

Barriers to the Delivery of Timely, Guideline-Adherent Adjuvant Therapy Among Patients With Head and Neck Cancer

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QUESTION ASKED: Can multilevel barriers to timely, guideline-adherent postoperative radiation therapy (PORT) after surgery for head and neck squamous cell carcinoma (HNSCC) be identified and organized into a conceptual model?

SUMMARY ANSWER: Barriers causing delays starting guideline-adherent PORT following HNSCC surgery occur at the intrapersonal-, interpersonal-, healthcare team-, organizational-, and community levels. These barriers inform a theory-based, multilevel conceptual model for understanding the delivery of timely, guideline-adherent PORT to patients with HNSCC.

WHAT WE DID: Semi-structured interviews with key informants were conducted with a purposive sample of patients with HNSCC and oncology providers across diverse practice settings (n = 45); thematic analysis was performed to identify the themes that explain barriers to timely PORT and develop a conceptual model.

WHAT WE FOUND: Five themes explain the mechanisms underlying delayed, guideline-non-adherent PORT following surgery for HNSCC: (1) inadequate education about timely PORT, (2) post-surgical sequelae that interrupt the tight treatment timeline, (3) insufficient care coordination and communication during care transitions, (4) fragmentation of care across healthcare organizations impeding care delivery, and (5) travel for HNSCC care as a burden for socioeconomically disadvantaged patients. Our conceptual model, by organizing themes at levels of healthcare

delivery, reflects 1) individual behaviors of patients and providers, 2) reciprocal interactions between patients and providers and providers with each other, 3) that clinicians are embedded within and across numerous healthcare teams (surgical oncology, radiation oncology, etc.), 4) that teams are situated within and across healthcare systems, and 5) that healthcare systems are located within communities.

BIAS, CONFOUNDING FACTORS: Although we included patients and providers across diverse practice settings, an important study limitation is that all patients underwent HNSCC surgery at a single tertiary academic medical center. Additional qualitative work in other settings is therefore necessary to establish the generalizability of our findings. We identified 5 themes that explain the mechanisms underlying delays starting guideline-adherent PORT after HNSCC surgery.

REAL-LIFE IMPLICATIONS: Our conceptual model provides a framework to understand the multilevel barriers to timely sequential multimodal cancer care delivery (e.g. surgery followed by PORT). These foundational qualitative data will enable future studies to gather prospective quantitative data about barriers to timely PORT to characterize the frequency, number, timing, and dynamic evolution of barriers as patients progress through treatment. In addition, interventions targeting these barriers could improve the delivery of timely, guideline-adherent PORT and decrease mortality for patients with HNSCC.

ASSOCIATED CONTENT

Appendix

Author affiliations and disclosures are available with the complete article at ascopubs.org/journal/op.

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abstract

PURPOSE Delays initiating guideline-adherent postoperative radiation therapy (PORT) in head and neck squamous cell carcinoma (HNSCC) are common, contribute to excess mortality, and are a modifiable target for improving survival. However, the barriers that prevent the delivery of timely, guideline-adherent PORT remain unknown. This study aims to identify the multilevel barriers to timely, guideline-adherent PORT and organize them into a conceptual model.

MATERIALS AND METHODS Semi-structured interviews with key informants were conducted with a purposive sample of patients with HNSCC and oncology providers across diverse practice settings until thematic saturation ($n = 45$). Thematic analysis was performed to identify the themes that explain barriers to timely PORT and to develop a conceptual model.

RESULTS In all, 27 patients with HNSCC undergoing surgery and PORT were included, of whom 41% were African American, and 37% had surgery and PORT at different facilities. Eighteen clinicians representing a diverse mix of provider types from 7 oncology practices participated in key informant interviews. Five key themes representing barriers to timely PORT were identified across 5 health care delivery levels: (1) inadequate education about timely PORT, (2) postsurgical sequelae that interrupt the tight treatment timeline (both intrapersonal level), (3) insufficient coordination and communication during care transitions (interpersonal and health care team levels), (4) fragmentation of care across health care organizations (organizational level), and (5) travel burden for socioeconomically disadvantaged patients (community level).

CONCLUSION This study provides a novel description of the multilevel barriers that contribute to delayed PORT. Interventions targeting these multilevel barriers could improve the delivery of timely, guideline-adherent PORT and decrease mortality for patients with HNSCC.

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INTRODUCTION

Head and neck squamous cell carcinoma (HNSCC) is diagnosed in 65,000 patients annually in the United States and results in 14,600 deaths per year.¹ Standard of care for locoregionally advanced HNSCC consists of multimodal therapy that includes combinations of surgery, radiation therapy, and chemotherapy.² Unfortunately, treatment delays are common and are a key driver of mortality.³ For patients with locoregionally advanced, surgically treated HNSCC, standard of care, according to the National Comprehensive Care Network (NCCN) Guidelines, is to initiate postoperative radiation therapy (PORT) with or without concurrent chemotherapy within 6 weeks of surgery.² The time interval between surgery and PORT is the

only measure of timely care incorporated in NCCN Guidelines for HNSCC and is a measure of quality head and neck oncology care.⁴ Unfortunately, more than half of patients with HNSCC who are undergoing surgery and PORT experience a treatment delay,^{4,5} increasing their risk of recurrence and decreasing survival.^{3,6-8}

The failure to deliver timely, guideline-adherent PORT is a major quality gap in care delivery for patients with HNSCC.⁴ Although studies have described risk factors for PORT delay^{5,9} and cancer care processes associated with that delay,¹⁰ the barriers to timely, guideline-adherent PORT and mechanisms underlying these delays remain unknown. The objectives of this study are to identify the barriers to timely,

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guideline-adherent PORT and develop a conceptual model of multilevel barriers to timely sequential multimodal care among patients with HNSCC.

MATERIALS AND METHODS

To identify barriers to timely, guideline-adherent PORT, we performed a qualitative study in which head and neck oncology providers and patients (key informants) participated in one-on-one interviews. The study was approved by the Medical University of South Carolina (MUSC) Institutional Review Board and reported in accordance with Consolidated Criteria for Reporting Qualitative Research Guidelines.¹¹

Sampling

Participants were enrolled by using purposive and criterion-based sampling strategies (Appendix Table A1, online only) to ensure the comprehensive identification of barriers to timely PORT.¹²⁻¹⁵ Participants were identified in the MUSC Head and Neck Clinic, screened by the project coordinator, and enrolled face-to-face by a study investigator after they provided written informed consent. Forty-five participants (27 patients, 18 providers) were screened; all accrued to the study. Our sample size was not determined a priori but instead reflects thematic saturation (ie, accrual stopped when performance of additional interviews failed to reveal previously unidentified themes [patterns of responses of meaning with the data]).¹⁴

Data Collection

A male and female team member trained in qualitative methods (E.M.G. and K.R.S.) conducted the interviews in person in individual sessions by using a semi-structured interview guide in a research suite. The interview guide and codebook were informed by our clinical expertise, previous research,^{5,10} literature review of postsurgical care transitions,¹⁶ and barriers to timely cancer care.¹⁷⁻¹⁹ The interview guide was pilot tested and refined to reflect language about the process of starting PORT. Interviews lasted between 9 and 49 minutes (median, 25 minutes) and used open-ended questions to elicit thought processes, knowledge, attitudes, experiences, barriers, and facilitators to timely PORT. Interviews were digitally recorded, transcribed verbatim, and entered into NVivo Version 12 for coding and analysis.

Analysis and Reflexivity

Coding and analysis were performed by E.M.G. and K.R.S. using thematic analysis (TA). TA is an inductive-deductive approach to analyzing qualitative data that generates meaning through the identification, analysis, organization, description, and reporting of themes (ie, patterns of meaning within the data).²⁰⁻²² During TA, researchers start with a preliminary coding framework based on a priori codes (deductive), analyze a subset of the data, refine and develop new codes in an iterative fashion as they analyze

additional data (inductive), and combine codes into themes until data are thoroughly coded.²² Themes are expressed as sentences that summarize the key meaning of the data.^{23,24} Although we identified facilitators to timely PORT, they generally represented the inverse of barriers, did not add explanatory value beyond barriers, and were dropped from the final codebook. After data analysis, we organized the themes into a theory-based²⁵⁻²⁹ multilevel conceptual model to facilitate understanding of the structure of care delivery and the levels at which the barriers to timely, guideline-adherent PORT operate^{30,31} and to guide the development of multilevel intervention.

We maintained a critical realist epistemological paradigm (ie, theoretical position about the justification of knowledge and subsequent assumptions about the nature of the data)^{22,32} that was congruent with our beliefs that a qualitative approach can generate knowledge about how barriers to timely initiation of PORT can explain and be responsible for the observed phenomena.³³ We used a team approach to reflexivity (ie, the conscious and systematic attention to the effect of the researcher on knowledge construction)³⁴ (Appendix Table A2, online only) and took numerous steps to ensure trustworthiness and rigor during data analysis^{22,35} (Appendix Table A3, online only).

RESULTS

Of the 27 patients, 70% were male, 41% were African American, 26% had Medicaid or no insurance, 93% had American Joint Committee on Cancer (AJCC) Stage III to IV HNSCC, 56% received concurrent chemoradiation, and 37% had surgery and PORT at different facilities (Appendix Table A4, online only). Forty-four percent of providers were radiation oncologists, 61% were physicians, and 33% were not affiliated with MUSC. Five key themes of barriers to timely, guideline-adherent PORT were identified: (1) inadequate education about timely PORT, (2) postsurgical sequelae that interrupt the tight treatment timeline, (3) insufficient care coordination and communication during care transitions, (4) fragmentation of care across health care organizations that impedes care delivery, and (5) travel for HNSCC care as a burden for socioeconomically disadvantaged patients. We describe each theme, expressed as a sentence, that describes the major findings of a barrier to timely, guideline-adherent PORT, and we include illustrative quotes supplemented by additional quotes in Tables 1, 2, and 3.

Theme 1: A failure to educate about timely, guideline-adherent PORT leaves patients ill-equipped to receive, and providers to deliver, necessary care.

Almost universally, patients did not know that national treatment guidelines recommend starting PORT within 6 weeks of surgery, and ancillary staff were not made aware of guidelines for timely PORT, both of which led to delays in

TABLE 1. Intrapersonal-Level Barriers to Timely, Guideline-Adherent PORT

Subtheme	Patient	Patient Quotes	Provider	Provider Quotes
Theme 1: Failure to educate about timely, guideline-adherent PORT leaves patients ill-equipped to receive, and providers to deliver, necessary care.				
Guidelines for timely PORT are not discussed.	Patient 21	"I don't remember like say a specific time for getting started with the radiation."	Provider 17, radiation oncologist	"I may not tell them exactly what...the time goal is [for starting postoperative radiation] and maybe I should."
	Patient 2	"I don't know of any specific time goals to start radiation."	Provider 14, surgeon	"Some scheduler in a back office somewhere...may not get the timely appointment with the patient because they just don't know the acuity of it...so that radiation can get started on time."
The oncologic consequences of delays in starting PORT are not perceived.	Patient 6	"They didn't really say whether there were any consequences to starting radiation sooner or later."	Provider 4, radiation oncologist	"Yeah, both a lack of knowledge about the six-week timeline and a lack of perceived importance. Because I think everything flows from the top. If the physician has bought into this idea, that it's really important, then it will flow from there. They'll get to the dentist to get the things done sooner, they'll get the dosimetrist to get the patient in quicker and plan it sooner and you know. Most people don't have that sense of the time frame."
	Patient 27	"Well it's just his girls that were in charge of doing the mask and scheduling just didn't seem to care and were like 'Oh we don't see anybody within 5 days or 7 days.' Yeah, they were like 'it's like it's going to be a month before we can get you in and they get the computers set up for the mask.'"	Provider 5, surgery APP	"If [the patients] haven't been convinced... they will cancel or not show up to their consultation appointment, which can certainly lead to delays."
			Provider 4, radiation oncologist	"They [the radiation oncologists] don't really know how bad it is to wait. They don't know that, once you go past eight, ten weeks, it's like your survival drops... Another thing is...a generalist, how much literature do you think they are keeping up with? And it is quite conceivable that they don't know that this is as bad as it is in the postoperative setting for head and neck patients."
The steps and timeline for starting PORT are not discussed thoroughly.	Patient 20	"That was the biggest challenge...what somebody needs to do, if you want to set someone up for radiation, is that number one, you talk to the patient and you talk to the caregiver and you explain the...situation."	Provider 6, surgery APP	"Even if you do tell them, sometimes they don't remember it. I mean they're hearing so much on that first visit. And they just don't remember. They can't process it. They're worried about the surgery first and you tell them that other stuff and it's like...they get overwhelmed."
			Provider 2, radiation oncology nurse	"I think if there's a way to maybe prepare the patients on that first visit...But they've already checked out. They just mentally don't collect the stuff you're telling them, because they've been through not having food that morning for a PET scan and then rushing to go meet speech and nutrition and then trying to see a medical oncologist and have lab work done. It's a lot. Mentally, they are just drained."

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TABLE 1. Intrapersonal-Level Barriers to Timely, Guideline-Adherent PORT (continued)

Subtheme	Patient	Patient Quotes	Provider	Provider Quotes
			Provider 8, surgeon	"So, uncertainty about the importance or need for receiving postoperative radiation is a major barrier...they're just recovering from surgery. The pathology comes back. They are excited about going home and moving on with their life, and then they hear they might need radiation. They're wondering why would I need it, you told me you got all the cancer."
			Provider 14, surgeon	"When they don't decide on a place for radiation until after surgery, it can definitely lead to delays. It's just hard when they are so overwhelmed."
			Provider 12, medical oncologist	"They get set up to see us here [MUSC] and they actually want to get treatment locally [non-MUSC]. So they have the referral here two weeks after surgery or whatever, and then they see us and at that point they are like, 'No, I don't want treatment here. I want it there.' So we call, set up the next appointment, and it's two weeks later, so now four weeks after surgery is the first time they see the person who will be doing their adjuvant treatment...Second opinions about radiation, if they're both happening postoperatively, it seems are almost untenable to make them both work from a timely scheduling perspective."
Theme 2: Postsurgical sequelae interrupt the tight treatment timeline.				
Postsurgical wounds result in objective and subjective concerns about the safety of starting PORT.	Patient 2	"I went to see the radiation oncologist, they said 'I can't touch you for at least a month...' So then I went to find a different radiation oncologist and he started [radiation] in like ten days."	Provider 4, radiation oncologist	"A lot of times [the radiation oncologists] say 'Oh! I have this flap. I have this. I have that. I can't start...' Those guys [radiation oncologists] are already not very comfortable with that huge flap or whatever and they say, 'Okay, we will bring you back in 2 weeks'."
	Patient 3	"They wanted to wait until the swelling goes down before they actually start the radiation...and the first mask wouldn't fit because of the swelling so she had to wait until the swelling goes down."	Provider 8, surgeon	"The radiation oncologist's subjective view that the patient's wounds have not healed well enough...the radiation oncologist is very concerned about causing side effects or complications or toxicities almost to the point of making that a higher priority than cancer treatment and cure."
	Patient 10	"He said we've got to get this straightened up before we can do any radiation. We can't do it with an infection. We've got to get the infection out before we could do the radiation."		
Patients recovering from surgery don't feel ready to start PORT.	Patient 21	"I sort of just needed a break...once you get through a big surgery, and you're like...maybe we can take a pause button for a minute to let your mouth recover...like, okay we're gonna wait on this for a month or two."	Provider 3, head and neck surgery nurse practitioner	"They don't like the number of six weeks because they're just feeling good and they're just getting out of surgery. So sometimes I tell them they can wait and do it longer. Okay, they're not going to argue with that because they feel like crap."

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TABLE 1. Intrapersonal-Level Barriers to Timely, Guideline-Adherent PORT (continued)

Subtheme	Patient	Patient Quotes	Provider	Provider Quotes
Prolonged index length of stay and unplanned hospital readmissions lead to missed appointments.			Provider 3, surgery APP	"You're up to two weeks in the hospital, then a week to get an appointment, then 10 days to do the simulation [to make the radiation mask] after that, and then some other time. There's no gap...no wiggle room."
			Provider 7, surgeon	"For the patients that are in the hospital forever, they're never gonna start that radiation, cause there's something that kept them in there so long...So something is going to prevent them from starting it."
			Provider 5, surgery APP	"If it's an outside radiation oncologist and an outside readmission...The radiation oncologist might not call to say, 'Hey, they're missing the appointment'."
			Provider 6, surgery APP	"[the patients] get readmitted and they're on the medicine service. And they miss their radiation appointment."

Abbreviations: APP, advanced practice provider; MUSC, Medical University of South Carolina; PET, positron emission tomography; PORT, postoperative radiation therapy.

scheduling appointments (Table 1). There was a concern that some radiation oncologists, particularly those with a more general radiation oncology practice, did not appreciate the consequences of delayed PORT for patients with HNSCC. As a result, patients were not convinced of the importance of starting PORT and would skip necessary appointments, which would lead to delays.

In addition, patients were not adequately educated regarding the numerous steps required to initiate PORT and the associated timeline for each step. Providers believed that patients and caregivers were too overwhelmed to retain information about timely PORT in the hectic preoperative setting or while recovering from surgery in the hospital; thus, they omitted educating the patient until well after surgery:

"Even if you do tell them, sometimes they don't remember it. I mean they're hearing so much on that first visit. And they just don't remember. They can't process it. They're worried about the surgery first and you tell them that other stuff and it's like...they get overwhelmed" (Provider 6; surgery advanced practice provider [APP]).

However, patients said that the lack education about the steps to start PORT was a key barrier:

"That was the biggest challenge...what somebody needs to do, if you want to set someone up for radiation, is that number one, you talk to the patient and you talk to the caregiver and you explain the...situation" (Patient 20).

Theme 2: Postsurgical sequelae after complex head and neck surgery interrupt the tight treatment timeline.

After major head and neck surgery, which often includes complex reconstructions, patients and providers were

forced to navigate a challenging array of postsurgical sequelae that could interrupt the tight treatment timeline and result in a delay starting PORT (Table 2). Objective surgical site complications (eg, fistulae, infections) can necessitate a delay in starting radiation to allow for more healing. However, there was subjectivity in determining whether a postsurgical wound was sufficiently healed to start PORT, contributing to delays:

"I went to see the radiation oncologist, they said I can't touch you for at least a month...So then I went to find a different radiation oncologist and he started [radiation] in like ten days" (Patient 2).

Complex reconstructions, even when healing well, were a source of uncertainty and thus delay:

"A lot of time [the radiation oncologists] say 'Oh! I have this flap. I have this. I have that. I can't start'...Those guys [radiation oncologists] are already not very comfortable with that huge flap or whatever and they say, 'Okay, we will bring you back in 2 weeks'." (Provider 4; radiation oncologist).

Importantly, even when surgical wounds were healing well, radiation could be delayed because patients recovering from their extensive surgery did not feel ready to continue the marathon by starting radiation:

"I sort of just needed a break...once you get through a big surgery, and you're like...maybe we can take a pause button for a minute to let your mouth recover...like, okay we're gonna wait on this for a month or two" (Patient 21).

Finally, postsurgical sequelae often resulted in prolonged hospitalizations and hospital readmissions, making for a very tight treatment timeline in which any deviation could result in a delay:

TABLE 2. Interpersonal-, Team-, and Organizational-Level Barriers to Timely, Guideline-Adherent PORT

Subtheme	Patient	Patient Quotes	Provider	Provider Quotes
Theme 3: Communication and coordination of care among patients, providers, and health care teams during care transitions are insufficient.				
There is no point person.	Patient 20	"There's a problem right here that there is no navigator to make sense of helping recover from surgery and starting radiation...If I've got that one nurse navigator and I know I can call and get, get that question to them, they get back to me with an answer. I'm not having to try to catch up with you."	Provider 3, surgery APP	"And as a provider, I don't know who's always driving the ship...I feel like sometimes certain people don't want to like claim the patient at that point...It's great having a team but sometimes having a team is confusing."
	Patient 21	"I mean yeah, there was no like point person...I was just like, hoping on hope that everybody was in sync."		
Surgeons and radiation oncologists fail to communicate relevant information to one another.	Patient 26	"There was a problem in communication between the doctors. Well, the radiation got started later than we wanted it to start. Somebody dropped the ball. Several times we called back and forth to here...over three weeks...It didn't get scheduled."	Provider 17, radiation oncologist	"There is nothing in the notes that very specifically addresses...the actual adjuvant treatment recommendation."
	Patient 10	"The other doctors are like, 'What's going on there?' and relying on us to give them all the information on what's going on instead of them going there and looking at that note and we tell them that this is the doctor that did this...and go call them. Go call them. Go talk to them."	Provider 4, radiation oncologist	"The problem is when there is no communication between the surgeon and the radiation oncologist about the wound and then the patient just shows up and the radiation oncologists say, 'what the hell is this?'"
			Provider 14, surgeon	"The problem is, it's the whole lack of understanding of what we did surgically, what might need to be radiated, when they can radiate. So that can lead to problems getting their adjuvant treatment. We send them to XX [radiation facility] and just expect them to take over and do everything and just read our notes to try and find out what we did. So on some level that communication is lacking."
Necessary dental care is challenging to coordinate.			Provider 2, radiation oncology nurse	"Either they [patients] forget to be seen or they prefer to be seen by a local dentist, which causes more issues because then they are not as familiar with cancer patients and what they need to have done with the radiation."
			Provider 9, surgery clinic nurse	"The dental people are like, 'I don't know what the plan is yet,' like 'exactly where are you radiating? I don't know which teeth I'm going to need to have extracted' and so then everything goes to surgery, gets set up, but no one ever comes back to close the loop once the answer is known that these would be the relevant teeth. That information doesn't make it back to the teeth pullers."
			Provider 13, radiation oncologist	"[The dentists] tell the patient 'You can't start treatment for 15 days or 14 days'...after extractions. And you know when I see the patients, maybe 3 to 4 weeks after surgery and then we set up the dentist, and then the dentist tells them 2 to 3 weeks, and then we're looking at being outside of our window."

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TABLE 2. Interpersonal-, Team-, and Organizational-Level Barriers to Timely, Guideline-Adherent PORT (continued)

Subtheme	Patient	Patient Quotes	Provider	Provider Quotes
			Provider 16, radiation oncologist	“We'll have delays due to dental stuff. They have to get teeth extracted...Sometimes, people don't have a dentist or dental extraction isn't covered [by their insurance].”
		Pathology reports are delayed and difficult to interpret for the oncology providers.	Provider 4, radiation oncologist	“If they wait two weeks for the pathology report and then try to make the referral at that point, then the patient may not be seen by a radiation provider for another two weeks. Now it is 4 weeks after surgery and then it is a very tight timeframe to start on time.”
			Provider 18, radiation oncologist	“The pathology reports...are incredibly unwieldy from my point of view. It's impossible to discern what they [the key findings that we base the decision for adjuvant therapy on] are...how many nodes, exactly the final margins.”
		Gaps in care develop between the inpatient and outpatient surgical teams.	Provider 6, surgery APP	“The biggest problem transitioning between inpatient and outpatient is people waiting on the pathology. The pathology doesn't come back before they go home and then [the inpatient team is] like, ‘Oh, it's not my problem now.’ And then it's like 2 weeks before they come back for their postoperative visit, and then you're almost 4 weeks out of surgery. And that's too late.”
			Provider 9, surgery clinic nurse	“So either the plan is not carried from the inpatient to the outpatient side. Or maybe it's just not even thought of on the inpatient side. Like, ‘hey we need to have like, a plan for getting the tube out of the nose since they're going for radiation’.”
Theme 4: Fragmentation of care across health care organizations impedes timely delivery of care.				
	Patient 10	“When you're getting your treatments done in a different place than where the surgery was done and all that, it all would've been a whole lot better in my opinion if the doctors here and the doctors there communicate more with each other...Unfortunately, the doctor that was taking care of him at XX did not call or talk with the doctors here. He knew nothing that was going on.”	Provider 9, surgery clinic nurse	When they leave here and they go to some outside place, it's kind of like out of my hands at that point what I can do.”
			Provider 3, surgery APP	“It's kind of like a pain in the butt to print out a 100 papers and fax them all to someplace and physically get a [CT] scan to mail to them. Like it is a process to refer them...”
			Provider 17, radiation oncologist	“It's crazy that we need a disc [with the CT scan] to be mailed...We're trying to get away from the actual physical discs...That will be very helpful.”
			Provider 1, surgery nurse navigator	“You don't really hear anything until like they [the patients] come back [to clinic] and you find out...‘What? What do you mean you never got radiation?’”

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TABLE 2. Interpersonal-, Team-, and Organizational-Level Barriers to Timely, Guideline-Adherent PORT (continued)

Subtheme	Patient	Patient Quotes	Provider	Provider Quotes
			Provider 3, surgery APP	“Let’s say they’re dehydrated and like they’re passing out; they’re going to send them to the local ER who is going to admit them...and I don’t even hear about it until after the patient has been discharged, and the wife is like ‘XX just got out of the hospital’ and I am thinking ‘XX was in the hospital?’”
			Provider 5, surgery APP	“If it’s an outside radiation oncologist and an outside readmission, there’s no way to guarantee that we would even know that it happened. The radiation oncologist might not call to say, ‘Hey, they’re missing the appointment.’”

Abbreviations: APP, advanced practice provider; CT, computed tomography; ER, emergency room; PORT, postoperative radiation therapy.

“You’re up to two weeks in the hospital, then a week to get an appointment, then 10 days to do the simulation [to make the radiation mask] after that and then some other time. There’s no gap...no wiggle room” (Provider 3; surgery APP).

Theme 3: Communication and care coordination among patients, providers, and health care teams during care transitions are insufficient.

As patients transition across the numerous health care teams (eg, surgical, radiation, medical oncology, dental) and from inpatient to outpatient care, communication and care coordination were insufficient (Table 2). Because there were so many teams and care transitions involved, it was unclear to patients and providers who was in charge at any point in time. In addition, care coordination across teams was often out of sync, leading to delays:

“There was a problem in communication between the doctors. Well, the radiation got started later than we wanted it to start. Somebody dropped the ball. Several times we called back and forth to here...over three weeks...It didn’t get scheduled” (Patient 26).

Necessary preradiotherapy dental extractions were particularly challenging to coordinate:

“Either they [patients] forget to be seen or they prefer to be seen by a local dentist, which causes more issues because then they are not as familiar with cancer patients and what they need to have done with the radiation” (Provider 2; radiation oncology nurse).

Communication between the radiation and surgical teams was primarily restricted to indirect communication via the medical record, which lacked sufficient clinical detail:

“We send them to XX [radiation facility] and just expect them to take over and do everything and just read our notes to try and find out what we did. So on some level that communication is lacking.” (Provider 14; surgeon).

In addition to the challenges of coordinating care during transitions between teams, providers struggled to coordinate across transitions between care settings (eg, inpatient to outpatient after hospital discharge):

“The biggest problem transitioning between inpatient and outpatient is people waiting on the pathology. The pathology report doesn’t come back before they go home and then [the inpatient team is] like, ‘Oh, it’s not my problem now.’ And then it’s like 2 weeks before they come back for their postop and then you’re almost 4 weeks out of surgery. And that’s too late.” (Provider 6; surgery APP).

Theme 4: Fragmentation of care across health care organizations impedes timely delivery of care.

Fragmentation of care across health care organizations, required for patients who have surgery and PORT at different facilities, impeded delivery of care necessary for timely PORT (Table 3). Providers felt limited in their ability to cross-organizational boundaries to help get radiation started:

“When they leave here and they go to some outside place it’s kind of like out of my hands at that point what I can do.” (Provider 9; surgery clinic nurse).

Because different health care organizations had incompatible electronic medical records that precluded electronic sharing of information, the clinical information needed to start PORT was transmitted by fax and physical mail. This cumbersome and time-consuming process delayed receipt of information necessary to meet the tight treatment timeline:

“It’s kind of like a pain in the butt to print out a 100 papers and fax them all to someplace and physically get a [computed tomography (CT)] scan to mail to them. Like it is a process to refer them...” (Provider 3; surgery APP).

The circumscribed authority for crossing organizational boundaries, combined with the challenges of sharing clinical information, impeded referral tracking and follow-up across health care organizations:

TABLE 3. Community-Level Barriers to Timely, Guideline-Adherent PORT

Subtheme	Patient	Patient Quotes	Provider	Provider Quotes
Theme 5: Traveling for HNSCC care is a significant burden, particularly for socioeconomically disadvantaged patients.				
	Patient 20	“So the transportation for us...it did hinder a lot and then we tried to call to get free transportation. Once you got the free transportation set up, the date before the appointment they call and said, ‘We can’t do it.’ So that really, really put us in a pickle.”	Provider 10, surgery clinic nurse	“If they didn’t arrive for their appointment, we find out why... And a lot of times it’s because no one could take them. It was too far for them to go. Their car is broken down or they didn’t have the gas money.”
			Provider 9, surgery clinic nurse	“I think after y’all leave the room and we’re coming in to discuss. So, I’m going to set up 800 million appointments for you and they [the patients] are like... ‘I don’t have any family members, and I live 200 miles away.’ How can we help?”
			Provider 1, surgery nurse navigator	“The family members work, they’re coming from far away...[the patients] have to come back and they say, ‘I’ve already missed such and such amount of days of work, I’m going to get fired’...or patients that don’t have anyone, no family members.”
			Provider 4, radiation oncologist	“When they can’t come, they can’t come...if they don’t have help, they won’t be able to come in. And so the delays [starting PORT] predominantly happen to those people who are the most socially and economically vulnerable, the medically disadvantaged.”
			Provider 12, medical oncologist	“The common denominator for many of the barriers is actually the travel distance. To me, the people who live farther away have more transportation issues, either have a caregiver that has to bring them or they don’t have money for gas.”

Abbreviations: HNSCC, head and neck squamous cell cancer; PORT, postoperative radiation therapy.

“You don’t really hear anything until like they [the patients] come back [to clinic] and you find out... ‘What? What do you mean you never got radiation?’” (Provider 1; surgery nurse navigator)

Theme 5: Traveling for HNSCC care is a significant burden, particularly for socioeconomically disadvantaged patients.

Because complex HNSCC surgical procedures are frequently regionalized to high volume facilities, patients often have to travel significant distances for care. The multidisciplinary nature of HNSCC care and logistics of surgical care result in multiple clinical encounters (before, during, and after surgery). Patients who lack reliable transportation, financial resources, or a caregiver to assist with travel were disproportionately burdened, missed necessary clinical encounters, and experienced delays (Table 3):

“If they didn’t arrive for their appointment, we find out why...And a lot of times it’s because no one could take them. It was too far for them to go. Their car’s broken down or they didn’t have the gas money.” (Provider 10; surgery clinic nurse).

Conceptual Model

Our conceptual model (Fig 1) provides a framework for understanding the multilevel barriers to timely sequential multimodal delivery of cancer care (eg, surgery followed by PORT). By organizing themes at levels of health care

delivery, the model reflects individual behaviors for both patients and providers and reciprocal interactions between patients and providers and among providers. It also shows that clinicians are embedded within and across numerous health care teams (eg, surgical oncology, radiation oncology), that teams are situated within and across health care systems, and that health care systems are located within communities.³⁰

DISCUSSION

In this study, we identified 5 themes that explain the mechanisms underlying delayed, guideline-nonadherent PORT after surgery for HNSCC: (1) inadequate education about timely PORT, (2) postsurgical sequelae that interrupt the tight treatment timeline, (3) insufficient communication and coordination of care during care transitions, (4) fragmentation of care across health care organizations, which impedes care delivery, and (5) travel for HNSCC care as a burden for socioeconomically disadvantaged patients. Using these themes, we developed a theory-based, multilevel conceptual model to enhance our understanding of the delivery of sequential multimodal cancer care to patients with HNSCC and to guide the development of multilevel intervention.

These foundational qualitative data will enable future studies to gather prospective quantitative data about barriers to timely PORT that will characterize the frequency,

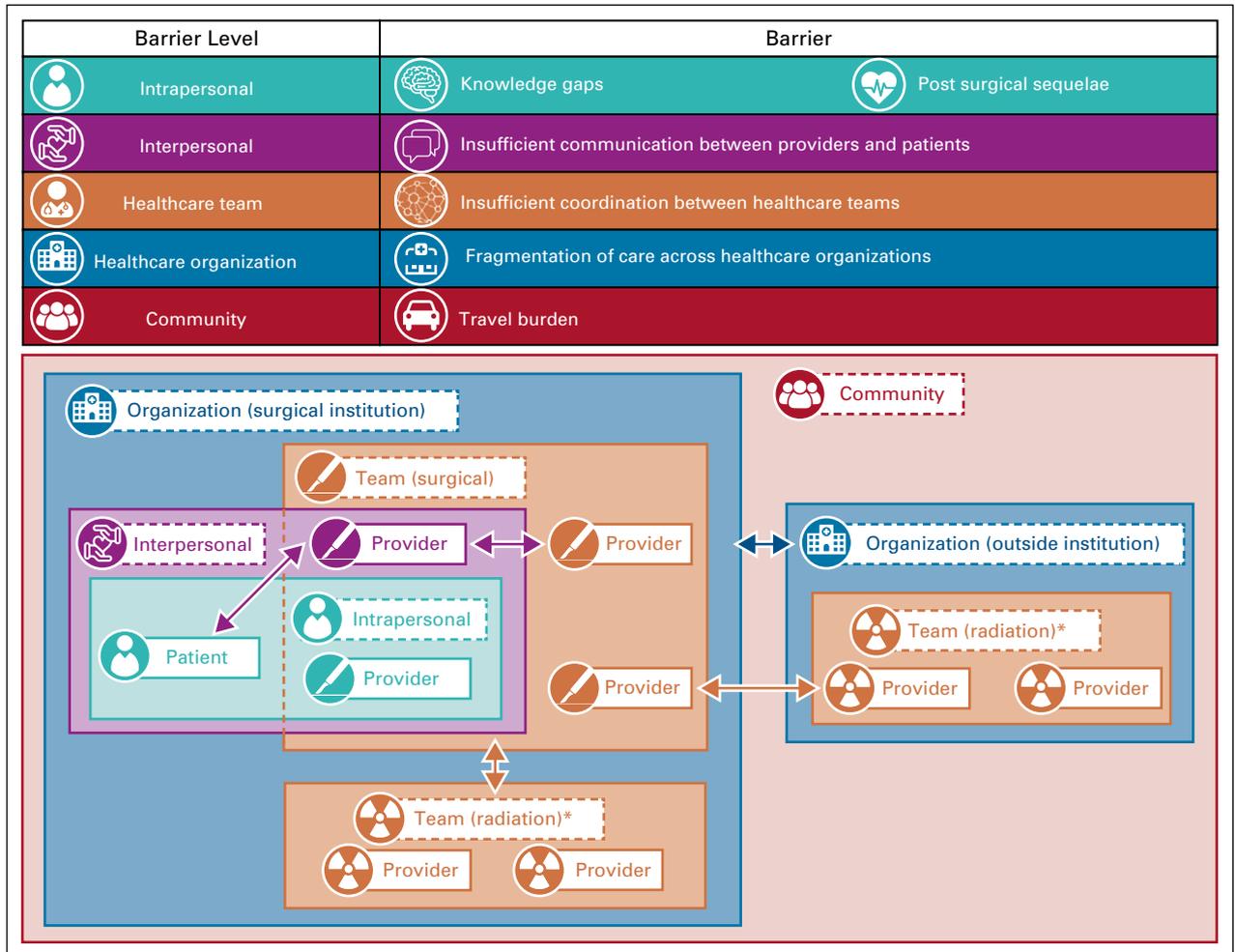


FIG 1. Conceptual model inset: Barriers to timely, guideline-adherent postoperative radiation therapy (PORT) after surgery for head and neck cancer occur at multiple levels (intrapersonal, interpersonal, team, organizational, and community). Because cancer delivery occurs in a multilevel system in which behavior is affected by multiple levels of reciprocal interactions, key themes of barriers to the delivery of timely PORT reflect (1) individual behaviors of patients and providers (blue box), (2) reciprocal interactions between patients and providers and patients and caregivers (green box), (3) clinicians embedded within and across numerous health care teams (red boxes), (4) teams situated within and across multiple health care systems (purple boxes), and (5) health care systems located within communities across a geographic space (orange box). (*) Although the conceptual model depicts only 2 teams (surgical and radiation oncology), additional teams within and across organizations that routinely participate in the delivery of (and thus barriers to) timely PORT include medical oncology, dental, oral surgery, maxillofacial prosthodontics, speech language pathology, general surgery/gastroenterology/interventional radiology, and primary care.

number, timing, and dynamic evolution of barriers as patients progress through treatment. Our findings are hypothesis generating for quantitative studies to evaluate the strength of the association between these barriers and PORT delay (ie, to quantitatively compare how the number and/or type of barriers differ between patients who do and do not experience a delay). Importantly, our findings extend previous research on barriers to cancer screening, treatment initiation, and postsurgical care transitions by providing a theory-driven conceptual model to explain the determinants of timely multimodal sequential cancer care for patients with HNSCC who are undergoing surgery and PORT.

Our findings have significant translational importance as a way of informing the design of multilevel interventions to

improve the delivery of timely, guideline-adherent PORT after surgery for HNSCC. Our data suggest that for an intervention to decrease PORT delays, it should target multiple levels (eg, intrapersonal and interpersonal) and address specific barriers related to inadequate education about timely PORT, postsurgical sequelae, insufficient communication and coordination of care during care transitions, fragmentation of care across health care organizations, and travel burden. Whether an intervention needs to target all barriers (or levels) or only a few critical barriers (or levels) is not known and should be explored in future research.

Finally, our rigorous qualitative approach also allowed us to overcome key methodologic limitations of previous studies about PORT delay. Previous research, which focused on

risk factors for PORT delay, identified that race, social determinants of health, travel distance, and care fragmentation were associated with delays.^{5,9} Themes identified in this study reflect previously identified risk factors for PORT delay. However, this study goes beyond risk factors and correlations to identify (and conceptualize) the mechanisms responsible for PORT delay,³⁶ thus enhancing our understanding of the determinants of timely, multimodal HNSCC care delivery and facilitating future translational research to decrease treatment delays.³⁷

An important study limitation is that all patients underwent HNSCC surgery at a single institution. However, our themes are likely generalizable to other institutions because the prevalence of delays and risk factors for delayed PORT at MUSC¹⁰ resemble national data,⁵ and because we used numerous strategies¹²⁻¹⁵ to increase generalizability and ensure comprehensive identification of barriers. Nevertheless, additional qualitative work in other settings will

help establish the generalizability of our findings. Because of our selected analytic approach, we could not compare the barriers faced by patients who experienced a delay when starting guideline-adherent PORT with those faced by patients who received PORT in a timely fashion. Therefore, future quantitative research is necessary to characterize how the number, type, and/or timing of barriers differs between patients with and without a delay.

In summary, we identified 5 themes that explain the mechanisms underlying delays in starting guideline-adherent PORT after HNSCC surgery. These barriers, which occur at the intrapersonal, interpersonal, health care team, organizational, and community levels, inform a theory-based, multilevel conceptual model for understanding the delivery of timely, guideline-adherent PORT to patients with HNSCC. Interventions targeting these barriers could improve the delivery of timely, guideline-adherent PORT and decrease mortality for patients with HNSCC.

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AUTHORS' DISCLOSURES OF POTENTIAL CONFLICTS OF INTEREST AND DATA AVAILABILITY STATEMENT

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AUTHORS' DISCLOSURES OF POTENTIAL CONFLICTS OF INTEREST

Barriers to the Delivery of Timely, Guideline-Adherent Adjuvant Therapy Among Patients With Head and Neck Cancer

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Open Payments is a public database containing information reported by companies about payments made to US-licensed physicians ([Open Payments](#)).

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APPENDIX

TABLE A1. Recruitment and Sampling Strategies to Increase Rigor and Reproducibility of Study Results and Ensure Comprehensive Barrier Identification

Strategy	Study Methods
Purposive sampling for patient enrollment ¹²	Enrollment was stratified by risk factors for PORT delay ⁵ to reflect the at-risk population and capture major variations in themes across relevant strata <ul style="list-style-type: none"> • Race • Insurance status • Travel distance • PORT facility
Criterion-based and maximum variation sampling for provider enrollment ¹³	Provider enrollment was stratified by: <ul style="list-style-type: none"> • Specialty (surgical, radiation, medical oncology) • Clinician type (physician, advanced practice provider, registered nurse) • Practice setting (MUSC, non-MUSC)
Data-directed accrual targets ^{13,14}	Enrollment continued until thematic saturation (ie, performance of additional interviews failed to reveal previously unidentified themes)
Diverse set of data sources ¹⁵	Heterogeneous practice and care delivery settings were used to ensure convergence of thematic data

Abbreviations: MUSC, Medical University of South Carolina; PORT, postoperative radiation therapy.

TABLE A2. Strategies Used for Team-Based Approach to Reflexivity³⁴

Strategy	Study Methods
Share individual reflexive tools at team meetings	<ul style="list-style-type: none"> • Reflexive diaries • Field notes • Memos detailing analytic and methodologic decisions

TABLE A3. Strategies for Establishing Trustworthiness During Each Phase of Data Analysis²²

Strategy	Study Methods
Phase 1: Data familiarity	<ul style="list-style-type: none"> • Document theoretical and reflective thoughts • Document potential code/theme • Organize and archive raw data • Archive records of field notes, transcripts, and reflexive journals
Phase 2: Initial code generation	<ul style="list-style-type: none"> • Perform reflexive journaling • Perform iterative re-evaluation of coding framework • Create audit trail of code generation and evolution • Document team meetings
Phase 3: Theme searching	<ul style="list-style-type: none"> • Create diagram to make sense of thematic connections and hierarchies • Create audit trail about code and theme development and hierarchy
Phase 4: Review of themes	<ul style="list-style-type: none"> • Perform researcher triangulation • Have team members vet themes • Analyze thematic coverage and referential adequacy
Phase 5: Theme naming and definition	<ul style="list-style-type: none"> • Achieve team consensus • Create audit trail about theme naming and definition
Phase 6: Report production	<ul style="list-style-type: none"> • Provide explicit, detailed description of coding and analysis • Provide explicit description of audit trail • Provide explicit explanation of epistemology, methodology, and methods throughout the study

NOTE. Trustworthiness was assessed by using the following established criteria: (1) credibility (concordance between the respondents' views and their representation in the research), (2) transferability (generalizability of the data), (3) dependability (performance of the research in a manner that is logical, traceable, and clearly documented), and (4) confirmability (that study findings are derived from the data).³⁵

TABLE A4. Participant Characteristics

Characteristic	No.	%
Patients	27	
Sex		
Female	8	30
Male	19	70
Race		
White	16	59
Black	11	41
Insurance		
Private or Medicare	20	74
Medicaid or self-pay	7	26
AJCC pathologic stage		
I-II	2	7
III-IV	25	93
Tumor site		
Oral cavity	16	59
Oropharynx	7	26
Hypopharynx/larynx	3	11
Sinonasal	1	4
Free flap reconstruction		
No	5	19
Yes	22	82
Concurrent chemotherapy		
No	12	44
Yes	15	56
Location of radiation facility		
MUSC	17	63
Non-MUSC	10	37
Providers	18	
Oncologic specialty		
Surgery	9	50
Radiation	8	44
Medical	1	6
Provider type		
Medical doctor	11	61
Advanced practice provider	4	22
Registered nurse	3	17
Practice location		
MUSC	12	67
Non-MUSC	6	33

Abbreviations: AJCC, American Joint Committee on Cancer; MUSC, Medical University of South Carolina.