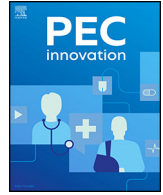




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Patient perspectives of pandemic-related disruptions in gastrointestinal care: developing communication strategies

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ARTICLE INFO

Keywords:

Endoscopy
Telemedicine
Coronavirus
Pandemic

ABSTRACT

Objective: Normal elective outpatient care has been impacted during the COVID-19 pandemic, due to limitations imposed by healthcare systems. Clear communication is necessary to address patient concerns as resumption of elective care gains pace.

Methods: Thirty patients who had diagnostic gastrointestinal (GI) testing within our motility lab during the initial viral surge in our state spring 2020 underwent semi-structured interviews. Codes were derived from transcripts using the constant comparative method.

Results: Framework analysis revealed several patient themes, including (1) patient specific factors such as age and comorbidity; (2) pandemic-related evolution including case surges; and (3) healthcare related function – or dysfunction – that directly influenced patient perceptions of disrupted gastrointestinal care. These themes provide areas in which to focus communication using the shared decision making model to achieve resumption of delayed care.

Conclusions: When communicating with patients, it is difficult to predict patient preferences and as much flexibility as possible should be offered. Concrete steps of (1) identification of patient barriers; (2) intervening upon them, and (3) having concrete plans to influence care will need to guide such communication.

Innovation: Our patients' perspectives during the first viral surge can guide new communication strategies should healthcare delivery be compromised in the future.

1. Introduction

With the COVID-19 pandemic caused by the severe acute respiratory syndrome coronavirus-2 (SARS-CoV-2), normal clinical activity has suffered [1]. There also has been avoidance of medical care by nearly 50% of US adults [2]. Rapid acquisition of vaccines over the course of 2021 was thought prevent future healthcare system dysfunction. However, the delta and omicron variants and resistance to vaccination resulted in a fourth and fifth surge in the United States summer 2021 and fall 2021 and forced certain states to curb elective care [3,4] or operate at crisis standards of care with rationing [5,6]. Additionally, individuals preferring to exit healthcare rather than comply with vaccine mandates are feared to provoke further disruption [7-9]. Even if the pandemic were to end today in the United States, it may take 2-years working above 100% capacity to address procedural backlogs [10,11], further exacerbated by new requests from patients who are sicker after having delayed care [12]. Procedural specialties such as gastroenterology (GI) have been particularly hit hard with a slower rebound compared to non-procedural specialties [13].

These are all new factors in patient care that require thoughtful healthcare communication strategies due to the possibility of further disruptions in the coming months-to-years [14]. These strategies should be rooted in patient perceptions of disrupted care as they will suffer the consequences of delays, and should be centered in shared decision making between patient and provider.

We need a better understanding of the GI patient perspective of the pandemic and of changes in care that have been forced upon patients. Postponing purely elective procedures like screening colonoscopies and insisting on emergent care for hemorrhage are easy decisions when viral surges are raging or if multiple patients are clamoring to resume care once vaccinated. We encounter difficulties when treating patients with chronic medical illness, including patients with gastrointestinal illness along the spectrum of neurogastroenterology and motility disorders: who do we prioritize, when, and why. Here, we examine our patients' perspectives of GI care during the initial surge of the pandemic in our region, focusing on (1) delays in diagnostic testing; (2) personal experiences with altered healthcare function and delivery, including the provision of telemedicine at time we

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were mandated by our local government to limit patient autonomy. We aimed to understand if there was fraying of the therapeutic alliance in a subset of patients used to healthcare system mistreatment [15] in order to guide future communication strategies given healthcare system dysfunction is likely to continue. Qualitative methods have been previously used in chronic benign gastrointestinal disorders to assess patient experiences with their disease [16,17]; this study represents an effort to use a qualitative approach to understand the difficulties patients may be experiencing with disrupted subspecialty care.

2. Methods

2.1. Data collection

A list of patients undergoing diagnostic testing within our institution's motility lab was queried with approval from the system-wide institutional review board. Inclusion criteria included those who had their procedures canceled pursuant the Massachusetts "stay-at-home" order implemented March 2020 through May 2020 [18] during the first surge in viral cases, were above the age of 18, were able to consent, and who spoke English. Our study cohort consisted of 30-patients who were assigned a code formatted "MD-XX" from MD01-MD30 who were interviewed from May 27th, 2020 through June 12th, 2020 (as Massachusetts began phased re-opening). Semi-structured interviews (Table 1) touched upon key considerations such as their conceptions of disease, their experience with illness during the pandemic, their thoughts surrounding the pandemic as it related to their testing delay and outpatient care, as well as the opportunity to provide an open-ended closing statement. Participants then completed an accompanying survey.

2.2. Theoretical framework and analysis

Interviews were transcribed with the "TranscribeMe!" platform [19] were charted into a framework matrix derived from the review of 4 random transcripts (CV, MP, and Skarbinski). Codes were assigned to categories by 2 individuals (CV with MP or CV with Skarbinski) using the iterative constant comparative method of inductive data acquisition during 6 transcript review sessions [20,21]. Unlike in quantitative studies, qualitative studies do not necessarily have a pre-specified "n;" interviews continue until no

new salient codes are identified, or "saturation" [22]. Therefore, achieving saturation was the principal end point.

2.3. Participants

A total 311 patients had motility testing canceled in our academic tertiary care urban medical center during our state's mandated cessation spring 2020. We had permission from our institution review board to recruit 68 patients by mail who were referred for motility testing by members of our institution's motility group given institution-mandated curbs of pandemic research involving human subjects. We had permission to contact these 68 patients as they were under direct care. The other 243 individuals were not cared for in our Center for Neurointestinal Health were not allowed to be contacted by our institution given limitations placed by our institutional review board limiting recruiting for studies not devoted to obtaining observational data or investigating novel COVID-19 therapeutic agents. Interviewers called patients on a rolling basis over a 2-month period from June and July 2020, initially calling 52 of these patients, the order of which was chosen at random. Of these 52 patients, 16 patients could not be reached by phone, 6 patients declined to participate, and 30 interviews were completed. We had achieved saturation at the 28th interview (no further codes were drawn from transcripts); no further attempts were made to continue recruitment.

3. Results

During transcript analysis, 4 "parent" codes categorized a total of 30 "child" codes, which themselves were grouped into 151 subsidiary codes. Participants' demographics, income, gastrointestinal testing types, ordering indications, and patient perceptions of testing delay are shown in Table 2. Regarding delays in gastrointestinal care and its resumption, three themes were generated during thematic analysis of parent, child, and subsidiary codes: (1) patient-specific factors influenced patients' perception of testing delay and urgency of need to resume care; (2) pandemic-related factors such as trajectories of cases changed over time patients acceptance' of testing delay and willingness to re-establish care; and (3) healthcare disruption, in particular, impaired communication, was variably tolerated.

Table 1

The semi-structured interview of patients with delayed gastrointestinal testing. Two individuals performed 30 interviews of patients with delayed gastrointestinal motility testing at our institution, with the same call script used by both interviewers. There were minimal prompts to allow patients to freely express their experience with delayed testing, their health, their interactions with the healthcare system, as well as describe their own conceptions of the pandemic.

Patient Background, Testing, Perspectives, and Self-Assessment		
Percent total (N)	Percent total (N)	Percent total (N)
Demographics/ Socioeconomics	Type of Diagnostic Testing	Satisfaction/ Concern with Testing Delay
Gender	Catheter-based foregut testing	Upset gastrointestinal testing was delayed
Female	Esophageal manometry (HREM)	Not at all upset
Male	Catheter pH testing	Mildly/ moderately upset
Race/ ethnicity	HREM and pH testing	Severely/ extremely upset
White	Endoscopy-based foregut testing	No response given
Non-White	EGD ¹ and wireless pH testing ²	Concerned about safety of waiting for delayed test
Age	EGD and EndoFLIP ³	Not at all concerned
18–24	EGD alone	Mildly/ moderately concerned
25–34	Catheter-based hindgut testing	Severely/ extremely concerned
35–44	Anorectal manometry	No response given
45–54		Self-Assessment of Quality of Life and Mental Health
55–64	Indications for Diagnostic Testing	Quality of life
65–74	Foregut complaints/ diseases/ clinical status	Poor/ fair
Over 75	Dysphagia (not specified)	Good
Annual household income	Achalasia	Very good/ excellent
Below \$10,000	GERD ⁴	No response given
\$10,001–\$50,000	Lung transplantation	Rating of mental health and mood
\$50,001–\$100,000	Hindgut complaints/ diseases/ clinical status	Poor/ fair
\$100,001, \$150,000	Constipation	Good
Over \$150,000	Fecal incontinence	Very good/ excellent
No response given		No response given

Table 2

Baseline demographic data, diagnostic testing parameters, and patient assessments. Patients with delayed gastrointestinal testing were overwhelmingly female and White although there was representation of male voices and those of people-of-color. Given age-based prevalence of gastrointestinal disease, it is not surprising the majority of patients were aged 55 or older. Household income tended to reflect those of favorable socioeconomic status although 26.7% did not provide information on annual household income. Percentages may not add up to 100% due to rounding.

Qualitative Protocol for Semi-structured Interview in Patients with Delayed Testing	
Question category	Question example
Opening questions	Can you tell me briefly about what motility/ endoscopy test(s) you were scheduled to have? What were you expecting to hear at your first appointment with the physician? How did your expectations differ from what you were actually told?
Patient's experience during the COVID-19 pandemic	I am worried about COVID-19 infection and its consequences on my health and daily life. 1-Very little, 2-A little, 3-Some, 4- Much, 5-Very much How have your thoughts regarding your safety from COVID changed since the start of the pandemic? How, if at all, has the COVID pandemic impacted your expectations regarding your treatment?
Patient's thoughts on motility/ endoscopy testing delays due to the COVID-19 pandemic	What were you told about the need to delay your motility/ endoscopy test? How much worry have you been experiencing related to your health? How did your family/ friends react to the news that your motility/ endoscopy test would be delayed? Everything considered, which would you say has worried you more: COVID or your gastrointestinal/ motility problem?
Closing	Is there anything else you would like to tell us about your experience as a patient during the COVID-19 pandemic?

Testing modalities listed include:

- (1) EGD or esophagogastroduodenoscopy.
- (2) wireless pH testing or BRAVO™.
- (3) functional luminal imaging probe or EndoFLIP™.

Disease states include:

- (4) GERD or "gastroesophageal reflux disease" which coincided with additional diagnoses such as Barrett's esophagus or esophagitis and other complaints such as chronic cough, dysphagia, or globus sensation.

There was varying degrees of dissatisfaction and concern with gastrointestinal testing delay. Despite a cohort derived from those awaiting motility testing, there was a balanced self-assessment of overall quality of life and mental health.

3.1. Patient-specific factors (such as illness, age, comorbidities, concern about risk) directly influenced how patients viewed their disrupted gastrointestinal care

3.1.1. There were factors that influenced patients to welcome disruption in care

When interviews occurred over summer 2020, prompts in semi-structured interviews allowed some patients to describe not only an understanding of the rationale for cancellation, but, a sense of relief. That is not to say that acceptance was without caveats; while 50% of patients were not upset by delays related to the pandemic, 56.6% of the patients also being concerned about the delay. There were patients who were not upset about cancellation in care because they were going to do it themselves. There were three domains in which patients were willing to cancel the test themselves. First, there was a reticence to do testing even before the pandemic began due to not wanting to undergo testing. Testing in the motility laboratory can be invasive and unpleasant, including trans-nasal passage of catheters while receiving only topical anesthetic, tests requiring 24-h insertion of trans-nasal probes, or insertion of a catheter into the rectum. The pandemic gave these patients an excuse

to forgo these tests. One patient who was scheduled to undergo an anorectal manometry stated:

"I was kind of relieved just because it's an embarrassing test. 'It's not that bad. I'm not pooping my pants or anything ... do I really need it?'"

Second, patients stated that they were seeing over the course of spring 2020 worsening reports of illness and death and healthcare system dysfunction. Patients were concerned about inserting themselves into this dysfunction and risking contracting a novel infection, and viewed the risk of the procedure to their health to be greater than the risk of not undergoing testing. One patient noted:

"Well, I sent an e-mail when COVID first came out, and I said I'm not coming to the hospital for the test because I don't want to risk – it's too risky at this point. So, if you're not canceling, I am."

A third reason patient-specific factor was comorbidities that placed themselves at risk for worse COVID-19 outcomes should they come in for gastrointestinal testing and contract nosocomial infection. While this included patient's with respiratory disease, there were also people with other comorbidities that over the course of 2020 were recognized as having worse COVID-19-related outcomes, with patient noting:

"I'm a person in the risk category, having had three open-heart surgeries and a prosthetic aortic valve. I figured that probably would put me along with – being 78 would put me in the high-risk category. So I started getting really careful."

3.1.2. There were factors that made other patients unhappy with disruptions in elective gastrointestinal care

There were two principal concerns mentioned by patients who felt factors related to their health were being potentially harmed during disruptions of care during the first viral surge. One patient-specific factor was a concern that their overall health or gastrointestinal-specific conditions were decompensating over the course of the pandemic. Particularly if symptoms worsened over the course of the pandemic, there was a desire to get on with diagnostic evaluations in order to progress forward with treatment. These were patients who felt the harm of postponing testing outweighed the risk of becoming ill with COVID-19. One patient stated:

"Everyone [author note: friends and family] thought it was bullshit, excuse my language. But they literally think that it's ridiculous. And their responses were literally like, 'You got to be f-word kidding me.' They can't comprehend how someone in my condition ... overlooked and overpassed."

Another group of patients felt that their gastrointestinal health was not a major concern. Patients may have been accepted a delay in testing as their symptoms were transiently improved. Yet, their frustration with having elective care deferred centered on their being a plan in place with providers to further evaluate symptoms. While the symptoms were stable, this plan was on hold, which meant that the eventual diagnosis and treatment plan was also going to be delayed. Another patient noted:

if I hadn't had to wait so long for my initial appointment in October this could've been already identified, so now, I'm going to probably have to wait another couple months and that's stressful in itself, just wanting to have this over with and not knowing, at this point, when that's going to be. "

3.2. Pandemic-related factors (as in the fluctuation of cases and changes in hospitalizations) impacted perceptions of disrupted gastrointestinal care

3.2.1. When cases were increasing, patients generally were receptive to deferring gastrointestinal care

Repeatedly, patients stated their understanding of delayed gastrointestinal care during the initial early spring 2020 surge in coronavirus cases in the northeastern United States. There was a desire among study participants to pursue testing as cases eased during the time interviews were performed summer 2020. It is important to note that these interviews were performed during a portion of the pandemic when vaccinations were not

available. One patient summarized this duality between being disappointed but understanding as follows:

“I was a little disappointed that I didn't get in before, but then as I saw how bad things got, I was fine.”

Another patient stated:

“I think I was just told that they weren't seeing patients at that time. It would be rescheduled. It bothered me a little bit, but I have to tell you that I completely understood why. It made complete sense that it would be postponed. The hospital itself was going through such shortages of everything that they needed just to see patients, and all the PPE and stuff, that it just made sense to me that it should not happen, that I shouldn't be there, because I wasn't sick. And at that point in time, and probably still, it's incredibly important to take care of the people who are ill, immediately ill [laughter]. So I mean, it just made sense to me. I want this to go away or want something to happen because it's happening to me, the throat and esophageal things - excuse me - but basically, I totally get it. It was not my place to be at that hospital at that time.”

3.2.2. *When cases were decreasing, patients generally were receptive to resuming gastrointestinal care*

As interviews ended after the first viral surge resolved summer 2020, patient interviews tied their perceptions to disrupted gastrointestinal care to the improving statistics in our state (which escaped the summer surge of 2020 due to continued enforcement vs acceptance of state and local mandates). Generally, there was an understanding why cases needed to be canceled when cases were surging and hospitalizations were improving. But, patient naturally viewed pandemic-related improvement on the societal front and linked it with resuming gastrointestinal care. One patient stated:

“Just I would love to come back. I've got a couple different hospital things that I want to have taken—visits that I want to have taken care of. I think in the very beginning I would have been—I know I was afraid to go to the hospital, but now I kind of feel like that might be the safest place considering all the precautions and everything that people are taking.”

3.2.3. *Given contention surrounding patchwork local, state, and federal responses to the pandemic, pandemic-related restrictions influenced patient's perception of disruption in gastrointestinal care*

Politics and healthcare are intertwined in the United States, and partisanship has marked multiple facets of the pandemic, including responses to recommendations from public officials [23,24]. Patients commented on both perceived inaction/missteps of government leaders as impacting their perception of the pandemic. As interviews occurred during the state's progressive re-opening, some had concerns about restrictions being relaxed too slowly at the insistence of overly cautious doctors. Others felt that that government's reopening of society was unsafe. Therefore, when patients are experiencing disruptions in care, they may view it from the lens of overarching public policy considerations during the pandemic.

“We're just waiting for things to open up. It's like, ‘Come on, open up this economy. What's going on?’ So I mean, we all feel the same way. It's been too long, too long. It's just time to open up, ... So that's the problem of having this. So is my family, it's like, ‘Come on, just open up.’ So I think the doctors are overly cautious at this point. They really need to open up.”

3.3. *Healthcare-related factors influenced patients' perceptions of disrupted gastrointestinal care*

3.3.1. *Satisfaction and trust (or distrust) contributed to perceptions of disrupted gastrointestinal care*

Patients do not view their institutional experience in a vacuum. During interviews, patients tied their response to the pandemic to their overall trust in our hospital. Namely, in those patients who were generally satisfied with the care they received in our institution, patients appears to be more likely to give our institution the benefit of the doubt. One patient described:

“I mean, it's been a little disappointing to have stuff canceled but overall, I still experienced really good care.”

Another stated:

“But other than that, but the hospital's [inaudible] very, very, very outstanding. It's just I think there's a couple of tweaks involved with it. As I'm sure every hospital, but driving three hours up, three hours back, that's quite a hit for an appointment that already should have been on the computer.”

However, for others, the delay in testing as well as with their perception that the healthcare system was in chaos was related to less trust in our institution. Our patients felt non-COVID-19 healthcare considerations were being impacted by the pandemic. One patient in particular felt that:

“And I'll be honest with you. One of the reasons why, I don't think [the hospital] has really educated the patients enough in how safe the procedures are right now and how much you have COVID under control in the hospital. I think that needs to be educated a little more to the patients, that it is a safe environment, “If you come in here, we're going to protect. Our unit doesn't have COVID patients. We take temperatures. We make sure that you're not going to be exposed to anyone.” And I haven't got that reassurance from [the hospital] yet.”

3.3.2. *Effective communication (or lack thereof) also contributed to patient's considerations of delayed gastrointestinal care*

When the semi-structured interview was being crafted, we had not intended to describe communication as the initial focus of the intended interview was delineating how patients felt that procedures were canceled. Yet, several patients highlighted how electronic communication was a factor in how they felt about their elective gastrointestinal care being disrupted. One patient felt that despite the challenges of the pandemic that communication was effective at our institution:

“Well, I find that [the hospital] work differently, and they're very good. They're on top of you. I use the portal more than the phone to connect with the doctors. They're always there”

However, this satisfaction was not universal. Patients stated that they were frustrated that there were increased barriers to communication with offices that were not functioning normally. One particularly unhappy patient stated:

“I have severe acid reflux, and I've just been doing whatever we've done to try to stop that. But I think it's just—and the only other thing was when I got the call, I missed the phone call that my appointment was canceled. And the message was to please call back, at this certain person, at this number, and we'll reschedule. And I've called back probably 10 times over period of a couple of weeks and I've never got an answer. So I went on the patient portal and I've actually written two different letters and I've even write a letter to your provider and I've never received an answer. So I think in that respect, it was disappointing”

3.3.3. *The provision of virtual care was welcomed by some patients, but, looked down upon by others despite healthcare providers at our institution having no control over the cancellation of in-person care*

We had not intended during our semi-structured interview protocol to query regarding telemedicine provision as our manuscript had sought to focus on the unique circumstances surrounding testing delays. However, telemedicine became a very prominent during interventions and represented a rich source of coding. Reaction was mixed to telemedicine, at a time when patients had no choice but to accept telemedicine encounters. Some patients felt it was a poor substitute to in-person care, considering it no better than a symptom check-up. One patient described the experience of telemedicine as follows:

“It was challenging as a patient. I mean, you can get a virtual visit, but that's [inaudible] support and triage and something—it's not really resolving the issue as it would be in person and being examined. That examination is [inaudible] important for me. I can tell you my signs, my symptoms, and so forth, but I think for me, I'm more confident that my health is being addressed with a in-person exam.”

Others were thankful that they still could address aspects of their care from the safety of their homes. Regulation of telemedicine was greatly

relaxed during the pandemic, and there is already a push to make sure that it remains a viable method of healthcare delivery [25]. One content patient stated during interviews:

“No, it has been easier to get in touch though since the pandemic, to get in touch with all of—reaching primary care, and I feel that that’s been a little bit easier. The televisits has helped tremendously.”

4. Discussion and conclusion

4.1. Discussion

During the initial viral surge, our state progressed from a March 2020 “stay-at-home” order through to a phased re-opening initiated May 2020 [18]. As such, our institution began offering near-normal GI-related care summer 2020. While a second surge came and eased from end-of-2020 to early 2021, the delta-variant surge in our state summer 2021 did not shutter the economy or result in canceled elective care: such perturbations did occur in less vaccinated states. However the omicron-driving variant surge did require our institution to cut back and begin delaying care early 2022 in compliance with state public health department curbs. This suggests that lessons learned from the disrupted subspecialty care during the first wave of the pandemic remain salient.

Here, we present one of the first systematic patient-centered assessments of disrupted gastrointestinal care during the COVID-19 pandemic in an attempt to determine how best to preserve the therapeutic alliance should future disturbances occur in US healthcare and guide communication strategies to minimize patient unease. The framework derived from these interviews (Fig. 1) reveals that in three separate domains (or, themes)

there are factors that pull patients and providers towards resuming gastrointestinal care or that result in increased likelihood of care being delayed or disrupted during future waves, as can be seen by diametrically opposed responses to the same question prompt (Table 3). For example, there may be a patient for whom in-person care is appropriate given favorable pandemic parameters such as decreasing cases. Yet, they may have underlying medical conditions that make them reticent to resume in patient care or if they are from a traditionally disadvantaged community are worried that if they become sick when coming into care they will not be able to pay rent at the end of the month. Or, there may be patients who are anxious to resume care in states where the pandemic is easing once hospitalizations are decreasing but, cannot do so because healthcare systems are applying the breaks to in-person care due to healthcare shortages.

Our patients represent among the most challenging cases when healthcare distribution is impacted by viral surges: they have chronic symptoms that do not rise to the urgency of emergent intervention yet are longstanding and debilitating enough to make any delay frustrating. What we show is the need to individualize communication talking points and leverage existing provider to address these widely varying considerations. It is possible to understand patients’ preferences only through systematic study by applying qualitative semi-structured methods where patients are able to freely highlight frustrations and fears surrounding disrupted subspecialty care. Patients whose care is deemed urgent may be too fearful to pursue it even if providers insist they should present for care irrespective of local COVID-19 parameters. Those patients with less urgent need for in-person care may not tolerate delays even this is demanded of them as variants cause local surges or elective care is compromised by health care workers quitting in the face of vaccine mandates. Those with the same

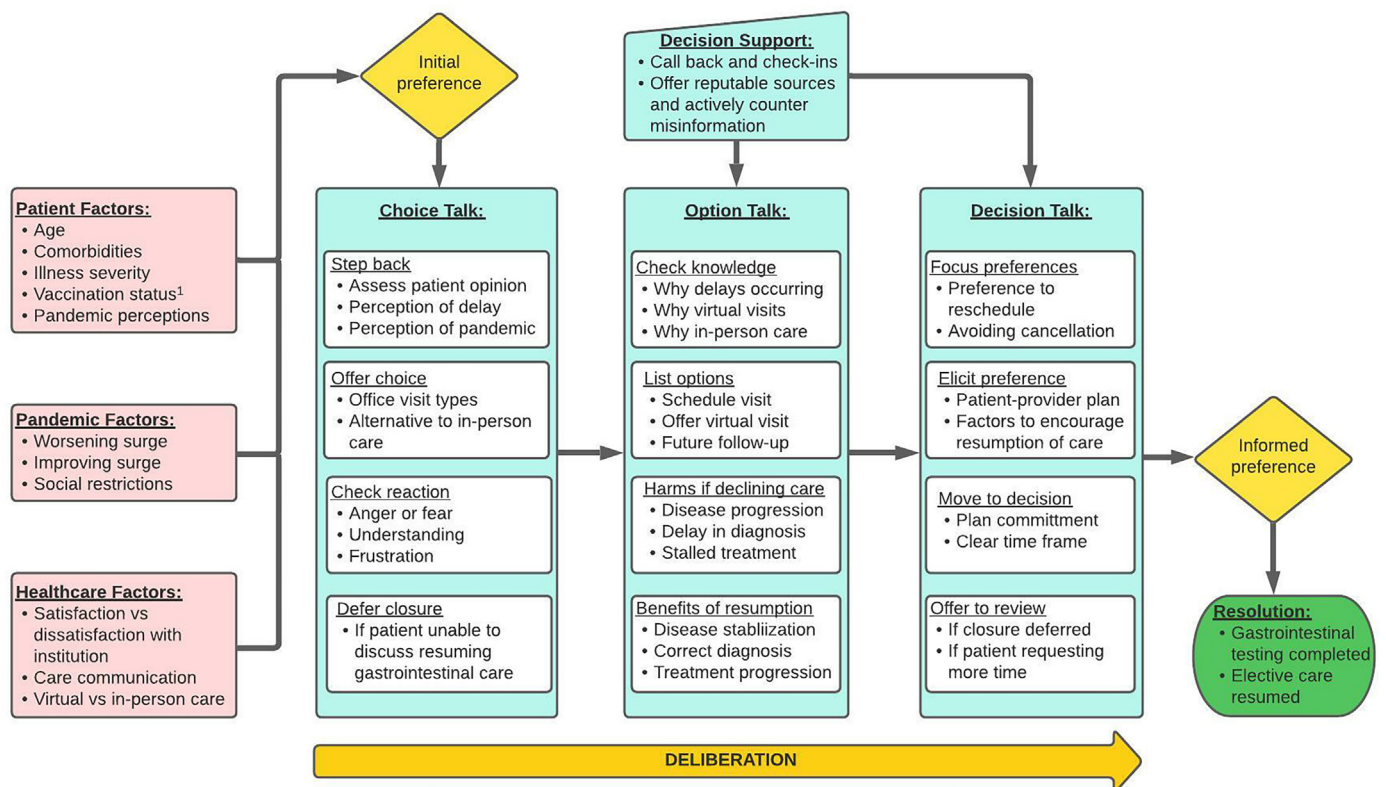


Fig. 1. Integrated framework of patient perspectives into the shared decision making model. Our methods revealed that patient perceptions to disrupted gastrointestinal care were highly variable with themes centering on patient-specific factors, pandemic-related factors, and healthcare function informing patients’ initial preferences surrounding resumption of subspecialty care. They are adapted from description of the model described by Elwyn *et al* [29], represented here in green, blue, and yellow. Within each of the 3 themes (represented in pink), there are at times diametrically opposed conceptions that can be resolved via the use of the shared decision making model between patients and providers to move towards resumption of care through thoughtful patient-focused deliberation and communication. (For interpretation of the references to colour in this figure legend, the reader is referred to the web version of this article.) (1) Vaccination was not queried officially as interviews occurred summer 2020 before vaccines were available. Undoubtedly, vaccination status (of patients, healthcare workers) would influence patient’s perception of risk.

Table 3

Simplified framework matrix. A sample of questions that were asked as part of the semi-structured interview is represented with sample codes that derive from patient quotations. During transcript analysis, 4 “parent” codes categorized a total of 30 “child” codes, which themselves were grouped into 151 subsidiary codes.

Sample Question	Sample Codes	Sample Quotes
How much worry have you been experiencing in the past week related to the COVID pandemic?	<p><u>Concern about becoming ill:</u></p> <ul style="list-style-type: none"> - Predisposing condition making COVID-19 infection worse - Worsened overall health <p><u>Lack of concern about being ill:</u></p> <ul style="list-style-type: none"> - Restrictions themselves will make me ill - Health overall improving. 	<p>“One, I’m in real good health in terms of being in shape and I exercise a lot, bike a lot. But just my age and also the fact that I have diabetes which I’m not a good candidate to be getting the virus. So those kind of things. It’s not like a paranoid. It’s just that I want to be safe, stay safe, and really be careful in that respect.”</p> <p>“I mean, I think that it’s reasonable to worry about, potentially getting sick. But I feel a young, healthy person, I would be okay if I got sick.” But I wasn’t phased by it. Actually, I was kind of relieved. I didn’t want to go in while they were still trying to figure out what was going on.”</p> <p>“Because of the current situation with COVID they had decided that no procedure was going to be done in the hospital unless it was an emergency. So my case was not an emergency, even though for me it was an emergency because I had to live with it”</p>
What were you told about the need to delay your motility/endoscopy test? What were your initial reactions to this news?	<p><u>Relief</u></p> <ul style="list-style-type: none"> - Support at home - Glad testing was canceled <p><u>Frustration</u></p> <ul style="list-style-type: none"> - Disappointment testing was canceled - Everyone is focusing on COVID-19 but I’m sick from not-COVID reasons. 	<p>“It wasn’t a big concern. I don’t mean it like that. They obviously cared but it wasn’t a big-- there was so many other things going on that no one had actually even asked me about it, so. Yeah.”</p> <p>“And my wife agrees that, “Yeah, I can see why you’re not having that test.”</p> <p>“My sister was a little concerned because she had noticed that I was having a little bit of problems swallowing. But, like me, she kept saying, ‘It’s better to be safe.’”</p>
How did your family/friends react to the news that your motility/endoscopy test would be delayed until the end of the pandemic? How has their input influenced your views of the situation	<p><u>Agreed with delay:</u></p> <ul style="list-style-type: none"> - Relatives had medical care deferred as well - Relatives in healthcare explained delay <p><u>Supportive of patient:</u></p> <ul style="list-style-type: none"> - Provided reassurance <p><u>Worried by delay:</u></p> <ul style="list-style-type: none"> - Concern about patient getting ill 	<p>“I would say COVID, and I say that because– I keep referring back to the GI problem is underlying to a much bigger issue. So if that issue were thrown in the mix, it would be scleroderma first and then COVID”</p> <p>“Again, just depending on- early on it was the COVID concern and now it’s just more the concern about the GI issue and just trying to get that resolved before my lung issue gets– before it starts to affect my lungs again, so I’d say now, probably more the GI issue.”</p>
Everything considered, which would you say has you worried more: COVID or your gastrointestinal/motility problem?	<p><u>COVID-19 worries me more:</u></p> <ul style="list-style-type: none"> - Not understanding a lot about a new virus <p><u>My illness worries me more:</u></p> <ul style="list-style-type: none"> - Because disease could be decompensating - Gastrointestinal illness will be around after the pandemic is over 	<p>“I would say COVID, and I say that because– I keep referring back to the GI problem is underlying to a much bigger issue. So if that issue were thrown in the mix, it would be scleroderma first and then COVID”</p> <p>“Again, just depending on- early on it was the COVID concern and now it’s just more the concern about the GI issue and just trying to get that resolved before my lung issue gets– before it starts to affect my lungs again, so I’d say now, probably more the GI issue.”</p>

disease may have radically different perceptions of the risks versus benefits of presenting for the elective care of their chronic illness and will need to receive different patient information tailored to their concerns and perceptions. While vaccines offer a tantalizing promise of an end to the pandemic the procedure backlog generated by restricted elective care that will be a potential health crisis itself [26-28]. As we march through this tumultuous decade of the 21st century, even if herd immunity were achieved in developed countries, providers likely will still be dealing with the ramifications of disrupted care that will require understanding of patients' perceptions of the impact of the pandemic on their care in order to address fears, anger, and distrust that may have developed (risks highlighted by the patients interviewed here).

4.2. Innovation

Here, we introduce a novel application of the shared decision making model to subspecialty care during the pandemic. In our framework diagram (Fig. 1), we have included how to consider the themes of patient-, pandemic-, and healthcare-specific factors that result in variable initial patient preferences. Mutual provider and patient deliberation can resolve variable patient perceptions using shared decision making [29]. It offers a practical and flexible way in which to help guide communication strategies for patients towards the ultimate endpoint of resuming elective gastrointestinal care.

During “choice talk,” when a provider is seeking to re-establish care, open ended questions and stepping back to assess patient's belief (correct or incorrect) is critical. Patients in this study may have conflicting perceptions of the pandemic. Before accepting a “no” from a patient who may not accept that despite the pandemic having improved that procedures are delayed due to staffing shortages, offer choices such as an office visit or consider a virtual visit to maintain a therapeutic alliance for a patient who cannot obtain affordable child care. Take time to reflect: some patients may be ecstatic delaying care further because they did not want to have testing or will be angered that they cannot get care. During “option talk,” make sure patients are aware of the ramifications if they decline testing once it is available (for example, inability to be listed for transplantation if a transplant center requires colorectal cancer screening). List options that may give some information if gastrointestinal procedures are not available (for example, computerized tomography colonoscopy). If patients decline to resume care, emphasize benefits (such as remaining on a transplantation list). Finally, during decision talk, before concluding a patient encounter, focus and elicit preference and move to a decision (for example, prior to canceling a screening colonoscopy for a patient on the lung transplant list because cases are surging, reschedule for 2–3 months in the future when cases should have eased). Throughout this deliberative process (which may be iterative if decision support is needed for the patient unable to confirm to a decision), the initial patient preference becomes an *informed* patient preference. Should application of the shared decision making model be successful, this results in completion of gastrointestinal testing and resumption of elective subspecialty care.

4.3. Conclusion

Our principal limitation of this study was conducted when highly effective vaccines were not available to patients, which initially would seem to present two challenges. First, patients who were concerned about presenting for healthcare likely would feel less so with this additional buffer of protection. They also may be less likely to be understanding about disruptions in care now that they are strongly protected against severe disease. Second, vaccine mandates for health care workers likely will reduce patient fears about in-person care. An additional limitation includes the study consisting of a predominantly female, White, and socioeconomically privileged cohort. However, there are particular strengths to this work gastrointestinal patients in our motility lab represent an ideal cohort to examine such considerations of non-emergent yet non-screening indications for care that are difficult to triage both during surges of the virus as well as nadirs in disease

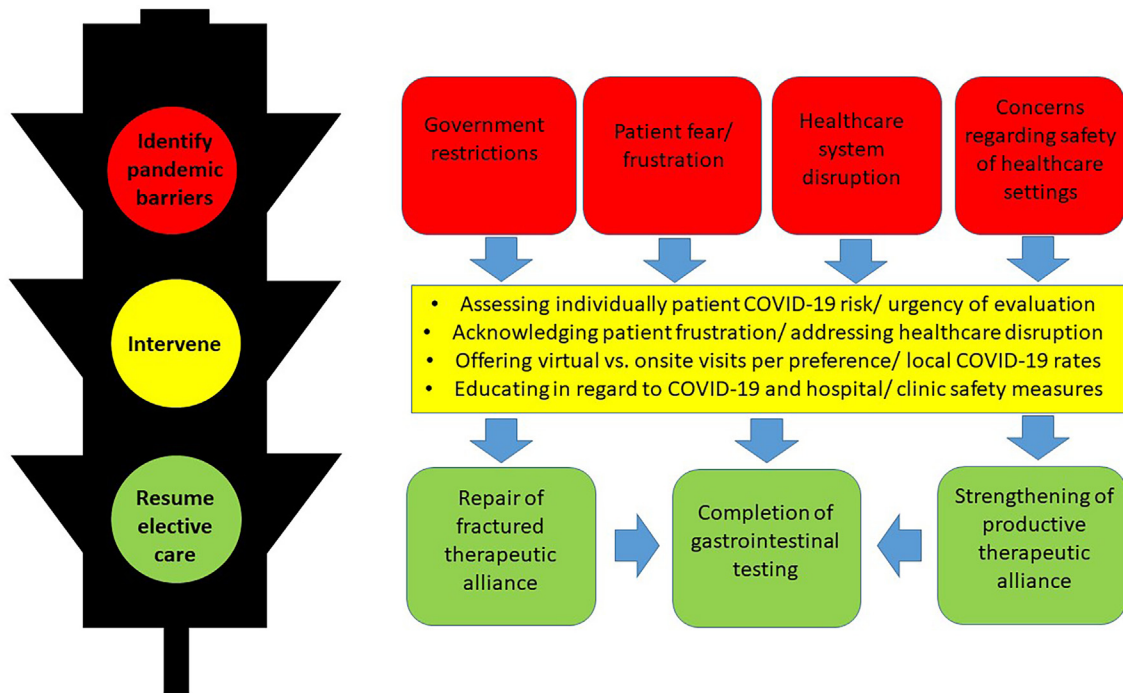


Fig. 2. Approaching disrupted gastrointestinal care. Qualitative methods allow for a patient-centered assessment of potential barriers in care, thus identifying ways in which to address these barriers, to come up with solutions that promote resumption of elective care as pandemic parameters progress.

prevalence. Conditions represented here ranged from nuisance yet non-fatal conditions like fecal incontinence, to more severe organic disease such as those with compromised respiratory function requiring lung transplantation. We suspect the themes described above are broadly applicable to the wider provision of gastrointestinal care.

What our patients have told us about disruptions during the first wave continues to have implications for subspecialty practice in the US. First, tens of millions in the United States are eligible for vaccination and are not vaccinated; they may still not wish to engage in in-person care. Second, vaccinated patients who were initially confident when resuming in-person care may have similar fears as in the pre-vaccine era in the face of the delta and omicron variants due to break through infections. Third, some of the most severe pandemic-related restrictions in US health care, the crisis standards of care initiated in Idaho and Alaska, have occurred as a consequence of vicious surges that occurred *after* vaccines have been widely available. Finally, with projected backlogs that likely will stretch through 2022, some patients who want to return to in-person testing and care may face delays due to long waiting lists which will leave patients frustrated. Even if the nature of COVID-19 disruptions may differ in the future, healthcare function remains precarious; we should learn from the mistakes we have made with healthcare communication during the first wave of the pandemic to avoid repeating them.

We offer the following recommendations from our patients for GI-related care during the COVID-19 pandemic to improve patient and healthcare communications in three steps. These recommendations, drawn from patient experiences during the first wave of the pandemic, remain applicable given the risk of future disruption as they (1) identify barriers that must be overcome; (2) offer interventions informed by the shared decision making model; and (3) either re-inforce strong therapeutic alliances or repair fractured ones that have suffered during the pandemic (Fig. 2).

(1) **Identify barriers:** Identify how the 3 main themes (patient-, pandemic-, or healthcare-related factors) are influencing patient perceptions of their disrupted gastrointestinal care. When disrupting care, acknowledge the validity of patients' concerns. Even if they state agreement to care delay, it is likely that they have concerns surrounding these changes. Leverage strengths and address patients' stressors to make them feel more at ease.

- (2) **Intervene:** Offer timely access to telemedicine with a clinical provider particularly for those more fearful urgent patients. When possible, offer in-person care when local coronavirus parameters are favorable. Ask patients for their visit preference. Clearly communicate measures to reduce risk of COVID-19 related healthcare exposure and how the pandemic is propagating through the local community. Remind them not to delay urgent/emergent care. In areas with high healthcare worker vaccination: remind patients of this. In places with limited healthcare worker vaccination: emphasize how personal protective equipment keeps patients safe. Offer concrete steps and discuss published data when making plans for follow-up (e.g. frequent updates to patients awaiting diagnostic testing, when crisis standards of care are being de-activated). For the vaccinated who are nervous pursuing in-person care, remind them of their excellent protection from severe illness.
- (3) **Resume elective care:** In patients with whom you are struggling to connect due to their frustration with deferred care: explore ways to resolve difficulties even during surges where care is curtailed or if there are long waiting lists once surges subside. For patients with whom the physician-patient relationship is sound, leverage this to keep patients content.

Author contributions

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Declaration of Competing Interest

The authors listed certify that they have no affiliations with or involvement in any organization or entity with any financial or non-financial interest in the subject matter or materials discussed in this manuscript. This work received no funding.

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