

# Impact of Care Coordination on the Content of Communication Between Surgeons and Patients With Rectal Cancer

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**Background:** Management of patients with rectal cancer can be complex, requiring significant care coordination and decisions that balance functional and oncologic outcomes.

**Objective:** To characterize care coordination occurring during surgical consultation for rectal cancer and consequences of using face-to-face time in clinic for care coordination.

**Methods:** Secondary analysis was performed on audio recordings of clinic visits with colorectal surgeons to discuss surgery for rectal cancer at 5 academic medical centers. Analysis included the content of communication related to types of care coordination, specific details and conditions under which care coordination was conducted, and consequences.

**Results:** The cohort included 18 patients seen by 8 surgeons. Care coordination consumed much of the conversation; on average 23.7% (SD 14.6) of content. Communication about care coordination included gathering information from work-up already performed, logistics for completing further work-up, gathering multidisciplinary opinions, and logistics for treatment planning. Obtaining imaging results was particularly challenging and surgeons went to great lengths to gather this information. To mitigate information gaps, surgeons asked patients about critical clinical details. Patients expressed remorse when they could not provide needed information, relay technical details, or had missing reports. Surgeons voiced frustration at the system related to the need to gather information from multiple sources and coordinate logistics. Surgeons worked to inform patients about their disease and discuss important lifestyle and cancer-related tradeoffs. However, the ability to solicit patient input and engage in shared decision making was often limited by incomplete data or conditioned on approval by a multidisciplinary tumor board.

**Conclusion:** Much of the conversation between surgeons and patients with rectal cancer is consumed by care coordination. Organizing care coordination outside of the clinic visit would likely improve the experience for both patients and surgeons, addressing both clinician burnout and variation in management and outcomes.

**Keywords:** care coordination, colorectal surgery, qualitative, quality of care, rectal cancer

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## INTRODUCTION

There is significant variation in outcomes for the ~45,000 patients diagnosed with rectal cancer nationwide each year.<sup>1,2</sup> Evidence-based guidelines representing substantial advances in rectal cancer care are associated with decreased rates of recurrence and improved survival.<sup>3,4</sup> However, studies reveal that close to half of patients with rectal cancer do not receive guideline-recommended staging and treatment, leading to significant disparities in outcomes such as cancer recurrence and permanent ostomy.<sup>5-8</sup> Importantly, survival at 5 years approaches 75% for patients who receive guideline-recommended care but drops substantially for patients who do not receive this standard.<sup>1,7,9</sup>

Care for patients with rectal cancer is complex, requiring integration of multiple information sources and coordination of physicians from different specialties and often different sites of care. Given major quality of life concerns, treatment decision making must also balance significant functional and oncologic outcomes. Although guidelines for management of rectal cancer are well accepted and readily available,<sup>3,4</sup> there is little practical guidance on how to achieve guideline-recommended care in clinical practice or how to best coordinate the care required to achieve optimal outcomes for all patients. We theorize that failures of care coordination before surgery may contribute to variation in receipt of guideline-recommended care for patients with rectal cancer and may ultimately contribute to disparate outcomes. Under ideal circumstances, a surgeon would have all necessary diagnostic and staging information, input from

clinicians on the treatment team, and logistical details for reasonable access to treatment, before meeting the patient.

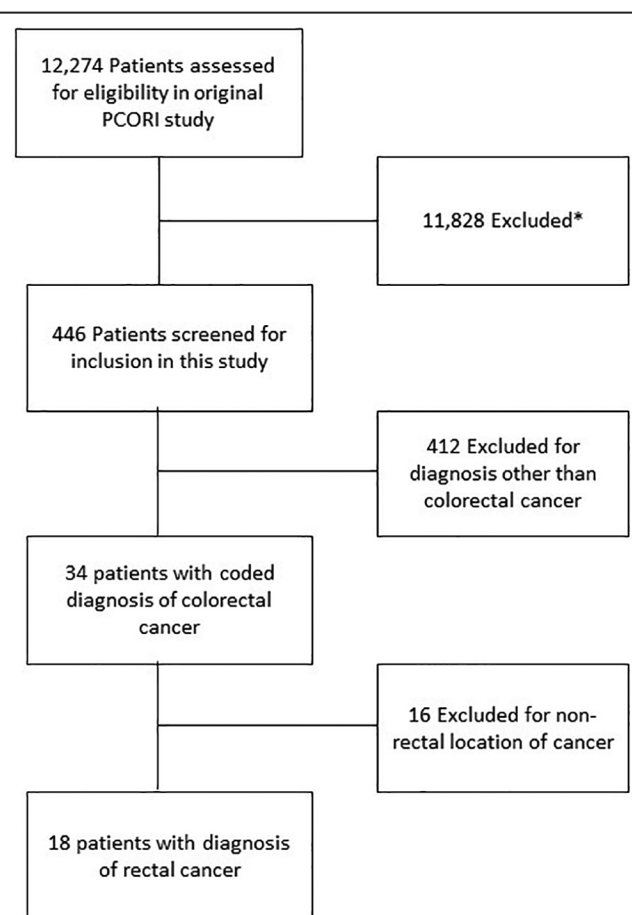
During an exploratory study about shared decision making, we reviewed transcripts of recorded conversations of the treatment decision-making visit between surgeons and patients with rectal cancer and expected to find discussion of risks and benefits of surgery and navigation of treatment decisions. However, we were struck by how often this important conversation appeared to be side-lined, with much of the visit instead consumed by care coordination and in the moment investigation of critical clinical details by the surgeon. Notably, the Agency for Healthcare Research and Quality classifies failures in care coordination when healthcare professionals perceive that “unreasonable levels of effort [are] required on their part in order to accomplish necessary levels of coordination.”<sup>10</sup> The objective of this study is thus to describe and classify specific elements of care coordination that occur during the surgical consultation and the consequences of using face-to-face time in clinic for care coordination. Specifically, we aimed to characterize how the content of communication about care coordination determined what could be achieved in relation to treatment decision making by the surgeon and patient during the visit.

## METHODS

We performed secondary analysis of audio recordings collected for a large multicenter Patient Centered Outcomes Research Institute (PCORI)-funded study. The original study received approval by the institutional review boards of the University of Wisconsin School of Medicine and Public Health, University of California San Francisco, Rutgers New Jersey Medical School, Brigham and Women’s Hospital, and Oregon Health and Science University. Briefly, the trial used a purposeful sampling strategy and included patients  $\geq 60$  years old with  $\geq 1$  comorbid condition who were meeting with a surgeon to discuss high-risk oncologic or vascular operations. Surgeons who expressed interest in participating in the study were stratified by institution and specialty then randomly selected to ensure at least three surgeons per specialty. Clinic lists were then screened by the study team and eligible patients invited to participate, with the goal of enrolling 2–3 patients per surgeon. The entire clinic visit was audio recorded and transcribed with removal of identifying information. Audio recordings were conducted between June 2016 and November 2018. Further details of the original study are published elsewhere.<sup>11</sup>

For this study, we identified patients who consented to inclusion in future research and had a diagnosis of “colorectal cancer” coded in the initial study ( $n = 34$ ). We read transcripts to further limit to patients with rectal cancer. This produced a study population of 18 patients seen by eight colorectal surgeons across 5 academic medical centers. Figure 1 describes patient selection.

For coding, we developed a team of 4 investigators from varied backgrounds: general surgeon with palliative care training, colorectal surgeon, vascular surgeon with expertise in patient-doctor communication, and PhD researcher with expertise in patient-doctor communication and empathy. We used common coding techniques for qualitative data, including using a series of iterative steps to develop our code structure.<sup>12–16</sup> We coded each transcript individually and met frequently as a group to create and refine a coding taxonomy using the process of constant comparison, recording codes with NVivo software (version 11, QSR international). Our initial study framework for coding was focused on patient-doctor communication, shared decision making, addressing symptom management, and palliative care needs. However, as we progressed through the transcripts, we observed that a considerable amount of time was spent in the domain of care coordination. We thus created new codes to account for this content including efforts to communicate



**FIGURE 1.** Flowchart of patient selection. \*Reasons for exclusion include not meeting the inclusion criteria for original PCORI study (age,  $n = 7,116$ ; surgical indication,  $n = 2,549$ ; insufficient comorbidities,  $n = 892$ ; other,  $n = 398$ ), declined to participate ( $n = 235$ ), and unavailable ( $n = 638$ ).

information about patients between providers, involvement of multiple providers, patient responsibilities for obtaining information or identifying treatment sites, and outstanding “things we need to know” to precisely describe information that was lacking at the time of consultation.

As a surrogate for time, we compared the number of characters in transcripts consumed by care coordination versus other topics to describe and understand the impact of care coordination on the overall content of the clinic visit. For our qualitative data analysis,<sup>12–16</sup> we conducted a higher-level thematic analysis of coded transcripts using tables to fully capture and sort similar elements. We then used the tables to describe and classify the observed elements of care coordination. We continually looked for similarity and differences in the data and how each researcher coded the data within and across transcripts. Through group discussion, we developed a framework for summarizing our findings that included characterization of the specific elements of care coordination, the conditions under which care coordination occurs, and the consequences of using face-to-face time in clinic for care coordination in relation to the content of other communication and what could and could not be accomplished related to treatment decision making by the surgeon and patient during the consultation based on the overriding needs for care coordination. We received critical feedback on study design and analysis throughout our study from the *UW-Madison Institute for Clinical and Translational Research Qualitative Research Group*, which is led by a senior scientist with expertise in qualitative methods in health services research.

## RESULTS

Of the 18 patients and 8 surgeons in our study sample, there were 1-2 surgeons from each of the five academic medical centers, and a range of 1-4 patients per surgeon. Surgeons ranged in age from 36 to 58 years old (mean 45.3 years) and were split evenly between men and women (Table 1 and 2). Patients ranged in age from 64 to 89 years old (mean 72.6 years) and were also split evenly between men and women. The majority of patients self-classified as non-Hispanic white ethnicity and race. Patients reported a range of educational backgrounds and health literacy, with the majority having a college degree or higher (61%) and rarely or never needing help when reading written medical materials (83%).

Throughout the clinic visit, much of the conversation between the surgeon and the patient was consumed by care coordination. The percentage of the visit related to care coordination ranged from 1.2% to 56.5%, with an average of 23.7% (SD 14.6, median 21.4, interquartile range 15.4-33.1). Communication about care coordination included gathering clinical and staging information from work-up already performed, logistics for completing further work-up, gathering multidisciplinary opinions for treatment options and planning, and navigating the logistics for completing the treatment plan—including issues related to geographic location, access to care, and transportation needs (Figure 2). In real time, while meeting face-to-face with the patient for the first time, surgeons needed to decipher which elements of the work-up were completed, which data were available but not presently locatable, and how to obtain needed but outstanding testing and plan treatment for both local and remote care. To mitigate information gaps, surgeons asked patients about critical technical details, such as the specific location of the tumor in relation to the anal sphincter or the

**TABLE 1.**  
Characteristics of Patient Population Included in Study

Variable	Number (%) (n = 18)
Age, mean (SD), y	72.6 (6.1)
Female sex	9 (50)
Self-reported race	
White	14 (77.8)
Black or African American	2 (11.1)
Other	1 (5.6)
Unknown	1 (5.6)
Asian; American Indian or Alaska native; Native Hawaiian or Other Pacific Islander	0
Self-reported ethnicity	
Hispanic, Latino, or Spanish origin	0
Unknown	1 (5.6)
Educational attainment	
Some high school or less	2 (11.1)
High school diploma or GED	1 (5.6)
Vocational degree or some college	3 (16.7)
College degree	6 (33.3)
Graduate degree or higher	5 (27.8)
Unanswered	1 (5.6)
How often need help reading material from physician or pharmacy?	
Never	8 (44.4)
Rarely	7 (38.9)
Often	1 (5.6)
Always	1 (5.6)
Unanswered	1 (5.6)
Insurance	
Medicare only	8
Medicare + Medicaid	2
Medicare+ supplemental insurance	3
Private insurance	5
Charlson Comorbidity Index, mean (SD)	5.7 (3.5)

GED indicates general equivalency diploma.

extent of invasion. Patients expressed remorse when they could not provide needed information or relay technical details or had missing reports. Surgeons voiced frustration at the system in their discussions with patients, related to the need to gather clinical details from multiple sources and coordinate logistics for neoadjuvant treatment. Surgeons attempted to inform patients about their disease and discuss important lifestyle and cancer-related tradeoffs with treatment options, such as need for an ostomy or consequences of a low anastomosis. However, the ability to solicit patient input and engage in shared decision making was at times limited by incomplete clinical data or conditioned on approval by a multidisciplinary tumor board.

### Gathering Information

At the beginning of the clinic visit, conversations initially focused on collecting information needed to define the patient's diagnosis and extent of disease. Clinical details gathered include tumor characteristics (location, pathology, appearance), results of imaging performed for staging (CT, MRI, and US), prior work-up completed by other clinicians, and details of relevant past medical and surgical history.

Frequently, information regarding staging as well as clinical details regarding comorbid conditions and prior surgical procedures or treatments was not available or did not appear readily accessible to the surgeon. This had multiple etiologies: the staging studies were not yet ordered or completed, the study report or documentation for colonoscopy, pathology, or radiology had not been obtained or had not been seen by the surgeon before meeting the patient, or the report was present but missing critical details. When needed clinical information was not readily available, surgeons asked patients for copies of reports or to confirm what their report said or what another doctor told them. At times, conversation centered simply on who the doctors were and determining how they could be contacted.

Patients were asked to validate or confirm critical details regarding their diagnosis, such as the exact location of their tumor or the extent of invasion. Patients tried to provide results but did not always have the information or did not understand technical details well enough to communicate them. This led to confusion regarding essential details for treatment decision making.

**Surgeon:** And they told you... Do you remember the results of the ultrasound?

**Patient:** Um...

**Surgeon:** What I have is T2N0. Does that sound...?

**Patient:** T2 or T3.

**Surgeon:** Yeah, the MRI was T3, but...

**Family Member:** I thought one was 3 and one was 4.

**Surgeon:** Oh, maybe I'll look back at the ultrasound. I know that they read the MRI as T3. The ultrasound was secondhand information, so let me go back and see if I can find the firsthand...

**Family Member:** Yeah, the MRI was T3.

**Surgeon:** Uh huh. So, the ultrasound was T4. Does that sound right?

**Patient:** Yes.

**Family Member:** Yes, um was T4.

[Pause]

**Surgeon:** Okay. Right, okay.

[Long pause]

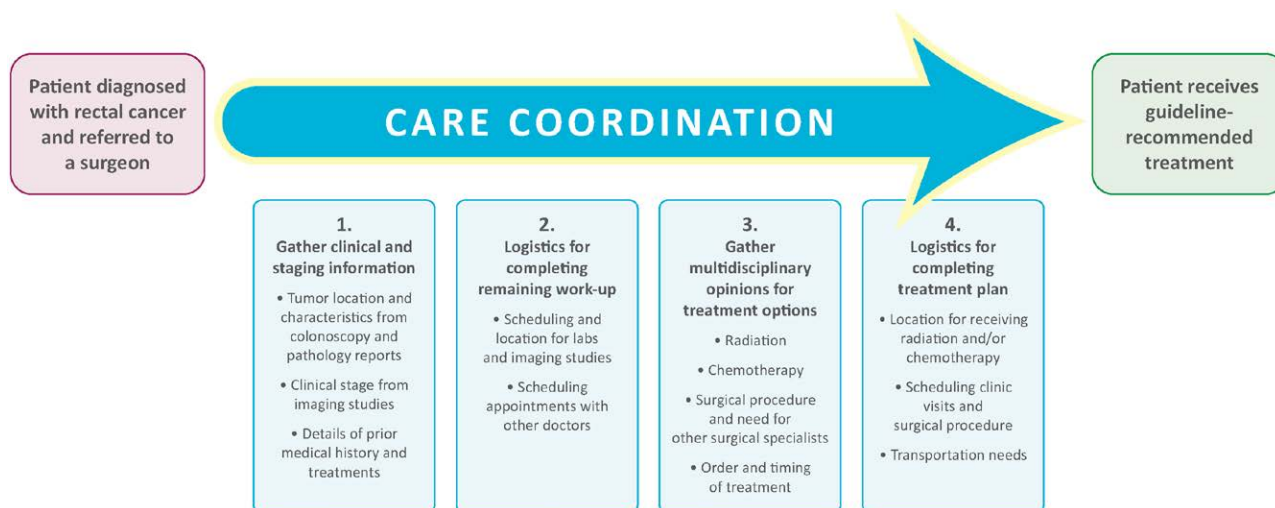
**Surgeon:** And did she say T4 because I can see the report where she says T4, but... Did she think it was invading the prostate?

**Family Member:** Um, she said that it was very, very close to the prostate. Um [clears throat]... Do you have pictures up there?

Surgeons expressed frustration directly to the patient about incomplete information and the difficulties of gathering clinical data from multiple sources.

**Surgeon:** Do you know the name of the doctor that did your scope?

**Patient:** Uh [DOCTOR-1]. He re-did it.



**FIGURE 2.** Components of care coordination for patients diagnosed with rectal cancer.

**Clinical Staff:** [DOCTOR-1]?

**Surgeon:** Yeah, I don't know.

**Patient:** Mhm.

**Surgeon:** I'll look it up again.

**Clinical Staff:** Maybe we can call him?

**Surgeon:** We can try, I mean [PERSON'S-NAME] did-

**Clinical Staff:** Oh, she called [DOCTOR-1]'s office?

**Surgeon:** Yeah, she called yesterday.

**Patient:** What do you need?

**Surgeon:** We just wanted to know what they saw!

**Patient:** Oh!

**Surgeon:** Yeah, we don't have any reports, so we don't know what they found in there!

**Patient:** I thought you would have all that stuff because, I had uh-

**Surgeon:** Well, you know it's really a different hospital, so.

**Patient:** Yeah, that's true. They, they gave me paperwork when I left. You know, and had pictures of the rectum and stuff on it.

**Surgeon:** Oh, it did? Huh, uh, it's too bad you didn't bring that.

Patients expressed surprise that clinical details and reports were not readily available. At times, patients apologized for not having complete details of work-up readily available or for missing or incomplete reports.

**Patient:** I apologize for, uh, the records deal. I've been working on those records almost nonstop every day.

**Nurse:** I know. Amazing, it's not your fault—

**Surgeon:** Don't even know what to tell you but you're not alone, meaning this is a constant problem, especially when someone's from far away.

At times, surgeons went to great lengths to obtain missing information themselves, including making or receiving phone calls during the clinic visit to obtain results. Some described the lengths they went to to demonstrate how difficult or time consuming it was to obtain results before the visit.

“So, I wanted to make sure I talked to your doctors before we made any decisions or even thought about doing anything. Um, I think you probably know this place is a little bit of a mess sometimes getting in touch with people is not the easiest, so I called [DOCTOR-2] three times and they gave me three non-working numbers. So, I said, “you know what, I need a little exercise.” I decided to walk up and go find out. So, I went up there and I talked to him in person, went over all your films, looked at, talked about some of the details of it and that's why it took a little bit longer, okay?”

Obtaining the results of needed imaging studies was particularly challenging, with the report or the images themselves not commonly available for review. Even when performed in the same institution, this did not guarantee the report would be

available during the clinic visit. Often, imaging studies were ordered by someone other than the surgeon, such as the gastroenterologist who diagnosed the cancer, the patient's primary care doctor, or an outside oncologist or surgeon referring the patient for colorectal surgical consultation. Imaging was also often performed at another institution either because of insurance requirements or simply because the surgeon was part of a different hospital system than where the patient was initially diagnosed.

Occasionally, imaging was performed before the clinic visit but was performed incorrectly or was of insufficient quality, particularly in the case of pelvic MRI. This led to a need to repeat studies and defer decision making.

“So, it's a hard area to get information from. Um, so I... the first thing I would suggest, and I'll give you kind of a rundown either way, but the first thing I would suggest is that we um repeat one or both of those tests. The ultrasound and the MRI. Particularly the MRI, you know, we have a way better protocol here specifically for rectal cancer than the scan that you had.”

### Treatment Planning

Patients often left the clinic visit without a clearly formulated treatment plan. At times this was because items from the staging work-up needed to be gathered or completed before decision making could occur. Surgeons also discussed the need to confer with other clinicians before recommending a final plan for treatment, including the decisions to proceed with radiation, chemotherapy, or surgery (including type of surgical procedure) and the order and timing of treatments. Multidisciplinary tumor board was frequently mentioned as the mechanism for gathering these opinions, with specific reference to radiologists, medical and radiation oncologists, and other surgeons. The tumor board meeting was generally scheduled to occur after the patient's clinic visit.

In situations where further work-up or multidisciplinary discussion was needed before decision making, surgeons often explained multiple complex hypothetical scenarios to the patient as treatment plans. Patients were reassured that someone would contact them when the treatment plan was finalized with statements such as “we'll lead you through this,” “we'll give you all the information, don't worry,” and “we're gonna move as quickly as we can, okay?”

Patients for whom there were multiple viable options for treatment without a clear best choice presented an additional hurdle for determining a treatment plan:

“Any one of these three or four choices might be reasonable for us. The short—The just making a colostomy, and not trying to take the rectum out, maybe even trying to avoid an operation as our first thing with radiation therapy. All of those may be reasonable choices for the situation that we’re in. Trying to balance doing enough to try to help solve the things that are bothering you in terms of how you feel and what your goals are... Um, without just automatically saying, ‘We should do this, this, and this. We’re gonna do the biggest thing.’ Right? Because the biggest thing is not always the best thing.”

In these situations, surgeons sometimes deferred decision making until another in-person clinic visit. “And that also gives us a chance to catch up again in a couple weeks whenever we can do that and go over how we feel about the decision-making.”

Coordinating treatment delivery for patients was sometimes challenging as treating physicians (surgeon, medical oncologist, radiation oncologist, etc.) often practiced in different clinic locations, even when they worked within the same healthcare system. For patients traveling long distances to be seen by the surgeon, additional coordination was required to form a treatment plan and communicate it back to local medical and radiation oncologists who would be delivering portions of the patient’s care. The identity, availability, and accessibility of local oncologic expertise was sometimes not known, making it difficult to develop a feasible plan for neoadjuvant treatment.

## DISCUSSION

When surgeons are talking to patients with a diagnosis of rectal cancer, much of the conversation is consumed by care coordination. Surgeons focus on gathering clinical information regarding the diagnosis and staging work-up performed before the visit. When this information is not readily available, surgeons go to great lengths to piece together the story by tracking down reports or specialists themselves or asking the patient to provide technical details. The process of information gathering is often incomplete and frustrating for both surgeons and patients. When the clinical history is incomplete or multidisciplinary tumor board discussion is needed, surgeons describe multiple possible options for a treatment plan or delay discussion to a later date when more information is available. The consequences of this are disruption of the patient-surgeon relationship and fewer opportunities for integration of patient preferences and priorities into shared decision making. Additionally, the disjointed nature of care coordination and the burden placed on the surgeon likely contribute to clinician burnout and may be a contributing factor to the well-documented variation in management and outcomes for patients with rectal cancer, though further research is needed to definitively demonstrate this relationship.

A commonly identified barrier to shared decision making and improved informed consent is a perceived lack of time to achieve these goals. Time pressure is a reality in medicine, with surgeons facing growing documentation burdens and administrative responsibilities, as well as pressure to see increasing numbers of patients per clinic session.<sup>17</sup> The clinic visit when diagnosis, prognosis, and surgical planning occurs is a chance for patients and their families to contribute to their care and actively engage with the surgeon to determine their needs and develop an appropriate and comprehensive treatment plan. Our findings suggest that a substantial portion of the clinic visit is often instead consumed by care coordination and tasks that could be performed outside the clinic visit. Using limited existing face-to-face time between a surgeon and their patient for care coordination rather than discussion of topics such as symptom management, goals of care, and preparing for surgery is a missed opportunity that could be addressed at the healthcare system level.

For surgeons, the unaccounted work and extra effort expended in trying to coordinate complex care for patients with rectal cancer likely contributes to burnout, or perhaps more specifically to moral injury, which is described as, “the

**TABLE 2.**

**Characteristics of Colorectal Surgeons Included in Study**

Variable	Number (%) (n = 8)
Age, mean (SD), y	45.3 (6.9)
Female sex	4 (50)
Self-reported race	
White	5 (62.5)
Asian	3 (37.5)
Black or African American; American Indian or Alaska native; Native Hawaiian or Other Pacific Islander	0
Self-reported ethnicity	
Hispanic, Latino, or Spanish origin	0
Hospital Affiliation	
Rutgers New Jersey Medical School	1 (12.5)
University of California, San Francisco	2 (25.0)
Brigham and Women’s Hospital	2 (25.0)
Oregon Health and Science University	2 (25.0)
University of Wisconsin School of Medicine and Public Health	1 (12.5)
Years in practice, mean (SD)	18.6 (6.9)

challenge of simultaneously knowing what care patients need but being unable to provide it due to constraints that are beyond our control.”<sup>18</sup> It is not just the additional burden of work that is objectionable, but the repeated experience of working within a system that is not designed to deliver guideline-recommended patient-centered care, despite a surgeon’s best intentions to do so. One can imagine the deep frustration experienced by a surgeon who is familiar with the literature for rectal cancer and understands the consequences of not adhering to management guidelines, and thus feels personally responsible for ensuring all the details of work-up and treatment are done correctly. As the complexity and multidisciplinary nature of cancer care increases, so does the burden of care coordination, which has been described as “invisible work” being performed by patients, caregivers, and clinicians.<sup>19</sup> Redesign of the healthcare system to make the work of care coordination explicitly visible, valued, and compensated may decrease the risk of burnout or moral injury among surgeons. For example, future studies could evaluate if defining the tasks of care coordination in clinical protocols that can then be delegated to nonsurgeon clinical professionals such as navigators and nurses effectively decreases the risk of burnout or moral injury among providers.

Studies consistently demonstrate variation in implementation of evidence-based guidelines and limited efficacy for changing physician behavior, despite information being readily available and accessible.<sup>5,6</sup> As such, professional societies and organizations creating guidelines should also focus on how they should be implemented without the burdens falling on clinicians in an unaccountable and uncompensated fashion. Of note, the National Accreditation Program for Rectal Cancer explicitly requires an “institutional administrative commitment” from hospital leadership with written documentation of financial and administrative support, as well as designation of a “Rectal Cancer Program Coordinator,” whose job description includes navigating patients through diagnostic and treatment pathways, as well as coordinating communication between health care providers and with patients.<sup>20</sup> Although these standards should be achievable for large hospital systems and academic medical centers, they are resource intensive and as such may not be a feasible for all hospitals as the cost for a care coordinator or navigator is not as simple to recoup as the cost of a diagnostic test or procedure that can be billed to the patient. Currently, the majority of patients with rectal cancer are treated in low and medium volume hospitals. If these hospitals do not have the capacity or resources to coordinate care for patients with rectal cancer, then this suggests a high potential for exacerbation

of existing disparities, especially as care becomes increasingly complex and administratively burdensome.

Our study has important limitations. The hospitals included in the study were all academic medical centers and findings may thus not be relevant to all practice settings. In addition, the study only included recording of one clinic visit and thus we cannot comment on the content of communication at subsequent visits or telephone conversations. Further, surgeons were not interviewed regarding their intentions for the content of communication with their patient. Our conclusions regarding the impact of care coordination on the content of communication are thus informed by observations of shared decision-making conversations getting interrupted or side-lined in the transcripts by the need for care coordination and our assumption that surgeons intend to use the patient visit to discuss the risks and benefits of surgery and to help patients navigate treatment decisions.

Although we did use a purposeful sampling strategy for the original study, the colorectal surgeons included are not representative of all colorectal surgeons. That said, the rigor of the findings, given the study design, should not be judged on generalizability or used to make statistical inferences. Given the consistency of findings between surgeons despite practicing in five independent academic medical centers in different geographic locations and the resonance of the analysis, the sample size is adequate to ensure rigor. Finally, the patients included were a relatively homogeneous group, with the majority self-classifying as non-Hispanic white ethnicity and race and having high health literacy and educational background. This may reflect a self-selection of patients who seek care at academic medical centers or who felt comfortable participating in a study with audio recording of their conversation with their surgeon. However, it is likely that the challenges experienced by our population of patients are even worse for patients with lower health literacy and educational background.

## CONCLUSION

A significant amount of the conversation between surgeons and patients with rectal cancer is consumed by care coordination. Interventions aimed at organizing care coordination outside of the clinic visit would likely improve the experience for both patients and surgeons and increase the opportunity to discuss important topics such as symptom management, goals of care, and preparing for surgery. Additionally, optimizing care coordination may result in improved clinical outcomes by addressing a root cause of observed variation in management of patients with rectal cancer.

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