

Fractured and delayed: A qualitative analysis of disruptions in care for gynecologic malignancies during incarceration

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HIGHLIGHTS

- During incarceration, patient and institutional factors delayed the initial gynecologic oncology visit
- Discharge planning and loss to follow-up during and after incarceration introduced delays in the hospital-prison transition
- Transportation, authorization, and the use of restraints were concrete delays
- Abstract delays included communication and the patient's emotional experience

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ABSTRACT

Objective. Women are experiencing growing rates of incarceration at twice the pace of that for men. Additionally, one-third will be older than 55 years of age by the end of the decade. Women who are incarcerated experience a higher prevalence of gynecologic malignancies and present with higher stage disease, which may be contributing to the greater mortality from cancer than the age-adjusted US population. Limited access to guideline-recommended screening and prevention and resource limitations across correctional facilities may result in gynecologic cancer disparities. Reasons for delayed gynecologic cancer care in prisons remain underexplored. Therefore, we sought to identify contributors to delayed gynecologic cancer care among women experiencing incarceration.

Methods. Women at a single tertiary center in the Southeastern U.S. who were incarcerated and were diagnosed with a gynecologic cancer during 2014–2021 were identified in the electronic medical record. Note text was extracted and contributors to delay were identified and categorized using the RADaR method. Descriptive statistics were used to assess quantitative data.

Results. 14 patients were identified with a total of 14,879 text excerpts. Data reduction was performed to identify excerpts that were relevant to the central research question resulting in 175 relevant note excerpts. Delays prior to the tertiary care visit included patient and institutional contributors. Delays during transition from the tertiary center to prison included discharge planning and loss to follow-up during/after incarceration. Transportation, authorization, and restraints were concrete contributors. Abstract contributors included communication, and the patient's emotional experience.

Conclusions. We identify myriad contributors to delayed or fractured gynecologic cancer care in women experiencing incarceration. The impact of these issues warrants further study and intervention to improve care.

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1. Introduction

The aging demographic of the 1.9 million individuals detained in the U.S. criminal legal system raises serious concern for carceral and community capacities to provide adequate health care for those who are incarcerated [1,2]. By 2030, the United States (U.S.) population

experiencing incarceration age 55 years and older is conservatively estimated to constitute more than 1/3 of its total population [3], with the population of incarcerated individuals aging at an even more rapid rate [4]. Despite the constitutional right to health care identified in the US Supreme Court decision *Estelle v. Gamble* [5], quality of care varies by facility and accreditation for healthcare services is voluntary and not standardized across many U.S. carceral settings [6]. Individuals who are incarcerated experience a disproportionate burden of disease including HIV, hepatitis C, diabetes, substance use disorders, mental illness, and cancer [7–10]. The aging demographic trends within U.S. carceral systems, high disease burden, and variable and limited healthcare access during incarceration coalesce into disparities in mortality for people who are incarcerated. The Bureau of Justice Statistics reported that in 2018, U.S. carceral facilities recorded the highest number of deaths and greatest mortality rate since 2001 when mortality data was first collected [11]. Notably, those in state prisons were more likely to die of cancer than the age-adjusted U.S. population [11].

Along with the increasing proportion of older adults who are incarcerated, the rate of women experiencing incarceration has grown at twice the pace of that for men [12]. With Black, Hispanic/Latino, and Indigenous Americans significantly more likely to be incarcerated, the uneven distribution of mass incarceration across the population magnifies health inequalities seen within and outside the walls of prisons and jails [13]. Despite massive increases in the incarceration of women, they nonetheless constitute a relatively small proportion of the overall population in custody, resulting in similar de-prioritization of women's healthcare during incarceration that is seen elsewhere [14,15].

Individuals who are incarcerated and undergoing cancer treatment, and especially women who comprise a minority of the carceral population, are at the nexus of numerous drivers of health disparity [16,17]. Fragmented healthcare data and inability to accurately link prison and specialty center data limit much of the research on factors associated with cancer disparities [10,18]. The higher incidence of cancers, including gynecologic malignancies, has been attributed to limited access to guideline-recommended screening and preventive care [18–22]. Human Papillomavirus (HPV) vaccination rates, a preventative measure against one of the major causes of cervical cancer, are lower among individuals who are incarcerated [23]. Single-center studies have reported that people who are incarcerated are both more likely to present with high-grade cervical cytology and to be lost to follow up compared to non-incarcerated groups [24]. Additionally, people who experience incarceration have frequently had the adverse childhood experiences and other trauma prior to incarceration that are linked to future cancer diagnoses, particularly among women [25]. These disparities likely underpin disproportionate absolute and relative burden of cervical cancer among incarcerated people compared with people without incarceration histories (13.8 vs 9.1 per 1000 people and 32% vs 12% of cancer diagnoses) [26,27].

Beyond higher prevalence and later disease presentation of gynecologic cancer among those experiencing incarceration, countless unique challenges in maintaining continuous quality cancer care may explain part of the differential cancer mortality in prisons. These include complicated care transitions – jail-to-prison, prison-to-hospital, hospital-to-prison, and community re-entry. In other populations, some of the important determinants of oncologic care include the presence of social support, trusting patient-physician relationships, and frequent access to a care team; it is unclear how these factors might affect the care of people who are incarcerated [28,29]. It is also unknown how barriers unique to the criminal legal system, such as custody officer presence, use of restraints, and mandatory unclothed body searches at facility exit and re-entry, compound the emotional, psychologic, and physical experience of cancer diagnosis and treatment. Understanding the nuances of these challenges may illuminate targets for improving the processes with which individuals in the criminal legal system receive cancer care. This project aimed to explore these questions by

qualitatively analyzing patient medical records to identify drivers of health disparities in gynecologic oncologic care.

2. Methods

Our population of interest was patients who were incarcerated and received a diagnosis or treatment for gynecologic cancer at a single tertiary care center in the Southeastern U.S. from 2014 to 2021. This tertiary care center serves as the primary referral site for local jails and the state's central processing prison for women (i.e., all people assigned female at intake in the state prison system pass first through this facility and most individuals with medical needs remain at this facility). Many states in the region have higher incarceration rates than the U.S. average, and Southern states are less likely to have expanded Medicaid than states in other region [30]. Included patients were identified by diagnostic codes and payor status in the electronic medical record system and demographic and clinical data were abstracted. The ICD codes used exclusively indicated gynecologic cancer care (**Supplement 1**). Patients in the state prison system are not covered by public or private insurance programs during their incarceration, so visits during incarceration indicate the state prison system as the payor.

It is important to note that while most of the literature in gynecologic cancers refers to women, not everyone at risk of or diagnosed with a gynecologic malignancy identifies as such. The authors strive to use gender-inclusive language to describe those with gynecologic cancers. The state prison system and other carceral institutions generally use sex assigned at birth, regardless of a person's gender identity or expression, and this information is transmitted to outside facilities and may then be reflected in the medical record. Where prior literature has used the terms “women” or “female,” the same terms were used here for consistency.

The Rigorous and Accelerated Data Reduction (RADaR) technique was used as the basis of our qualitative analysis strategy [31]. A central question was developed by the research team: *What are reasons for delays in gynecologic cancer care for people experiencing incarceration?* All clinical notes and relevant documentation (“notes” from here forward) were extracted from the electronic medical record and similarly formatted to develop an all-inclusive Phase 1 data table (Microsoft Excel, 2019, Version 16, Redmond, WA: Microsoft Corporation). Two analysts (WB and YI) reviewed the table and identified notes relevant to the central research question. Including only these notes, the analysts produced a reduced Phase 2 data table. A codebook was created through open and axial coding and consensus in primary and secondary codes was achieved through discussion among the research team. Text that was extraneous to the central research question was removed from the notes at this time to produce relevant excerpts. Each analyst then individually coded the first 10% of the Phase 2 data table. Inter-coder agreement was assessed qualitatively through discussion and increased with subsequent modifications to the codebook. Next, the two analysts individually coded another 10% of the Phase 2 data table with the updated codebook to confirm concordance between analysts. The codebook was finalized at this point (**Supplement 2**). The remaining 80% of the Phase 2 data table was coded by one analyst (WB). The emergent themes were then organized into a conceptual model, which was refined iteratively by the entire study team. [Biorender.com](https://biorender.com) was used to create figures of the data reduction process and the conceptual model.

Descriptive statistics were used to present demographics data and excerpt frequencies (StatCorp, 2021, Stata Statistical Software: Release 17, College Station, TX: StataCorp LLC).

This retrospective qualitative study was approved by the University of North Carolina Institutional Review Board (IRB# 20-2598).

3. Results

Seventeen patients were initially identified, but two were subsequently noted not to have a gynecologic cancer diagnosis and were

removed from the analysis. The 15 included patients had a total of 14,732 clinical notes. Of these, 14,557 were determined to be irrelevant to the research question, resulting in 175 excerpts for the analysis. One patient did not have any included chart excerpts, resulting in a final sample of 14 patients. A flow chart for the data reduction is shown in Fig. 1.

The final analytic dataset included 14 patients. Nearly all patients were incarcerated in the state prison system rather than local jails. Demographic and clinical presentations are summarized in Table 1. The average age was 38 years and 86% were reported as White. Most patients (71%) had a diagnosis of cervical cancer. One patient had a synchronous uterine and cervical cancer. Approximately one-third (36%) of patients had an advanced or metastatic staged cancer at the time of diagnosis and the remaining 64% had a localized staged cancer, defined as confined to the site of origin. Two patients had a documented family history of either breast, ovarian, uterine, or colon cancer. Frequency counts of excerpts by patient and code are shown in Fig. 2.

The concept model of contributors to delays in gynecologic cancer care visualizes points of susceptibility to delays in cancer care from the prison or jail to the tertiary care center and back to the carceral facility (Fig. 3). Additional pre-incarceration points of delay were also identified and included in the model, such as existing comorbidities or health problems that prevented or prolonged time to diagnosis, and after release, such loss to follow up and lack of insurance coverage. Delays associated with inadequate nutrition were localized to the carceral facility and delays related to trust were primarily associated with the tertiary care center. We identified certain codes as concrete contributions to care delays – physical or operational issues – such as transportation and carceral facility authorization, and others as abstract – emotional or interpersonal issues – such as communication challenges and emotional experience. Illustrative quotes for each of the codes and sub-codes are summarized in Table 2.

3.1. Factors that impact timely cancer care from before incarceration

This part of the concept model describes events prior to entering the criminal legal system. Preexisting or newly diagnosed medical conditions and poor general health, including mental health, were described in the notes as barriers to timely cancer care. An excerpt from one clinic visit stated, “I explained to her that her CD4 counts and HIV should be in control not only for HIV treatment, but also to allow further treatment of her cervical cancer” (54-year-old with cervical cancer). Another example, seen in a 27-year-old with gestational trophoblastic neoplasia,

Table 1
Patient Characteristics.

Characteristic	Distribution (N = 14)
Age, median (IQR)	38 (34–45)
Race, n (%)	
White	12 (86%)
Black	1 (7%)
Other	1 (7%)
Cancer, n (%) ^a	
Cervical	10 (71%)
Uterine	2 (14%)
Ovarian	1 (7%)
Vaginal	1 (7%)
Gestational trophoblastic neoplasia	1 (7%)
Stage, n (%)	
Localized	9 (64%)
Advanced	5 (36%)
Documented family history of breast, ovarian, uterine, or colon cancer, n (%)	2 (14%)
Chemotherapy, n (%)	
Received treatment	7 (50%)
No treatment received and was not recommended	6 (43%)
Recommended treatment, but treatment documentation not available	1 (7%)
Treated with radiation, n (%)	6 (43%)
Treated with surgery, n (%)	8 (57%)

^a 1 patient with synchronous uterine and cervical cancer.

substance use disorder, and a history of involuntary commitment to a psychiatric facility, highlights how insufficient treatment of mental health can delay workup needed to establish a cancer diagnosis. “She ... needs to undergo several tests to aid in diagnosis for proper treatment. However, the patient refuses due to inadequate pain control and anxiety about the procedures and being able to tolerate them due to pain.”

We also identified patients who experienced delays prior to incarceration, which were exacerbated by delays during incarceration. For example, a 36-year-old patient had a substantial delay in cancer diagnosis before incarceration compounded by a 17-month interval of repeat screening tests in jail, prison, and hospital facilities after her diagnosis of a pre-invasive cancer.

3.2. Factors primarily confined to the carceral system

Several themes were localized to the carceral facility itself. Trouble accessing high-quality and palatable nutrition, emphasized in the

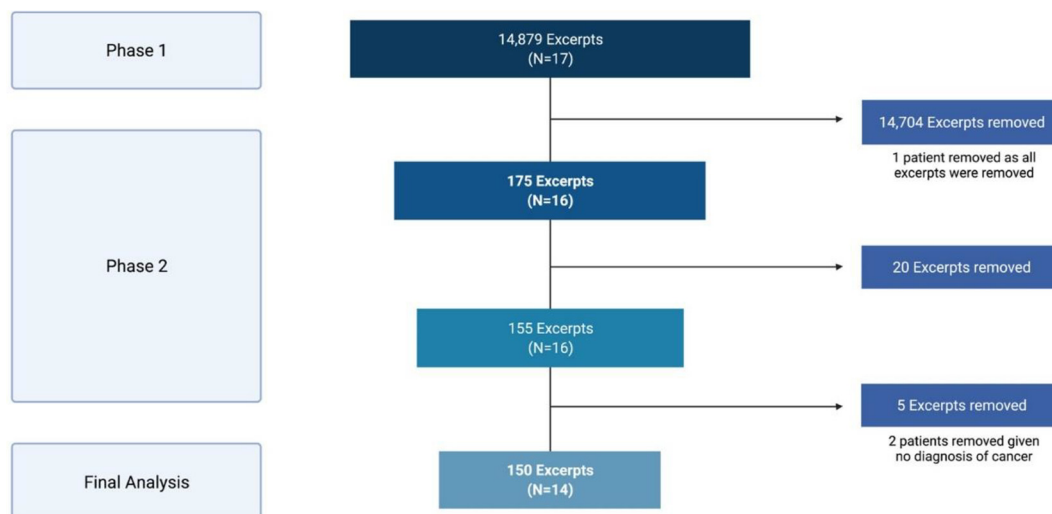


Fig. 1. Flow Chart of Data Reduction. Created with Biorender.com.

Communication	1	3	1	2	4	2	0	2	0	0	4	1	1	0
Contact	0	1	0	0	2	0	1	0	0	0	3	0	0	0
Scheduling	0	2	0	2	12	1	1	3	1	0	2	1	0	0
Gaps in care	2	2	0	0	3	1	1	0	0	1	2	0	0	0
Lost to follow-up	7	1	0	5	5	0	0	2	0	0	4	0	0	0
Transportation	3	0	0	0	9	0	0	2	0	0	0	0	0	0
Medical records	0	1	0	4	1	1	0	0	1	1	1	1	0	0
Carceral facility authorization	0	1	1	0	0	1	1	0	0	1	0	0	0	0
Insurance	1	0	0	0	1	0	0	3	3	0	0	0	0	0
Nutrition	2	0	0	0	0	2	2	0	0	0	0	0	0	0
Discharge planning	0	2	0	0	1	0	0	0	0	0	0	0	0	0
Medication	3	2	0	1	0	0	0	1	0	0	0	0	0	0
Side effects	1	2	0	0	0	1	2	0	0	0	0	0	0	0
Medication reconciliation	0	0	1	0	0	0	0	0	0	0	0	0	0	0
Pain control	0	0	0	5	0	3	0	0	0	0	1	0	0	0
Prolonged symptoms	2	2	0	0	1	2	0	1	1	0	0	2	0	0
Comorbidities, general health	0	3	0	5	6	0	3	0	0	0	0	0	0	0
Post-op care	0	0	0	0	0	0	0	0	0	0	0	0	0	0
Wound care	0	0	2	0	0	0	0	0	0	0	0	0	0	0
Activity	0	0	1	0	0	0	0	0	0	0	0	0	0	0
Restraints	0	0	1	0	0	2	0	0	0	0	0	0	0	0
Adherence	0	1	0	14	9	2	0	3	0	0	2	0	0	0
Emotional experience	2	0	0	3	1	5	0	0	0	0	0	0	0	0
Trust	0	0	0	1	1	0	0	0	0	0	0	0	0	0
Protocol restrictions	0	5	0	1	0	1	1	0	1	0	0	0	1	2
Administrative burden	0	0	1	0	0	0	0	0	0	0	0	0	0	0
Patient	1	2	3	4	5	6	7	8	9	10	11	12	13	14

Fig. 2. Heat map demonstrating barriers experienced by each patient. Numbers in the cells represent the number of excerpts coded for each barrier, and higher numbers correspond to darker shading of the cell. The mean number of barriers experienced per patient was 7.71.

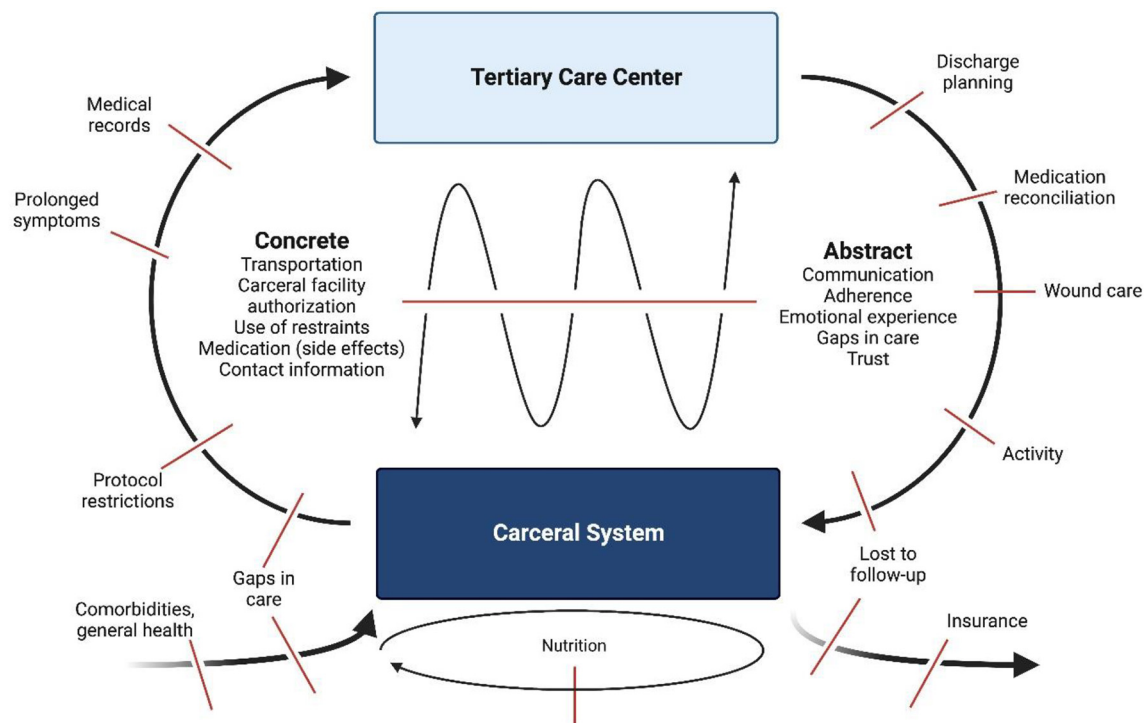


Fig. 3. Concept model depicting thematic elements contributing to disruptions in gynecologic cancer care in those experiencing incarceration. Created with Biorender.com. The figure depicts points of susceptibility to delays in cancer care from the prison or jail to the tertiary care center and back to the carceral facility, including pre-incarceration points of delay (e.g., existing comorbidities) and post-incarceration points of delay (e.g., lack of insurance coverage). The figure also shows concrete contributors to care delays – physical or operational issues – and abstract contributors – emotional or interpersonal issues – that resulted in care delays.

Table 2
Qualitative Codes with Illustrative Quotes*

Parent Code	Child Code	Illustrative Quotes
Communication	Contact information	- I called the number but the voicemail was not set up and no one answered. I have written a certified letter that I will send to the given address - Called to r/s, received message this number is not excepting calls at this time - She is getting release from prison this week. We do not have a contact phone number for her once she gets discharged
Scheduling		- I was informed that you did not keep your Radiation Oncology appointment with Radiation Oncology...As explained to you previously, it is very important that you completed the remaining radiation treatment course. Please get in touch with their office to reschedule your appointment and I encourage that you do so this week as soon as possible. - Discussed the challenges of rescheduling surgery given that she has now cancelled twice. Counseled that if she changes her mind, she should at least come to [tertiary care center] so that we can discuss on the day of surgery
Gaps in care	Lost to follow-up	- Completed a partial course of radiation in the fall of [year], but did not finish when released from prison despite multiple rescheduled appointments and extensive coordination with social work for transportation arrangements. Now, back in prison, seen for consideration of completing her treatment for cervical cancer. - She was lost to follow up and unable to be contacted when she was discharged from the correctional facility. - She has demonstrated multiple barriers to care and has missed appointments after her recent incarceration.
Transportation		- She had no way to get to the office in [city A] so they referred her to there office in [city B]. They called this morning and said that the patient didn't show up for her appointment. - As pt.'s case is complex secondary to lack of consistent social, family, financial, housing, transportation supports in addition to reported current illicit substance abuse issues, putting together a solid plan for wrap-around services in order for pt. to return to [tertiary care center] for her treatments continues to be difficult.
Medical records		Records are not available to us at the time of this visit, but the patient reports a long-standing history of cervical dysplasia and possible cervical cancer
Carceral system authorization		We are unable to schedule the patient's PET scan until we have authorization and I conveyed that she has surgery scheduled for next week and requires a PET scan and office visit prior to proceeding.
Insurance		- She had not returned for FU because she lost insurance. - Patient stated that she has recently signed up for "VA Benefits" but the VA in [city C] told her that their cancer center is full and she cannot go there for treatment ... Patient also stated that the Sw at the prison has been helping her with her Medicaid application.
Nutrition		- Needs boost/ensure since she cannot eat the meat at the facility - States she cannot eat three full meals, prefers smaller more frequent meals which is difficult in the prison
Discharge planning		Contacted by [patient name] as she was d/ced from DOC and needs medication refills.
Medication	Side effects	She is currently with chemoradiation with cisplatin. Last week she did not get chemotherapy because low PLT count (84 K - done at the prison), the CBC done on [date]-WBC 2.7 (ANC 1.7), PLT 90 K. She did not get the chemotherapy today as well because of the low PLT count.
	Medication reconciliation	- She was taking stool softeners but the DOC is holding these now. She states that the DOC did not provide her with cream for her skin per our recommendations. - She also was not getting her home Vistaril for anxiety.
Pain control		- In brief, patient presented as a direct admit from the DOC with poorly controlled pain in the setting of newly diagnosed SCC of the cervix. - She has been seen by Gynecology, Psychiatry, and Thoracic Surgery, and needs to undergo several tests to aid in diagnosis for proper treatment. However, the patient refuses due to inadequate pain control and anxiety about the procedures, and being able to tolerate them due to pain.
Prolonged symptoms		- She notes that symptoms began in [month] with swelling in her LLE. It wasn't until last month, however, that the swelling became really significant and she was diagnosed with a DVT. - Reports that she has been bleeding for weeks. Reports that every time she urinates she passes large clots.
Comorbidities, general health		- I explained to her that her CD 4 counts and HIV should be in control not only for HIV treatment, but also to allow further treatment of her cervical cancer. - Weight loss continues, has lost 7 more pounds since [month]. Still does not have dentures but says a mold was made.
Post-operative care	Wound care	The wound appears more deep today than it did on [gynecologic oncology fellow's] examination earlier this month. I think this is likely to the accumulation of this mucus and incomplete wet-to-dry dressing changes at the department of corrections.
	Activity	- I again recommended no activity restrictions and wrote a note stating such. - Of note, with regards to her tachycardia, the patient endorsed significant anxiety overnight mainly because she was shackled on both of her legs and one arm and felt very claustrophobic. - Significant amount of time spent providing active listening and therapeutic support as patient having significant distress related to his current situation (new cancer diagnosis, being transferred to new prison in [city D], difficulty coping with presence of officers in her room and being chained to the bed, feeling alone and estranged since she is not able to talk to her family, and significant fear/worry that her painful symptoms are going to come back and she would be able to receive relief)
Restraints		- I discussed the risks of leaving AMA with the patient including complications with repeat attempts of venous access for chemo, failure to obtain scheduled chemotherapy which could lead to inadequate treatment of her cancer and possible recurrence. - Patient left AMA prior to having blood drawn.
Adherence		- Pt reports feeling alone and depressed. She wishes that her family could know that she is back in the hospital. - Patient declined surgery when it was initially scheduled to anxiety about sexual functioning after partial vulvectomy. - Patient states that "she does not trust the prison doctors and hopes to find a cure when she is released." - Pt reported feeling "alone" and noted that she has very few people in her life whom she can trust.
Emotional experience		- She is not eligible for genetic testing while an inmate. - CKC from [month] confirms invasive cervical cancer. Pt in correctional facility so cannot call her. Referral made to GYN ONC.
Trust		Because pt. is an inmate, the Correctional Officer has been asked to contact the prison for chaplaincy care. If the prison allows it, chaplains here will be granted permission to visit with pt.
Protocol restrictions		
Administrative burden		

* The quotes are transcribed directly from the medical record. We have not corrected spelling or grammatical errors nor spelled out abbreviations where they occurred in the text.

provider notes as an important component in maintaining health through taxing cancer treatments, was a predominant one. One hospital note exemplified this challenge: “intermittent decreased po intake and appetite, but associates this largely with the food provided at the prison holding facility she is at” (43-year-old with cervical cancer). Additionally, specialized dietary support did not appear to be available during incarceration and required a written order from a provider. For example, “Overall feeling better, not eating well due to not liking food offered at prison. I have written for her to see the dietician [at the carceral facility]” (43-year-old with cervical cancer). The medical record abstracts outlined the downstream consequences of poor food quality on weight and attitudes towards food (e.g., indifference) with one patient note included the following: “Patient states she has not been eating well. Does not like prison food and doesn't care if she loses [sic] weight” (30-year-old with cervical cancer). This same patient required supplementation with nutrition drinks, “Needs [nutritional drinks] since she cannot eat the meat at the facility.”

Provider notes highlighted that it is not uncommon for patients with gynecologic malignancies to eat frequent small meals throughout the day as eating three full meals can be difficult with cancer symptoms or treatment side effects. However, eating frequent small meals also posed a challenge. One patient's chart documented the patient's preference for smaller, more frequent meals which was not granted by the prison (39-year-old with cervical cancer).

Clinical notes also described mechanical limitations to obtaining adequate nutrition from the standard dietary options available while incarcerated and emphasized that appropriate adjustments were not readily available. Access to dentures was one example: “Weight loss continues, has lost 7 more pounds since [month]. Still does not have dentures but says a mold was made” (39-year-old with cervical cancer).

3.3. Factors contributing to delays preceding specialty care center visit

These delays identified in the concept model were attributed to gaps in care, protocol restrictions, prolonged symptoms that were not addressed, and access to accurate and up-to-date medical records. While these four elements all individually contributed to delays, they frequently co-occurred, exacerbating delays.

Gaps in care were described in patients who had prolonged courses until reaching a final diagnosis. One patient's convoluted history exemplifies these care gaps: “Colposcopy recommended but pt moved to [state A]. Pap in [date] in [state A] was abnormal, colpo[scopy] done [three months later] and cone biopsy showed ‘Stage 0 cervical cancer.’ Path report, which is scanned into EPIC, from [hospital] in [state A]... shows severe endocervical dysplasia consistent with Adenocarcinoma in Situ, Ki67 and P16 stains supportive. Pt had routine screening Pap at [the carceral facility] in [one month later] showing ASCUS, HPV +. Pt was seen by GYN in [one month later] Utilization Review request for surgery first placed in [the same month] and was requested a second time in [two months later]. Due to concern about time to surgery, we elected to have the cone biopsy done by General OB-Gyn” (36-year-old with cervical cancer).

Inadequate recognition and management of symptoms was another theme that emerged in this category. Several patients experienced prolonged symptoms related to their cancer pathology or comorbid disease. For example, “Since [menopause], the patient endorses almost daily bleeding requiring the use of a panty liner or pad. She notes asking to be seen by somebody for this bleeding but was “told that her name was not on the list” to be seen by an MD. She was ultimately seen at [tertiary care center] and unable to be sampled in clinic due to vaginal atrophy” (63-year-old with endometrial cancer).

Lack of interoperability between medical records at the carceral system and tertiary care center was also identified as contributing to care delays. Delays due to the lack of availability of outside medical records were evident in the clinical notes. This example demonstrates medical record inaccessibility: “[Date]: Complete molar pregnancy on

pathology after a 20 week TAB. Initial beta was 98,000 with no documented follow-up beta hCGs ... [Two years later]: Patient was seen in the [regional hospital] ED with complaints of vaginal bleeding. Beta hCG was 858 transvaginal ultrasound was indeterminate. She was recommended follow-up at the prison. Records not available. [Later the same month]: Patient reports being 6 weeks pregnant per ED documentation. Patient left AMA prior to having beta drawn. [Six months later]: Patient again reports being 6 weeks” (27-year-old with GTN).

3.4. Factors contributing to delays after the tertiary care center visit

Delays in care were observed when patients were discharged from the specialty care center and transitioned back to the prison. During this transition, common points of delay included discharge planning, medication reconciliation, post-operative wound care and activity instructions, and follow-up. Issues related to access or continuity of high quality care were considered as delays because the patient was often only able to access these items at follow-up appointments at the tertiary care center or after prolonged and repeated advocacy by the provider writing the note.

One source of friction was identifying the correct point of contact within the carceral system. This challenge is captured in one patient's discharge planning: “SW called [registered nurse at a county jail], again re: d/c plan and plan for Pt to rcv HIV care in [city]. However, SW informed that Pt never in [county jail] system - SW contacted wrong institution. Pt prisoner in [prison name and telephone contact number]. SW called, req [name of carceral facility social worker], Correctional Institute SW, who is off today. SW instructed to call above # tomorrow and ask for [name of carceral facility social worker]. SW will f/u tomorrow, connect w/ [name of carceral facility social worker] in order to determine Pt's plan for HIV care once home” (54-year-old with cervical cancer).

Issues around medication management and reconciliation following discharge were pervasive, including medication management within the prison. For example: “She states that the [carceral system] did not provide her with cream for her skin per our recommendations” (30-year-old with cervical cancer).

Like medication access, post-operative wound care and activity were lacking among patients returning to prisons. One example revealed discrepancies between the recommendations and what the patient received after discharge: “Here for wound check. The wound had a mucous plug that was removed today. The wound appears more deep today than it did on [gynecologic oncology fellow's] examination earlier this month. I think this is likely to the accumulation of this mucus and incomplete wet-to-dry dressing changes at the department of corrections. I recommend continued twice-daily wet-to-dry changes. We will see her back in 2–3 weeks for a wound check. I again recommended no activity restrictions and wrote a note stating such” (41-year-old with cervical cancer).

Finally, patients were frequently lost to follow up during the transitions from hospital to carceral facility to the community. The following exemplifies delays secondary to lost to follow up: “In [month], she was noted to have this mass and had a follow-up CT scan, noting the size to be 1.5 x 2.5 x 2cm lobulated mass without calcification. At the time she was asymptomatic. Close outpatient follow-up was recommended with which she did not comply. In her recent admission to [tertiary care center], workup for the apical mass seen on CXR involved a subsequent CT scan of the chest with contrast on [nine months later], showing significant interval growth of the right apical mass as well as multiple innumerable pulmonary lesions bilaterally and a new significant left pleural effusion” (a 27-year-old with GTN).

3.5. Concrete contributions to delayed care

Concrete contributions to delays in care – physical or operational issues – were identified during diagnosis, treatment, and surveillance.

These included transportation, carceral facility authorization, use of restraints, medication use and side effects, and acquisition of contact information.

Transportation barriers were identified across many patient records. These encompassed challenges in getting to appointments at the tertiary care center due to awaiting prison transportation, as well as difficulty coordinating transportation following prison release. The following is a representative example: “Completed a partial course of radiation in the fall of [year] but did not finish when released from prison despite multiple rescheduled appointments and extensive coordination with social work for transportation arrangements. Now, back in prison, seen for consideration of completing her treatment for cervical cancer” (54-year-old with cervical cancer).

Administrative processes for obtaining carceral facility authorization for individuals to receive appropriate care was another contributor to delayed care. This process was found to impact delays when arranging follow-up, scheduling surgery, requesting referrals, or even coordinating spiritual care provided by the inpatient chaplain services as demonstrated here, “Because pt is an inmate, the Correctional Officer has been asked to contact the prison for chaplaincy care. If the prison allows it, chaplains here will be granted permission to visit with pt” (41-year-old with cervical cancer). Authorizations were broad in nature and often lacked consistency across carceral systems.

Patient charts also documented the concrete impact of restraint use on their care. As described by one 41-year-old patient with cervical cancer, “[she] endorsed significant anxiety overnight mainly because she was shackled on both of her legs and one arm and felt very claustrophobic. She also was not getting her home Vistaril for anxiety.” The emotional impact of being restrained was compounded by potential sequelae of officer retaliation in another patient’s chart: “worse than labor and she felt like she was ‘chained to the bed and abandoned.’ She also reports frustration with the correctional officers in her room, noting that she got into a ‘screaming match’ with one of the officers this morning and is now worried she will receive retribution at the prison” (43-year-old with cervical cancer).

Failure to recognize or adequately accommodate to side effects from cancer treatments were a concrete contributor to delay. The following patient was immunocompromised and could not adequately isolate herself in the congregate living environment such that she experienced a new scabies infestation. She did not feel well but was not brought to the tertiary care center for evaluation until the scheduled date of her chemotherapy, leading to delays in her treatment. “She has completed her external beam radiation and 5/6 cycles of cisplatin and is currently receiving concurrent brachytherapy. She was admitted to [tertiary care center] on [date] for fever of unknown origin on the day she was supposed to receive cisplatin cycle [6 of 6]. At [tertiary care center] she was found to have MRSA Bacteremia and Scabies” (34-year-old with advanced cervical cancer).

Another salient concrete contributor to delayed care was challenges with acquiring the correct patient contact information. This issue was observed throughout incarceration and after release from prison: “Will delay [patient]’s case until this pathology is read. She is getting release[d] from prison this week. We do not have a contact phone number for her once she gets discharged. However, I spoke with [prison administrator] in [prison medical] wing who states that she will give [patient] our clinic number for her to call once she is released for further scheduling” (35-year-old with cervical cancer).

3.6. Abstract contributions to delayed care

Abstract themes – emotional or interpersonal issues – included communication breakdown due to lack of mutual understanding of system structure, trust and emotional experiences. Communication breakdown was a common challenge, in particular involving the oncology team and the carceral facility. In one instance, a patient’s oncologist became concerned about cancer progression and faced several hurdles in

confirming this with the prison, “I called the [carceral facility] about this patient. It is rumored that ‘her numbers were up to above 10,000’. The [carceral facility nursing supervisor] was not available and no information could be given. I asked that [carceral facility nursing supervisor] call the transfer center or Gyn Onc Clinic ASAP- was informed that she would not be in until Monday” (a 27-year-old with GTN)

Acceptance of and adherence to the treatment plan during incarceration was described across stages of cancer treatment. The following exemplifies this: “She was supposed to have received ultrasound last Friday to determine if she had an intrauterine pregnancy, but the patient declined, stating that she ‘she was sure to be released this week and would take care of it’” (27-year-old with GTN). Adherence to medications, such as HIV antiviral medications, was also described as an issue in clinic notes (54-year-old with cervical cancer).

Another abstract theme that emerged across many patients’ encounters was patients’ emotional experiences, a theme that co-occurred with the theme of restraint use. One patient’s clinical note documented this theme poignantly: “Patient is frustrated with her current situation. She is hopeful to be transferred back to prison located closer to home and is hopeful that her family/lawyer will be able to find a way to get her out of prison so she can have their support while she goes through this. Significant amount of time spent providing active listening and therapeutic support as patient having significant distress related to his [sic] current situation (new cancer diagnosis, being transferred to new prison in [state], difficulty coping with presence of officers in her room and being chained to the bed, feeling alone and estranged since she is not able to talk to her family, and significant fear/worry that her painful symptoms are going to come back and she would be able to receive relief) - Pt reports feeling alone and depressed. She wishes that her family could know that she is back in the hospital” (43-year-old with cervical cancer).

Trust is vital to the provider–patient relationship in any cancer treatment process, but perhaps even more important for patients who are incarcerated and without access to their usual support systems. Trust was identified in the concept model and contributed to psychosocial disruptions and delays in care. One patient encounter documented this theme, “Pt reported feeling ‘alone’ and noted that she has very few people in her life whom she can trust. She reported a fractured relationship with her mother, that stretches back to when she was young. Pt reported feeling as if MDs and RNs were ‘looking at [her] different’ because of her history with drug abuse. She indicated feeling that people looked down upon her and intimated worry that this affected her medical care” (27-year-old with GTN). Mistrust towards medical providers was described as a motivator among patients who chose to forego cancer care during incarceration. For example, “Patient states that ‘she does not trust the prison doctors and hopes to find a cure when she is released’” (54-year-old with cervical cancer).

4. Discussion

To our knowledge, this is the first study to qualitatively analyze and identify factors that contribute to delays in gynecologic cancer care among individuals experiencing incarceration. We identified a multitude of factors that contribute to delays in gynecologic cancer care in those experiencing incarceration. Overall, we found that the drivers of delayed care were pervasive and overlapping, rather than being isolated to issues at one facility, time-point, or patient characteristic. These findings are consistent with existing literature which reports delays in cancer care for patients who are incarcerated stemming from multifactorial causes [18,32,33]. While we believe the most effective way to systematically address these care disparities is through decarceration and the expansion of accessible healthcare coverage [34], more proximal and immediate steps should be taken to care for those currently impacted by incarceration. For example, many of the challenges in providing equitable care to carceral communities stem from poor communication. This

could be rectified by streamlining medical record access, formalizing communication lines between all settings of care, and improving collaboration and professionalism between at all levels – providers, nursing staff, and case managers and social workers.

Our findings also suggest targets for future research and quality improvement. Cancer outcomes among carceral populations are inherently difficult to assess, and disparities in care quality are further challenging to quantify. Lack of standardized data reporting systems among U.S. carceral facilities makes it challenging to conduct large-scale analyses of cancer outcomes across prison populations. Lack of medical record interoperability makes even single center studies difficult to conduct as sample sizes are small and documentation is scattered across systems. Our findings point towards specific areas that future research may target to more meaningfully assess care gaps (e.g., time from Pap smear in prison to cancer diagnosis at specialty center). Our qualitative analysis also revealed ample room for improvement in prison and tertiary care centers' medical teams to ensure guideline-concordant care. For example, quality improvement efforts may focus on improving concrete barriers we identified in this study, such as transportation mechanisms, post-operative wound care, or nutrition resources, to avoid further delays in oncologic care.

Similarly, these findings suggest opportunities for policy change. The poignant accounts of emotional distress secondary to restraint use suggest an area where policy changes may be largely beneficial. A small number of facilities have implemented policies prohibiting the use of restraints during patient care activities [35]. Our findings support the need for similar policies to improve the quality of care received during cancer treatment. Further, the lack of Medicaid expansion in many states in the Southeastern US is a known driver of cancer disparities [30]; the federal Medicaid exemption that precludes use of public health insurance during incarceration and complicates re-activation or re-enrollment after incarceration likely exacerbates these disparities in states with high rates of incarceration. Finally, policies standardizing data reporting practices remain integral for ensuring health equity research can continue and include more robust patient-level data. The lack of transparency in healthcare data reporting poses an ongoing challenge for researchers and will likely require largescale policy changes to significantly improve data quality and reporting practices among prisons.

4.1. Limitations

This qualitative study's limitations include those inherent to our qualitative analysis, including human error in manual sorting and curation of the codebook. This analytic set was comprised of patients treated at a single tertiary care center, which primarily included individuals incarcerated at a state prison. Patients who were incarcerated at state prisons were readily identifiable through payor status, however, other carceral facilities (such as jails and federal prisons) may not have been identified in the data extraction process. The generalizability of our results to the larger carceral population, including those in federal prison, tribal facility, immigration detention center, or local jail, is therefore unknown. Additionally, by using the electronic medical record system, we were able to obtain a vast number of texts allowing us to identify causes for disruptions in care. However, the electronic medical record tells the story from a limited perspective and is subject to interpretation. It is likely that some barriers were neither experienced directly by those documenting in the medical record nor mentioned by the patients during their clinic and hospital visits, resulting in an underestimate of delays in cancer care. We were unable to include medical records from the facilities where patients were incarcerated, and unable to make comparisons in medical recommendations or adherence patterns across multiple settings. Future directions include patient interviews to contextualize our findings and improve gynecologic cancer care in those experiencing incarceration.

In addition, this study was conducted at an academic tertiary care hospital and primarily included patients coming from the state prison

system. Because prison incarcerations are often longer than jail incarcerations [36] and academic centers may have greater resources for care coordination, this particular setting likely represents one of the most stable and well-integrated settings in which patients receive cancer care during incarceration. As such, our results likely represent an example of a best case scenario and may substantially underestimate the number of barriers that patients experience in other carceral settings.

5. Conclusions

Those who care for patients with gynecologic malignancies within the carceral health care system need to acknowledge that the U.S. is approaching a nexus between an increasing rate of women experiencing incarceration and an aging population which will test our ability to provide quality and equitable healthcare. While the burden to improve gynecologic cancer care in those experiencing incarceration should not fall solely on those who provide healthcare services for these individuals, we should be leaders in advocating for system changes to improve the care we deliver for those affected with a gynecologic malignancy during incarceration.

Declaration of Competing Interest

None.

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Appendix A. Supplementary data

Supplementary data to this article can be found online at <https://doi.org/10.1016/j.ygyno.2023.06.017>.

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