

Gaps in patient-physician communication at the time of malignant bowel obstruction from recurrent gynecologic cancer: a qualitative study.

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Abstract

Purpose We sought to investigate the patient and physician approaches to malignant bowel obstruction (MBO) due to recurrent gynecologic cancer by 1) comparing patient and physician expectations and priorities during a new MBO diagnosis, and 2) highlighting factors that facilitate patient-doctor communication.

Methods Patients were interviewed about their experience during an admission for MBO, and physicians were interviewed about their general approach towards MBO. Interviews were analyzed for themes using QDAMiner qualitative analysis software. The analysis utilized the framework analysis and used both predetermined themes and those that emerged from the data.

Results We interviewed 14 patients admitted with MBO from recurrent gynecologic cancer and 15 gynecologic oncologists. We found differences between patients and physicians regarding plans for next chemotherapy treatments, foremost priorities, communication styles, and end-of-life discussions. Both patients and physicians felt that the patient-physician communication was improved in situations of trust, understanding patient preferences, corroboration of information, and increased time spent with patients during and before the MBO.

Conclusion Gaps in patient-physician communication could be targeted to improve the patient experience and physician counseling during a difficult diagnosis by focusing on education, symptoms, home support, nutrition, and end-of-life care.

Introduction

A malignant bowel obstruction (MBO) is a turning point in the care of women with a gynecologic cancer. From the patient perspective, MBO is associated with many distressing symptoms including nausea, vomiting, pain, and inability to eat that are difficult to control for many women who may have been previously only mildly symptomatic during initial treatment for recurrent disease. Physicians reevaluate whether to stop previously established treatment plans, including chemotherapy, until MBO resolution or indefinitely.

Literature on MBO prognosis and interventions shows a median survival after MBO ranging between one and six months [1] [2] [3] [4] [5]. However, qualitative studies have shown that it is not always clear to ovarian cancer patients that a MBO is a turning point of disease trajectory and prognosis [6]. There is a gap between the medical data available and the patient understanding of MBO. Studies in settings other than MBO have shown that although oncologists report discussing prognosis or palliative intent of interventions such as chemotherapy, at least one third of patients were unable to reflect that understanding [7]. Communication strategies have focused on how to bridge such gaps. For example, qualitative studies have shown that patients prefer serious news disclosures to occur in quiet places, one-on-one, with a physician who can give a comprehensive evaluation of the diagnosis, prognosis, and

treatment options [7]. In transitions from curative to palliative care, patients have highlighted the importance of clarity of information, grieving loss, and sustaining hope [7] [8].

In this qualitative study, our objective was to explore physician and patient approaches to communication and treatment management for the diagnosis of MBO. We interviewed patients during the MBO admission at two academic-affiliated hospitals and gynecologic oncologists who frequently cared for women with MBO at these and other hospitals. Our goals were to 1) compare patient and physician expectations and priorities during a new MBO diagnosis, and 2) highlight factors noted by patients and physicians to facilitate patient-doctor communication.

Methods

Patient interviews were conducted at two institutions (the University of Chicago and Northshore University Health System). The patient interviews were granted IRB approval and cancer center approval at both institutions at which the interviews were conducted, and the physician interviews were granted an IRB exemption through the University of Chicago. The patient census was followed and those admitted for a MBO between 5/2016 and 10/2018 were flagged by the primary researcher (CH). The primary researcher was a research fellow. During her clinical years, she was involved in the care of the last three patients interviewed, and worked with seven of the interviewed gynecologic oncologists.

Inclusion criteria included malignant bowel obstruction based on clinical findings and/or imaging, known recurrent or progressive gynecologic with previous treatment, age 18-89, English-speaking, and able and willing to participate in an interview. Patients considering hospice after discharge from the hospital were included. The charts were reviewed and after discussion with the primary team to ensure the patient was a suitable candidate, she was approached by the researcher regarding participation in the study to help describe her experience with MBO. If the patient agreed, consent was signed and the semi-structured interview was performed in person and recorded by a single interviewer (CH). The timing of all interviews was one to two days prior to anticipated discharge, after most of the decision-making and counseling had occurred. If patients were readmitted during the study period, they could be re-interviewed regarding their post-discharge experience. All interviews were recorded and transcribed, with all patient identifiers and treating institutions removed prior to analysis.

For physician interviews, a list of local gynecologic oncologists was collected from a department contact list. A standardized email was sent to 27 gynecologic oncologists and a positive response was considered consent to participate. Semi-structured interviews were then scheduled and conducted via phone or in person by a single interviewer (CH). After obtaining oral consent, interviews were digitally recorded and subsequently transcribed, either by the interviewer or professionally. After transcription, all identifiers were removed from transcripts.

The interview guides were created after a literature review and follow-up questions were revised iteratively in response to the focus of previous interviews (Suppl 1). The patient interview guide was designed to assess patient symptoms and needs during admission for MBO, decisions made during the admission as

well as since diagnosis, communication with her doctor, and plans after discharge. The physician guide was designed to explore the physicians' approach to care of patients admitted with MBO from recurrent or progressive gynecologic cancer. Questions addressed standard management practices, patient concerns, comfort with end of life discussions, and personal toll of managing MBO. The backbone of the interview guides did not change over the course of the interviews but follow up questions and clarifications were adjusted based on each individual interview to allow interviewees to highlight areas that they prioritized.

Data analysis:

Interviews were recorded and transcribed. QDAMiner qualitative analysis software (Provalis Research, Montreal, Canada) was used to organize, store and compare notes. The interviews were then systematically analyzed for themes using the framework analysis, which uses a constant comparative technique across interviews to refine themes as new data is analyzed throughout the process [9] [10] [11]. Framework analysis uses both deductive codes and themes, predetermined by prior research, and open coding, which is developed and refined from the data itself, and these themes are then organized and connections are created based on the data abstracted from interviews to develop an overarching theory [12] [9] [10] [11].

Predetermined objectives included (1) a comparison of the priorities of physicians and patients regarding symptom control, home support, and end of life concerns, (2) description of aspects of patient-doctor communication during the time of MBO that functioned well, and (3) eliciting communication strategies from physicians. The first 3-4 interviews were coded immediately to help inform subsequent interviews on areas requiring clarification, and analysis continued throughout the interviews to establish when theme saturation was reached. Data dictionaries were developed for the patient and physician interviews and iteratively revised by 2 co-investigators (CH and NL for physician interviews, CH and FH for patient interviews). Codes were reviewed for concordance and differences in coding were resolved by mutual agreement. While there was overlap in the data dictionaries, creating different dictionaries for patients and physicians provided more flexibility to highlight unique aspects of each interviewed group.

The total number of interviews required was determined by theme saturation. Once interviews stopped providing new themes or adding to the theories developed, no further interviews were conducted. Thematic saturation was reached after 11-13 interviews for both patients and physicians, and 2-3 further interviews were conducted for each group to ensure that no further themes emerged.

Results

Twenty patients were approached for interviews, and 14 agreed to proceed (Table 1a). The most common reason for refusal was not feeling well enough for the interview. Five of the six patients who declined to be interviewed identified as Black. More than half of patients who agreed to participate identified as white (53%) and most had ovarian/peritoneal cancer. Age ranged from 36 to 81 years of age. Eleven patients were married. Thirteen participants were interviewed at the time of a first admission for MBO (PT 2 had a

remote history of an MBO). PT 5 was readmitted and had surgery days after her first discharge; information from a second interview was combined with the first interview. Interview length ranged from 20 minutes to 90 minutes.

For the physician interviews, 27 physicians were contacted via a standardized email. Absence of response was followed up with an attempt at contact by phone. Six were never reachable, one responded and declined participation, five were willing but unable to schedule the interview, and 15 gynecologic oncologists were interviewed (Table 1b). All 15 gynecologic oncologists provided both surgery and chemotherapy for their patients.

Discrepancies in approaches and priorities

Several differences emerged in the patient experience and physician approaches to MBO (see Table 2 for select quotations). These can be categorized as differences in patient goals, expectation for end-of-life conversations, ability to communicate information, communication style, and decision-making.

In discussing their goals, patients repeatedly mentioned a next, future line of chemotherapy. Physicians, however, emphasized the fact that an MBO was an end-of-life diagnosis. Additionally, when physicians were asked what they believed were patients' primary concerns at the time of MBO, almost all reported nutrition as foremost. Participating patients did mention nutrition but tended to emphasize the benefits of being at home.

Patients had a wide range of responses to questions regarding end-of-life goals. In particular, young patients with small children (PT 6, PT 9) had the shortest interviews and focused on next treatments and survival. They were not ready to discuss end-of-life planning. On the other hand, some patients who were diagnosed 5-10 years before their interview (such as PT 2, PT 10 and PT 14) seemed to accept the diagnosis and had specific goals of care. Almost all participating physicians described the importance of end-of-life and goals-of-care conversations with patients admitted for MBO.

Participants also brought up several differences in communication. The amount of information was a frequent theme; many patients voiced frustration with the paucity of information they received, while physicians struggled with how to prognosticate and provide counseling in the setting of so much data and uncertainty. In terms of style, patients valued positive thinking, while many physicians were worried about keeping expectations realistic.

Lastly, the experience of decision-making was very different for patients and physicians. Patient participants were asked specifically what decisions they had made about their care during their hospitalization; most patients denied having made any. Many commented that they deferred to their physicians' recommendations, and some even reported hoping they would not have to make decisions. Participating physicians wrestled with the pros and cons of medical managements as well as whether to take a patient to surgery. They noted that the amount of uncertainty about risks and benefits of all options made counseling and decision-making difficult at the time of MBO.

Factors that facilitate patient-physician communication

Patients and physicians did agree on many factors that positively influenced patient-doctor communication at the time of MBO diagnosis (see Table 3 for select quotations). First, a patient's trust of her physician was a common factor that allowed patients to understand and accept the diagnosis. Second, both patients and physicians reported that patients "being and feeling heard" improved a physician's ability to counsel the patient. The responsibility was not only on the physicians; some patients blamed themselves for not expressing themselves clearly or loudly enough, and when asked what they recommended to other women in their situation, many patient participants suggested speaking up more for themselves. Third, patients and physicians valued corroboration of information and validation of decision-making. For patients, this took the form of second opinions, personal research, and discussions with family. Physicians consulted other services (most commonly general surgery or palliative care) and stressed the importance of discussing MBO patients with colleagues. Lastly, both patients and physicians noted that time was important; both time for counseling during the acute MBO episode, and the length of time to develop a relationship with the patient prior to their admission for MBO.

Time with the patient did prove to be a double-edged sword for some physicians: although a long-term relationship with the patient could make conversations easier, it came with more personal sadness and distress during goals of care discussion. Some physicians recognized that this closeness might also introduce bias into the decision-making process.

Communication strategies

The participating physicians noted multiple communication strategies for difficult conversations (Table 4). The strategies depended on physician preferences, but many also reported adapting their approach to individual clinical situations. Physicians overall were divided between offering options and always having a more directed recommendation. When multiple options appeared equivalent, they were more likely to offer options. At the same time, many physicians felt strongly that it was their professional duty as a physician to provide a recommendation. Overall, they did not find that providing statistical data was helpful to assist patient decisions, but some used best- and worse-case scenarios to put potential outcomes in perspective.

Discussion

An MBO diagnosis is devastating for many patients, and is also challenging personally and professionally for the physicians caring for them. It results in high symptom burden and need for increased supportive care, and forces a reevaluation of the treatment plan, an acknowledgement of an uncertain prognosis, and an exploration of end-of-life preferences. This qualitative study highlighted some differences in the priorities and concerns brought up by patients and gynecologic oncologists regarding MBO. We hope that acknowledging these differences can help physicians lead more patient-centered discussions.

The widest gap between the patients and physicians approaches to MBO was in expectations for future treatments. A primary priority for many patients was to get back on chemotherapy, and at the time of discharge, almost all interviewed patients reported plans to have more chemotherapy. Yet the broad-sweeping approach of the participating physicians was that chemotherapy after MBO was unlikely to be beneficial. This discrepancy may in part be explained by the fact that almost all participating patients were diagnosed with their first MBO episode, and still had good performance status and symptom control. Only one participant was discharged with hospice. In fact, retrospective studies have found that after a first diagnosis of MBO from recurrent ovarian or uterine cancer, almost half of patients had subsequent chemotherapy [1, 13]. The difference between the reported physician counseling and studies showing chemotherapy use suggests that either physicians act differently than they admit in interviews, or that when physicians reflect about MBO, the most memorable discussions are those with patients transitioning to hospice, not the counseling at the first MBO. It may be helpful for physicians to acknowledge this bias when preparing to counsel a patient with MBO regarding future options and expectations.

Patient participants focused on their desire to be home, in parallel with concerns about being able to manage symptoms at home. Fewer physician interviewees addressed this issue. Programs focusing on outpatient follow-up of patients with MBO have been able to support patients in their desire to be at home, as well as addressing issues of nutrition. Lee *et al* provided patients with education on MBO symptoms and diagnosis, as well as frequent check-ins after discharge home [14]. A qualitative analysis showed that patients valued these interventions, and their daily concerns and changes in symptoms could be managed outpatient by an expert team, to prioritize their ability to be home [6].

Patients' worry about acquiring information manifested in two ways: concern about physician communication and, more commonly, frustration at diagnostic or prognostic uncertainty of their MBO. Uncertainty is a common concern for cancer patients, and it has previously been associated with lower quality of life throughout the course of cancer treatment [15]. Participating physicians also struggled with managing uncertainty in counseling and discussion, and uncertainty is a known barrier to difficult conversations [16]. Studies suggest providing patient education can counteract some of the negative effects of prognostic uncertainty [17], but participating physicians did not find that providing statistical data was helpful for patients. Determining how to provide patient-centered information about MBO may help bridge this communication gap between patients and physicians.

Some physicians used best case-worst case scenarios in their discussions. Surgeon and ethicist Margaret Schwarze suggests this as a strategy to communicate with patients in the face of uncertainty. She describes using best and worst case scenarios related to a patient's diagnosis or upcoming procedure [18]. Rather than depend on statistics, the scenarios provide anchors for likely and possible outcomes, giving a range and managing expectations about whether returning to a prior baseline is an option. Scenarios allow a description of what is known, and what is uncertain. It allows personalization to a patient's specific case and preferences. In light of the physicians' concerns over use of numerical data, best-worst case scenarios can provide patient education without being overwhelming.

Physician participants were asked about communication strategies, and none reported using guides or decision aids. Yet a structured communication tool could address many of the struggles they and patients describe, including managing uncertainty and communicating overwhelming quantities of information. In a Cochrane review of 105 studies evaluating patients facing treatment and screening decisions, decision aids helped patients have a more active role in decision-making [19]. They also helped patients feel better informed about their diagnosis and their values. The average consultation length was not increased. Decision aids have been evaluated in the setting of suboptimally debulked ovarian cancer, and were found to successfully provide patient education [20], but no decision aids have been made for MBO in the literature.

In a review of decision aids based on shared decision-making, Wieringa *et al* define 6 key elements of a decision aid: situation/diagnosis, choice awareness, option clarification, harms and benefits discussion, patient preference deliberation, and making a decision [21]. While a “decision aid” may not be appropriate in a setting such as MBO where many patients did not remember making decisions, a structured communication guide for physicians could help bridge communication gaps highlighted in our interviews (Table 5). We would suggest a guide using elements of Weiringa *et al*s decision aids in combination with facilitators and discrepancies elicited during patient and physician interviews. Ideally, it would prompt physicians and patients to better define realistic patient goals. In particular, many of our participants wanted to go home; eliciting home needs and providing follow-up could help empower patients after discharge. Uncontrolled symptoms and a plan for worsening of symptoms should be discussed. It should address the possibility of future treatments, and events that would require stopping chemotherapy.

As was previously published, most participating gynecologic oncologists feel comfortable having these goal-of-care discussions, although they are frequently conducted in conjunction with palliative care [22]. Almost all participating physicians reported planning end-of-life conversations for patients with MBO, but not all patients were ready for that discussion. It is a difficult conversation. Training during and after fellowship can help support physicians through the process. Tips from well validated and accessible communication skills programs such as Vital Talk, for example, can provide strategies to address difficult aspects of the conversation (<https://www.vitaltalk.org/clinicians/>). Our study highlights the particular difficulty in addressing these concerns for recently-diagnosed, young patients, and early palliative care referrals in particular for these patients may help provide support for physicians and patients in planning for end-of-life care.

Our study is not without limitations. Both physicians and patients were limited to a single urban Midwest geographic area. Additionally, most patients who agreed to the interview were admitted for their first admission for MBO and had good symptom control; they may not be as representative of patients with more advanced or recurrent MBO. Only women with gynecologic cancer were included in this study, and they may not be representative of men and women with other cancer histologies, or at other time courses in their disease. It is unknown whether patients who declined to participate in the interviews would have provided different insight. Physicians were questioned in general terms about patients with MBO, while participating patients were focused on their individual experience, which can limit the comparisons

between the two interview groups. As a qualitative study, it is designed to bring further questions that can be explored. Other perspectives that would be interesting to investigate include those of bedside nursing, family members, home health, and palliative care/hospice teams.

Our study's strengths include the ability to interview both patients and gynecologic oncologists to address different perspectives of the challenging topic. The interviews were conducted by one interviewer for consistency, and she was not clinically involved in the majority of the care of the patients interviewed. The framework method allowed us to start with themes from the literature while simultaneously developing codes and themes coming from the interviews themselves.

Conclusion

Interviews with women with MBO and gynecologic oncologists who care for women with MBO revealed discrepancies in approach between the two groups, but also factors that facilitate the patient-physician communication that can be further developed. A patient-centered communication guide for physicians and patients may be helpful to trigger discussions about aspects of care that patients highlighted, such as nutrition and timing to discharge home. It could also leave patients feeling better informed in the face of uncertainty and physicians better supported to provide information, which were themes in both groups of interviewees. Further research to develop a formal communication aid and to tailor it to specific patient and physician populations and hospital resources is needed.

Declarations

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Conflicts of Interest/Competing interests: The authors have no conflicts of interest to report.

Availability of data and material: Not applicable

Code availability: Not applicable

Author contributions: CH, FH, JC, SDY and NL all contributed to the project development and study design. CH conducted the interviews and some of the transcription. CH, FH and NL shaped the data dictionary and analyzed the transcripts. CH, FH, JC, SDY and NL contributed to writing the manuscript.

Ethics approval: The patient interviews were approved by the IRBs of the University of Chicago and Northshore University Health System. Physician interviews were granted IRB exemption by the University of Chicago.

Consent to participate: Patients signed a standard IRB-approved consent prior to participation, which included agreeing to audio recording. Physician consent was confirmed by a positive response to a standard email, and verbal consent was elicited for audio recordings.

Consent for publication: Patients consented to publishing of the findings from the study.

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Tables

Table 1a: Characteristics of participating patients admitted for MBO from recurrent/progressive gynecologic cancer (n=14)

ID#	Age ¹	Race ²	Religion ²	Cancer site ¹	Interventions ¹	Post- discharge plan ¹
1	69	White	Catholic	fallopian tube	duodenal stent	chemo
2	68	White	Catholic	endometrium	medical ³	chemo
3	46	Hispanic	Catholic	ovary	medical ³	chemo
4	68	White	None	ovary	medical ³	chemo
5	63	White	Catholic	ovary	surgery (diverting ostomy)	clinical trial
6	36	Black	None	cervix	medical ³	chemo
7	57	Black	Baptist	cervix	surgery (diverting ostomy)	chemo
8	60	Hispanic	Christian	ovary	medical ³	chemo
9	43	White	None	ovary	medical ³	clinical trial
10	55	White	Catholic	ovary	medical ³	chemo
11	69	Black	Catholic	cervix	medical ³	consider surgery
12	81	Black	Christian	ovary	medical ³	chemo
14	62	White	None	ovary	percutaneous gastrostomy tube	hospice
15	54	White	Jewish	peritoneum	percutaneous gastrostomy tube	second opinion

1 Collected from the medical record

2 Self-identified

3 Patients treated with medications for symptom control, with or without nasogastric tube placement, without further intervention.

Table 1b: Characteristics of participating gynecologic oncologists (n=15)

Gender	
Female	8 (53%)
Male	7 (47%)
Practice type	
Academic	10 (67%)
Academic/community	5 (33%)
Years since fellowship:	
<5	2 (13%)
5-15	8 (54%)
15-25	2 (13%)
>25	3 (20%)

Table 2: Discrepancies in approaches and priorities between patient and physician participants

Patient perspectives	Physician perspectives
Next treatments	
Getting back to chemotherapy So once I can get this under control and everything's all right, they said we would talk back about [the trial]. (PT7)	Stopping treatments So there's stress related to having to communicate that we have, for most of these patients the reality is that we have reached the end of the road in terms of active chemotherapy or tumor therapy. (MD10)
I'm worried about how soon can I get back on track with my treatments. (PT8)	Most patients get to that point by being resistant to multiple chemotherapeutic agents, so it's a different situation to offer another chemotherapy with limited efficacy and a poor prognosis. But, that's also sometimes on the agenda to discuss. (MD 3)
Goals	
Prioritizing being home I'm looking forward to just being at home. Just being home. Like I said, we've got this trip planned to go to Colorado, though I won't be hiking this time. (PT 10)	Prioritizing nutrition I think most patients want to get back to eating, tasting and enjoying foods. That becomes the hardest conversation if you don't think you can do that. (MD13)
My hopes are to get home and being able to manage this with no pain. I'm still hopeful that it will resolve, but I don't know, it's been so long. (PT15)	I think the [gastric] tube gets placed and whether it's a partial placebo effect from the new intervention that brings with it promise and hope, or not, the patients get better, and they have also the idea that they're going to be able to have some nutrition through that. (MD1)
Just taking a shower in my own shower, playing with my kids (PT9)	It's really the eating. And then the calories (MD5)
Oh, my God, just to sit in my living room. I mean it's not real fancy or nothing, but I just want to go home (PT8)	
But I just wanted to do... you know, just regular things. Day to day routine. (PT7)	
End Of Life conversation	
Range of readiness I'm not ready to end my life. I'm ready to have fun, this is my prime time. (PT7)	Need to talk about dying I feel a bowel obstruction is typically a terminal event, but I guess the word terminal kind of varies it could be months, it could be weeks (MD12)
I don't care about my hair. I don't care about any of that. I just want to live. (PT9)	The way I try to bring it up is that "we know this is not going to be a curative situation. We do know there's a limited amount of time that you have, ... but it is important to think about what you want to do with the time that you have." (MD15)
And my family's dying for me get stuff [will and advanced directives] in place. And so with this hospitalization I just realize anything can happen, and I have to do that. (PT2)	You also can't predict completely how things are going to go, so that's really hard because you want to counsel appropriately but sometimes things don't go that way. So I think the unknown for the patient is really hard, then it makes it hard for you too. (MD15)
I just have to pray to God and tell him, I don't want cancer, take it away, but if I die, I die. (PT12)	
I just want to really enjoy what I can. We're prepared for end of life, so to speak. (PT14)	
Communication of information	
Paucity of information	Difficulty synthesizing information

They're being very diplomatic, choosing their words well. Because they realize that I realize how serious it is. I don't think they want to tell us too much either, too much in advance, because they don't know exactly. (PT5)

[My doctor] acts as though he doesn't want to talk to me about certain things that are painful. He acts as though he'd rather someone else to talk to me. [...] I'm a grown-up woman. I am 81 years old. I can take anything. (PT12)

Some of the stuff they tell you contradict themselves. Oh, we want you to eat, really keep up with your nutrition. But just little things throughout the day. But don't go do this. So, what am I supposed to do?? You know, you're going to have to follow me around and say what is what. (PT5)

Communication style

Positive thinking	Keeping expectations realistic
I don't know how long is it going take before I see some light. It's all I can see right now, but I don't know, I'm just holding on. (PT8)	There's a misunderstanding of hope, how hope is defined and managed. And the tension between hope and reality and the importance of some degree of reality in allowing people to work through what the last months of their life mean. (MD9)
Don't give up. They say oh, well, this isn't going to work, that isn't. Don't do that. Don't stop. Keep going. Because there is a way. God is good. And He will pull out all our needs for us. So don't give up. Don't say no. (PT7)	Their expectation of health outcomes were more black and white. "This is my problem, it should be a solvable problem. And solving a problem should mean that I should get back to exactly where I was before, to how I was feeling a number of years ago." And that's where it's hard. (MD2)

And I trust that they have the experience not to tell me too much right now. Because I am feeling fairly optimistic for some reason, and like I say I'm not questioning it, it's there, so I'm taking advantage of that optimism to help me. (PT5)

Decision-making	
Desires direction	Uncertainty
She had mentioned this trial which I guess I'm no longer an option for. So I need to know what to do next. (PT9)	Go in with an open mind into reviewing each case. I had a case in my fellowship [...] there were 3 different attendings who had 3 different opinions about her. (MD12)
We just, we ask for our marching orders and she tells us what to do. (PT1)	You can't predict completely how things are going to go, so that's really hard because you want to counsel appropriately [...] I think the unknown for the patient is really hard, then it makes it hard for you too. (MD15)
I didn't write the book on cancer, I'm not a doctor. You're kind of blindsided. So you're looking for their opinion and you hope it's a good one. (PT14)	How much does it really benefit the patient, or not. And what is the line between a palliative diversion and a surgery that will provide a much longer benefit in terms of continuing chemotherapy and so on. There's no good answer to that, we just don't know (MD10)

I think that actually the majority of patients when they come in for their first malignant bowel obstruction really don't know what it means. I'm actually kind of surprised that they really don't understand how bad of a diagnosis it can be. Across the board, no matter how educated or how much experience they have the health care system, they think, I can beat this, this is overcome-able. (MD2)

I can think of one patient who was unique in that she was really direct and was not afraid to ask the next question. I think most patients, even if they get it, they're afraid to ask. (MD1)

their options more closely than my own gut at this point. (PT2)

If you could predict who's going to have the horrible, God-awful life-ruining complications, it would be easier. (MD5)

That's one thing I've learned, things change from minute to minute, sometimes. (PT5)

Table 3: Factors that facilitate patient-physician communication

Patient Perspectives	Physician perspectives
Trust I think that [my doctor] has put everything out there and has explained all the different options. I trust her with everything. We discuss everything, and then I'll tell her what I'm feeling. She'll tell me what she's feeling. Usually, we come up with the same answer. (PT10) He was very calm and you didn't see any panic in his eyes, you didn't see like, oh, we're going to cure you in his eyes, so I trusted him to tell me the way it is now. (PT5) That's why I listened to him because he knows of the problem of the future. (PT15)	Of course it helps if it's your patient that you've been treating and it's her third or whatever number of recurrence, and you have a relationship, that always makes the conversation a lot easier. (MD10) And a lot of it comes down to trust, it's much easier to have these conversations with someone you've followed for a really long time. They've seen some successes in their treatment, and then are now not seeing success, it's a much easier conversation. (MD2)
Being heard I think it's important for everybody to sometimes trust the patient, and especially if they've been sick for a while, to trust where they're at in their sickness. (PT2) I think being proactive yourself was essential, without becoming... I'm very proud of not being a hypochondriac, but I've become more of a hypochondriac now, I'm more inclined to speak up for myself. (PT1)	I guess it depends on the patient, if they're an "I like all the information" kind of patient, then, yes, but there are also some patients, who are like, "I just want to move on, I don't really need all the cerebral information, and I would rather just deal with it when it comes," so I kind of gage it. (MD12) I really, really want them, to the extent they're interested, to verbalize what they're feeling about it. I don't usually get any Oprah-profound comments. I'm eliciting that just so that they're heard, I think that's one of the basic things about our interactions with them is that they be heard. (MD1)
Corroboration of information It's been always really good that [my doctor] reaches out to other colleagues to get their input. It's not just her making decisions which I really enjoy. (PT10) My thing is, I want to do some more research on [an ostomy] and what life is like with that routine, and maybe talk to some people who've had it actually. (PT11) Again, I think every person owes themselves to not just be blindly led by the collar. People do have lives, even though they're surgeons or whatever they're doing for you. You have to do some of your own research and be your own advocate because they can't do it all. (PT14)	I think it's okay to talk to someone about it, it's not clear-cut and maybe when you review the chart you don't know the answer for a reason, it's because there's no right answer, and maybe you need someone who has done this before a few times. (MD12) And even for me it's so difficult that I consult with my senior colleagues and try to talk with them or with my fellows, and just use them as a mirror to think if I missed something. (MD7) I would definitely ask my partners ideas and opinions, and not take the burden of making a decision alone, because, again, with the prolonged relationship, your decision-making may not be as clear as you think it is, or may be compounded by biases that you don't even realize. (MD3)
Time So when I heard that option, as the top option, I want to go home, think about the next options in my own	The clinic visits we have seem so time-pressured that it's really challenging to know what really [patients] are capable of talking about, and what they're interested in talking about, because

environment. (PT11)

Sometimes, I just need a few minutes of just taking it all and putting it on the side for a while. Not thinking about it. Then come back to it and think about it. Instead of just diving in. [laughs] So, that's how I deal with it (PT10)

I think that since this has been going on for so many years, probably the hardest lesson for me to learn is I've always been a planner, plan ahead. Now I've learned to just wake up and see what each day brings me. (PT10)

they're doing the same thing we are doing, which is making these guesstimations about what we can spare in terms of attention and focus. ... This is such a complicated one that I think those patients who do have specific concerns about it, we don't usually talk about it. (MD1)

Something I feel like, if we don't have the time, [palliative care doctors] have time, more time, to spend with the patient. (MD12)

Table 4: Communication strategies used by physicians in the setting of difficult conversations associated with MBO diagnosis

Shared decision-making

A lot of it is about whether they have realistic understanding about what they may end up with, that they could end up with short bowel, and could end up with an ostomy or with chronic diarrhea and be IV dependent. ... And when people have said to me, I totally get it, but I'm willing to take that risk, and I change my mind. (MD9)

I usually try to put myself in their shoes and figure out what I would do. But the problem with that paradigm is that my patients are not me. But I usually do tell them what I think is best, and I tell them what we're considering, and if they feel strongly about an option that maybe I wouldn't do for myself but I think is reasonable, then I would do it. (MD12)

When somebody's looking you in the eyes and saying, "How can you not offer me this thing, why won't you give it to me?" ... I don't think it's right, but I don't think it's outside the standard of care to offer it to you, and if you want it and you understand the risks, I don't feel like it's my place to decide. (MD5)

Providing options

I give options. I let them think over the options, but then I tell them, "I'm going to come back and tell you what my preferred option is and why." ... Sometimes when you come back and you ask them, they pick the option that you'd prefer, so it saves you some time. When they don't pick the option you prefer, that takes a little more time. (MD13)

I'm probably not directive enough. I was raised in the mindset that you just need to give the patient the options and let the patient decide. And the longer I practice, the more I think a lot of patients do better with more clear recommendations or direction from the physician. (MD5)

In general, I tend to give people options. ... I do tell people that if I feel strongly about something, I'll let them know. (MD14)

Directive recommendations

I am pretty directive with what I recommend. Because I think that it is one of the patient complaints, ... "you're the doctor, I don't know how to make sense of these options, you tell me what you think." (MD2)

I tell them the options, but I do believe that the patients deserve to hear a recommendation from me. ... So I commit to something I think is the right thing to do, knowing a little bit at least their life circumstances. And it's such a difficult decision for me, that I think it's almost impossible for a patient to make an educated decision about this, it's almost impossible. (MD7)

I always make a recommendation. I usually talk to them about: here are all the options, here's why I recommend this one, and go from there. (MD4)

There's very few situations in medicine where you actually have equivalent alternatives. [...] Most of the time, you have pros and cons, and you have to weigh them for the patient. [...] I think it's our duty as doctors. You have to give them time. (MD11)

Use of data

I keep it more general. I've found that the faster I go into offering statistics, the more difficulty most patients have, I don't think most patients deal with that too well, from either a distress standpoint or the numbers helping them translate to a rational, satisfactory, not that "rational" is the goal, but a satisfactory decision for them. (MD1)

If we were to have some specific numbers, I would go back to a patient and say, there are our numbers, this is kind of where you are on the spectrum of what we've seen, and this is potentially what you could expect in terms of quality of life with some of the interventions that we've done, and how does that fit with what you think about, what your goals are. (MD2)

Emphasizing risks

I would probably offer surgery and scare the heck out of the patient by excessively talking about the risks. (MD5)

I usually counsel people that [TPN] doesn't make people feel better and that there are a lot of risks associated with doing the TPN, like infection, liver abnormalities, etc. ... And usually, people don't want it after that. I definitely don't sell it. I do the negative spin on it, that's usually how I counsel people. (MD14)

Scenarios

If I am resolute about my recommendation, which is not all the time but is most of the time, I feel obliged at that point to be more and more detailed about how I tell them what the best and worst case scenarios are. And that leads me to this other thing that I've kind of learned in recent years, to use descriptions of scenarios as a way of communicating all that stuff. (MD1)

I think that the whole benchmarking thing sometimes will help with that as well, because they'll remember specific examples of what you said. And I have had family members come back and say: last time we were in you said that this would not be a good sign, that this is a big step back. (MD2)

Table 5: Communication Guide for inpatient MBO diagnosis.

AIN*	SAMPLE STATEMENTS	THEMES REFLECTED IN INTERVIEWS
Initial Considerations		
<p>Setting: with the patient. or family/ caregivers e present in person, ne or video. sider recording or g notes</p> <p>atient feeling rushed w patient to feel ritized</p>	<p><i>I would like to discuss your current clinical situation and be sure you and I are on the same page.</i></p> <p><i>Where do you want to start our discussion today?</i></p>	<p>Discrepancies (Table 2)</p> <ol style="list-style-type: none"> 1. Paucity of information vs Difficulty synthesizing information 2. Range of readiness for EOL conversations vs Need to talk about dying <p>Facilitators (Table 3)</p> <ol style="list-style-type: none"> 1. Trust 2. Time
Confirming the Diagnosis of MBO		
<p>cribe cause and ings of MBO ess overall prognosis IBO ress the likelihood of istent, recurrent or gressive MBO</p>	<p><i>A malignant bowel obstruction is a sign that the cancer is getting worse [despite treatments].</i></p> <p><i>Would you like to see some of the images from your CT scan?</i></p>	<p>Discrepancies (Table 2)</p> <ol style="list-style-type: none"> 1. Paucity of information vs Difficulty synthesizing information <p>Facilitators (Table 3)</p> <ol style="list-style-type: none"> 1. Corroboration of information
Role Awareness		
<p>lain that there may be tiple appropriate agement options, now as the situation nges nowledge uncertainty.</p>	<p><i>We will keep having discussions as your symptoms and priorities change throughout your care. I do think that today there are multiple considerations about what to do next for your obstruction and your cancer.</i></p>	<p>Discrepancies (Table 2)</p> <ol style="list-style-type: none"> 1. Paucity of information vs Difficulty synthesizing information 2. Desires direction vs Uncertainty <p>Facilitators (Table 3)</p> <ol style="list-style-type: none"> 1. Trust
Decision Clarification		
<p>cribe options under sideration. lear with what may not n option and why sider short-term and er-term expectations. vide concrete and istic parameters for</p>	<p><i>There are no perfect options at this point. Everything will have risks and benefits.</i></p> <p><i>Surgery is not an option because we cannot fix all the areas of blockage.</i></p> <p><i>A gastric tube can help relieve nausea. It will not provide nutrition.</i></p>	<p>Discrepancies (Table 2)</p> <ol style="list-style-type: none"> 1. Prioritizing being home vs Prioritizing nutrition 2. Getting back to chemotherapy

<ul style="list-style-type: none"> re cancer-directed treatment. ify current symptoms discuss role of lications for nausea, el regimen, steroids if appropriate sider palliative care sultation 	<p><i>If you are unable to take in enough to stay hydrated, we could not give you more chemotherapy.</i></p>	<ul style="list-style-type: none"> vs Stopping treatments 3. Range of readiness for EOL conversations vs Need to talk about dying <p>Facilitators (Table 3)</p> <ul style="list-style-type: none"> 1. Trust 2. Corroboration of information <p>Communication strategies (Table 4)</p> <ul style="list-style-type: none"> 1. Shared decision-making 2. Providing options 3. Directive recommendation
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Harms and Benefits Discussion

<ul style="list-style-type: none"> ress expected comes and goals of each on. sider a hope-worry ement. sider best case/worst e scenarios, as well as t likely scenario, to ress uncertainty and range of possibilities. 	<p><i>I hope that you can travel to see your family, and I worry that after a surgery you will be more limited in your mobility and would not be able travel.</i></p>	<p>Discrepancies (Table 2)</p> <ul style="list-style-type: none"> 1. Positive thinking vs Keeping expectations realistic 2. Range of readiness for EOL conversations vs Need to talk about dying 3. Paucity of information vs Difficulty synthesizing information <p>Communication strategies (Table 4)</p> <ul style="list-style-type: none"> 1. Use of data 2. Emphasizing risks 3. Scenarios
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Patient preferences deliberation

<ul style="list-style-type: none"> it patient goals and rities. o evaluate how realistic ls are. us on short term goals longer term goals. e time and space for patient to speak and be rd. 	<p><i>Are your pain and nausea controlled? What else is bothering you?</i></p> <p><i>Who lives with you at home? How would they handle managing a wound or giving you injections? Are they able to be home whenever you need them?</i></p>	<p>Discrepancies (Table 2)</p> <ul style="list-style-type: none"> 1. Prioritizing being home vs Prioritizing nutrition 2. Getting back to chemotherapy vs Stopping treatments
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Is of care conversation including code status should be introduced		3. Range of readiness for EOL conversations vs Need to talk about dying Facilitators (Table 3)
		1. Being heard
Making Decisions patients look towards physician for help with decision-making. Include family members in discussion.	<i>What do you think?</i> <i>What further questions do you have?</i>	Discrepancies (Table 2) 1. Desires direction vs Uncertainty

*Domains adapted from Wieringa *et al* {Wieringa, 2019 #725}

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