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Social media use is associated with higher levels of anxiety and depression in patients with neuroendocrine carcinoma of the cervix: A NeCTuR study

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HIGHLIGHTS

- NECC patients exhibited low-to-average social media use and non-addictive Facebook behavior.
- NECC patients had relatively high levels of anxiety and depression.
- NECC patients displayed minimal symptomology, but poor emotional, social, physical, and functional wellbeing.
- A significant association between social media use and elevated anxiety and depression levels was seen among NECC patients.

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ABSTRACT

Objective. Neuroendocrine cervical carcinoma (NECC) is rare. Educational resources are limited for NECC patients, leading many to seek information online through patient-led social networks. We sought to characterize the relationships between anxiety and depression levels and social media use among NECC patients.

Methods. Seven surveys assessing social media use, anxiety, and depression were distributed to living NECC patients enrolled in our NECC registry. The primary outcomes were associations between Social Network Time Use Scale (SONTUS) global score and Generalized Anxiety Disorder (GAD-7) and Center for Epidemiologic Studies Depression Scale (CES—D) total scores.

Results. Eighty-eight patients enrolled; 81 who completed at least 1 survey were included. Ninety-seven percent (70/72) of patients completing SONTUS were low-to-average social media users. Seventy-four percent (53/72) of patients visited a patient-led NECC support-group page on Facebook within the past 4 weeks, and of those, 79% (42/53) reported receiving useful information. Among the patients who did not visit the page, 47% (9/19) reported that the page elicited anxiety and/or sadness. The mean GAD-7 and CES-D scores for the entire cohort were 7.3 and 18.1, respectively. The Spearman correlations between social media use and these scores were significant (GAD-7: 0.23 [$p = 0.05$]; CES—D: 0.25 [$p = 0.04$]). The estimated odds ratios for moderate/severe anxiety and depression as a function of SONTUS global score were 1.26 (95% CI 1.03–1.55; $p = 0.03$) and 1.23 (95% CI 1.01–1.49; $p = 0.04$), respectively.

Conclusions. NECC patients demonstrated low-to-average social media use and relatively high anxiety and depression. Increased social media use was associated with elevated anxiety and depression.

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1. Introduction

According to the 2018 Health Information National Trend Survey, 70% of US adults have used internet resources for health-related information [1]; cancer-related information is one of the topics most searched [2,3]. Online support groups, blogs, and forums on wide-reaching social networks such as Facebook and Twitter have allowed cancer patients, particularly those with rare tumors, to connect with one another, improve their morale, and change their outlook on their diseases [4,5]. Additionally, social media use and social media–based interventions have been found to improve quality of life (QOL) and alleviate depressive and anxiety symptoms in cancer patients [4,6,7].

Neuroendocrine carcinoma of the cervix (NECC) is a rare gynecologic malignancy accounting for <1% to 2% of all cervical cancers, or fewer than 250 new cases in the United States each year [8,9]. Patients with NECC are more likely to have recurrence than are those with squamous carcinoma or adenocarcinoma of the cervix; up to 80% of NECC patients experience recurrence [10,11]. Furthermore, recurrent NECC is almost always incurable, and median overall survival after recurrence is <18 months [12]. The high recurrence rate and short post-recurrence survival are likely a source of distress for patients with this disease. Because of the rarity of NECC, there are few published large studies, prospective studies, or clinical trials on NECC [9,13]. This not only limits the ability of researchers to establish standard treatment regimens but also limits the information about NECC available to patients on the internet, leading them to seek information online through patient-led social networks.

Zaid et al. [14] were the first to assess the feasibility of conducting epidemiologic and QOL research using NECC patients' social networks. These authors used the Small/Large Cell Carcinoma of the Cervix: Sisters United Facebook group to conduct a survey of anxiety and QOL in NECC patients. To our knowledge, no studies have assessed social media use by NECC patients and its impact on anxiety and depression. The objectives of this study were to (1) characterize social media use among NECC patients, (2) examine levels of anxiety, depression, and QOL among NECC patients, and (3) characterize the relationships between anxiety and depression levels and social media use among NECC patients.

2. Methods

This was a single-timepoint, cross-sectional study. The study population consisted of adult, English speaking, living patients diagnosed with NECC and enrolled in the Neuroendocrine Cancer Tumor Registry (NeCTuR) at The University of Texas MD Anderson Cancer Center. NeCTuR was established in 2013 and is open to patients with NECC from around the world. Patients who enroll in NeCTuR are prospectively followed. Patients were included in this study irrespective of their stage of treatment or surveillance or their recurrence status at the time of participation. Patients were excluded if they were enrolled in NeCTuR by waiver of consent, deceased or had unconfirmed NECC.

All patient communication was done via email, and the study was not advertised on social media platforms. After we obtained Institutional Review Board approval, eligible patients ($n = 177$) were informed about this study via an email containing a link to the informed consent form. Patients who signed the informed consent form received another email with links to seven surveys assessing QOL, anxiety, and depression levels, as well as social media use. The seven surveys were the following: Generalized Anxiety Disorder-7 (GAD-7), Center for Epidemiologic Studies Depression Scale (CES—D), MD Anderson Symptom Inventory – Cervix (MDASI-Cx), Functional Assessment of Cancer Therapy – Cervix (FACT-Cx), Social Networking Time Use Scale (SONTUS), Bergen Facebook Addiction Scale (BFAS), and Small/Large Cell Carcinoma of the Cervix: Sisters United Facebook Group (hereafter, " Sisters United Facebook group") survey. After patients signed the study consent form, their demographics, medical history, and cervical cancer diagnosis and treatment history were obtained from the NeCTuR registry. The study link was open from February 23, 2022, to June 27, 2022, and patients received up to three email reminders to complete the surveys during this period.

2.1. Generalized anxiety disorder-7

The GAD-7 is a seven-item instrument designed to screen for and measure the severity of GAD in the general population [15]. Questions cover symptoms of anxiety experienced over the past 2 weeks. Responses to each item are presented in four-point Likert scales and range from "0=not at all" to "3=nearly every day". A total score of 0–4 indicates minimal anxiety, 5–9 indicates mild anxiety, 10–14 indicates moderate anxiety, and 15 or greater indicates severe anxiety. To maximize sensitivity, using a score of 8 or greater to identify probable cases of GAD is recommended [16].

2.2. Center for epidemiologic studies depression scale

The CES-D is a 20-item instrument measuring how often depression symptoms have been experienced in the past week. Responses to each item are presented in four-point Likert scales and range from "0 = Less than 1 day" to "3 = 5–7 days". A score of 16 or greater indicates elevated risk for clinically significant levels of depression [17].

2.3. MD anderson symptom inventory – cervix

The MDASI-Cx is a 25-item instrument that includes the core MDASI items and cervical cancer–specific MDASI items. Responses to each item are presented in 10-point Likert scales and range from "0 = Not Present" to "10 = As Bad As You Can Imagine". Part I assesses the severity of core symptoms experienced by cancer patients (items 1–13) and the severity of specific symptoms experienced by cervical cancer patients (items 14–19) in the past 24 h. Part II assesses the interference of these symptoms with patients' daily living (items 20–25). MDASI-Cx total scores are provided in the form of 0–10 scale, and a lower total score indicates lower cancer-related symptom burden [18].

2.4. Functional assessment of cancer therapy – cervix

The FACT-Cx is a 42-item instrument used to assess the well-being and QOL of cervical cancer patients [19]. It includes the 27-item FACT General scale plus a 15-item cervix subscale. The FACT General scale has four subscales: physical well-being, social/family well-being, emotional well-being, and functional well-being [20]. The cervix subscale addresses additional physical and emotional concerns specific to cervical cancer patients [19]. Responses to each item are presented in five-point Likert scales and range from "0 = not at all" to "4 = very much". Each subscale yields a subscore, and subscores can be analyzed separately or added to get a total score; higher scores are correlated with better QOL and well-being.

2.5. Social networking time use scale

The SONTUS is a 29-item instrument that categorizes the level of activity on social media into low, average, high, and extremely high use. The SONTUS assesses time spent using social media over the past week across five different components: (1) during relaxation and free periods, (2) during academic-related periods, (3) in public places, (4) during stress-related periods, and (5) to maintain contact with family or friends or locate or learn about people. Answers to each item are presented in 11-point Likert scales and range from "1 = not applicable to me during the past week" to "11 = I used it more than 3 times during the past week, but spent more than 30 minutes each time". The Likert scale answers are coded as follows: 1–3 = 1, 4–6 = 2, 7–9 = 3, and 10 or 11 = 4. The codes are used to calculate the score for each

component, and the component scores are summed to calculate the total score. Social media users with total scores of 5–9, 10–14, 15–19, and >19 are categorized as having low, average, high, and extremely high use, respectively [21].

2.6. Bergen facebook addiction scale

The original 18-item BFAS was used to assess the six essential elements of addiction—salience, mood, modification, tolerance, withdrawal, conflict, and relapse—in the context of Facebook use [22]. Each item is scored on a five-point Likert scale with options ranging from "1 = very rarely" to "5 = very often". Only six items (item 1, 5, 7, 11, 13, and 16) are used to calculate the total score which ranges from 6 to 30 [22]. Categorization of the total score into addictive versus nonaddictive Facebook use can be based on a liberal approach (cutoff score ≥ 12) or a more conservative approach (cutoff score ≥ 18) [22].

2.7. Sisters united facebook group survey

The Sisters United Facebook Group survey is available in the Supplemental Appendix. Designed by the authors, the survey contains three questions assessing patients' uses and perspectives on the Sisters United Facebook Group, an unmoderated established patient-led support group for NECC patients.

2.8. Statistical analysis

Summary statistics were used to summarize demographic and clinical characteristics and responses to surveys. The Kruskal-Wallis test was used to compare survey scores across low, average, and high social media use groups as determined by SONTUS scores. Spearman's rank correlation was used to estimate the correlations between the SONTUS global score and the GAD-7 total score and the CES-D total score. Logistic regression was used to estimate the odds ratio for moderate or severe anxiety as measured by the GAD-7 and the odds ratio for depression (CES-D score ≥ 16) as a function of the SONTUS global score. No adjustments were made for multiple testing.

3. Results

Of the 177 patients emailed a link to the consent form, 88 signed the consent form, for an accrual rate of 50%. Eighty-one patients completed all or some of the surveys (12% partial, 88% full completion) and were included in the analysis (Fig. 1).

Patients' demographic and clinical characteristics are summarized in Table 1. The mean age at consent was 45.3 years (range, 29.0–71.0). Sixty-eight patients (84%) were White, 70 (86%) were not Hispanic or Latina, and 65 (80%) resided in the USA. Only 26 patients (32%) had been seen at MD Anderson. Sixty-five patients (65/76; 86%) displayed no evidence of disease at last contact. Seventy-four patients (74/77; 96%) received multimodal therapy as primary treatment: 10 patients (10/77; 13%) were treated with surgery and chemotherapy, 23 (23/77; 30%) with radiation and chemotherapy, and 41 (41/77; 53%) with all three modalities.

The responses to the surveys are summarized in Table 2. According to the SONTUS, most patients (70/72; 97%) were low to average social media users; only 2 patients (2/72; 3%) were high users, and none were very high users. Similarly, the BFAS mean score was 10.6, indicating non-addictive Facebook use. Ten patients (10/71; 14%) and three patients (3/71; 4%) displayed addictive Facebook behavior according to the liberal and conservative definitions, respectively. Fifty-three patients (53/72; 74%) reported visiting the Sisters United Facebook group page in the past 4 weeks. Of those, 42 (42/53; 79%) indicated it was true or somewhat true that they "received useful information from this Facebook group," while six (6/53;11%) disagreed with that statement. Nineteen patients (19/72; 26%) reported not having visited the Facebook page, nine (9/19; 47%) because it caused them anxiety and/or sadness and six (6/19; 32%) because they were not Facebook members or did not know the page existed. There was no significant difference in demographic and clinical characteristics between patients who visited the Sister's United Facebook page and those who did not visit the page owing to anxiety and/or sadness.

The mean GAD-7 score was 7.3 (Table 2), which corresponds with mild anxiety. Twenty-six patients (32%) had minimal anxiety, 32 (40%) had mild anxiety, 13 (16%) had moderate anxiety, and 10 (12%) had severe anxiety (Table 2). The mean CES-D score was 18.1 (Table 2), and 43 patients (43/77; 56%) had a CES-D score ≥ 16, indicating elevated risk for clinically significant levels of depression. Both GAD-7 and CES-D mean scores increased with increasing SONTUS category of social media use; however, this increase did not reach statistical significance (Table 3). The Spearman correlation between the SONTUS global score and the GAD-7 score was 0.23 ($p = 0.05$), and the Spearman correlation between the SONTUS global score and the CES-D score was 0.25 ($p = 0.04$).

The odds ratio estimated by logistic regression for moderate or severe anxiety measured by the GAD-7 as a function of the SONTUS global score was 1.26 (95% CI 1.03–1.55) ($p = 0.03$). To maximize sensitivity, the odds ratio for probable cases of anxiety (GAD-7 score ≥ 8) was also estimated as a function of the SONTUS global score, and it was 1.23 (95% CI 1.01–1.48) (p = 0.04). These findings indicated a significant positive association between increasing social media use and diagnosis and severity of anxiety. Similarly, the odds ratio estimated by logistic regression for high risk of clinically significant depression measured by CES-D (score ≥ 16) as a function of the SONTUS global score was 1.23 (95% CI 1.01–1.49) (p = 0.04), indicating a significant positive association between increasing social media use and depression.

Scaled from 0 to 10, the mean total MDASI-Cx symptom severity score was 2.6, and the mean MDASI-Cx interference score was 3.2, indicating good QOL (Table 2). In contrast, the means of all the FACT-Cx subscores were low: physical well-being, 19.3; social/family well-being, 18.5; emotional well-being, 15.3; and functional well-being, 17.7. The mean cervical cancer subscore was 38.5. The mean FACT-Cx total score was 109.4 (Table 2). The mean FACT-Cx emotional well-being subscore was 16.2 in the patients with no evidence of disease at last clinic visit versus 10.7 in those alive with disease ($p = 0.007$), indicating better emotional well-being in the patients without evidence of disease. The FACT-Cx cervical cancer subscore decreased with increasing SONTUS category of social media use, from 40.9 in low users to 36.1 in average users and 29.5 in high users ($p = 0.034$) (Table 3), suggesting poorer QOL in high users. No other MDASI-Cx or FACT-Cx total or sub-scores were significantly different across vital status at last contact or levels of social media use.

4. Discussion

The majority of the NECC patients in this study displayed low to average social media use and nonaddictive Facebook behavior. Twenty-eight percent of the patients had moderate or severe anxiety according to the GAD-7, and 56% of the patients who completed the CES-D had a score indicating elevated risk for clinically significant depression. We found significant positive correlations between social media use and anxiety and depression. Similarly, high users of social media had worse QOL related to cervical cancer–specific symptoms.

4.1. Correlation between social media use and anxiety and depression and QOL

Whereas we found significant positive correlations between social media use among NECC patients and anxiety, depressive symptoms,

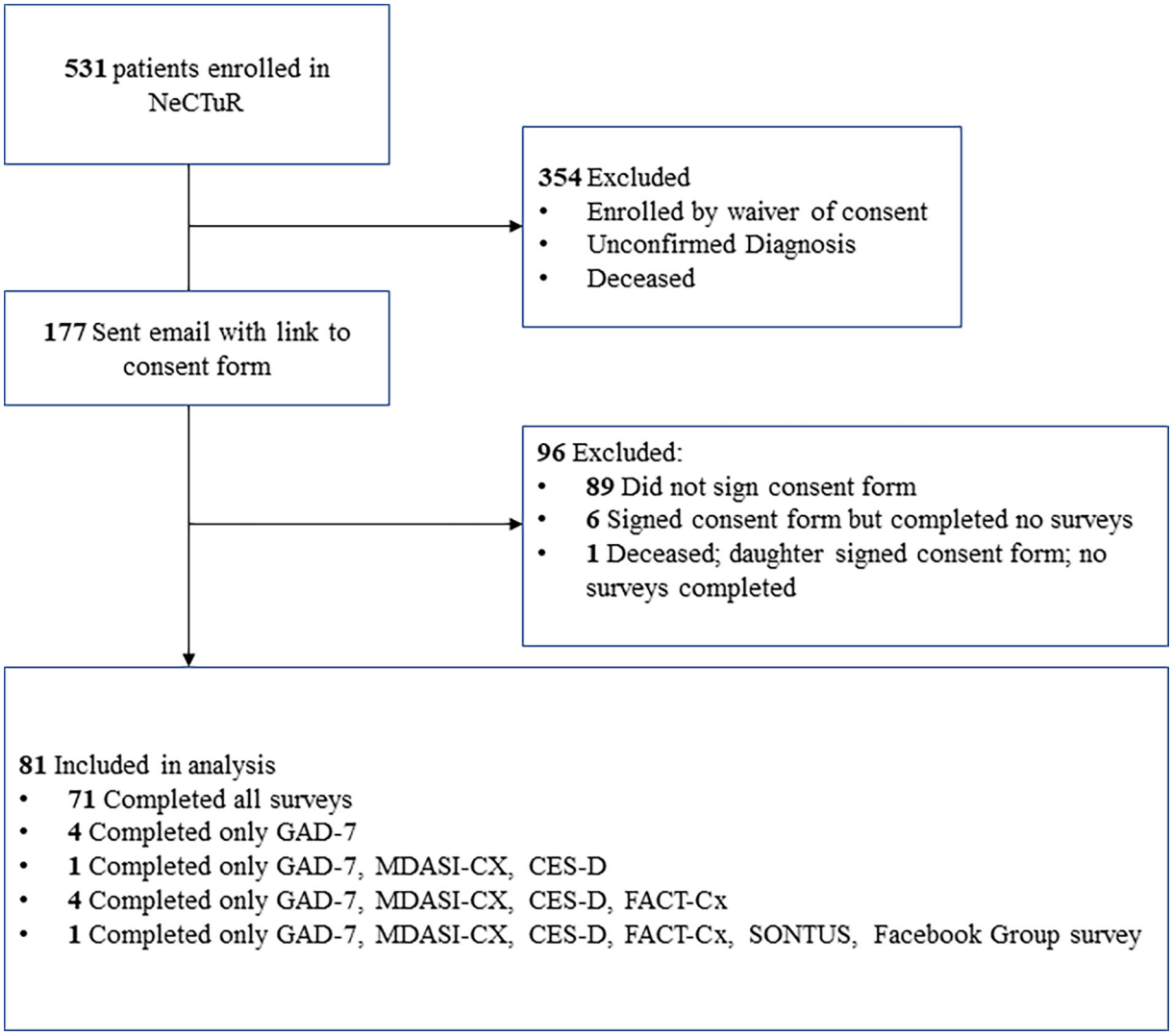

Fig. 1. Patient selection and survey completion. NeCTuR, Neuroendocrine Cervical Tumor Registry; GAD-7, Generalized Anxiety Disorder-7; MDASI-Cx, MD Anderson Symptom Inventory Cervix; CES—D, Center for Epidemiologic Studies Depression Scale; FACT-Cx, Functional Assessment of Cancer Therapy – Cervix; SONTUS, Social Networking Time Use Scale.

and worse QOL pertaining to cervical cancer–specific symptoms, an integrative review assessing online interventions in gynecologic cancer patients demonstrated that these interventions enhanced QOL and body image [23]. However, findings from that review regarding the effects of online interventions on symptom and psychological distress, social support, and sexual well-being were inconclusive [23]. Multiple other studies have found that social media use and social media–based interventions are associated with improved QOL and alleviate depressive and anxiety symptoms in cancer patients [4,6,7]. NECC patients' witnessing the negative experiences of other patients and being reminded of the poor prognosis of their rare cancer might contribute to the discrepancy between the findings of this study and previous studies of the impact of social media.

Remaining unanswered is the question: *Did social media use lead to anxiety and depression in NECC patients, or were patients with anxiety and depression more likely to visit social media platforms for information and support?* Bender et al. [24] showed that cancer patients who were experiencing distress were more likely to resort to social media for information about their disease and support from others experiencing this disease. While their findings attempt to answer the question about causality, more research is needed to elucidate the impact of social media use on anxiety and depression in cancer patients, specifically those with rare cancers.

4.2. Social media use among NECC patients

The majority of NECC patients in our study displayed low to average social media use and non-addictive Facebook behavior. While we found no previously published data on social media use in NECC patients, high rates of use of social media have been described among cancer patients in general. Bender et al. [24] showed that among 376 cancer patients, 79% were social media users, and of those, 39% used social media to seek cancer information and support. Facebook was the most commonly used platform [24]. This is in line with our results, which showed that 74% (53/72) of NECC patients reported visiting the Sisters United Facebook page in the past 4 weeks and 79% (42/53) of those believed it provided useful information. These findings indicate potential benefits of social media. Previously reported benefits of social media use in oncology include engaging and empowering patients, increasing their psychosocial and informational support, strengthening patient-physician relationships, and broadcasting research and clinical trial opportunities [5,25].

On the other hand, social media use might be a source of distress for cancer patients [24,26], as was the case for the nine patients in our study who reported not having visited the Sisters United Facebook group in the past four weeks because it elicited anxiety and/or sadness. Although there were no demographic and clinical differences between these nine

Table 1
Demographic and clinical characteristics of patients with NECC included in the analysis ($N = 81$).

Characteristic	Value
Age, y	
Mean (SD)	45.3 (9.9)
Range	29.0–71.0
MD Anderson patient, n (%)	
No	55 (68)
Yes	26 (32)
Race, n (%)	
Asian	2 (2)
White	68 (84)
Unknown or not reported	11 (14)
Ethnicity, n (%)	
Not Hispanic or Latina	70 (86)
Hispanic or Latina	1 (1)
Unknown	10 (12)
Country of residence, n (%)	
USA	65 (80)
Canada	8 (10)
Australia	3 (4)
England	1 (1)
Other	4 (5)
Vital status at last contact, n (%)	
No evidence of disease	65 (86)
Alive with disease	11 (14)
Missing	5
Modes of therapy, n (%)	
One	3 (4)
More than one	74 (96)
Missing	4
Primary treatment(s), n (%)	
Surgery	2 (3)
Chemotherapy	1 (1)
Surgery + chemotherapy	10 (13)
Radiation + chemotherapy	23 (30)
Surgery + radiation + chemotherapy	41 (53)
Missing	4
Radiation therapy, n (%)	
No	13 (17)
Yes	64 (83)
Missing	4
Intent of primary radiation therapy, n (%)	
Curative	61 (97)
Palliative	2 (3)
Missing	1
Radiation therapy mode, n (%)	
EBRT	7 (13)
Brachytherapy	21 (38)
EBRT + brachytherapy	27 (49)
Missing	9
Brachytherapy type, n (%)	
HDR	35 (73)
LDR/PDR	7 (15)
Vaginal cuff	6 (13)
Prophylactic cranial irradiation, n (%)	
No	61 (95)
Yes	2 (3)
Unknown	1 (2)
Missing	17

EBRT, external beam radiation therapy; LDR/PDR, low dose rate/pulsed dose rate; HDR, high dose rate.

Table 2
Patients' responses to surveys about social media use, anxiety, depression and quality of life.

Survey and endpoint	Value
SONTUS score distribution, n (%)	
5–9 (low user)	44 (61)
10–15 (average user)	26 (36)
15–19 (high user)	2 (3)
Missing	9
BFAS total score ($n = 71$)	
Mean (SD)	10.6 (4.7)
Range	6.0–24.0
BFAS addictive Facebook behavior per liberal definition, n (%)	
No	61 (86)
Yes	10 (14)
Missing	10
BFAS addictive Facebook behavior per conservative definition, n (%)	
No	68 (96)
Yes	3 (4)
Missing	10
Visited Sisters United Facebook group in previous 4 weeks, n (%)	
No	19 (26)
Yes	53 (74)
Missing	9
If visited Sisters United group, received useful information, n (%)	
True	31 (58)
Somewhat true	11 (21)
Neither true nor untrue	5 (9)
Somewhat untrue	6 (11)
If did not visit Sisters United group, reason, n (%)	
I am not a member of Facebook	3 (16)
I am a member of Facebook but did not know the support group existed	3 (16)
I have not had time	1 (5)
It caused me anxiety and/or sadness	9 (47)
Other (free text)	3 (16)
GAD-7 score (n = 81)	
Mean (SD)	7.3 (5.3)
Range	0.0–21.0
Score distribution, n (%)	
0–4 (minimal anxiety)	26 (32)
5–9 (mild anxiety)	32 (40)
10–14 (moderate anxiety)	13 (16)
≥15 (severe anxiety)	10 (12)
CES-D score ($n = 77$)	
Mean (SD)	18.1 (11.9)
Range	0.0–46.0
Score distribution, n (%)	
<16	34 (44)
≥16	43 (56)
MDASI-Cx core symptom severity score (n = 77)	
Mean (SD)	2.6 (1.9)
Range	0.0–8.2
MDASI-Cx cervical cancer symptom severity score (n = 77)	
Mean (SD)	2.7 (1.8)
Range	0.0–7.7
MDASI-Cx total symptom severity score (n = 77)	
Mean (SD)	2.6 (1.8)
Range	0.0–7.8
MDASI-Cx interference score (n = 77)	
Mean (SD)	3.2 (2.6)
Range	0.0–9.5
FACT-Cx physical well-being subscore ($n = 76$)	
Mean (SD)	19.3 (6.2)
Range	5.0–28.0
FACT-Cx social/family well-being subscore ($n = 76$)	
Mean (SD)	18.5 (6.3)
Range	3.0–28.0
FACT-Cx emotional well-being subscore (n = 76)	
Mean (SD)	15.3 (5.2)
Range	5.0–24.0
FACT-Cx functional well-being subscore (n = 76)	
Mean (SD)	17.7 (6.0)
Range	3.0–28.0
FACT-Cx cervix cancer subscore (n = 76)	
Mean (SD)	38.5 (9.0)
Range	15.0–55.0
FACT-G total score (n = 76)	

patients and the recent Facebook group users, the small sample size might have limited this comparison. Other social media drawbacks described in the literature are overwhelming patients with information, violating their privacy, exposing them to financial exploitation, and spreading misinformation [25]. Teplinsky et al. [27] described two main cognitive biases that contribute to the spread of health misinformation: confirmation bias, ie, only seeking information that is in line with one's personal beliefs, and echo chamber bias, ie, personalized social media experience that eliminates opposing viewpoints and magnifies pages with large followings. The abovementioned drawbacks and biases may contribute to the distress experienced by cancer

Table 2 (*continued*)

Survey and endpoint	Value
Mean (SD)	70.8 (18.2)
Range	33.0–104.0
FACT-Cx total score (n = 76)	
Mean (SD)	109 (24.7)
Range	57.0–157.0

GAD-7, Generalized Anxiety Disorder-7; CES—D, Center for Epidemiologic Studies Depression Scale; FACT-Cx, Functional Assessment of Cancer Therapy – Cervix; BFAS, Bergen Facebook Addiction Scale; MDASI-Cx, MD Anderson Symptom Inventory – Cervix.

patients on social media. To decrease health misinformation, healthcare professionals should inform patients about the availability of the DISCERN instrument: a validated scale used to assess the quality of written consumer health-care related information on the internet and social media platforms [28].

4.3. Anxiety and depression among NECC patients

The mean GAD-7 score in our study, 7.3, is within the range indicating mild anxiety. However, this score is higher than the mean GAD-7 score, adjusted for age and sex, in the general population, which is 2.97 (95% CI 2.86–3.07), and the mean GAD-7 score in the female subgroup of the general population, which is 3.2 (3.52) [15]. Similarly, the mean CES-D score in our study, 18.1, is higher than the mean CES-D score in the general population, 9.25 [29]. Furthermore, the rates of moderate and severe anxiety among the NECC patients in our study, 16% and 12%, respectively, are higher than those in the general population sample, which are 4.1% (95% CI: 3.5–4.6) and 1.0% (95% CI: 0.7–1.3), respectively.

Higher levels of anxiety and depression have been previously described in cancer patients. The prevalence of depressive symptoms was twice to three times as high in cancer patients as in the general population [30–32] and differed by site of cancer, stage of disease, and phase of treatment [30,33,34]. Interestingly, the prevalence of depression in patients with gynecologic cancers ranged from 12% to 23% and was lower than the prevalence in patients with oropharyngeal, pancreatic, breast, and lung cancers [31]. Naser et al. [30] evaluated the severity of anxiety in 612 cancer patients in an outpatient setting using GAD-7 scores and found that 13.1% had moderate anxiety and 8.3% had severe anxiety, slightly lower rates than in our study. The proportions of patients with any level of anxiety and with elevated depression symptoms were much higher in our study of patients with NECC than in a previous study of patients with ovarian cancer who were assessed using the same measures [35].

More specifically, multiple studies have demonstrated high levels of anxiety and depression in women with cervical cancer [36–38]. Zaid et al. [14] were the first to assess disease-related anxiety in NECC patients, using the Concerns about Recurrence Scale and Lerman Cancer Worry Scale. They found that anxiety levels among these patients were high, especially levels of health-related and death-related anxiety [14]. A comparison of our results to the cervical cancer and Zaid et al. studies is hindered by the usage of different measures for anxiety and depression across these studies.

Anxiety and depression in cancer patients can be attributed to financial challenges, fear of treatment and death, and physical and functional status changes associated with cancer treatments that negatively affect self-esteem and body image and possibly lead to social isolation [39]. The 5-year survival rate in NECC patients is around 36% (31%–51% for stages I-II and 0%–7% for stages III-IV), the median overall survival is 22 to 25 months [11], and the median time to first relapse from treatment initiation is 8.4 months (range, 3.6–28 months) [40]. The poor prognosis and high recurrence rate, in addition to the rare nature of NECC and ambiguity surrounding its treatment, most likely contribute to the high anxiety and depression levels in NECC patients.

Table 3
GAD-7, CES—D, and FACT-Cx cervical cancer subscale scores by social media use per SONTUS.

	Low Use ($N = 44$)	Average Use ($N = 26$)	High Use (N = 2)	Total ($N = 72$)	P value[a]
GAD-7 score					0.373
Mean (SD)	6.4 (4.6)	7.8 (5.8)	12.5 (10.6)	7.1 (5.3)	
Median	5.0	7.5	12.5	6.0	
Range	0–18	0–18	5–20	0–20	
CES-D score					0.070
Mean (SD)	15.9 (10.7)	20.4 (13.0)	31.0 (0.0)	17.9 (11.8)	
Median	14.0	21.5	31.0	18.0	
FACT-Cx cervical cancer subscale score					0.034
Mean (SD)	40.9 (8.5)	36.1 (9.3)	29.5 (0.7)	38.8 (9.0)	
Median	43.0	37.5	29.5	39.5	
Range	15.0–55.0	23.0–53.0	29.0–30.0	15.0–55.0	

GAD-7, Generalized Anxiety Disorder-7; CES—D, Center for Epidemiologic Studies Depression Scale; FACT-Cx, Functional Assessment of Cancer Therapy – Cervix; SONTUS, Social Network Time Use Scale.
[a] Kruskal-Wallis p value.

4.4. QOL among NECC patients

While there are no clear cutoffs for mild, moderate, and severe MDASI-Cx symptoms, previous MDASI validation studies have used 50% (5 on a scale of 0–10) as a cutoff between the "good QOL" group and the "poor QOL" group [41]. According to that categorization, the total MDASI-Cx symptom severity and interference scores in our study were relatively low (2.6 and 3.2, respectively, on a scale of 0–10), indicating minimal cancer symptoms and interference of these symptoms with daily activities. Good QOL pertaining to minimal symptoms among NECC patients can be explained by the fact that most patients in our study displayed no evidence of disease (86%). In contrast, the FACT-Cx scores were low, indicating poor emotional, social, physical, and functional well-being. Unsurprisingly, patients alive with disease had poorer emotional well-being than those who had no evidence of disease, although the two groups did not differ in other QOL measures. Our FACT-Cx scores were similar to those reported in 46 NECC patients by Zaid et al. [14] and lower than those reported in 149 cervical cancer patients by Fernandes and Kimura [19]. This indicates that NECC patients have worse QOL than other cervical cancer patients.

4.5. Strengths and limitations

Our study is the second study to assess patient-reported outcomes in NECC patients and the first to evaluate their social media use and its impact on anxiety, depression, and QOL. Our sample size of 81 patients is good given the rare nature of the disease. As such, our findings build a solid foundation for future research on the incorporation of online interventions into routine care for patients with rare gynecologic cancers. On the other hand, our accrual rate of 50%, although typical of rates for email surveys, presents a possible limitation. Multiple factors could have contributed to this non-response bias, including (1) age (older patients with little access to or difficulty navigating email might have been less likely to respond), (2) health status (sicker patients might not have checked their emails as often as those who were feeling well), (3) time available (patients had to complete seven surveys, which can be overwhelming and time-consuming), and (4) comfort with survey questions (the surveys included questions that might be perceived as personal or private, which patients might be hesitant to answer). Factors 1 and 2 also introduce a selection bias that might limit our study's generalizability. Additionally, with 84% of our respondents being

white, underrepresentation of diversity introduces another limitation to our study limiting its generalizability and perpetuating disparities in healthcare outcomes. Underrepresentation of diverse groups in social media studies should always be considered as social media presence can vary across diverse racial and ethnic groups.

5. Conclusion

In this study, we found relatively high levels of anxiety and depression and poor QOL with good symptom outcomes in patients with NECC. Patient-reported outcomes complement clinical outcomes, and understanding the prevalence and levels of anxiety, depression, and QOL in NECC patients will allow oncologists to create a holistic approach to patient care. Although most NECC patients were low or average users of social media, more use was significantly associated with both anxiety and depression. Additionally, most patients found online support groups useful. Oncologists are encouraged to recognize the influence of social media on their patients and recommend ways to navigate social media platforms with minimal harm.

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CRediT authorship contribution statement

Reem H. Saab: Conceptualization, Methodology, Writing – original draft. **Gloria Salvo:** Conceptualization, Data curation, Writing – review & editing. **Naomi R. Gonzales:** Conceptualization, Writing – review & editing. **Mark F. Munsell:** Methodology, Formal analysis, Writing – review & editing. **Eileen H. Shinn:** Conceptualization, Writing – review & editing. **Anuja Jhingran:** Writing – review & editing. **Priya Bhosale:** Writing – review & editing. **Preetha Ramalingam:** Writing – review & editing. **Michael Frumovitz:** Conceptualization, Supervision, Validation, Writing – review & editing.

Declaration of Competing Interest

Michael Frumovitz – Consulting/speaking Stryker; Consulting Astellas; Research funding AkesoBio.

Eileen Shinn – Education track leader ASCO, Co-Leader TBCRC Patient Reported Outcomes, Reviewer DOD 2023.

All other authors have no conflict of interest to disclose.

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Appendix A. Supplementary data

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