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Disclosing a Diagnosis of Cancer: Considerations Specific to Gynecologic Oncology Patients

Lindsay M. Kuroki, M.D.^{1,*}, Qihong Zhao, M.S.², Donna B. Jeffe, Ph.D.³, Matthew A. Powell, M.D.¹, Andrea R. Hagemann, M.D.¹, Premal H. Thaker, M.D., M.S.¹, L. Stewart Massad, M.D.¹, David G. Mutch, M.D.¹, and Israel Zigelboim, M.D.^{1,†}

¹Division of Gynecologic Oncology, Department of Obstetrics and Gynecology, Washington University School of Medicine, and Alvin J. Siteman Cancer Center. St Louis, MO

²Division of Clinical Research, Department of Obstetrics and Gynecology, Washington University School of Medicine. St Louis, MO

³Division of Health Behavior Research, Department of Medicine Washington University School of Medicine, and Alvin J. Siteman Cancer Center, St. Louis, MO

Abstract

Objective—To characterize gynecologic oncology patients' perceptions of the process of disclosure of cancer diagnosis.

Methods—We surveyed 100 gynecologic oncology patients between December 2011 and September 2012. An 83-item tool based on three validated assessment tools evaluated patient-centered factors, physician behavior and communication skills, and environmental factors. Associations between patients' satisfaction and these variables were analyzed using Wilcoxon rank-sum, Kruskal-Wallis, and Spearman's rho tests. Poisson regression was used to assess factors associated with patient's satisfaction.

Results—Twenty-four percent of patients were notified of their diagnosis by phone, 60% in the physician's office and 16% in the hospital. Disclosure was performed by an obstetrician–gynecologist (58%), gynecologic oncologist (26%), primary care physician (8%), or other (8%). Fifty-two percent of all patients were accompanied by a support person. Higher patient satisfaction scores were associated with face to face disclosure (mean score 91% vs. over the phone 72%, $p=0.02$), a private setting (mean score 92% vs. impersonal setting 72%, $p=0.004$), and duration of the encounter of greater than 10 minutes (mean score 94% vs. less than 10 minutes 79%, $p<0.001$). Multivariate analysis confirmed that both physician communication skills ($p<0.001$) and patient-centered factors (eg, perception of physician sensitivity and empathy, opportunities to ask questions and express emotion, and set the pace of conversation) ($p=0.013$) were associated with higher patient satisfaction.

Conclusions—Effective physician communication skills and patient-centered factors resulted in higher patient satisfaction with the gynecologic cancer diagnosis disclosure experience.

*CORRESPONDING AUTHOR: Lindsay Kuroki, MD, Department of Obstetrics & Gynecology, 4911 Barnes Jewish Hospital Plaza, Box 8064, St. Louis, MO 63110, Phone: (314) 454-7882, Fax: (314) 362-2893, kurokil@wudosis.wustl.edu.

†Current affiliation: St. Luke's Cancer Care Associates, Temple University School of Medicine, Bethlehem, PA.

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Introduction

The disclosure of bad news calls for compassionate yet effective communication skills. Breaking bad news is one of the most challenging experiences for the practicing clinician. The disclosure of cancer diagnosis is especially challenging, as approximately 25-35% of newly diagnosed patients experience high levels of emotional distress(1). Pre-existing psychosocial factors (e.g. social support, past medical history, life stressors, education, employment status, etc) have previously been shown to influence a patient's ability to cope with cancer (1).

There is a growing body of literature dedicated to disclosure of bad news, and more recently an even greater focus on cancer patient communication experiences and preferences has developed (2–5). However, prior literature is largely non-empirical, consisting of letters, opinion pieces, correspondence and reviews (6–10). Step-wise protocols and guidelines (6) have been published, but less than one-fifth of studies involve an intervention trial and greater than 90% of studies fail to measure psychosocial outcomes for patients (11).

Identifying modifiable factors in the disclosure process has potential to optimize patient care, enhance the physician-patient relationship, and improve transition of care to specialists. Our primary objective was to characterize the experience of cancer diagnosis disclosure among gynecologic oncology patients. We identified patient, physician, and environmental factors and assessed which were associated with higher patient satisfaction. Our secondary objectives were to measure patient's anxiety level at diagnosis disclosure and assess its effect on patient satisfaction. We hypothesized that higher patient satisfaction would be associated with lower anxiety levels and longer conversations that take place in a personal setting. Among patient, physician, and environmental factors we considered that physician communication skills and behavior would have the most influence on higher patient satisfaction.

Materials and Methods

We performed a single institution survey study of 100 women recently diagnosed with a gynecologic cancer (cervical, endometrial, fallopian tube, ovarian, peritoneal, vaginal or vulvar cancer) within 6 months prior to study enrollment. Prior to the initiation of the study, all procedures were reviewed and approved by Washington University's Human Research Protection Office (HRPO# 201103279). All participants were at least 18 years of age, able to read and write in English, and provide signed informed consent. We excluded patients with recurrent disease and confirmed all diagnoses by documented histology on pathology reports. Gynecologic oncology patients treated by members of the Division of Gynecologic Oncology at Washington University School of Medicine and Siteman Cancer Center (a National Cancer Institute-designated comprehensive cancer center) were invited to participate between December 2011 and September 2012.

Patients were approached if eligible and were assured that participation was completely voluntary and anonymous. They were allowed to complete the questionnaire at the time of their outpatient appointment in a private room or take the survey home and return it in a self-addressed envelope provided. Those who did not return the survey after 2 weeks were followed up with a telephone call as a courtesy reminder. Our study population was a convenience sample of 100 patients. This was determined primarily based on clinical feasibility rather than statistical power since prior literature was insufficient to allow estimation of strength of associations for power calculations. One hundred twenty-one patients were eligible. Twenty-one did not return their survey and 11 patients were approached, but declined enrollment. Seventeen patients completed the entire 83-question

survey (see the Appendix online at <http://links.lww.com/xxx>), however overall response rate was high. The average number of questions missing per patient was 6.7 (SD 6.6, median 4, range 1–30).

An 83-item questionnaire was administered based on three previously validated assessment tools as well as a literature search of prior surveys on disclosure of cancer diagnosis. Data collected included patient demographics and factors related to diagnosis disclosure (e.g. location, people present and length of discussion). Questions were grouped into three broad categories: patient, physician and environmental factors. Each question was scored separately and within each category a summary score was calculated by adding the scores from each question and dividing by the number of items answered.

Fourteen questions from the Communication Assessment Tool (CAT)(12) were used, asking respondents to rate different dimensions of the communication and interpersonal skills of the physician using a 5-point rating scale (1=poor, 2=fair, 3=good, 4=very good, 5=excellent). In addition, the 5-item Wake Forest Trust Scale (13, 14) was incorporated to evaluate patients' trust in their physician, measuring physician professionalism and patient care skills. A 5-point scale was used, ranging from 1=strongly disagree to 5=strongly agree, with a higher score indicating a higher level of trust. The mean overall score for each questionnaire was calculated. Lastly, the 20-item State-Trait Anxiety Inventory (STAI)-Trait scale (15) was used to measure trait anxiety, a stable propensity to experience anxiety or view stressful situations as threatening. The STAI-trait anxiety measure is balanced for acquiescence, with both directly scored and reverse-scored items. After reverse scoring 9 items, a total score was computed, with higher scores indicating greater trait anxiety.

Patients were also asked to rate their overall experience at the time of diagnosis disclosure on a scale of 1-100. Associations between patients' satisfaction and each of patient, physician and environmental factors were analyzed using the Wilcoxon rank-sum, Kruskal-Wallis, and Spearman's rho tests as appropriate. The mean value of patients' reported satisfaction score was used as the cutoff to define a dichotomized satisfaction score. Poisson regression with robust error variance was used to assess factors associated with satisfaction and estimate relative risk (RR) and 95% confidence intervals. This analytic approach is a reasonable alternative for logistic regression in cross-sectional studies, providing an unbiased estimate of the RR when the outcome is common (16). The significant factors from the univariate analysis were included in the multivariate analysis using a stepwise approach. Analysis was performed using Stata 10 (College Station, Texas) and an association was considered statistically significant if $p < 0.05$.

Results

Data was collected on 100 women regarding their experience at the time of diagnosis disclosure of gynecologic cancer. Their mean age was 58 years and the majority were married (52%), Caucasian (90%), and diagnosed with uterine cancer (71%). Ovarian, fallopian tube or peritoneal cancer composed 20% of the study population, followed by cervical, vulvar, or vaginal cancer (11%). Two patients had synchronous tumors (Table 1).

Twenty-four percent were told their diagnoses over the telephone, 60% in the physician's office and 16% in the hospital (Table 2). The majority of disclosures were performed by an obstetrician-gynecologist (58%), versus 26% by a gynecologic oncologist, 8% by a primary care physician, and 8% by a member of the patient's care team. These included a reproductive endocrine infertility physician, an emergency medicine physician, a physician of unspecified specialty, 2 physician assistants, a resident, and a women's health nurse practitioner. Fifty-two percent of women were accompanied by a support person, most often

a spouse, child, or parent. Forty-eight percent of disclosure discussions lasted between 1-10 minutes, 46% between 11-30 minutes (46%), and 2 patients recalled a discussion length less than 1 minute. Treatment options were included 73% of the time. Future fertility was only relevant for 32 patients, and of these 17 (53%) reported that their physician discussed how their diagnosis of gynecologic cancer would affect their ability to become pregnant in the future.

Patient satisfaction regarding their overall experience with the disclosure process was rated on a scale of 1 to 100. The mean score was 86.5, SD 24.4 and the median was 100. We found that face-to-face disclosure ($p=0.02$), location of disclosure in a personal setting ($p=0.004$), and length of conversation over 10 minutes ($p<0.001$) were all associated with higher patient satisfaction ratings (Table 3).

Patient-centered factors were also associated with higher patient satisfaction ($p<0.001$). They were scored per question and represented as a mean cumulative score. Examples of these survey statements included, "The doctor let me set the pace of the conversation," "I was given the chance to ask questions," and "The doctor took into account what I already knew about the situation."

Physician-centered factors were also represented as a cumulative mean score and subdivided into behavior and communication (Table 3). Both were associated with higher patient satisfaction scores ($p<0.001$). Examples included: "The doctor did not seem nervous as I received the news," "The doctor checked with me several days later to see whether I had any questions or concerns," and "The doctor used body language and nonverbal cues to let me know that bad news was forthcoming." Other factors associated with higher patient satisfaction included strong trust in their physician ($p<0.0001$), environmental factors such as a quiet, private, and comfortable setting without interruptions ($p<0.001$). Disease-related factors such as tumor site and stage were not significantly associated with higher patient satisfaction.

Lower anxiety levels were also associated with higher patient satisfaction ($p<0.001$). Among the 86 patients who had complete anxiety data, the mean total STAI-Trait score was 38, SD 12.2, median 36. Using the standard cutoff (45.81) for a female adult according to the manual for the STAI-Trait, 25 patients in our study (29%) had at least moderately high level of stress.

We noted associations between how different types of physicians disclosed a cancer diagnosis and each of several aspects of the disclosure experience (Table 4). Regardless of specialty there were no significant differences in length of discussion; whether a support person was present; patient, physician, or environmental factors; level of physician trust; or patient anxiety at the time of diagnosis disclosure. Gynecologic oncologists were more likely to disclose a cancer diagnosis in person ($p=0.016$) and in a personal setting ($p=0.03$) compared to their professional counterparts. There was no significant difference in patient satisfaction by physician type ($p=0.19$), however we acknowledge that our study was underpowered to adequately evaluate this relationship.

Poisson regression analysis was performed using a dichotomized satisfaction defined using the cutoff at the mean score. Significant factors from the univariate analysis were entered into the multivariate Poisson model using a stepwise approach. In this multivariate analysis, patient-centered factors (RR 2.8, 95% CI 1.75-4.49, $p=0.013$) and patient perception of physician communication skills (RR 4.05, 95% CI 1.34-12.26, $p<0.001$) were significantly associated with higher patient satisfaction regarding the disclosure experience. Among 11 patient-centered statements, 2 were most significantly associated with higher patient satisfaction: a) "The doctor seemed to think about my needs during the interaction," and b)

“Rather than sticking to a plan, the doctor allowed my reaction to dictate the flow of the transaction.” With regards to physician communication skills, the following statements were most significantly associated with higher patient satisfaction: a) “The doctor understood my main health concerns,” b) “The doctor talked in terms I could understand,” c) “The doctor showed care and concern,” d) “The doctor spent the right amount of time with me.”

Discussion

Our study characterized the experience of cancer diagnosis disclosure among gynecologic oncology patients. Overall patient satisfaction was high, but equally importantly, our results offer insights into how disclosure can be improved, especially with regards to discussion length of time. Conversations should take place in a private setting, for greater than 10 minutes, and include discussion of treatment options if appropriate. Furthermore, opportunities to ask questions, express emotion, and set the pace of conversation are important patient-centered factors that should be taken into consideration to optimize the disclosure process. Our findings not only strengthen the current body of literature regarding communication of bad news to patients, but also expand the scope of evidence by identifying issues specific to gynecologic oncology patients.

While interpreting our results, consideration should be given to the fact that cancer diagnosis disclosure is often complicated by the need to expedite referrals to oncology specialists. This time-sensitive issue has potential to play a major role in how disclosures are performed and ultimately may have a negative effect on a patient’s experience. Establishing with patients upfront (e.g. at the time of the initial procedure consent) how they would prefer results disclosed may facilitate more individualized counseling and ultimately enhance patients’ experiences when dealing with bad news. Unfortunately, our study questionnaire did not specifically inquire whether or not patients were asked how they would like test results disclosed. However, this could be incorporated into a future intervention trial to further evaluate the feasibility and patient and physician preferences of individually-tailored diagnosis disclosures.

Other limitations of our survey study stem from the inherent nature a cross-sectional design and asking patients to reflect on a past experience. The former limits our ability to infer causality from associations observed between the outcome, patient satisfaction, and specific factors of interest. Furthermore, given the sensitive nature of this topic and weight of emotions to cloud memories, recall bias has potential to affect our results. To minimize this effect, we restricted study eligibility to patients who were diagnosed within 6 months of study enrollment and were approached no later than their 6-week postoperative appointment. This also minimized exposure to any adjuvant treatment which also has potential to cause cognitive deficits in recall. Additionally, we excluded patients with recurrent or progressive cancer, as disease status may confound results and exaggerate bias.

Patient selection bias is another limitation that may have influenced our results. However, the overwhelming majority of our practice is referral-based, and our results confirm that diagnosis disclosure was most often performed by the referring gynecologist. It is possible that members of the research team avoided asking patients who appeared upset or distraught, or alternatively, were more inclined to approach patients who they had established a good relationship. Again, it should be noted that 74% of patients answered their survey questions based on experiences with their referring physician. Unfortunately, there is no way to know if those that declined, did so based on their dissatisfaction with the disclosure experience.

Racial disparities and cultural differences also have potential to affect our results. Given that the majority of our study population was white (90%), our results may not be generalizable

to all gynecologic oncology patients. For example, Fujimori et al(3) found marked cross-cultural differences and wide variation with respect to having relatives present when receiving bad news and desire to receive information regarding their life expectancy.

Despite this racially homogenous sample, our study highlights an important point that gynecologic oncology patients are willing to share their diagnosis-disclosure experiences. There may be some presumptions that asking patients to recall their diagnosis disclosure will provoke anxiety with potential to negatively affect a patient's well being. Previously published research has reported that women with gynecologic cancer suffer from significant psychological problems caused by diagnosis and treatment, and that the most persistent of them is fear of death (23%)(18). However, this should not discourage future studies related to this topic. Our results provide useful insights into the disclosure process and can be tested in other populations. Moreover, results from this study have potential to improve clinical training, enhance the physician-patient relationship, as well as optimize patient care and its effect on family members. It may also facilitate transition of care from primary physician offices to specialists and referral centers.

Disclosing a cancer diagnosis is as much of an art form as the treatment options that come afterwards. Discussions should be tailored to the individual and involved family members, approached with an open mind, and adaptive to different patient needs and reactions to receiving news of a cancer diagnosis. One of our study participants wrote, "There is no easy way to tell a person they have cancer. I elected to stay home from work, because I thought I would hear from my ob-gyn regarding my biopsy. In a way, I was glad to be home...so I could gather myself together and get ready for the fight of my life." We hope our findings underscore the importance of effective communication, especially when the diagnosis is gynecologic cancer, as such conversations are a fundamental component of training for the practicing obstetrician-gynecologist.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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Table 1

Sociodemographic Characteristics

Characteristic	n *
Mean age (SD)	58.2 (12.5)
Relationship status	
Single	22
Separated	2
Married	52
Divorced	12
Widowed	12
Race	
Caucasian	90
African American	7
Other	3
Ethnicity	
Hispanic	2
Non-Hispanic	98
Type of cancer [†]	
Uterine	71
Ovarian, fallopian tube, peritoneal	20
Cervical, vulvar or vaginal	11
Religion	
None	10
Protestant	46
Catholic	18
Other	26
Participation in faith-based organizations	
Not at all	19
<6 times per year	17
6-12 times per year	5
Monthly	10
Weekly or more	46
Income	
<25,000	29
25,000-49,999	21
50,000-74,999	14
75,000-99,999	7
100,000	10

Characteristic	n *
I prefer not to answer	15
Education	
6-11 years of schooling	3
High school diploma	33
Some college	25
College graduate	20
Trade school	7
Postgraduate	12

SD, standard deviation.

* Values in the right hand column represent corresponding percentages given (n=100).

[†] Two patients had synchronous tumors.

Table 2

Disclosure of Cancer Diagnosis to Patient

Parameter	n*
Method of disclosure	
By phone	24
In a physician's office	60
In the hospital	16
Emergency room	2
Patient room	10
Other	4
Person who disclosed diagnosis	
Primary care physician	8
Gynecologist	58
Gynecologic oncologist	26
Non-physician	1
Other	7
Another support person present	
Yes	52
No	48
Support present at time of disclosure[†]	
Parent	5
Spouse	22
Sibling	4
Child	7
Significant Other	4
Other	4
Length of discussion (minutes)	
Less than 1 minute	2
1-10	48
11-30	46
31-60	3
Discussion of treatment options	
Yes	73
No	17
Not applicable	8
Discussion regarding effect on future fertility	
Yes	17
No	15
Not applicable	65

* Values in the right-hand column represent corresponding percentages given (n=100).

[†] More than one person may have been present at the time of diagnosis disclosure.

Table 3

Diagnosis Disclosure and Patient Satisfaction Score

Parameter	Satisfaction Score				P [*]
	n	Mean	Median	SD	
Method of disclosure					
In person	70	91.3	100	16.5	
Over the phone	23	72	90	36.6	0.02
Another person present					
Yes	51	90.9	100	16.7	
No	42	81.1	100	30.6	0.31
Location of disclosure					
Personal setting	66	91.7	100	16.6	
Impersonal setting	25	72.2	90	35.1	0.004
Length of discussion (minutes)					
10	45	78.5	90	29.2	
> 10	47	93.9	100	15.8	<0.001
Discussion of treatment options					
Yes	69	91.8	100	16.0	
No	16	58.1	52.5	37.5	<0.001
Discussion regarding effect on future fertility					
Yes	15	92.9	100	15.6	
No	15	72.0	90	37.0	0.049
Stage					
1	61	88.9	100	19.7	
2	6	79.2	100	40.1	
3	20	77.6	94	32.4	
4	6	99.2	100	2	0.12 [†]
Type of cancer					
Uterine	66	88.9	100	22.3	
Ovarian	16	83.1	95	23.9	

Parameter	Satisfaction Score				<i>P</i> [*]
	n	Mean	Median	SD	
Cervical	9	75.9	95	38.2	0.17 [‡]
Patient-centered score		0.56 [‡]			<0.001
Physician-centered score					
Physician behavior		0.4 [‡]			<0.001
Physician communication		0.78 [‡]			<0.001
Trust		0.63 [‡]			<0.001
Environmental factors		0.4 [‡]			<0.001
Anxiety score		-0.25			0.01

* Performed by Wilcoxon rank-sum test.

[‡] Performed by Kruskal-Wallis test.

[‡] Spearman's rho.

Table 4

Aspects of Disclosure and Type of Physician

Parameter	PCP (8)	Gynecologist (58)	Gynecologic Oncologist (26)	Others (8)	P
Method of disclosure					
In person	6(75)	40(69)	25(96)	5(63)	
Over the phone	2(25)	18(31)	1(4)	3(37)	0.016*
Another person present					
Yes	5(62)	26(45)	17(65)	4(50)	
No	3(38)	32(55)	9(35)	4(50)	0.345*
Location of disclosure					
Personal setting	5(63)	38(68)	23(92)	4(50)	
Impersonal setting	3(38)	18(32)	2(8)	4(50)	0.03*
Length of discussion (minutes)					
10	5(62)	30(53)	11(42)	4(50)	
> 10	3(38)	27(47)	15(58)	4(50)	0.73*
Patient-centered score	0.82 (0.74, 0.33)	0.90 (0.80, 0.28)	1 (0.94, 0.11)	0.89 (0.82, 0.17)	0.13†
Physician-centered score					
Physician behavior	0.38 (0.46, 0.39)	0.41 (0.52, 0.46)	0.47 (0.49, 0.21)	0.44 (0.48, 0.27)	0.85†
Physician communication	4.14 (4.08, 0.92)	4.89 (4.33, 0.89)	4.89 (4.60, 0.66)	4.93 (4.58, 0.67)	0.35†
Trust	3.40 (3.55, 0.58)	3.80 (3.83, 0.50)	4.20 (3.92, 0.39)	3.90 (3.78, 0.47)	0.35†
Environmental factors	0.83 (0.79, 0.19)	0.83 (0.77, 0.29)	0.83 (0.92, 0.43)	0.83 (0.71, 0.34)	0.41†
Trait anxiety score	1.80 (2.03, 0.76)	1.78 (1.93, 0.64)	1.80 (1.81, 0.54)	1.78 (1.93, 0.53)	0.91†

Data are n(%) or median (mean, standard deviation) unless otherwise specified.

* Performed by Fisher exact test.

† Performed by Kruskal-Wallis test.