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Use of Social Media to Conduct a Cross-Sectional Epidemiologic and Quality of Life Survey of Patients with Neuroendocrine Carcinoma of the Cervix: A Feasibility Study

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Abstract

Objective—To determine the feasibility of using social media to perform cross-sectional epidemiologic and quality-of-life research on patients with rare gynecologic tumors, we performed a survey of patients with neuroendocrine tumors of the cervix using Facebook.

Methods—After approval from our Institutional Review Board, a support group of patients with neuroendocrine tumors of the cervix was identified on Facebook. Group members were asked to complete a survey comprising 84 questions evaluating clinical presentation; treatment; recurrence; quality of life; and sexual function.

Results—The survey was posted for 30 days, during which 57 women responded from 8 countries across 4 continents treated at 51 centers. All respondents provided a detailed clinical and tumor history. The mean age was 38.5 years. The stage distribution was stage I, 36 patients (63%); II, 13 (23%); III, 2 (4%); and IV, 6 (11%). Forty-nine patients (86%) had small cell and 8 (14%) large cell tumors. Forty-five of the respondents (79%) had completed primary therapy, 53 (93%) had no evidence of disease, and 8 (14%) had recurrent disease. Forty-one patients (72%) reported symptoms at time of presentation. Thirty-seven patients (65%) received multimodality primary therapy. Quality of life instruments demonstrated high scores for anxiety and a negative impact of anxiety and cancer on functional and emotional well-being. Sexual function scores did not differ significantly between respondents and the PROMIS reference population.

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Conclusions—Use of a social media network to perform epidemiologic and quality of life research on patients with rare gynecologic tumors is feasible and permits such research to be conducted efficiently and rapidly.

Keywords

cervix; neuroendocrine; small cell; large cell; social media; Facebook

Introduction

Rare tumors of the female reproductive tract have traditionally posed a challenge for researchers because of the inherent difficulty of aggregating data from a small sample of patients spread over a wide geographic area. Most studies of rare tumors of the female reproductive tract conducted to date are single-institution experiences over many years. These studies, combined with expert opinion, form the basis for many of the standard-of-care management guidelines for such tumors.

Neuroendocrine carcinoma of the uterine cervix is a rare gynecologic tumor with histologic features that resemble those of neuroendocrine tumors from other primary sites, such as small cell carcinoma of the lung [1]. Neuroendocrine carcinoma of the cervix accounts for less than 1% of all cervical cancers, and fewer than 100 cases are diagnosed annually in the United States [2]. The majority of patients have advanced-stage disease at diagnosis, and even those diagnosed at an early stage have a higher risk for recurrence and disease progression than patients with other histologic types of cervical cancer [3]. Treatment strategies for neuroendocrine carcinoma of the cervix are extrapolated from management of more common cervical carcinomas and neuroendocrine cancers from other primary sites [1]. Radical hysterectomy and pelvic lymphadenectomy are usually performed for early-stage disease [4]. Postoperative adjuvant chemotherapy with platinum or combined etoposide/platinum regimens is reported to increase survival [3, 5]. Some studies suggest that primary concurrent chemoradiation is also an option for early-stage disease [6, 7]. Treatment of advanced disease is often palliative [8].

To our knowledge, there are no published reports regarding studies conducted in a cross-sectional fashion evaluating the presentation at the time of diagnosis, initial staging evaluation, treatment, or surveillance of women with neuroendocrine carcinoma of the cervix. There are a few published single-institution case series that have addressed some of these issues through retrospective reviews. Additionally, there are no published data about quality of life or patient reported outcomes (PROs) for this patient population.

The advent of social media has enabled many patients with rare tumors to connect in the public domain [9]. These connections often occur through online support groups or forums on popular social media websites such as Facebook [10]. These groups allow patients to exchange information, provide support to each other, and, often, solicit expert opinion from physician members of those social networks [11]. The online presence of these groups may present a new opportunity to perform research outside the traditional confines of single-institution databases. In an attempt to assess the feasibility of such an approach, we identified a Facebook group for patients with neuroendocrine cancer of the cervix and

invited patient members of the group to complete an epidemiologic and quality of life survey.

Methods

After obtaining Institutional Review Board approval, we asked members of an established support group for women with neuroendocrine cancer of the cervix on the social networking site Facebook (present at <https://www.facebook.com/groups/scccsisters/>) to anonymously complete an online survey. Specifically, we posted a link to the survey in the support group's Facebook news feed, along with a brief description of the inclusion criteria and survey goals. Any woman who self-reported a history of small or large cell carcinoma of the cervix was included. Confirmation of diagnosis through medical records or pathology review was not obtained.

The survey was stored on a remote secure server. Once a member clicked the link to the survey, the survey was presented on a separate screen. All responses were anonymous. Once respondents completed the survey, they were taken back to the support group's Facebook page. No results were shared with the participants. The study was open for 30 days from July 29-August 28, 2012. Multiple reminders of the ongoing survey were posted on the group's news feed throughout the 30 days period. Any questions about the survey posted on the group's news feed were answered by the investigators.

The survey contained 84 items. The first questions addressed sociodemographic factors, clinical presentation, initial work-up, treatments received, past and current disease status, follow-up, and recurrence pattern. The remaining questions were used to assess patients' anxiety and posttreatment sexual function and were derived from 4 validated quality-of-life instruments: the Concerns About Recurrence Scale (CARS), the Lerman Cancer Worry Scale (LCWS), the Functional Assessment of Cancer Therapy–Cervix (FACT-Cx), and the Patient-Reported Outcomes Measurement Information System (PROMIS) on sexual functioning.

Concerns About Recurrence Scale

Originally developed by Vickberg to measure worry related to breast cancer recurrence, the CARS consists of 30 items scored from 1 (not at all) to 5 (extremely) [12]. An overall worry score and 4 subscores (health, role, womanhood, and death) are calculated.

Lerman Cancer Worry Scale

The LCWS includes 3 items. One item measures the frequency of worrying about cancer and has five 5 responses ranging from “never” to “all of the time.” Two items measure the impact of worry on mood and performing daily activities and have 5 possible responses ranging from “not at all” to “extremely” [13].

Functional Assessment of Cancer Therapy–Cervix

The FACT-Cx is the FACT-G plus the cervix subscale. The FACT-G (version 4) is a 27-item self-reported quality-of-life instrument developed and validated among cancer patients

for use in clinical trials. It consists of 4 subscales measuring physical well-being, functional well-being, social/family well-being, and emotional well-being. Each subscale produces a score, and the subscale scores can be added to derive a total score. The cervix subscale contains 15 additional items developed by cervical cancer patients and clinicians [14]. Lower scores indicate better well-being.

PROMIS on Sexual Functioning

The PROMIS Sexual Function–female instrument provides scores on several different subdomains of sexual function: Interest in Sexual Activity, Vaginal Discomfort, Lubrication, and Global Satisfaction with Sex Life. The survey consists of 9 multiple-choice questions. Each question asks respondents to report on their experiences over the past 30 days. All subdomain scores are expressed as T scores (mean = 50, standard deviation [SD] = 10). At present, a T score of 50 corresponds to the mean response among the cancer survivors used for item testing during survey development [15].

Statistical Analysis

This was a 1-time-only cross-sectional survey of patients. Descriptive statistics were used to summarize participants' responses to survey questions. Contingency tables were constructed comparing patients stratified by stage, treatment(s), and pathologic subtype. Quality of life instruments were scored according to previously published methodology [12-15]. Nonparametric tests were conducted to test for differences in outcomes and quality of life based on stratification on clinical variables. Data were coded, stored, and analyzed using SPSS 16.0 software (IBM Corporation, Armonk, NY).

Results

Fifty-seven patient members of the support group participated in the study during the 30 days it was available online. The total number of patients in the support group was not evaluable because the group included family and supporters; hence, response rate was not calculated. Forty-six of the respondents (81%) completed the survey within the first 2 weeks it was posted.

The majority of respondents (79%) were women residing in 26 different states across the United States. (Table 1) The mean age at time of survey response was 38.5 years (SD, 8.9 years; range, 24-68 years). Respondents had received cancer care at 51 different centers; 30 respondents (51.8%) had received care in an academic setting. Forty-nine patients (86%) had small cell and 8 (14%) had large cell tumors. Thirty eight patients (67%) were cared for primarily by a gynecologic oncologist; 25 patients (44%) and 23 patients (48%) also reported being cared or co-managed by medical oncologists and radiation oncologists, respectively.

The mean age at diagnosis was 36 years (SD, 8.6 years; range, 23-68 years). Forty-one patients (72%) were symptomatic at diagnosis, and 38 patients (66%) reported vaginal bleeding and/or vaginal discharge. Of the 16 patients without symptoms at diagnosis, 9 (56%) had an abnormal Pap smear. Only 11 patients (19%) reported testing positive for human papillomavirus (Table 2).

At the time of the survey, 45 patients (79%) had completed primary therapy with no evidence of disease with 3 (5%) reporting persistent disease. Four patients (7%) were still undergoing primary therapy and 5 (9%) had recurrent disease. Nineteen (33.3%) of 57 patients were treated with a single modality: 7 (12%) were treated with surgery alone, 11 (19.2%) with radiation alone, and 1 (1.7%) with chemotherapy alone. The remaining 38 patients (66.7%) were treated with multimodality therapy: 14 (24.5%) were treated with surgery plus radiation, 11 (19.2%) with surgery plus chemotherapy, 8 (14%) with chemotherapy plus radiation, and 5 (9%) with all 3 modalities.

For surveillance after treatment, 38 patients (66.6%) were seen by gynecologic oncologists, while 9 (15.7%) were seen by medical oncologists, and the remaining 10 (8.3%) saw a combination of physicians. Most patients (39 patients; 68.4%) reported use of scheduled tomographic imaging studies (positron emission tomography, computed tomography) as part of their routine follow-up care.

Patients exhibited high levels of anxiety across the CARS subscales; the median overall anxiety score was 4.4 out of 5. Scores were highest for health-related anxiety and death-related anxiety (Table 3). Stratification by stage and treatment did not reveal any significant differences. Results for the LCWS were similar: 33 patients (57.8%) reported worrying about cancer often or all of the time, and this worry had a pronounced effect on mood (Table 4). Perceived quality of life scores on the FACT-Cx showed low scores across all dimensions, with the lowest scores for the emotional well-being and cervix cancer subscales. When patients were subdivided by treatment received, a nonsignificant trend was noted towards decreased scores in patients treated with combinations of modalities. Forty-six respondents (80.7%) indicated that they were in a relationship that could involve sexual activity; however, only 30 patients (52.6%) had engaged in sexual activity in the past 30 days. PROMIS scores were all within 1 standard deviation of the population mean of the survey, indicating no overall difference in sexual function between respondents and the PROMIS reference cancer population.

Discussion

Researchers interested in rare tumors of the female reproductive tract face many obstacles. In the absence of an institutional database or a tumor registry, identification of sufficient numbers of patients and collection of sufficient data for studies of such tumors may span many years and prove impractical. Our work demonstrates that use of a social media platform may eliminate many of these obstacles and may allow a diverse patient sample to be recruited and surveyed in a short period of time.

Compared to the patients in other reported case series (Table 5), our patients were younger. This difference may be due to heavier use of social media by younger patients. The distribution of disease stage in our study was similar to that in other case studies and a study based on Surveillance, Epidemiology, and End Results (SEER) data [1]. Unlike previously published studies based on chart reviews, our study lacked data from deceased patients and hence had fewer recurrences. This difference is likely attributable to the cross-sectional nature of our study and limited time of follow-up.

To our knowledge, there are no published data on quality of life of patients with cervical neuroendocrine tumors. However, studies of patients with more prevalent cervical cancer subtypes, such as squamous cell carcinoma and adenocarcinoma, have revealed findings similar to those seen in our study population. Ferrandina et al [16] recently reported a prospective evaluation of quality of life measures among patients with cervical cancer. In this study, patients reported high anxiety, increased worry, diminished well-being, and decreased sexual function after treatment. Interestingly, the study demonstrated significant improvement of these measures over a 2 year period of follow-up care. Park et al reported similar findings in disease-free survivors of cervical cancer [17]. In contrast, Fernandes and Kimura conducted a cross-sectional survey of 149 patients with cervical cancer utilizing the FACT-Cx and reported higher quality of life than in our population, with a median total score of 148 (compared to 103 in our current study) [14]. This higher quality of life score was mainly due to higher reported emotional and social well-being. Higher anxiety, worry, and emotional distress among our study patients may be explained by the poorer prognosis associated with neuroendocrine tumors, perceived uncertainty regarding treatment success, and lack of patient support because of the rare nature of the disease. The high rate of radiotherapy in our population may also have contributed to the poor quality of life findings and their persistence [18].

Clinically, our study population had a symptom profile and screening detection rate similar to those reported in other cervical cancer studies [19]. Given that most recurrences of neuroendocrine cervical tumors result from hematogenous spread [8] and given the reported benefits of chemotherapy for treatment of this tumor [6], it is notable that the most common multimodality therapy among our respondents was surgery plus radiotherapy, delivered to over 30% of respondents. Of note, 57% of our respondents did not receive adjuvant chemotherapy. Our respondents reported more extensive use of positron emission tomography and computed tomography for surveillance than has been reported in previous studies of patients with squamous cell carcinoma or adenocarcinoma of the cervix.

To our knowledge, ours is the first published study on the use of social media as a platform for conducting a cross-sectional epidemiologic and quality of life study of patients with a rare tumor. Thus, there are no published data with which to compare our findings. Nevertheless, our ability to recruit participants and collect data for our study within 30 days is notable. Patients provided clinical data and completed several quality of life instruments without missing data, demonstrating a high degree of motivation among the study population. These women were able to provide us with clinical details usually only obtainable through chart reviews or personal interviews.

Our results suffer from some several drawbacks. First, there are the limitations shared by all studies based on patient reported outcomes ascertained at only one time point. These include recall bias and lack of follow-up. However, as our use social media is a novel approach to this type of research, there are several interesting potential limitations unique to this methodology. As we were unable to calculate a response rate, understanding the degree of non-response bias is difficult. In addition, there is likely a selection bias favoring young patients as they are more likely to be active Facebook users. A recent Pew research study showed that a statistically significant difference among age groups using Facebook with

86% of all people aged 18-29 years old using the site compared to 73% of people aged 30-49, 57% of people 50-64 and only 35% of people older than 64 years old [20]. In addition, the quality of life data may also suffer from selection bias as sicker patients may not be as active on Facebook as those who are feeling well. One other source of selection bias may result from the fact that this study was performed among a neuroendocrine cervical cancer support group where women may have increased health literacy and knowledge of their disease compared to those who are not part of a support group. For all of these reasons, the results of this study may not be generalizable to a larger population of small and large cell cervical cancer patients. Finally, we assume in good faith that those who responded actually have small or large cell cervical cancer although certainly we are unable to confirm that they are indeed who they say they are.

To that end, we currently are enrolling patients in the Neuroendocrine Cancer Tumor Registry (NeCTuR), a large tumor registry for patients with this disease. Through this registry we will be able to obtain medical records and verify diagnoses and demographics. The Internet (www.necervix.com) and, in particular, social media will play an important role in advertising of the registry and recruitment of patients.

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Highlights

- Use of Facebook is a feasible method for performing epidemiologic and quality of life studies in patients with rare tumors.
- Women with neuroendocrine cervical cancer have high levels of anxiety.

Table 1

Profile of study respondents (n=57)

Characteristic	No. of patients (%)
Histologic subtype	
Small cell	49 (86)
Large cell	8 (14)
Stage	
I	36 (63)
II	13 (23)
III	2 (4)
IV	6 (11)
Country of residence	
Australia	3 (5)
Canada	1 (2)
China (Hong Kong)	1 (2)
Ireland	1 (2)
New Zealand	1 (2)
Norway	2 (4)
United Kingdom	3 (5)
United States	45 (79)
United States region	
South	14
West	15
Midwest	8
Northeast	8
Specialty of primary oncology provider	
Gynecologic oncology	38 (67)
Medical oncology	9 (16)
Radiation oncology	3 (5)
More than 1 specialty	7 (12)

Table 2

Presenting symptoms and human papillomavirus (HPV) status

Finding	No. of patients (%)
Symptoms present	41 (72)
Pelvic pain	13 (23)
Irregular/heavy vaginal bleeding	27 (47)
Vaginal discharge	23 (40)
Pain/bleeding with intercourse	24 (42)
Non-pelvic symptoms	8 (14)
No symptoms	16 (28)
Abnormal Pap test	9 (16)
Mass/abnormal findings on examination	7 (12)
HPV status	
Positive	11 (19)
Negative	43 (75)
Unknown	3 (5)

Table 3

Concerns About Recurrence Scale (CARS) scores

Scale	Mean score (range, 0-5)	Standard deviation
Health-related anxiety subscale	3.9	0.9
Womanhood anxiety subscale	2.6	1.1
Role-related anxiety subscale	3.6	1
Death-related anxiety subscale	4.4	1
Overall CARS anxiety score [*]	4.4	1.2
Stage I	4.2	
Stage II	4.4	
Stage III	4.8	
Stage IV	4.7	

* Median overall score did not differ by stage.

Table 4

Quality of life instrument results

Question/scale	Result
Lerman Cancer Worry Scale	
How often do you worry about your cancer?, n (%)	
Never	2 (4)
Rarely	9 (16)
Sometimes	13 (23)
Often	19 (33)
All of the time	14 (25)
During the past month how often have thoughts about your chances of getting cancer affected your mood?, n (%)	
Not at all	4 (7)
A little	13 (23)
Moderately	14 (25)
A lot	13 (23)
Extremely	13 (23)
During the past month how often have thoughts about your chances of getting cancer affected your ability to perform your daily activities?, n (%)	
Not at all	18 (32)
A little	14 (25)
Moderately	13 (23)
A lot	5 (9)
Extremely	7 (12)
FACT-Cx score, mean (SD)	
Physical well-being subscale (range, 0-28)	16.6 (8.1)
Social well-being subscale (range, 0-28)	17.8 (5.3)
Emotional well-being subscale (range, 0-24)	13.1 (5.9)
Functional well-being subscale (range, 0-28)	18.4 (8.7)
Cervix cancer subscale (range, 0-60)	37.2 (7.7)
FACT-Cx total (range, 0-168)	103.3 (28.7)
PROMIS Sexual Function T score,* mean (SD)	
Interest in sexual activity	44.9 (3.1)
Lubrication	52.7 (3.9)
Vaginal discomfort	49.2 (3.0)
Global satisfaction with sexual activity	43.6 (4.1)

FACT-Cx, Functional Assessment of Cancer Therapy–Cervix; PROMIS, Patient-Reported Outcomes Measurement Information System.

Table 5

Reported case series of cervical neuroendocrine tumors

Author	N	Mean age, years (range)	Distribution of patients by stage, %			
			I	II	III	IV
Chan et al [4]	34	42 (48-79)	66	17	15	2
Viswanathan et al [8]	21	46 (27-78)	70	15	15	0
Zivanovic et al [5]	17	44 (25-62)	65	6	6	23
Hoskins et al [21]	34	43 (23-75)	51	17	20	12
Bermudez et al [22]	20	42 (27-69)	40	25	15	20
Weed et al [23]	15	47 (20-83)	33	20	7	40
Current study	57	39 (24-68)	63	23	4	11