

ORIGINAL RESEARCH

Patients with cervical cancer may under-report physical and emotional symptoms: a mixed-methods study of symptoms and quality-of-life to inform palliative care needs

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Abstract

Background: Despite high physical and emotional burdens, palliative care (PC) is underutilized in cervical cancer. There are limited data exploring patient perspectives on how treatments, symptoms and side effects contribute to PC needs. We investigated treatment experiences of patients with cervical cancer to determine potential PC strategies and intervention areas. **Methods:** We performed a convergent mixed methods study. Eligible patients were ≥ 18 , English-speaking, with newly (≤ 12 months) diagnosed cervical cancer. Participants completed semi-structured interviews followed by the Functional Assessment of Cancer Therapy survey with cervix-specific subscale (FACT-Cx). Interviews were de-identified, professionally transcribed and coded. Descriptive statistics were performed for demographics and treatment information. **Results:** 17 patients participated. Most were white (11/17, 64.7%) and received radiation (11/17, 64.7%). Central interview themes were the significant impact of physical and emotional symptoms, a desire for on-going support services during periods of illness adjustment, and the high emotional toll of cervical cancer. Median scores on functional (18/28) and emotional (17/24) domains of the FACT-Cx were lowest. Pain and fatigue were the most reported symptoms. Patients disclosed more symptoms on the FACT-Cx than in interviews, particularly regarding mental health. **Conclusions:** Patients with recently diagnosed and treated cervical cancer reported high physical symptom burdens, rates of anxiety and depression, and need for social support. There was discrepancy in symptom reporting between qualitative and quantitative study components. Improved symptom screening, monitoring and assessment of psychosocial symptoms, and development of enhanced social support are priority areas in developing early integrated PC in this population.

Keywords

Cervical cancer; Palliative care; Mixed methods; Quality of life

1. Introduction

Annually, over 14,000 patients are diagnosed with cervical cancer (CC) in the United States. Half have locally advanced or metastatic disease at diagnosis [1, 2]. Compared to other gynecologic malignancies, patients with CC are younger [3], may face years of debilitating treatment sequelae [4] and have high physical and emotional burdens [5, 6]. Frequent use of multimodality therapy imparts significant toxicity and distress [7, 8].

Because the negative impact on quality-of-life (QOL) can persist for years following treatment, these patients often have needs that would benefit from palliative and supportive care (PC). However, specialty PC utilization in gynecologic cancers is traditionally low and not initiated until end-of-life [9–12]. Studies on PC in gynecologic cancers include low numbers of

CC patients [13]. Barriers to timely PC in CC are multifactorial and involve patient- and provider-based factors, though prior work investigating barriers to utilization focuses on provider perspectives [14–20]. There are limited qualitative data to guide translating these PC needs into actionable interventions. Thus, our objective to explore the experiences of patients with CC relative to their symptoms and QOL to determine potential meaningful PC intervention areas.

2. Methods

2.1 Study design

This was a convergent mixed methods study. Qualitative (semi-structured interviews) and quantitative (QOL survey) data collection occurred during the same scheduled telephone

interview. Fig. 1 depicts the study design.

2.2 Sample and setting

Eligible participants included all English-speaking patients age ≥ 18 diagnosed with CC within the past 12 months seen at our institution (August 2022–August 2023). All stages, histologic subtypes and received/planned treatment modalities were included. Patients with a second malignancy were excluded. Participants were identified via chart audit and were mailed a study information packet (recruitment letter, study information sheet and copy of the Functional Assessment of Cancer Therapy-Cervix (FACT-Cx) survey). An opt-out strategy was employed. Up to three contact attempts were made. Telephone interviews were scheduled for those who elected to participate. Following the interview, participants received a pre-paid debit card (\$50). Study procedures were approved by our Institutional Review Board (Protocol IRB-300010213, waiver of informed consent) and gynecologic oncology working group.

2.3 Measures

2.3.1 Qualitative: semi-structured interview

Our qualitative aim was to explore individual patient experiences with their CC symptoms, diagnosis and treatment in individual, semi-structured interviews. Interviews ranged from 19 to 59 minutes (mean 29) and were conducted by the study principal investigator (PI) (JAW) or a trained research assistant (TNP). The interview opened with the following statement: “I would like to understand the experience you have had with your cancer diagnosis and treatment. Tell me about finding out you had cervical cancer.”. Topics included symptoms and diagnosis, treatment, side effects (SE) and concerns about their disease and future. Interviews were audio-recorded, de-identified and professionally transcribed.

2.3.2 Quantitative: functional assessment of cancer therapy-cervix (FACT-Cx)

Our quantitative aim was to measure patient-reported health-related QOL. Participants completed the FACT-Cx, a standardized, validated tool for assessing health-care related QOL [21] with high acceptability [22]. The FACT-Cx includes 42-items measuring QOL across physical, social/family, emotional, and

functional domains [23]. Scores for each item are 0 (not at all), 1 (a little bit), 2 (somewhat), 3 (quite a bit) and 4 (very much). Items from each domain were summed to create a domain score. Higher scores indicate better QOL at time of survey. Table 1 depicts overlap between interview and FACT-Cx questions.

2.4 Data analysis

2.4.1 Quantitative

We performed descriptive statistics for participant demographics and treatment information. FACT-Cx domain and total scores were calculated. In reporting symptoms from the FACT-Cx, a response of 1 or greater was included. We also calculated a percentage score for each domain by dividing the median domain score by the maximum possible sub-scale score. The goal of this was to capture the reported scores in an easy-to-understand way given that each domain had a different maximum score.

2.4.2 Qualitative

Qualitative analysis was completed using NVivo 14.23.2 (Lumivero, Denver, CO, USA). Interview transcripts were analyzed using conventional content analysis [24]. JAW and MB developed an initial codebook analyzing an interview transcript. Subsequent coding was performed by JAW and reviewed by MB. JAW and TNP met regularly to address interview issues and discuss emerging codes/themes. After interviews and coding were completed, codes were organized into categories and summarized. JAW and MB reviewed the code summaries and identified over-arching themes.

2.4.3 Mixed methods

Following qualitative and quantitative analysis, symptoms and treatment SE reported in interviews were compared with responses from the FACT-Cx for our mixed methods analysis.

3. Results

3.1 Demographics

Seventeen interviews were conducted. Table 2 details demographic and treatment information. Median age at diagnosis was 52 (range 31–75). Most patients were White (11/17,

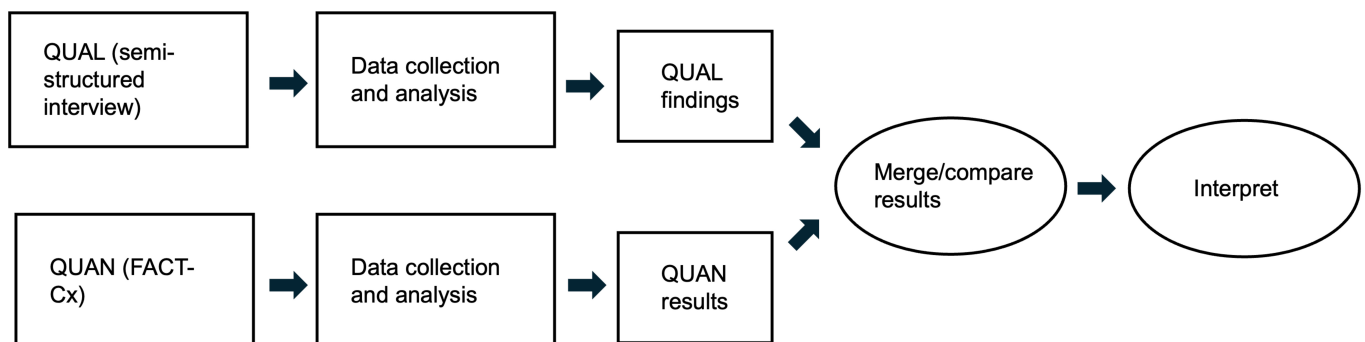


FIGURE 1. Mixed methods diagram. FACT-Cx: Functional Assessment of Cancer Therapy-Cervix; QUAL: qualitative; QUAN: quantitative.

TABLE 1. FACT-Cx and interview questions.

Interview questions	FACT-Cx assessment (0–4 scale)
Symptoms	
- What are the most challenging symptoms you have had?	- I have a lack of energy
- Why are these challenging for you?	- I have nausea
- How has your life changed because of these symptoms?	- I have pain
	- I feel ill
Support	
- What types of support have you needed and received from your friends, family and healthcare team?	- I feel close to my friends
	- I get emotional support from my family
	- I get support from my friends
	- I feel close to my partner (or the person who is my main support)
Mental and emotional well-being	
- How have you been doing mentally and emotionally since receiving your diagnosis?	- I feel sad
- What concerns do you have about your disease or treatment?	- I am satisfied with how I am coping with my illness
	- I am losing hope in the fight against my illness
	- I feel nervous

FACT-Cx: Functional Assessment of Cancer Therapy-Cervix.

TABLE 2. Patient demographics.

	N (%)
Age at diagnosis (median, range, SD)	52, 31–75, 13.9
Race	
White	11 (64.7)
Black	5 (29.4)
Unknown/decline	1 (5.9)
Marital status	
Married/partnered	8 (47.1)
Single	7 (41.2)
Divorced/separated	1 (5.9)
Widowed	1 (5.9)
Smoking status	
Former	12 (70.6)
Current	3 (17.6)
Never	2 (11.8)
Insurance	
Private	9 (52.9)
Medicaid	4 (23.5)
Medicare	3 (17.5)
Tricare	1 (5.9)
Cancer stage	
I	6 (35.3)
II	3 (17.6)
III	8 (47.1)
IV	0
Cancer histology	
Squamous cell carcinoma	13 (76.5)
Adenocarcinoma	4 (23.5)
Treatment	
Chemo-RT	11 (64.7)
Surgery	5 (29.4)
Surgery and RT	1 (5.9)

SD: standard deviation; RT: radiation.

64.7%), married/partnered (8/17, 47%) and all had insurance. Most had stage III disease (8/17, 47%) and received radiation therapy with sensitizing chemotherapy (11/17, 64.7%).

3.2 Qualitative: symptoms, treatment and SE reported in interviews

Patients reported numerous symptoms and SE (Table 3). Most reported fatigue (11/17, 64.7%), bleeding (9/17, 52.9%) and pain (8/17, 47.1%). They also reported diarrhea (6/16, 35.3%), nausea (5/17, 29.4%), urinary symptoms (4/17, 23.5%), anxiety (1/17, 5.9%) and depression (2/17, 11.8%).

3.3 Qualitative: interview themes

We identified three central themes. Exemplary quotes are provided in Table 4.

Theme 1: Patients with CC face high physical symptom burdens from their disease and treatments.

Patients experienced varied symptoms prior to diagnosis, most frequently pain and bleeding. Some attributed symptoms to other things; one cited stress, another menopause, stating, *“I’ve already been through menopause, and then started bleeding again and just put it off thinkin’ it was just part of the menopause.”*. Others reported ignoring their symptoms; *“I think that the symptoms actually had been going on for quite a long time, maybe even a couple years.”*. Symptom duration was variable but up to several years. One was diagnosed with early-stage disease during routine screening and was asymptomatic.

Patients were heavily burdened with SE. Most cited were fatigue/weakness, pain and gastrointestinal issues. One patient

suffered a pelvic fracture following radiation. Fatigue interfered with completing routine tasks and work during and after treatment. Collectively, SE required patients to adjust their routines.

Theme 2: Patients with CC appreciate and desire services centering on continued support as they adjust to their illness.

The physical impact of disease and treatment was profound. Discrepancies in understanding disease-related information were cited by several participants; most frequently noted was desiring more clarity regarding treatment SE, even for those they were told could occur, and not initially understanding the potential magnitude; *“I don’t know if you can prepare for something like this.”*. A resultant desire for additional symptom support services was expressed, for example, requesting counseling. Participants also described gratitude towards family and friends, noting they reduced feelings of isolation and helped them navigate their disease. Those who received support services found them to be helpful: *“I do the activities that she suggests during the week just like I did with the physical therapist. And that’s helped a lot.”*

Theme 3: The emotional toll of CC is profound and deeply impacts many aspects of patient life.

The emotional impact of illness permeated interviews. Patients repeatedly reflected on how their cancer impacted their well-being, particularly causing illness uncertainty, worry or anxiety. They wondered about the future after treatment and noted the impact cancer had on their identities. Some felt discomfort, others felt driven to share their experiences to benefit others, and some described feeling stressed about their new self-perception, for example, *“not bein’ able to work anymore and my daughter havin’ to support me, I don’t like*

TABLE 3. Patient age, treatment received and symptoms/side effects reported in interviews.

Age at diagnosis	Stage	Treatment	Interview-reported symptoms and side effects
66	IIIB	XRT	Vaginal bleeding; nausea
60	IIIC	XRT	Bleeding; fatigue; pain
52	IIIC	XRT	Bleeding; dysuria; fatigue; pain
34	IIA2	XRT	Diarrhea; fatigue; nausea; pain; vomiting
49	IIB	XRT	Bleeding; fatigue; nausea; tinnitus
51	IA1	Surgery	Anxiety, bleeding
58	IA1	Surgery	None
52	IIIC	XRT	Depression, bleeding; fatigue; diarrhea; nausea
35	IA1	Surgery	Fatigue; surgical complication (abscess)
71	IIB	XRT	Diarrhea; dysuria; fatigue; pain; urinary incontinence
44	IB1	Surgery	Brain fog; menopausal symptoms; pain
75	IIIB	XRT	Bleeding; brain fog; diarrhea; fatigue; urinary frequency; weakness
35	IIIC	XRT	Bleeding; constipation; diarrhea; fatigue; hair loss; nausea; pain; skin changes; urinary frequency; weight loss
68	IA2	Surgery, RT	Depression, bleeding; fatigue
46	IIIB	XRT	Vaginal discharge
31	IB1	Surgery	Pain
66	IIIB	XRT	Appetite suppression; diarrhea; fatigue; pain

XRT: chemo-radiation; RT: radiation.

TABLE 4. Exemplary quotes.

Theme 1: Patients with cervical cancer face high physical symptom burdens from their disease and their treatments.
“I get tired really easy. I have to take pain pills sometimes when I have a lotta pain. I’m not very active. I get tired really quick.”—ID2, 60 yo with IIIC disease
“I didn’t think it would take this long and I’d be sick for this long and that I’d still be struggling with my health this many months later.”—ID3, 52 yo with IIIC disease
“I’m still having an issue with—from radiation as far as, and this is embarrassing to say but I have to be near a bathroom in order not to have an accident. And that’s one thing that I’m always conscious of when I go somewhere is how close am I to the nearest restroom.” —ID15, 75 yo with IIIB disease
Theme 2: Patients with cervical cancer appreciate and desire services centering on continued support as they adjust to their illness.
“I think the hardest part was thinking after my treatment I would be better, but that just wasn’t the case.” —ID16, 35 yo with IIIC disease
“At the beginning when they were explaining side effects, I was thinking that I was gonna have ‘em immediately. Then they didn’t start for weeks after. I think it’d be good to emphasize to new patients.” —ID4, 34 yo with IIA2 disease
“My healthcare team, they were calling, checking on me, and every time that I call, I had questions or anything, they’ll call me right back and they’ll answer my questions to their best of their knowledge and it really helped. With my family, they was there mentally and physically when I didn’t have the strength to either give up or stuff like that.” —ID10, 35 yo with IA1 disease
“The service that I have got it helped me really good... I have Home Health coming out. I have therapists coming out. I have a wound nurse coming out. Then I have my helper.” —66 yo with IIIB disease
“Where the treatments and stuff are goin’ on, they have a—they assign every cancer patient an advocate, and she’s been incredibly helpful, all kinds of information. She’s always been there, and if I was there for a chemo appointment or whatever, she’d be right there and visit. As far as that goes, that meant an awful lot.” —ID20, 66 yo with IIIB disease P20
Theme 3: The emotional toll of cervical cancer deeply impacts many aspects of patient life.
“I can’t have no more kids, I can’t have no more menstrual periods. That’s my concern. I’m scared I’m gonna die now. My body ain’t doing what it’s supposed to do no more. For real. I’m supposed to have menstrual cycles, and stuff...I’m still trying to understand it I don’t know...It’s stressful.” —ID19, 31 yo with IB1 disease
“That’s why...I don’t get radiation at all, just not right now with those little bitty kids that I’ve got... (I’ve got to be) able to be there for them” —ID19, 31 yo with IB1 disease
“Sufferin’ is no good for anybody, not the person who’s sufferin’, especially, but not the family, either.” —ID13, 44 yo with IB1 disease
“Having cervical cancer and having to have treatments that were—how do I say it—invasive, that has been a super big challenge for me emotionally. I think if I had had a different kind of cancer that wasn’t related to the female sexual reproductive organs, I think emotionally, it wouldn’t have been so hard on me.” —ID3, 52 yo with IIIC disease
“Mentally, I wasn’t prepared for it. Mentally, it took a toll on me because I was—I’m thinking in my head, I’m only 35 here. What did you not do or why didn’t you get checked off then or I questioned myself on what I should have done or what could I have did to prevent me from getting it... I was always down. If I didn’t have anyone around to pick up my spirit, I was just down. I was like a mopey person, I could say, and normally I’m a happy person.” —ID16, 35 yo with IIIC disease
yo: years old.

that.”. Participants worried their experiences would impact their families; one participant elected not to undergo adjuvant radiation because it precluded her from being able to care for her young children as a single mother. For others in caretaking roles, they expressed concern regarding changing family dynamics; “*I’m supposed to be her caretaker, not the other way around.*”.

3.4 Quantitative: FACT-Cx results

All participants completed the FACT-Cx (Table 5). Median total score was 126 (maximum 168; range 47–156). The social well-being sub-score had the highest median percentage score (92.9%). Functional well-being had the lowest (64.3%),

followed by emotional well-being (70.8%).

3.4.1 Physical well-being

Most¹ reported that they were bothered by treatment SE (11/17, 64.7%). Fatigue² (17/17, 100%) and pain (10/17, 58.8%) were the most reported symptoms, and 7/17 (41.2%) reported that they were forced to spend time in bed. Patients also reported nausea (8/17, 47.1%), urinary symptoms (10/17, 58.8%), constipation (9/17, 52.9%), sexual dysfunction (13/17, 76.5%), vaginal discharge (5/17, 29.4%) and bothersome vaginal odor (4/17, 23.5%).

¹Also contains responses regarding physical-well-being from the cervix-specific domain.

²Fatigue was derived from FACT-Cx question “I have a lack of energy.”.

TABLE 5. FACT-Cx results.

Scale*	Median, range, SD	Median percentage score, range of percentage scores
FACT-Cx	126, 47–156, 28.3	75.0%, 27.9–92.9%
FACT-G	80, 34–101, 17.0	74.1%, 21.5–93.5%
Physical	21, 3–27, 7.8	75.0%, 10.7–96.4%
Social	26, 8–28, 5.5	92.9%, 28.6–100.0%
Emotional	17, 4–24, 6.3	70.8%, 16.7–100.0%
Functional	18, 6–28, 6.1	64.3%, 21.4–100.0%
Cervix specific subscale	46, 13–55, 11.4	76.7%, 21.7–91.7%

*Maximum scores for each measure: FACT-Cx 168; FACT-G 108; Physical WB 28; Social WB 28; Emotional WB 24; Functional WB 28; Cervix specific subscale 60. FACT-Cx: Functional Assessment of Cancer Therapy-Cervix; SD: standard deviation; FACT-G: Functional Assessment of Cancer Therapy-General.

3.4.2 Social well-being

Patients reported excellent social support from family (15/17, 88.2%) and friends (15/17, 88.2%). Of those reporting familial support, 12/15 (80%) responded with a 3 (quite a bit) or 4 (very much), as did 10/15 (66.7%) reporting support from friends. Additionally, they reported feeling close to their partner/main support (16/17, 94.1%) and to friends (15/17, 88.2%).

3.4.3 Emotional well-being

Patients reported high emotional burdens, particularly sadness (12/17, 70.6%) and nervousness (11/17, 64.7%). Almost half worried about dying (8/17, 47.1%). Most worried their condition would worsen (13/17, 76.5%). Nearly half expressed they were losing hope in the fight against their illness (7/17, 41.2%).

3.4.4 Functional well-being

All patients reported that they accepted their illness (17/17, 100%). Most continued to enjoy life (16/17, 94.1%), enjoyed the things they usually do for fun (12/17, 70.6%), and were content with their QOL (16/17, 94.1%). Four (23.5%) were unable to work.

3.5 Mixed methods results

Interview content regarding physical and emotional symptoms was compared with FACT-Cx responses (Table 6). Patients disclosed more symptoms on the FACT-Cx. For example, only three (17.6%) reported anxiety/depression in interviews, but 13 (76.5%) disclosed sadness/nervousness on the FACT-Cx. They expressed meaningful social support in interviews and surveys. One noted “*with my family, they was there mentally and physically when I didn’t have the strength to either give up or stuff like that. They would help me walk around, they would cook for me. My son used to talk to me all the time and tell me I was gonna get through it.*”. Another stated “*I have no family, so my friends stepped in. They took me to treatment every day,*” and another noted the contributions of her coworkers; “*a lot of my coworkers also helped with getting me to treatment. I had great support systems with that.*”.

4. Discussion

We found that the physical and emotional burden of CC diagnosis and treatment profoundly influenced patient life. Our participants cited high physical symptom burdens, anxiety and stress, and significant alteration in their daily lives and routines due to illness.

On the FACT-Cx, patients reported many treatment-related, namely a high percentage of physical symptoms, decreased functional well-being, and frequent reports of anxiety and depression. We did not find similar symptom reporting in our interviews, with symptoms under-reported. A striking discrepancy was sadness/nervousness (akin to anxiety/depression), reported by 76.5% of patients on the FACT-Cx but only noted by 17.6% during their interview. This is notable clinically as patients do not universally complete symptom surveys during clinical encounters. Further, CC patients report more psychosocial issues, namely anxiety, depression, and stress, than patients with other gynecologic cancers [25] and the psychosocial impact of CC persists years after treatment [26]. Thus, developing sustainable mechanisms to ensure patients are adequately reporting symptoms are necessary to ensure that physical SE and mental health changes are addressed promptly. This will be important in developing PC strategies to ensure meet patients’ physical and emotional needs.

Over 70% of participants received radiation as either primary or adjuvant treatment. While primary chemoradiation confers five-year survival rates up to 75% for locally advanced CC [27, 28], short and long-term SE can be severely debilitating. Prior studies have demonstrated that QOL among patients who received radiation may be worse than those having surgery or surgery followed by chemotherapy [29]. In particular, long-term genitourinary and gastrointestinal symptoms may occur for years following treatment [30]. Given the high treatment-associated morbidity with receiving pelvic radiation, it will be prudent for future PC strategies to incorporate treatment modality-specific symptom screening to capture and meet the physical PC needs of patients more comprehensively.

We found congruence in that patients described strong social support systems in our qualitative and quantitative methods, and expressed the need for ongoing support from family, friends and cancer-care teams. This is consistent with prior work highlighting that during and after treatment, patients

TABLE 6. Mixed-methods analysis: comparison of symptoms reported in interview and FACT-Cx.

Symptom, "survey item/s"	Reported in FACT-Cx (N, %)	Mean score of measure in FACT-Cx	Reported in interview (N, %)	Participant quotes
Pain, "I have pain"	10, 58.8%	1.47	8, 47.1%	"All I could focus on really, was being in pain." "I'm still strugglin' from it. I could go to stores, but I can't go to a big store and shop all down the aisles because I start hurtin."
Fatigue, "I have a lack of energy"	17, 100.0%	2.58	11, 64.7%	"With me being so tired and everything, I really couldn't cook, I really couldn't even play with my kids as much. I couldn't work, I was always just tired." "One day I wanted to make a sandwich and put mayonnaise on it and I was unable to open the mayonnaise jar. I just didn't have enough strength."
Nausea, "I have nausea"	8, 47.1%	1.29	5, 29.4%	"I have nausea every day, and I still have dry heaves."
Constipation, "I am bothered by constipation"	9, 52.9%	1.18	1, 5.9%	"I had all of them." (nausea, constipation)
Urinary symptoms, "I have trouble controlling my urine"; "It burns when I urinate"; "I have discomfort when I urinate"	9, 52.9%	1.12; 0.59; 0.71	1, 5.9%	"These urinary tract infections stick around, because my mass is pushing on it, so it makes me not be able to drain my kidney all the way."
Sadness, "I feel sad"	12, 70.6%	1.41	2, 11.8%	"I was like a mopey person, I could say, and normally I'm a happy person." "You just are kind of going with the flow. Then depression is just something that happens with it. I don't think anybody can get away from it."
Nervousness, "I feel nervous"	11, 64.7%	1.47	1, 5.9%	"I was put on anxiety medication 'cause I was having issues with trying to concentrate and work and trying to sleep at night."
Sexual dysfunction, "I am afraid to have sex"; "My vaginal feels too narrow or short"	13, 76.5%	1.06, 1.29	0, 0.0%	

FACT-Cx: Functional Assessment of Cancer Therapy-Cervix.

with cancer desire independence while simultaneously fear becoming a burden to caregivers [31, 32]. Our participants cited strong relationships with their care teams while wanting additional information about both short- and long-term illness and treatment SE, as has been described in previously [33, 34]. A multidisciplinary, patient-centric approach to understanding social support needs and the role of incorporating caregivers will be critical in developing sustainable PC interventions.

All participants completed the FACT-Cx. To our knowledge, there is no available median score for patients taking the FACT-Cx; in other CC studies using the measure for patient reported QOL, mean scores ranged from 109.5–158 [35–38]. These were studies conducted for a variety of reasons and thus we cannot compare results. However, given the ease of

administration, this may be a useful tool for assessing and following QOL over time in future PC interventions. Median scores for emotional and functional well-being were the lowest of all sub-scales, consistent with prior work highlighting the high emotional burden of disease and the impact of disease burden and treatment SE on daily life and functioning. As such, a particular focus on mental health and adjustment to living with disease and treatment-related SE will be a crucial component of PC integration strategies and may make meaningful improvements to QOL.

The collective needs identified in our study center on symptom expectations and management, need for emotional and caregiver support and an opportunity for providers to develop sustainable means to assess patients' QOL. Given these find-

ings, a multidisciplinary approach for early PC integration will be necessary, and an implementation strategy that incorporates tele-health and remote visits to reach patients in resource-limited environments is critical [39].

Our study has several limitations, particularly the small sample size and limited diversity of participants. While all identified eligible participants were contacted, most participants were White (11/17, 64.7%). In future studies, purposeful sampling to ensure a diverse group of patients will be employed to best capture differences across patient racial and ethnic groups, especially Black and Hispanic patients given the higher annual rate of new CC diagnoses in these patients [40]. Some degree of bias may exist in that those who felt too burdened by symptoms may have elected not to participate. Our study design and small sample size preclude the use of statistical tests or the ability to draw causal inferences. Further, given the focus on newly diagnosed patients, we lack experiences on the change or development of symptoms overtime, a perspective that will be incorporated into future studies.

Our study has notable strengths. Participants represented diverse age groups and were distributed across stage. The robust patient experiences enrich existing data about the impact of disease and treatment on QOL. It adds to the limited body of mixed methods and qualitative CC research, particularly as to how this can inform PC interventions.

5. Conclusions

Patients with newly diagnosed CC report significant physical and emotional impacts of their illness and note the importance of social support. As we found notable discrepancies in symptom reporting between qualitative and quantitative analyses, improved physical and emotional symptom screening, monitoring and assessment of psychosocial symptoms, and development of enhanced social support are priority target areas to improve QOL for these patients. These findings will help guide interventions in future studies to develop early integrated PC.

AVAILABILITY OF DATA AND MATERIALS

De-identified data are available upon reasonable request to the first author. Requests should be directed to the corresponding author (JAW).

AUTHOR CONTRIBUTIONS

JAW—conceptualization, study design, data collection/interviewing, formal analysis, writing—original draft, writing—review and editing. TNP—data collection/interviewing. MB—conceptualization, formal analysis, writing—review and editing.

ETHICS APPROVAL AND CONSENT TO PARTICIPATE

The authors assert that all procedures contributing to this work comply with the ethical standards of the relevant national and institutional committees on human experimentation and with the Helsinki Declaration of 1975, as revised in 2008. The study protocol and data safety plan were approved by the University of Alabama at Birmingham Institutional Review Board (IRB), protocol IRB-300010213, waiver of informed consent.

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CONFLICT OF INTEREST

The authors declare no conflict of interest.

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