

# Illness perceptions matter: understanding quality of life and advanced illness behaviors in female patients with late-stage cancer

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**Background** Patients with late-stage cancer are living longer, making it important to understand factors that contribute to maintaining quality of life (QOL) and completing advanced illness behaviors (eg, advance directives).

**Objective** To examine whether illness perceptions—the cognitive beliefs that patients form about their cancer—may be more important guides to adjustment than clinical characteristics of the cancer.

**Methods** In a cross-sectional study, 105 female patients diagnosed with stage III (n = 66) or IV (n = 39) breast (n = 44), gynecological (n = 38), or lung (n = 23) cancer completed self-report measures of illness perceptions, QOL, and advanced illness behaviors. Clinical data was obtained from medical records.

**Results** Despite modest associations, patients' beliefs about the cancer were clearly unique from the clinical characteristics of the cancer. Illness perception variables accounted for a large portion of the variance ( $PS < .01$ ) for QOL and advanced illness behaviors, whereas clinical characteristics did not. QOL scores were predicted by patients' reports of experiencing more cancer related symptoms (ie, illness identity), believing that their cancer is central to their self-identity, and higher income. Higher completion of advanced illness behaviors was predicted by higher income, the cancer being recurrent, and participants perceiving their cancer as more severe but also more understandable.

**Limitations** This study was limited by a cross-sectional design, small sample size, and focus on female patients.

**Conclusion** Addressing patients' beliefs about their cancer diagnosis may provide important targets for intervention to improve QOL and illness behaviors in patients with late-stage cancer.

Late-stage cancer is a complex health experience as patients often have limited treatment options and may receive insufficient or misinterpreted information about their prognosis.<sup>1-3</sup> As treatments improve and patients with late-stage cancer live longer, it becomes increasingly important to examine factors associated with long-term quality of life (QOL) of people with a life-limiting illness<sup>4-8</sup> because QOL provides a multi-dimensional picture

of disease effects on patients' physical, mental, functional, and social well-being. Patients with late-stage cancer are also expected to navigate a complex system of advanced illness behaviors,<sup>9-11</sup> which if not completed may result in serious consequences for the patient, their caregivers, the hospital, and society.<sup>2,3,12,13</sup> For example, failure to engage in discussions about end-of-life issues or to complete advance directives has been associated with increased use of life-sustaining treatments (eg, CPR, ventilation), longer intensive care unit stays, lower levels of hospice care, and increased health care expenditure.<sup>3,12</sup> Although adult patients with late-stage cancer endorse varying degrees of adjustment difficulties,<sup>14-16</sup> female patients are known to be at higher risk for experiencing psychological distress after a cancer diagnosis.<sup>17-19</sup>

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When faced with a serious health threat, such as late-stage cancer, people instinctively organize information about the illness in their minds in a way that helps them make sense of and cope with the threat.<sup>20</sup> These schemas are called cognitive illness perceptions and may be better predictors of health-related QOL and advanced illness behaviors than personal or clinical characteristics.<sup>15,21,22</sup> Illness perceptions include beliefs about the extent of symptoms, the anticipated course of the illness, expected negative consequences, the extent to which the illness can be controlled, and whether patients have a clear and stable understanding of their diagnosis. How central cancer is to the patients' self-identity may also have important implications for psychological well-being and cancer-related behaviors.<sup>23,24</sup> Patients with negative illness perceptions report more distress and exhibit less coping flexibility when adjusting to an illness, even in the context of a treatable condition.<sup>25-29</sup> The relationships among illness perceptions, psychological adjustment, and illness behaviors have been widely studied in a variety of cancer types,<sup>21,22,25,28,30,31</sup> but have not been solely examined in the late-stage cancer population.

The present study examined factors associated with QOL and advanced-illness behaviors in a cross-sectional sample of female oncology patients diagnosed with late-stage breast, gynecological, and lung cancers. The aims were to determine:

- The overall level of QOL and the frequency of advanced illness behaviors completed by this understudied population; and
- The personal characteristics, clinical characteristics, and illness perception variables associated with QOL and behavior completion.

We hypothesized that female patients diagnosed with late-stage cancer would infrequently complete advanced-illness behaviors and experience poorer QOL when compared to normative samples of the general population and female oncology patients.<sup>32</sup> In addition, we predicted that illness perceptions would be a better predictor of QOL and advanced-illness behavior completion than either personal characteristics or clinical characteristics of the cancer. These findings have important implications for health care professionals treating female patients diagnosed with late-stage cancer and highlight the importance of understanding the patients' perceptions of their cancer diagnosis.

## Method

### Procedure and measures

The study was approved by the institutional review board at the University of Texas Southwestern Medical Center.

Eligible patients were identified through medical record review. Patients were approached at their routine outpatient oncology appointment through 2 sites of an NCI-designated cancer center that included a university-based practice (73%) and a safety-net practice (27%) that provides care to all patients regardless of insurance status. Both sites are teaching hospitals, with care supervised by the same group of medical oncologists. Participants were enrolled, provided written informed consent, and then completed a packet of questionnaires at their convenience. Participants were compensated \$15 for their participation.

Eligibility criteria included female patients diagnosed with stage III or IV breast, gynecologic, or lung cancer for at least 1 month, so that the initial heightened distress of the diagnosis itself did not impact the data.<sup>33</sup> Because data were being collected as part of a larger study, patients had to be living with a spouse or unmarried partner for at least 1 year ( $M = 28.81$  years;  $SD = 15.99$ ) and were eligible to participate in this leg of the study even if partners declined participation. Patients were excluded if they had a comorbid medical (eg, blindness) or psychiatric condition (eg, schizophrenia) that prohibited survey completion or if they could not read or write English.

**Illness perceptions.** Patients completed the Illness Perceptions Questionnaire – Revised (IPQ-R) to assess 7 aspects of their cancer beliefs.<sup>34</sup> Illness identity (ie, symptom experience) included 15 symptoms rated on a scale from 1 (never occurs) to 4 (occurs all of the time). The remaining items were completed using a Likert scale from 1 (strongly disagree) to 5 (strongly agree). We assessed patients' beliefs about the onset and course of the cancer (ie, chronic timeline and cyclical/unpredictable timeline), potential negative consequences of the cancer (ie, illness severity), whether the illness and treatment are understandable and consistent (ie, illness coherence), and how amenable the cancer is to various types of control (ie, patient control and treatment control). Internal consistency was greater than  $\alpha = .75$  for all subscales.

**Cancer self-representation.** A measure of illness centrality was included to assess perceptions of how cancer affects one's sense of self; such perceptions may be relevant to the cancer experience but are not measured by the IPQ-R. Items developed by Wiebe and colleagues<sup>35</sup> for patients with diabetes were modified by replacing the term diabetes with cancer. These items have been reliably used with cancer populations in previous research.<sup>23,24</sup> Four items assessing the extent to which the cancer diagnosis is central to the patient's sense of self (eg, "I think of my cancer when I think of who I am") were answered on a 1 (strongly disagree) to 5 (strongly agree) scale. Internal consistency was sufficient at  $\alpha = .78$ .

**TABLE 1** Descriptive information for measure of advanced illness behaviors

| Advanced illness behavior   | No. of participants (% yes) | If yes, helped by partner or family | If yes, helped by medical team |
|---|-----------------------------|-------------------------------------|--------------------------------|
| Participated in cancer survivorship organizations                       | 28 (27%)                    | 64%                                 | 14%                            |
| Completed a document to make medical wishes known                       | 49 (47%)                    | 78%                                 | 12%                            |
| Appointed a medical power of attorney                                   | 46 (44%)                    | 83%                                 | 9%                             |
| Considered or enrolled in a clinical trial                              | 46 (44%)                    | 72%                                 | 43%                            |
| Made wishes known about funeral arrangements                            | 56 (53%)                    | 80%                                 | 0%                             |
| Wrote a legal will for finances and property                            | 47 (45%)                    | 81%                                 | 0%                             |
| Talked with people in their life about their cancer and/or their future | 77 (73%)                    | 68%                                 | 13%                            |
| Put affairs in order  | 50 (48%)                    | 66%                                 | 2%                             |
| Obtained information about hospice programs                             | 8 (8%)                      | 88%                                 | 13%                            |

**Quality of life.** The Functional Assessment of Cancer Therapy General scale (FACT-G) assessed how cancer and its treatment affect QOL.<sup>36,37</sup> This well-validated 27-item instrument assesses 4 QOL domains:

- Physical well-being;
- Social/family well-being;
- Emotional well-being; and
- Functional well-being.

Items are measured using a Likert scale from 1 (not at all) to 5 (very much) with higher scores indicating better QOL. Individual subscale scores were highly correlated with each other ( $r_s = .40$  to  $.67$ ) and with the summed total QOL score ( $r_s = .68$  to  $.89$ ). Therefore the total score was used ( $\alpha = .93$ ). Normative data are available on the general population and female oncology population.<sup>32</sup>

**Advanced-illness behaviors.** An instrument was created to assess whether patients engaged in particular advanced illness behaviors (Table 1). Domains were chosen from the National Cancer Institute's booklet on coping with advanced cancer<sup>11</sup> and items were developed to reflect participation in cancer specific activities (eg, survivorship organizations), preparation for medical decision making (eg, completing an advance directive), and end-of-life planning (eg, obtaining information about hospice). An advanced illness behavior score was computed by counting the total number of behaviors that each participant endorsed (range = 0 to 9;  $\alpha = .76$ ).

**Demographic and illness information.** Participants also provided basic information about their personal characteristics (eg, age). Information about diagnosis, staging, treatment, prognosis, and overall functioning at the time of the clinic visit were obtained from electronic medical records. The Eastern Cooperative Oncology Group

(ECOG) performance status is well-validated<sup>38</sup> and represents the oncologists' rating of the patient's functional status on a scale from 0 (fully active) to 4 (completely disabled).

#### Statistical approach

All statistical procedures were conducted with the Statistical Package for the Social Sciences (SPSS) version 19. A mean (item) replacement strategy was used when a participant was missing less than 25% of the data for a given measure, while participants missing greater than 25% of data for a given measure were excluded from analyses utilizing that measure. Effect sizes and confidence intervals for regression analyses were calculated using macro software<sup>39</sup> based on recommendations by Cohen and colleagues, who suggest that effect sizes can be interpreted as 'small' ( $F^2$  of  $.02$ ), 'medium' ( $F^2$  of  $.25$ ), and 'large' ( $F^2$  of  $.40$ ).<sup>40</sup>

One-sample  $t$ -tests compared participants' QOL scores to the mean scores of normative samples for both the general population and the female oncology population.<sup>32</sup> Hierarchical regression analyses were conducted to determine which personal characteristics, clinical characteristics, and illness perceptions accounted for the most variance in QOL and advanced illness behaviors. Bivariate correlations were utilized to reduce the number of predictor variables used in the hierarchical regression analyses. Correlations that were significant at  $P < .05$  were retained for further examination; corrections for multiple comparisons were not conducted to ensure all potentially relevant variables were included in the primary analyses. Hierarchical regression analyses were run for each outcome variable with the predictor variables entered into the regression equation as blocks (ie, personal characteristics, clinical characteristics, illness perceptions). This allowed for the predictive ability of each set of variables to be interpreted using  $R^2$  change. In all cases,

**TABLE 2** Participant characteristics across treatment sites for total sample (N = 105)

| Characteristic                      | Total sample N (%) | University-based practice <sup>a</sup> N (%) | Safety-net practice <sup>b</sup> N (%) | Comparison statistic |
|-------------------------------------|--------------------|--|--|----------------------|
| <b>Race/Ethnicity</b>               |                    |  |  | $\chi^2 = 5.68^*$    |
| Non-Hispanic White                  | 68 (65%)           | 58 (75%)                                     | 10 (36%)                               |                      |
| Black                               | 13 (12%)           | 5 (6%)                                       | 8 (29%)                                |                      |
| Asian                               | 5 (5%)             | 5 (6%)                                       | 0 (0%)                                 |                      |
| Hispanic                            | 9 (9%)             | 4 (5%)                                       | 5 (18%)                                |                      |
| Multi-Racial                        | 7 (7%)             | 3 (4%)                                       | 4 (14%)                                |                      |
| <b>Education Level</b>              |                    |  |  | $t = 3.83^{**}$      |
| ≤ High school education             | 38 (36%)           | 21 (27%)                                     | 17 (61%)                               |                      |
| > High school education             | 64 (61%)           | 54 (70%)                                     | 10 (36%)                               |                      |
| <b>Income, n = 94</b>               |                    |  |  | $t = 8.00^{**}$      |
| < \$25,000                          | 28 (27%)           | 10 (13%)                                     | 18 (64%)                               |                      |
| ≥ \$25,000                          | 66 (63%)           | 60 (78%)                                     | 6 (21%)                                |                      |
| <b>Age (in years)</b>               |                    |  |  | $t = 2.75^{**}$      |
| Mean (SD)                           | 58.29 (11.05)      | 60.07 (11.32)                                | 53.54 (8.85)                           |                      |
| Range                               | 24 to 83           | 26 to 83                                     | 24 to 64                               |                      |
| <b>Cancer Type</b>                  |                    |  |  | $\chi^2 = 3.74$      |
| Breast                              | 44 (42%)           | 28 (36%)                                     | 16 (57%)                               |                      |
| Gynecological                       | 38 (36%)           | 30 (39%)                                     | 8 (29%)                                |                      |
| Lung                                | 23 (22%)           | 19 (25%)                                     | 4 (14%)                                |                      |
| <b>Illness Duration (in months)</b> |                    |  |  | $t = 1.55$           |
| Mean (SD)                           | 16.05 (25.62)      | 18.36 (29.18)                                | 9.68 (8.62)                            |                      |
| Range                               | 1 to 158           | 1 to 158                                     | 1 to 35                                |                      |
| <b>Cancer Stage</b>                 |                    |  |  | $\chi^2 = 1.66$      |
| IIIA                                | 21 (20%)           | 17 (22%)                                     | 4 (14%)                                |                      |
| IIIB                                | 11 (10%)           | 7 (9%)                                       | 4 (14%)                                |                      |
| IIIC                                | 34 (33%)           | 26 (34%)                                     | 8 (29%)                                |                      |
| IV                                  | 39 (37%)           | 27 (35%)                                     | 12 (43%)                               |                      |
| <b>Metastases Present</b>           |                    |  |  | $\chi^2 = 0.14$      |
| <b>Cancer is Recurrent</b>          | 45 (43%)           | 34 (44%)                                     | 11 (39%)                               | $\chi^2 = 0.20$      |
| <b>ECOG Performance Status</b>      |                    |  |  | $t = -0.78$          |
| Mean (SD)                           | 0.34 (0.68)        | 0.31 (0.59)                                  | 0.43 (0.88)                            |                      |
| Range                               | 0 to 3             | 0 to 3                                       | 0 to 3                                 |                      |

\*  $P < .05$ ; \*\*  $P < .01$ .<sup>a</sup> University-based practice (N = 77); <sup>b</sup> Safety-net practice (N = 28).

the residuals were normally distributed and the collinearity tolerance was greater than 0.55, supporting the assumptions underlying regression.

## Results

### Patient characteristics

Participants included 105 female patients diagnosed with stage III (n = 66) or IV (n = 39) breast (n = 44), gynecological (n = 38), or lung (n = 23) cancer. Of the qualifying patients approached (n = 144), 96% agreed to participate (n = 138), of whom 76% returned a

completed packet (n = 105). Reasons for not returning the packets included a lack of interest in participation (n = 10), illness progression or death (n = 6), and being lost to follow-up (n = 21). Eligible patients who did vs did not return a completed packet were more likely being treated for stage IV rather than stage III cancer ( $\chi^2 = 8.87$ ;  $P = .01$ ) or at the safety-net practice ( $\chi^2 = 5.50$ ;  $P = .03$ ). The patients did not differ on cancer type or illness duration ( $PS > .20$ ).

Table 2 describes the demographics and clinical characteristics of the sample. Compared to the university-

**TABLE 3** Sample means, SDs, and Pearson correlation coefficients between illness perception variables and clinical characteristics

| Variables                  | Mean (SD)   | Illness duration | Cancer stage <sup>a</sup> | Metastases <sup>a</sup> | Recurrence <sup>a</sup> | ECOG <sup>b</sup> |
|----------------------------|-------------|------------------|---------------------------|-------------------------|-------------------------|-------------------|
| <b>Illness Perceptions</b> |             |                  |                           |                         |                         |                   |
| Illness identity           | 2.08 (0.47) | -.060            | .032                      | .267**                  | .028                    | .120              |
| Chronic timeline           | 2.99 (1.10) | .333**           | .348**                    | .390**                  | .336**                  | .142              |
| Cyclical timeline          | 2.54 (0.81) | -.001            | .018                      | .333**                  | .260**                  | .011              |
| Illness severity           | 3.81 (0.75) | .016             | .055                      | .251*                   | -.112                   | .109              |
| Illness coherence          | 3.79 (0.77) | -.004            | -.073                     | -.156                   | -.137                   | .150              |
| Personal control           | 3.62 (0.70) | -.048            | -.362**                   | -.200*                  | -.093                   | -.067             |
| Treatment control          | 3.94 (0.66) | -.123            | -.342**                   | -.421**                 | -.169                   | -.247*            |
| Centrality beliefs         | 2.75 (0.94) | .019             | .140                      | .046                    | -.049                   | .072              |

Abbreviation: ECOG, Eastern Cooperative Oncology Group.

\* $P < .05$ ; \*\* $P < .01$ .

<sup>a</sup>Biserial correlations were used for all dichotomous variables. For cancer stage, lower numbers represented Stage III and higher numbers represented Stage IV. For metastases and recurrence, lower numbers represented not present and higher numbers represented that the cancer was metastatic or recurrent; <sup>b</sup>Higher ECOG scores represent poorer functional ability as assessed by the medical oncologist.

based practice, participants from the safety-net practice were younger, had lower education and income, and were a more diverse racial/ethnic group ( $PS < .02$ ). Patients treated at the safety-net practice had lower QOL ( $t(99) = 3.143$ ;  $P = .002$ ) than patients being treated at the university-based practice. However, this difference was no longer significant when controlling for income allowing analyses to be conducted using the full sample. A total of 82% of the participants classified under gynecological cancer ( $n = 31$ ) were specifically diagnosed with ovarian cancer. Compared to the other 2 cancer types, participants diagnosed with lung cancer were older ( $F = 3.41$ ;  $P = .04$ ), less likely to be experiencing a recurrence ( $\chi^2 = 10.73$ ;  $P = .01$ ), and had a lower performance status ( $F = 39.61$ ;  $P < .00$ ). Although participants with gynecological cancer were more likely diagnosed with stage III versus stage IV ( $\chi^2 = 28.78$ ;  $P < .00$ ), most (63%) were diagnosed with stage IIIc. There were no significant differences across cancer type for any of the outcome variables ( $PS > .20$ ).

### Descriptive information about QOL and advanced illness behaviors

The average QOL score of 73.97 ( $SD = 17.43$ ) was significantly lower than the normative average for both the general population (80.1;  $t(100) = -3.53$ ;  $P = .001$ ) and the female oncology population (82.1;  $t(100) = -4.69$ ;  $P < .00$ ) as presented in the literature.<sup>32</sup> Although there was a broad range of scores (14 to 106), more than 21% of participants scored below the 10<sup>th</sup> percentile for female oncology patients.<sup>32</sup> As shown in Table 1, there was wide variability in the number of advanced illness behaviors completed (range = 1 to 9;  $M = 3.96$ ;  $SD =$

2.45). The majority of participants had informally discussed their cancer and/or their future with important people in their life, but fewer had taken more formal steps to make their wishes known (eg, completing an advance directive). Patients reported relatively high percentages of communicating with their partners or family members about the advanced illness behaviors, while only a small percentage of participants reported receiving help from their medical team in completing these behaviors.

### Associations between illness perceptions and clinical characteristics

As can be seen in Table 3, participants' beliefs about the illness mapped onto the clinical characteristics of their cancer as obtained from medical record review. Participants diagnosed with stage IV cancer were more likely to perceive their illness as chronic, with less personal control and treatment control than participants with stage III cancer. Participants who reported the presence of metastases also reported more cancer-related symptoms, believed their cancer was more chronic and unpredictable, had greater negative consequences, and was less amenable to personal and treatment control. Participants with longer illness durations or a cancer recurrence were more likely to perceive their cancer as having a chronic timeline. Although significant, these associations were quite modest indicating that illness perceptions differed from the clinical characteristics that were measured and may offer unique predictive ability when assessing QOL and behavior completion.

**TABLE 4** Pearson correlation coefficients between personal characteristics, clinical characteristics, and illness perceptions with outcome variables

| Variables                       | Quality of life | Advanced illness behaviors |
|---------------------------------|-----------------|----------------------------|
| <b>Personal characteristics</b> |                 |                            |
| Age                             | .276**          | .215*                      |
| Ethnicity <sup>a</sup>          | -.132           | -.199*                     |
| Education level                 | .138            | .270**                     |
| Income                          | .263*           | .242*                      |
| <b>Clinical characteristics</b> |                 |                            |
| Illness duration                | .151            | .096                       |
| Cancer stage                    | -.035           | .047                       |
| Metastases present              | -.165           | .130                       |
| Cancer is recurrent             | -.029           | .206*                      |
| ECOG performance status         | -.149           | .099                       |
| <b>Illness perceptions</b>      |                 |                            |
| Illness identity                | -.745**         | -.070                      |
| Chronic timeline                | -.114           | .302**                     |
| Cyclical timeline               | -.372**         | .006                       |
| Illness severity                | -.484**         | .243*                      |
| Illness coherence               | .323**          | .257*                      |
| Personal control                | .170            | .148                       |
| Treatment control               | .193            | -.060                      |
| Centrality beliefs              | -.507**         | -.040                      |

\*  $P < .05$ ; \*\*  $P < .01$ .<sup>a</sup>Exploration of differences across minority racial groups did not reveal clear patterns. Therefore, these groups were condensed into Caucasian versus non-Caucasian categories.

### Regression analyses predicting QOL and advanced illness behaviors

Primary analyses were conducted using hierarchical regression modeling (see Table 5). To ensure that potentially important predictor variables were not excluded, all illness perception variables that were correlated with the outcomes and all clinical/personal characteristics that were correlated with either the outcomes or illness perception variables were entered as predictors (Tables 3 and 4). The final regression model was entered in 3 blocks:

- Personal characteristics (ie, age, ethnicity, income);
- Clinical characteristics (ie, presence of metastases, cancer recurrence, cancer stage, illness duration, and ECOG performance status); and
- Illness perceptions (ie, illness identity, chronic timeline, cyclical timeline, illness severity, illness coherence, and cancer centrality).

Education level was excluded as a variable in the regression analyses because it was highly correlated with income

level ( $r = .59$ ) and resulted in multicollinearity problems when entered simultaneously into the regression model. Income level was included because it was more highly associated with recruitment site. It was also associated with both outcome variables whereas education level was only associated with advanced illness behaviors. Regression analyses were conducted with education level in place of income and no changes were noted in the predictive ability of illness perceptions.

QOL scores were predicted by personal characteristics:  $\Delta R^2 = .119$ ;  $F(3, 83) = 3.73$ ;  $P = .014$ ;  $F^2 = .14$ ; 95% CI [0.02, 0.28]; specifically income ( $t = 2.19$ ;  $P = .032$ ); as well as illness perception variables,  $\Delta R^2 = .517$ ;  $F(6, 72) = 19.44$ ;  $P < .000$ ;  $F^2 = 1.08$ ; 95% CI [0.69, 1.73]. In particular, experiencing more cancer related symptoms (ie, illness identity;  $t = -6.23$ ;  $P < .00$ ) and perceiving the cancer as central to one's identity ( $t = -3.03$ ;  $P = .003$ ) were predictive of poorer QOL. Frequency of advanced illness behaviors was predicted by personal characteristics:  $\Delta R^2 = .116$ ;  $F(3, 81) = 3.53$ ;  $P = .018$ ;  $F^2 = .13$ ; 95% CI [0.02, 0.27]; specifically income ( $t = 2.24$ ;  $P = .028$ ), and illness perception variables  $\Delta R^2 = .205$ ;  $F(6, 70) = 3.83$ ;  $P = .002$ ;  $F^2 = .26$ ; 95% CI [0.10, 0.48]. Participants who reported completing a higher frequency of advanced illness behaviors perceived their cancer as more severe ( $t = 3.19$ ;  $P = .002$ ) but also more understandable (ie, illness coherence;  $t = 2.49$ ;  $P = .015$ ). Clinical characteristics were not significant predictors in either of the regression models, although cancer recurrence was a significant independent predictor of advanced illness behavior completion ( $t = 2.258$ ;  $P = .027$ ).

### Discussion

The current study was one of the first to examine the significance of illness perceptions in predicting QOL and advanced illness behaviors in a diverse group of female patients diagnosed with late-stage cancer. In general, participants' cognitive perceptions of the cancer, as well as their personal characteristics, were associated with QOL and behavior completion while clinical characteristics of the cancer were not. Although illness perceptions were modestly associated with clinical characteristics of the cancer, the 2 sets of variables were clearly unique, implying that patients' understanding of their illness is not purely based on diagnostic information. This finding is consistent with viewing adjustment to cancer and its treatment as not just a medical process but also a psychological one, and that what a patient believes to be true about their illness is often more important in guiding patients' behavior and emotional reactions than what is "medically" accurate.<sup>20</sup>

QOL scores were lower in our sample of late-stage cancer patients than in the general population or a normative

**TABLE 5** Hierarchical regression analyses testing personal characteristics, clinical characteristics, and illness perceptions predicting outcome variables

| Predictor variables             | Quality of life                                 |         | Advanced illness behaviors                     |        |
|---------------------------------|---|---------|--|--------|
|                                 | $\beta$   | SE      | $\beta$  | SE     |
| <b>Personal characteristics</b> | $\Delta R^2 = .119$<br>$F(3, 83) = 3.733^*$     |         | $\Delta R^2 = .116$<br>$F(3, 81) = 3.531^*$    |        |
| Age                             | .015  | (.116)  | .188   | (.023) |
| Ethnicity                       | -.063   | (2.939) | .014   | (.570) |
| Income                          | .155*   | (.593)  | .223*  | (.118) |
| <b>Clinical characteristics</b> | $\Delta R^2 = .045$<br>$F(5, 78) = 0.838$       |         | $\Delta R^2 = .054$<br>$F(5, 76) = 0.981$      |        |
| Illness duration                | .070  | (.048)  | -.040  | (.009) |
| Cancer stage                    | .029  | (2.885) | .001   | (.582) |
| Metastases present              | -.018   | (3.115) | .034   | (.617) |
| Cancer is recurrent             | -.111   | (2.879) | .265*  | (.578) |
| ECOG performance status         | -.059   | (2.039) | .069   | (.407) |
| <b>Illness perceptions</b>      | $\Delta R^2 = .517$<br>$F(6, 72) = 19.443^{**}$ |         | $\Delta R^2 = .205$<br>$F(6, 70) = 3.832^{**}$ |        |
| Illness identity                | -.576**   | (3.534) | -.202  | (.713) |
| Chronic timeline                | .096  | (1.600) | .062   | (.324) |
| Cyclical timeline               | .174  | (1.607) | .020   | (.319) |
| Illness severity                | -.178   | (2.221) | .446**   | (.447) |
| Illness coherence               | .137  | (1.716) | .269*  | (.340) |
| Centrality beliefs              | -.243**   | (1.476) | -.039  | (.292) |

\*  $P < .05$ ; \*\*  $P < .01$ .

sample of female oncology patients;<sup>39</sup> which clinically suggests that patients with late-stage cancer experience a higher physical and emotional burden, less satisfaction with their social and family life, and greater difficulty functioning at work and at home. Our findings indicate symptom burden (ie, illness identity) accounted for a significant portion of the variance in QOL scores. Patient reports of cancer-related symptoms may represent how severe patients perceive their cancer to be at the moment, how much their cancer interferes with their ability to function, and has been an important predictor of adjustment and QOL in studies of other cancer populations.<sup>25,29</sup> The addition of a measure of cancer self-representation (ie, cancer centrality) was a unique contribution, because this concept is relatively new<sup>35</sup> and has only recently been studied in the cancer population.<sup>23,24</sup> In our sample, females with late-stage cancer who believed that cancer was central to their self-identity reported poorer QOL, which suggests that it may be unhealthy for patients to define themselves in terms of their illness or that one cannot help but define one's self by cancer when it pervades all aspects of one's life. Understanding associations between illness perceptions and QOL is important as changes in illness perceptions are a likely contributor to the phenome-

non known as response-shift in longitudinal research and clinical trials.<sup>41</sup>

There was wide variability in both the types and total number of advanced illness behaviors that participants completed; however, total frequencies were consistent with previous literature on completion of advance directives.<sup>10</sup> These behaviors were based on the National Cancer Institute's booklet on coping with advanced cancer.<sup>11</sup> The appropriateness of these behaviors (eg, obtaining information about hospice) might vary for the range of cancer types and stages examined (ie, IIIA breast cancer vs IV lung cancer). Patients with a higher income were more likely to have completed advanced illness behaviors, which might be partially due to the association between education level and income as well as access to resources. Those with a cancer recurrence were also more likely to complete advanced illness behaviors. An examination of the correlations between recurrence and illness perceptions reveals that patients diagnosed with a recurrence may be more likely to recognize their illness as chronic or life-limiting. These patients might also receive less optimistic messages about prognosis from their medical team or family. Ethnicity was not found to be a significant contributor to advanced illness behaviors. However, this may

have been due to the limited ethnic variability in the current sample as previous research suggests that ethnicity plays an important role in end-of-life behaviors, such as completion of advance directives and hospice utilization.<sup>42</sup>

In regard to the illness perception variables, patients were more likely to engage in advanced illness behaviors if they had a stable understanding of their illness (ie, illness coherence) and recognized their cancer as a severe condition with the potential for negative consequences. This finding is consistent with previous research on illness perceptions that shows patients are more likely to engage in illness behaviors when their beliefs about the illness coincide with the clinical reality of the illness.<sup>43</sup> Although illness perceptions clearly play a role in completion of advanced illness behaviors, they only accounted for approximately 20% of the variance, which suggests the need for future studies to examine other potential factors that might contribute to the completion of advanced illness behaviors.

There are several limitations to the current study. First, the data are cross-sectional. Therefore, we cannot distinguish causal direction or rule out the influence of additional variables that were not assessed. Second, the sample size for the current study was fairly small, which resulted in large confidence intervals for effect sizes. Third, we relied on patients' self-report and the possibility exists that patients who are experiencing greater levels of distress are more likely to report negative perceptions of their illness. Finally, the current study focused on English speaking, female patients, who were diagnosed with specific types of cancer and involved in long-term relationships. In addition, participants in our study should be considered as higher functioning patients with late-stage cancer, because they were not hospitalized and were not yet receiving hospice care. Future work should consider extending the generalizability of this research to other cancer types, male patients, a more ethnically diverse sample, and those patients who are potentially in their last few months of life.

The findings from this research have implications for health care professionals who treat female patients diagnosed with late-stage cancer. The crucial first steps to improving QOL and increasing the frequency of advanced illness behaviors involve understanding the patients' perceptions of the cancer (particularly understanding their beliefs about how severe it is), the extent of the symptoms they experience, and how central the cancer diagnosis is to their self-image. Our data suggest that patients are most successful at completing advanced illness behaviors when their illness perceptions correspond with the medical facts of the illness. Therefore, once the clinician understands a patient's cognitive perception of the cancer, progress can be made toward bringing this perception closer in line with the medical reality. A randomized controlled trial with patients recover-

ing from myocardial infarction demonstrated that illness perceptions can be changed and may result in shorter hospitalizations as well as lower levels of anxiety.<sup>44</sup> In addition, when completing advanced illness behaviors, participants were more likely to turn to their partners or family members for help rather than to their medical team. This suggests that including partners and family members in future interventions may facilitate completion of advanced illness behaviors.

The current study detailed the variables associated with QOL and advanced illness behaviors in the rarely studied population of females diagnosed with late-stage cancer. Although results are limited by small sample size and the cross-sectional nature of this data, 3 findings seem relatively clear. First, how patients perceive their cancer does not completely align with diagnostic and clinical information. Second, how patients perceive their cancer is a better predictor of their QOL and illness behavior than clinical characteristics of their cancer. Third, predicting completion of advanced illness behaviors is a complex process, but an important one given that these behaviors are completed by a small proportion of patients and failure to complete these behaviors has been associated with numerous negative outcomes for patients, their caregivers, and society.<sup>2,3,12,13</sup> Interventions designed to target patients' beliefs about a late-stage cancer diagnosis have significant potential for improving QOL and increasing completion of advanced illness behaviors.

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