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Gender differences in the evolution of illness understanding among patients with advanced cancer

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Abstract

Background—Patient understanding of advanced metastatic disease is central to decisions about care near death. Prior studies have focused on gender differences in communication style rather than on illness understanding.

Objectives—To evaluate gender differences in terminal illness acknowledgement (TIA), understanding that the disease is incurable and the advanced stage of the disease. To evaluate gender differences in patients' reports of discussions of life expectancy with oncology providers and its effect on differences in illness understanding.

Methods—Coping with Cancer 2 patients (N = 68) were interviewed before and after a visit with their oncology providers to discuss scan results.

Results—At the prescan interview, there were no statistically significant gender differences in patient measures of illness understanding. At the postscan interview, women were more likely

than men to recognize that their illness was incurable (Adjusted Odds Ratio, [AOR] = 5.29; $P = .038$), know that their cancer was at an advanced stage (AOR = 6.38; $P = .013$), and report having had discussions of life expectancy with their oncologist (AOR = 4.77; $P = .021$). Controlling discussions of life expectancy, women were more likely than men to report that their cancer was at an advanced stage (AOR = 9.53; $P = .050$). Controlling for gender, discussions of life expectancy were associated with higher rates of TIA (AOR = 4.65; $P = .036$) and higher rates of understanding that the cancer was incurable (AOR = 4.09; $P = .085$).

Conclusions—Due largely to gender differences in communication, women over time have a better understanding of their illness than men. More frequent discussions of life expectancy should enhance illness understanding and reduce gender differences.

Patients' understanding of their terminal illness plays an important role in determining the medical care patients receive near the end of life (EOL). Advanced cancer patients who have more accurate illness understanding tend to receive less aggressive care and have better quality of life at the EOL.¹⁻⁵ Although oncologist-patient communication and receive less aggressive care and have better quality of life at the EOL.¹⁻⁵ Although oncologist-patient communication and shared decision-making are increasingly recognized as important influences on EOL care, many advanced cancer patients do not accurately understand the severity of their illness.

It is common and understandable for patients to misinterpret or retain very little information about their illness at the time of initial diagnosis.⁶ Many patients are in a state of shock or made emotionally numb by discussion of a terminal prognosis,⁷ which may inhibit their ability to comprehend the gravity of their condition. We have reported that among cancer patients with incurable metastatic disease only 38% acknowledged being terminally ill a median of 4 months prior to death.⁵ Additionally, recent findings indicate that advanced cancer patients' understanding of their disease improves little over time as death nears. In a longitudinal study, Craft et al found that when patients with advanced malignant disease were initially asked about the purpose of their treatment, only 47.3% correctly noted that their treatment was not intended to cure their disease whereas 52.7% either thought the intent of their treatment was to cure their disease or did not know what the goal of their treatment was.⁸ Twelve weeks later, patient understanding of treatment goals remained unchanged, with 47.9% of these patients recognizing that their treatment was not to cure their disease and 52.1% of these patients who either thought the goal of their treatment was to cure their disease or did not know what the goal of treatment was.⁸ In another more recent longitudinal investigation, Temel et al found that 32% of patients with newly diagnosed metastatic nonsmall-cell lung cancer believed their cancer to be curable and 69% incorrectly thought that the goal of their treatment was to get rid of all cancer.⁹ Over time, 25% of the surviving patients thought their cancer was curable and 57.9% incorrectly thought that the goal of their treatment was to get rid of all cancer. Evidently, many advanced cancer patients approaching death have misconceptions about the severity of their illness, which undermines their ability to make informed decisions regarding their EOL care.

Gender plays a significant role in the way patients with advanced cancer communicate with their oncologists and how they desire to receive information about their disease. Female

cancer patients are more likely to play an active role in decision making and desire more emotional support from their oncologists, whereas male cancer patients tend to play a passive role and desire more medical information from oncology providers.¹⁰⁻¹² Gender also plays a significant role in the way advanced cancer patients' family caregivers understand treatment intent. Female family caregivers of advanced cancer patients have a more accurate understanding of treatment intent than their male counterparts. Male family caregivers' understanding of treatment intent does not change over time.¹³ Patient and family caregiver gender influences treatment goal awareness within patient-caregiver dyads.¹⁴ These studies suggest that gender may play a significant role in determining illness understanding among patients with advanced cancer.

In the present study, we examine gender differences in advanced cancer patients' understanding of their illness, as measured by their terminal illness acknowledgment, recognition that their illness is incurable, and knowledge of the advanced stage of their cancer. We assessed patients' illness understanding in these terms before and after appointments, where oncology providers discuss restaging scan results with their patients. This allowed us to determine whether a gender difference exists in the evolution of advanced cancer patients' illness understanding. We also examine gender differences in patients' reports of discussing life expectancy with their oncologists; and whether and to what extent such differences explain gender differences in advanced cancer patients' illness understanding.

Method

Study sample

The patient sample analyzed in the present report (N = 68) was drawn from the Coping with Cancer 2 (CwC-2) study. The study, designed to evaluate disparities in end-of-life (EOL) communication and EOL care, is an ongoing National Cancer Institute funded, prospective, multi-institutional cohort survey of advanced cancer patients, their caregivers, and their oncology providers. To date, participants have been recruited at 5 comprehensive cancer centers across the United States: Dana-Farber/ Harvard Cancer Center (DF/HCC: including Dana-Farber Cancer Institute; Brigham and Women's Hospital; and Massachusetts General Hospital in Boston, MA), Parkland Hospital (Dallas, TX), Yale Cancer Center (New Haven, CT), Virginia Commonwealth University Massey Cancer Center (Richmond, VA), and Pomona Valley Hospital Medical Center (Pomona, CA). Criteria for patient eligibility included diagnosis of advanced cancer (presence of distant metastases and disease refractory to first-line chemotherapy); estimated life expectancy of 6 months or less; age ≥ 20 years; race/ethnicity self-reported as White, African American and/or Latino/Hispanic; adequate stamina to complete the interview; and fluency in English or Spanish. Patients with obvious signs of cognitive impairment (eg, dementia/delirium) and/or patients who made more than 6 errors on the Short Portable Mental Status Questionnaire¹⁵ (SPMSQ) were excluded because their responses were considered unlikely to be reliable or valid. Review boards of all participating institutions approved study procedures and all participants provided written, informed consent.

The present study focuses on patient illness understanding before and after a visit with his or her oncology provider to discuss scan results to evaluate potential disease progression. The study includes data from 68 CwC-2 participants (30 lung-, 22 ovarian-, 14 gastrointestinal-, 1 tongue-, and 1 thyroid-cancer patients). Participants completed both pre-and postscan visit interviews between January 2011 and May 2012. These interviews included questions about patients' illness understanding and the discussions they had with their oncology providers concerning their prognosis, curability, and goals of care. The median time between the pre- and postscan interviews was 38 days. Neither cancer type nor time between interviews was related to postscan interview measures of patient illness understanding. Neither cancer type nor time between interviews proved to be a confounding factor and, therefore, neither was included in the present analysis.

Measures

Patient demographic characteristics—Patients provided information regarding gender, age, race/ethnicity, annual household income, education, and marital status.

Patient Illness Understanding—Patient illness understanding was assessed as follows:

- *Terminal illness acknowledgement (TIA)*. Terminal illness acknowledgement was assessed during pre- and postscan visit interviews using the question “How would you describe your current health status?” Response options were 1) relatively healthy; 2) relatively health and terminally ill; 3) seriously ill but not terminally ill; 4) seriously ill and terminally ill; and 5) don't know. For analysis, TIA was coded “1” for response options 2 and 4; and “0” for response options 1, 3, and 5.
- *Incurable Disease*. Recognition of having an incurable disease was assessed during pre- and postscan visit interviews using the question “Which of the following best represents what your oncology providers have told you about a cure for your cancer?” Response options were 1) my cancer will be cured; 2) my cancer may be cured if treatments are successful; 3) my cancer cannot be cured but we will try to control the cancer with treatment; 4) my cancer cannot be cured and I am not able to have any further cancer treatment; and 5) don't know. For analysis, recognition of incurable disease was coded “1” for response options 3 and 4; and “0” for response options 1, 2, and 5.
- *Advanced Stage Disease*. Knowledge of advanced stage of cancer was assessed during pre- and postscan visit interviews using the question “What stage is your cancer?” Response options were 1) no evidence of cancer; 2) early stage of cancer; 3) middle stage of cancer; 4) late stage of cancer; 5) end stage of cancer; and 6) don't know. For analysis, knowledge of advanced stage of cancer was coded “1” for response options 4 and 5; and “0” for response options 1, 2, 3, and 6.
- *Patient-provider discussions of life expectancy*. Patient-provider discussions of life expectancy was assessed during the postscan visit interview using the following two questions, “At the last oncology visit, was there any discussion of your prognosis or life expectancy with this disease?” and “Have you discussed your prognosis/life expectancy with your oncology provider in past visits?” Response

options for each of these questions was “yes” or “no.” For analysis, patient-provider discussions of life expectancy was coded “1” for a “yes” response to either of these questions; and “0” for “no” responses to both of these questions.

Statistical analysis

Gender difference in age was evaluated using a 2-sample *t*-test. Gender differences in race/ethnicity, marital status, annual income, education, and recruitment site were evaluated using chi-square tests. Odds ratios between gender and pre-and postscan visit measures of patient illness understanding and having had discussions of life expectancy were estimated using multiple logistic regression analysis. Adjustment was made for potential demographic confounds.

Effects of gender and discussions of life expectancy on postscan visit measures of patient illness understanding, adjusting for corresponding prescan visit measures of patient illness understanding, were estimated using multiple logistic regression analysis. Demographic variables associated with gender in the present sample were found to be unrelated to postscan visit measures of patient illness understanding and, therefore, not considered to be confounds in this final analysis.

Statistical analysis was conducted using SAS statistical software, version 9.2 (Cary, NC). Statistical inferences were based on 2-sided tests with $P < .05$ taken to be statistically significant.

Results

Table 1 presents gender differences in sample demographic characteristics. Women were significantly more likely than men to be white and to be recruited at DF/HCC.

Table 2 presents gender differences in pre-and post-scan visit interview measures of patient illness understanding. At the time of the prescan visit interview, there were no gender differences in patient measures of illness understanding, adjusting for potential demographic confounds, race, and recruitment site. At the time of the postscan visit interview, adjusting for race and recruitment site, women were significantly more likely than men to recognize that their illness was incurable (AOR = 5.29; $P = .038$) and to know that their cancer was at an advanced stage (AOR = 6.38; $P = .013$).

Women (29/42 = 69%) were more likely than men (8/26 = 30.8%) to report having had discussions of life expectancy with their oncologist, adjusting for race and recruitment site (AOR = 4.77; $P = .021$).

Table 3 presents results from a series of multiple logistic regression models designed to evaluate the effects of gender and discussions of life expectancy on postscan visit measures of patient illness understanding, adjusting for corresponding prescan visit measures of patient illness understanding. In all models, prescan visit measures of patient illness understanding were highly significant predictors of corresponding postscan visit measures of patient illness understanding. In models that include gender but exclude discussions of life expectancy (Model 1), women were more likely than men to recognize that their disease is

incurable (AOR = 4.47; P = .033) and understand that their disease is at an advanced stage (AOR = 12.17; P = .023). In models that include discussions of life expectancy but exclude gender (Model 2), those who had discussions of life expectancy were more likely than those who did not to acknowledge that their illness is terminal (AOR = 4.02; P = .037) and understand that their disease is incurable (AOR = 6.11; P = .017). In models that included both gender and discussions of life expectancy (Model 3), women were more likely to understand that their cancer was at an advanced state (AOR = 9.53; P = .050); discussions of life expectancy were associated with higher rates of TIA (AOR = 4.65; P = .036) and higher rates of understanding that the cancer was incurable (AOR = 4.09; P = .085).

Discussion

Results of the current study show that in this cohort, over time, women advanced cancer patients develop a more accurate understanding of their illness than do men. At the prescan visit interview, before patients discussed re-staging scan results with their oncology providers, there were no significant gender differences in illness understanding. At the postscan visit interview, after patients had discussed scan results with their oncologist, women were significantly more likely than men to understand that their cancer was incurable and that they had an advanced stage cancer. Furthermore, female advanced cancer patients were significantly more likely than their male counterparts to report having had discussions of life expectancy with their oncologists at some point during the course of their disease. Results of the present study also suggest that this gender difference in having had discussions of life expectancy with oncologists may explain the observed gender difference in patients' understanding that their disease is incurable.

Results of the present study are most closely related to those of 2 prior studies that report gender differences in the caregiver¹³ and the patient-caregiver dyad¹⁴ awareness of treatment intent for patients with advanced cancer. In a study of family caregivers' understanding of the purpose of treatment for advanced cancer patients for whom they cared, Burns et al¹³ found that 35% of male caregivers, but only 19% of female caregivers, incorrectly thought that the goal of the patient's treatment was to cure his or her disease. Although patients and caregivers play different roles, findings of the present study show that male advanced cancer patients have less accurate illness understanding than female patients; mirrors the findings of Burns et al¹³ for caregivers of advanced cancer patients; and suggests that male patients and male caregivers display similar, unrealistic understanding of advanced cancer as compared to their female counterparts. In a subsequent study, Burns et al¹⁴ report that both patient and caregiver gender play a significant role in treatment goal awareness among patient-caregiver dyads. However, this latter study is limited in that its unit of analysis (ie, the patient-caregiver dyad) and its categories of dyad treatment goal awareness (ie, full awareness = both patient and caregiver are aware; partial awareness = either patient or caregiver is aware; and nonawareness = neither patient nor caregiver is aware that cure is not the goal of treatment) do not isolate advanced cancer patients' illness understanding apart from that of their family caregivers (who were more often female). This grouping of patients and caregivers makes it difficult to discern a gender difference in patient understanding of illness. Findings of the present study support the view that, over time,

female patients as compared to male patients are more likely to understand that their cancers are incurable and at an advanced stage.

Communication of prognostic information is intended to promote patients' understanding of the severity of their illness and, thereby, enable them to make appropriate treatment decisions.^{16,17} In the present study, advanced cancer patients who reported having had discussions of prognosis or life expectancy with their oncology providers were more likely to acknowledge that their illness is terminal and understand that their cancer is incurable. Female patients were more likely to have had discussions of life expectancy with their oncologists than male patients. This gender difference in prognostic communication may at least partially explain an observed gender difference in patients' understanding that they had incurable cancer. Therefore, it seems probable that gender differences in patient-physician communication contribute to gender differences in the evolution of illness understanding among patients with advanced cancer.

Prior studies indicate that female patients are more vocal and active participants in patient-physician communication, which may enable oncologists to understand what information they want. Whereas male advanced cancer patients play a more passive role in decision-making processes with oncology providers, desiring to leave treatment decisions up to their oncologists, female cancer patients are significantly more likely to play an active role in decision-making processes with their oncologists.¹⁸ Consistent with this, Beaver et al¹⁹ found, in a comparison of decision-making processes between 150 breast cancer patients to 48 colorectal patients (72% of whom were male), colorectal patients were significantly more likely to prefer playing a passive role in medical decision making than breast cancer patients. Gender differences in patient-physician communication style may translate into gender differences in the amount of information that patients receive. A recent literature review found that physicians give more information to female patients than male patients during office visits.²⁰ This is consistent with the present finding that female advanced cancer patients were more likely to have had discussions of prognosis or life expectancy with their oncologists. Ironically, men may desire prognostic information more than women do. Among nonterminal cancer patients who were asked what their prognostic disclosure preferences would be if their disease should advance, men were significantly more likely than women to want full prognostic disclosure.¹²

Men with advanced cancer receive more aggressive care at the EOL than women advanced cancer patients.²¹ Given that advanced cancer patients who have more accurate illness understanding receive less aggressive care at the EOL,¹⁻⁵ it is likely that gender differences in illness understanding such as those found in the present study contribute to gender differences in EOL care. Indeed, the current findings, in combination with the extant literature, provide piecemeal support for the following hypothesis: Gender differences in patient-oncologist communication processes (eg, active as opposed to passive roles in decision-making processes) and communication content (eg, discussion of prognostic information) contribute to gender differences in illness understanding (eg, understanding that the disease is incurable). In turn, this contributes to gender differences in aggressiveness of EOL care. Future studies should determine whether gender differences in illness understanding translate into gender differences in aggressiveness of EOL care.

The present study has several limitations. First, although all patients had incurable metastatic disease, we do not know how close to death they were at the time of the interviews. Without this information, it is unclear whether proximity to death or disease severity influenced patients' illness understanding. However, the present study focuses on gender differences in illness understanding. Therefore, proximity to death would affect the results of the present study only if it were to be confounded with gender. Second, although we have patients' reports of having had discussions of prognosis or life expectancy, it cannot be said for certain whether such reports provide an accurate representation of information discussed with oncology providers. Future studies should compare oncologist and patient reports of prognostic disclosure in order to elucidate whether gender differences in receipt of prognosis are actual or based on patient memory and interpretation. Third, we do not know how many visits, or rescan discussions, patients had with their oncology providers prior to their baseline interview. Future research should capture patient illness understanding upon initial diagnosis of advanced cancer and reassess this understanding after patients' first and subsequent rescan visits. Finally, we do not know specifically what was discussed during the clinic visit at which the oncologist shared scan results with the patient or whether postscan-visit gender differences in illness understanding were directly related to conversations at this clinic visit. Future investigations that include information from audio recordings of these clinic visits may shed more light on the origins of gender differences in illness understanding.

Conclusion

Based on results of the present study, female advanced cancer patients gain a more accurate understanding of their illness over time than their male counterparts. This gender difference in patients' illness understanding appears to be due, at least in part, to a gender difference in patient and oncology-provider communication. This means female patients are more likely than male patients to have had discussions of prognosis or life expectancy with their oncologists. Efforts to enhance prognostic communication for patients with advanced cancer, particularly for men, may improve patients' illness understanding and thereby provide a more solid foundation for patient medical decision-making at the EOL.

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TABLE 1

Gender differences in sample demographic characteristics (N = 68)

Characteristic	Women (N = 42)		Men (N = 26)		t	df	p
	mean	SD	Mean	SD			
	n	%	N	%	χ^2	df	P
Race							
White	36	85.7%	16	61.5%	5.22	1	.022
Black	6	14.3%	10	38.5%			
Marital status							
Married	24	58.5%	13	52.0%	0.27	1	.604
Not Married	17	41.5%	12	48.0%			
Annual income							
Below \$51K	14	33.3%	15	57.7%	4.69	2	.096
Above \$51K	22	52.4%	7	26.9%			
Not provided	6	14.3%	4	15.4%			
Education							
Less than 12 years	3	7.1%	6	23.1%	5.83	3	.120
Between 12 and 15 years	16	38.1%	12	46.2%			
16 or more years	15	35.7%	4	15.4%			
Not provided	8	19.0%	4	15.4%			
Recruitment site							
DF/HCC	29	69.0%	2	7.7%	24.37	1	<.001
Other	13	31.0%	24	92.3%			

Variables with missing data: age (2), marital status (2).

Abbreviations: DF, degrees of freedom; SD, standard deviation; t, *t*-test.

TABLE 2

Gender differences in illness understanding pre-and postscan visit adjusting for potential demographic confounds (N = 68)

scan visit	n	%	n	%	AOR^a	P
TIA	26	61.9%	18	69.2%	1.33	.682
Incurable	32	76.2%	14	53.8%	1.10	.889
Advanced stage	22	52.4%	11	42.3%	2.47	.168
Postscan visit	n	%	n	%	AOR^a	P
TIA	24	57.1%	15	57.7%	0.93	.913
Incurable	37	88.1%	15	57.7%	5.29	.038
Advanced stage	29	69.0%	10	38.5%	6.38	.013

Abbreviations: AOR, adjusted odds ratio; TIA, terminal illness acknowledgement.

^aOdds ratio adjusted for race and recruitment site.

TABLE 3

Effects of gender and discussions of life expectancy on postscan visit illness understanding, adjusting for prescan visit illness understanding (N = 68)

Model	Postscan visit illness understanding					
	TIA (39/68 57.4%)		Incurable (52/68 76.5%)		Advanced Stage (39/68 57.4%)	
Effect	AOR	P	AOR	P	AOR	P
Model 1						
Model 1						
Prescan visit TIA	20.04			<.001		
Prescan visit understand disease incurable					11.07	.001
Prescan visit understand disease advanced stage					117.00	<.001
Gender (women vs men)	1.30	.679	4.47	.033	12.17	.023
Model 2						
Prescan visit TIA	21.78	<.001				
Prescan visit understand disease incurable			14.14	<.001		
Prescan visit understand disease advanced stage					79.57	<.001
Discuss life expectancy	4.02	.037	6.11	.017	4.09	.097
Model 3						
Prescan visit TIA	21.24	<.001				
Prescan visit understand disease incurable			12.05	.001		
Prescan visit understand disease advanced stage					126.80	<.001
Gender (women vs men)	0.70	.617	2.52	.238	9.53	.050
Discuss life expectancy	4.65	.036	4.09	.085	1.85	.506

Abbreviations: AOR, adjusted odds ratio;

TIA, terminal illness acknowledgement.