 0.40, p < 0.001$ ). Paired sample statistics, used to investigate the first hypothesis, indicated that the means for caregivers ( $\bar{X}$  = 6.28, SD = 1.92) on aggregated levels of distress were higher than the aggregated means for survivor ( $\bar{X}$  = 5.77, SD = 2.26) distress ( $t[134] = 2.54, p < 0.012$ ).

As shown in Table 2, the item means for survivor distress were generally lower than those for caregivers. Significant but moderate bivariate correlation coefficients were shown between survivors and their caregivers for almost all items. Therefore, related measures procedures were used to investigate the second hypothesis. Results of paired t tests on individual distress items at various nodal points of the disease (i.e., diagnosis, treatment, recurrence, and future diagnostics such as test worries) showed that caregivers' mean scores were significantly higher than survivors' mean scores on distress caused by diagnosis and fear of cancer recurrence controlling for type I error (see Table 2). Cancer survivors did not differ from caregivers on any of the remaining distress measures, although trends were shown for anxiety and future diagnostic test worries.

To investigate the third hypothesis, a two (role: survivor and caregiver) by two (gender) analysis of covariance was performed on overall distress, controlling for years since diagnosis. Gender differences were detected among caregivers ( $F[1, 132] = 8.66, p < 0.004$ ) but were not shown among survivors ( $F[1, 132] = 0.16, p = 0.687$ ) on aggregated measures

**Table 2. Distress by Role**

| Variable        | Survivor  |      | Caregiver |      | r    | p                    | $\bar{X}$ Difference | SD   | t    | df  | p <sup>†</sup>     |
|-----------------|-----------|------|-----------|------|------|----------------------|----------------------|------|------|-----|--------------------|
|                 | $\bar{X}$ | SD   | $\bar{X}$ | SD   |      |                      |                      |      |      |     |                    |
| Diagnosis       | 7.98      | 2.70 | 8.83      | 2.20 | 0.15 | 0.091                | 0.85                 | 3.12 | 3.08 | 126 | 0.003 <sup>†</sup> |
| Treatment       | 7.11      | 2.81 | 7.52      | 2.71 | 0.27 | 0.003 <sup>**</sup>  | 0.41                 | 3.35 | 1.36 | 124 | 0.175              |
| Anxiety         | 3.88      | 2.65 | 4.50      | 2.86 | 0.32 | 0.001 <sup>***</sup> | 0.61                 | 3.22 | 2.15 | 126 | 0.033              |
| Recurrence      | 5.67      | 3.45 | 6.74      | 3.20 | 0.37 | 0.001 <sup>***</sup> | 1.07                 | 3.73 | 3.17 | 122 | 0.002 <sup>†</sup> |
| Diagnostic test | 5.06      | 3.30 | 4.24      | 3.26 | 0.18 | 0.043 <sup>*</sup>   | 0.83                 | 4.19 | 2.18 | 123 | 0.031              |
| Family          | 6.54      | 2.91 | 6.56      | 2.62 | 0.39 | 0.001 <sup>***</sup> | 0.12                 | 3.07 | 0.06 | 122 | 0.953              |
| Uncertainty     | 4.74      | 3.25 | 5.15      | 3.43 | 0.30 | 0.001 <sup>***</sup> | 0.41                 | 3.96 | 1.19 | 130 | 0.236              |

Note. N values vary from 123–131 for survivor-caregiver dyads.

\* p < 0.05

\*\* p < 0.01

\*\*\* p < 0.001

† p < 0.007

of cancer-related distress. Years since most recent cancer diagnosis were not significant on overall distress among survivors or their caregivers. A comparison of survivor and caregiver means by gender based on individual distress items is shown in Table 3. Controlling for years since diagnosis, results of a two (role) by two (gender) multiple analysis of covariance indicated that gender differences were significant only among caregivers. Female caregivers scored significantly higher than male caregivers on cancer-related anxiety, fear of cancer recurrence, worry about diagnostic tests, and uncertainty about the future. Gender differences among caregivers were not found on perception of familial distress or distress related to cancer diagnosis or treatment.

## Discussion

The primary goal of the current investigation was to examine role and gender differences on appraisals of psychological distress as a consequence of dealing with cancer. A high degree of concordance between survivors and their family caregivers on global distress and at various nodal points recalled in the disease trajectory was shown. As hypothesized, caregivers' appraisal of global cancer-related distress was

higher than that reported by survivors. Partial support was found for the second and third hypotheses. Caregivers reported significantly greater distress regarding the cancer diagnosis than did survivors themselves. Caregivers also reported greater fear of a cancer recurrence in their family members than survivors. Role differences on distress caused by treatment and future diagnostic test worries were not found, but gender differences by role on distress were partially supported. Female caregivers perceived more distress than male caregivers, but gender differences were not evident among survivors.

Overall, the results of this study support previous research (Cassileth et al., 1985; Fang & Manne, 2001; Ferrell et al., 1999; Northouse et al., 1998), suggesting that cancer does have pervasive effects on survivors and family members, and extend the literature by pinpointing particularly distressing areas of concern. The association between survivors' and caregivers' level of family distress were statistically significant, suggesting that the cancer experience was not an independent event but one that affected the family unit as a whole. Anxiety, treatment distress, fear of recurrence, worries about future diagnostic tests, and uncertainties about the future characterized other shared concerns. These data suggest a

**Table 3. Cancer-Related Distress by Role and Gender**

| Variable        | Survivor  |      |    |           |      |    |      |        |       | Caregiver |      |    |           |      |    |      |        |                    |
|-----------------|-----------|------|----|-----------|------|----|------|--------|-------|-----------|------|----|-----------|------|----|------|--------|--------------------|
|                 | Male      |      |    | Female    |      |    | F    | df     | p     | Male      |      |    | Female    |      |    | F    | df     | p                  |
|                 | $\bar{X}$ | SD   | n  | $\bar{X}$ | SD   | n  |      |        |       | $\bar{X}$ | SD   | n  | $\bar{X}$ | SD   | n  |      |        |                    |
| Diagnosis       | 7.41      | 2.81 | 37 | 8.21      | 2.63 | 90 | 2.36 | 1, 125 | 0.127 | 8.79      | 1.84 | 71 | 8.90      | 2.15 | 63 | 0.11 | 1, 132 | 0.736              |
| Treatment       | 7.31      | 2.56 | 36 | 7.03      | 2.91 | 89 | 0.24 | 1, 123 | 0.626 | 7.11      | 2.70 | 71 | 7.98      | 2.56 | 63 | 3.65 | 1, 132 | 0.058              |
| Anxiety         | 4.06      | 2.82 | 36 | 3.81      | 2.60 | 91 | 0.21 | 1, 125 | 0.645 | 3.96      | 2.55 | 71 | 5.16      | 3.01 | 64 | 6.26 | 1, 133 | 0.014 <sup>*</sup> |
| Recurrence      | 5.64      | 3.44 | 36 | 5.69      | 3.84 | 87 | 0.01 | 1, 121 | 0.941 | 6.29      | 3.03 | 70 | 7.40      | 3.14 | 63 | 4.24 | 1, 131 | 0.042 <sup>*</sup> |
| Diagnostic test | 4.92      | 3.24 | 37 | 5.19      | 3.34 | 91 | 0.17 | 1, 126 | 0.679 | 3.69      | 3.01 | 70 | 5.03      | 3.44 | 61 | 5.71 | 1, 129 | 0.018 <sup>*</sup> |
| Family          | 6.49      | 3.11 | 37 | 6.63      | 2.77 | 91 | 0.06 | 1, 126 | 0.803 | 6.38      | 2.56 | 69 | 6.89      | 2.58 | 61 | 1.27 | 1, 128 | 0.262              |
| Uncertainty     | 4.41      | 3.45 | 39 | 4.86      | 3.17 | 95 | 0.54 | 1, 132 | 0.466 | 4.51      | 3.26 | 69 | 5.87      | 3.50 | 62 | 5.32 | 1, 129 | 0.023 <sup>*</sup> |

Note. N values vary from 123–134 for survivors and 130–135 for caregivers.

\* p < 0.05

mutuality of psychological response. Rabkin, Wagner, and Del Bene (2000) asserted that when concordance between patient and caregiver distress is high, attention to the emotional health needs of caregivers may alleviate patients' distress.

Compared to survivors, caregivers reported significantly greater distress about the diagnosis of their family member's cancer and greater fear for the return of cancer. Too few survivors reported a cancer recurrence (10%) to test whether an actual recurrence is as distressing for the caregiver as fear of recurrence; future studies are needed to address this issue. Significant gender differences on the various aspects of distress were not found among cancer survivors. However, female caregivers were more anxious, fearful of a recurrence of their loved one's cancer, uncertain about the future of the person for whom they provided care, and worried about diagnostic tests in the future than male caregivers. These results support those reported in the literature (Baider et al., 1998; Lutzky & Knight, 1994; Morse & Fife, 1998) and are consistent with the results of more recent studies that also suggest that female caregivers are likely to experience greater cancer-related distress than male caregivers (Carlson et al., 2001; Cliff & MacDonagh, 2000; Hagedoorn et al., 2000). The results of the current study add to this literature by pinpointing specific areas of distress that may be amenable to intervention.

## Limitations

These findings should be interpreted in light of several methodologic limitations. First and foremost, the cross-sectional design limits conclusions based on temporal and causal relationships among variables. However, results from the current pilot study were meant to inform the larger, longitudinal study that now is under way. Another limitation that restricts the generalizability of the study findings is the nonrepresentative nature of the sample. Although efforts were made to recruit participants from a variety of sources, the sample was nonrandom and consisted primarily of whites who generally had at least some postsecondary education. Participants who voluntarily responded to media and press announcements or who were recruited from online services or by word of mouth may be different from those who were not represented in the sample; every effort was made to examine potential sources of bias caused by recruitment source, but little evidence was found. The few recruitment source differences that were found (e.g., online caregivers tended to be more educated and earn higher incomes) were expected and logical for the population. The findings of this study cannot be generalized to people of color, the poor, or cancer survivors in advanced stages of disease. Additionally, the sample in the current study, like the majority of others in the literature, consisted mainly of spousal or partner-type relationships between survivors and caregivers. Although the researchers wanted to examine gender differences on distress depending on relationship or disease status, categorically, the number of participants

was too small to analyze. Given these limitations, these findings must be viewed as an additional step in understanding the cancer experience from multiple perspectives and outcomes.

Several strengths of the study also should be noted. For example, the researchers sought to include rural respondents and members of nontraditional family groups in the sample. Additionally, male and female caregivers were represented almost equally. The current study also focused on long-term survivors. Only a few studies could be located (e.g., Andrykowski & Cordova, 1998; Cordova, Cunningham, Carlson, & Andrykowski, 2001) that examined cancer and its effects for at least five years postdiagnosis. Moreover, the current study was the first of its kind to go beyond generalized measures of distress and pinpoint specific areas of distress that occurred over the illness process that may be useful for planning interventions.

Rigorous statistical procedures were used to rule out the effects of several of the most common demographic and disease-related covariates on distress reactions for survivors and their caregivers. To rule out response bias, the recruitment source for the demographic and major outcome variable, distress, was examined. Additionally, demographic differences were studied according to gender to determine whether the differences in psychological distress noted among female caregivers were attributable, in part, to demographic differences between the two groups (e.g., male caregivers might have had significantly higher incomes and thus could hire supportive services or enjoy better health care). Such analyses also were performed with regard to survivors' stage of disease because the possibility existed that, if the cancers that male caregivers had to face were less severe, their distress reactions would be lowered. However, demographic and disease-related covariates were ruled out as a source of bias. Years since diagnosis was controlled for in the primary multivariate analysis.

Additional studies need to be conducted to determine mediators of distress among care dyads. This will allow health-care planners and professionals to devise gender-specific, tailored interventions aimed at enhancing the psychological well-being of caregivers and those who need care. Because nursing personnel often interact the most with patients and their families, they may be more likely to identify patients who are in need of aid. As expert caregivers, nurses can provide knowledge and valuable assistance to cancer survivors and their lay caregivers who need help with the caregiving process.

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