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REVIEW

Shared Decision Making in Gastroenterology: Challenges and Opportunities

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Abstract

This article reviews the current uses of shared decision making in gastroenterology and discusses additional areas of opportunity for shared decision making, especially in the area of functional gastrointestinal disorders. PubMed, MEDLINE, and Cochrane library databases were searched for articles published during a 10-year period from January 1, 2007, through December 31, 2017. Search terms included *shared decision making and gastroenterology*, *shared decision making in gastrointestinal disease*, *shared decision making in functional GI disorders*, and *shared decision making and irritable bowel syndrome*. Studies were not included in this review when a health care professional other than a gastroenterologist was involved, eg, an article that reported shared decision making regarding the use of radiation therapy in a patient with advanced rectal cancer in which the health care professional helping to make the decision was an oncologist.

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In this article, we review the current uses of shared decision making (SDM) in gastroenterology and discuss additional areas of opportunity for SDM, especially in the area of functional gastrointestinal disorders. For this review, PubMed, MEDLINE, and Cochrane library databases were searched for articles published during a 10-year period from January 1, 2007, through December 31, 2017. Search terms included *shared decision making and gastroenterology*, *shared decision making in gastrointestinal disease*, *shared decision making in functional GI disorders*, and *shared decision making and irritable bowel syndrome*. Studies were not included in this review when a health care professional other than a gastroenterologist was involved, eg, an article that reported SDM regarding the use of radiation therapy in a patient with advanced rectal cancer in which the health care professional helping to make the decision was an oncologist.

ABOUT SARAH

Sarah is a 27-year-old schoolteacher who presents for evaluation of poorly controlled diarrhea-predominant irritable bowel syndrome (IBS) properly diagnosed 6 years ago. She has had symptoms since high school. Initially intermittent, her symptoms—bloating, cramping, fecal urgency, and diarrhea—are now persistent and worsening. Loperimide, nortriptyline, and colesevelam have not alleviated her symptoms. Her stools vary from Bristol stool type 3 to type 6 or 7, rarely type 3 or 4. She has untreated anxiety. Her behavior has changed because of her symptoms. She foregoes breakfast or lunch to avoid disruptions at work, plans her day around bathroom access, and avoids social events when such access is uncertain.

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CARING FOR PATIENTS AND SDM

On hearing Sarah's history, a gastroenterologist might complete the evaluation, confirm her diagnosis, and then make an evidence-based treatment recommendation. An alternative approach may require going beyond her physical illness to learn about Sarah, especially aspects of her life that may be effecting, or affected by, her condition and her goals related to treatment. Sarah is the expert about herself, and her engagement is essential for arriving at a more holistic understanding of her situation and, in turn, a caring response.

To provide the best care for Sarah, the gastroenterologist and Sarah need to communicate with each other to develop a common understanding of both her situation and those aspects of her situation that need to be

ARTICLE HIGHLIGHTS

- Shared decision making is one of several treatment decision-making models. Shared decision making is unique in that it creates an open space in which both patient and clinician can share equally in the decision-making process.
- Shared decision making is distinct from and goes beyond patient education or the provision of informed consent in that it is bidirectional communication wherein the patient gains insight into treatment options and the clinician gains an appreciation for what matters to the patient.
- Decision aids are designed to promote active participation and provide a structure and tone for conversation, and although helpful, they are not required for shared decision making to occur.
- Shared decision making works best in circumstances in which there is no definitive best answer for the problem at hand.

addressed using evidence-based treatment approaches. With this diagnostic process, Sarah and her physician can discuss available options and consider each potential approach for resolving Sarah's disease burden to determine an appropriate path forward that is evident to both of them. This dynamic and interactive process is what occurs when patients and clinicians engage in SDM.

Shared decision making is one of several treatment decision-making models.[1] What is unique about SDM is that it outlines a process through which both patient and clinician can share equally in the decision-making process, with the clinician as the expert in treatment options and the patient as the expert in their preferences, priorities, and lifestyle. Other commonly used models are the paternalistic approach,[2] in which the clinician simply tells the patient what they should do, and the informational or educational model,[2] which gives all decision-making power and responsibility to the patient. Shared decision making, on the other hand, creates an environment in which communication between doctor and patient is paramount and all decisions are derived through the process of patient-physician communication. Shared decision making is often facilitated or standardized through the use of specific steps to follow or through the use of decision aids. One of many examples of standardized steps is the 5-step SHARE Approach for effective SDM[3]: (1) seek your patient's participation, (2) help your patient explore and compare treatment options, (3) assess your patient's values and preferences, (4) reach a decision with your patient, and (5) evaluate your patient's decision. In contrast, decision aids are educational tools that facilitate decision making, generally by providing evidence-based information and perspectives through print, online, or video formats.[4,5] Decision aids are designed to promote active patient and clinician participation and to help people think through their preferences and priorities so they can arrive at a decision that reflects their values and needs. These tools can provide a structure and tone for the conversation, helping to guide, illustrate, or even quantify elements of the patient's situation (eg, the patient's estimated lifetime risk of colon cancer). To accomplish this, certain design features are used, such as icon arrays and natural frequencies to pictorially display risk percentages (Supplemental Appendix 1, available online at http://www.mcpiqojournal.org). These features, combined with plain language, present options that both patient and physician can communicate about in a concrete way and help to overcome common barriers to patient involvement in the medical decision-making process.[6]

Although useful for introducing simple clinical behaviors, mechanically or routinely following the steps of SDM does not necessarily lead to patient-centered care. To succeed, SDM must take place in the context of humanistic bidirectional communication. This process necessitates open-mindedness from both participants to problems and treatments and empathy on the part of the clinician in regard to form, content, and purpose. More importantly, SDM must result in a plan of care that is likely to resolve the patient's problematic situation, one that makes intellectual, emotional, and practical sense.

Although patient education is a part of SDM, the overall purpose of SDM is distinct from, and goes beyond, the provision of information or asking a patient to prepare for decision making. Some patient decision aids focus on providing the information patients need to

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form their own preferences about the alternatives and outcomes, independent of their doctor. This process is often referred to as *informed decision making*.[1] Shared decision making is also quite different from the current practice of informed consent, which is typically more of a legal requirement than a deliberative process. Shared decision making is a 2-way street wherein patients gain insight into various treatment options and how they may or may not fit into their life and clinicians gain an appreciation for what matters to their patients and what solutions may work in the context of their situation. This goal is achieved in the process of working through a problem together. In this way, SDM shares features with some forms of behavioral modification, eg, motivational interviewing,[7] but differs in that SDM does not start with a "right answer" such as "exercise more" or "quit smoking." One aspect of motivational interviewing, however, termed *active listening*,[2] is also an essential component of SDM, a process whereby both patient and health care professional must be fully engaged in their conversation by listening attentively and, if needed, clarifying what the other has said before moving on in the conversation. Indeed, SDM requires clinicians and patients to genuinely appreciate the potential of each option to reasonably address all of the patient's issues that derive from or are influenced by their illness.

In this way, SDM is pertinent in most situations in which there is not a single, technically correct answer and in which the broader human condition is an important factor. This scenario is commonly the case in patients with chronic conditions and in those who live with poorly understood but debilitating symptoms. This article will review the role, challenges, and opportunities for using SDM in gastroenterology practice. We then depart from this discussion on the state of the art to explore how SDM may help us in the care of Sarah and other patients presenting with functional gastrointestinal disorders.

BACK TO SARAH

In getting to know Sarah, a picture emerges of a young woman with a busy lifestyle struggling to manage her symptoms. Lack of response to medications has isolated her from her work colleagues, as she avoided the lunch room. She even avoided eating at school altogether because she was afraid of having to leave her classroom for the bathroom. Anxious, tired, and hungry, she ate too much food at home in the evenings, gaining 11.25 kg during the past year. Adding to her anxiety was the specter of being overweight and unable to enjoy her own wedding, only 6 months away. Sarah wanted to enjoy her time in the classroom, socialize while eating lunch with her coworkers, lose weight before her wedding, and not worry about spending her wedding day in the bathroom.

SDM IN THE PRACTICE OF GASTROENTEROLOGY

There are many opportunities to improve the care of patients with or at risk for gastrointestinal conditions by implementing SDM. Shared decision making is appropriate, needed, and underdeveloped in the care of patients with motility and functional gastrointestinal disorders including IBS, gastroparesis, and functional dyspepsia. The Table lists some proposed areas of opportunity, many of which await exploration. Investigators have explored the role that SDM can play in other areas including colorectal cancer (CRC) screening[8-12] and treatment for inflammatory bowel disease (IBD),[13-20] Barrett esophagus with low-grade dysplasia,[21,22] and esophageal[23] and rectal[24,25] cancer.

Colorectal Cancer Screening

As people age, their risk of cancer increases. Colorectal cancer is among the most common causes of cancer death in developed countries, often ranking second overall only to lung cancer.[26] One means to reduce CRC morbidity and mortality is early detection and treatment; randomized trials have found that screening for CRC in adults aged 50 to 75 years can reduce disease-specific incidence and mortality.[9] Several screening modalities and intervals are available, so at-risk people must decide whether to participate in a screening program and if so, which modality fits best to their situation.

To date, most of the efforts to improve screening decisions have focused on supporting informed decision making through the use of patient decision aids.[4,5] These tools help patients recognize that they are at risk, review the relative advantages and disadvantages of responding to this risk by screening vs other

TABLE. Areas of Opportunity for Shared Decision Making in Gastroenterology

Disease/condition	Decision	Illustration
Pancreatic cyst	Surveillance or excision	Using the characteristics of the cyst and the patient's degree of comfort with uncertainty to help guide decision
Achalasia	Pneumatic dilation Surgical myotomy, POEM, Botox injection	Risk, benefits, cost, and durability of each treatment alternative
GERD	Proton pump inhibitor, Fundoplication, LINX procedure, Stretta procedure	Risk, benefits, cost, and durability of each treatment alternative, recovery time
Gastroparesis	Medication choices/adverse effects, Enterra device (Medtronic), Botox injection	Risk of adverse effects, drug interactions, cost, efficacy
IBS	Medication, Hypnosis, CBT	Drug interactions, adverse effects, efficacy, availability, and time commitment

CBT = cognitive behavioral therapy; GERD = gastroesophageal reflux disease; IBS = irritable bowel syndrome; LINX = magnetic sphincter augmentation system (Torax Medical); POEM = peroral endoscopic myotomy.

options (no screening, aspirin use), review the available screening modalities in comparison with one another, and integrate this information along with the patient's own values and preferences into a preferred option. Volk et al[12] performed a systematic review of studies examining these decision aids and found that they consistently increased knowledge and, presumably as a consequence, interest in and intent to receive screening.

Inflammatory Bowel Disease

The increasing array of treatment options and the chronic nature of IBD favor using SDM in the care of these patients. Multiple studies have indicated that patients with IBD, as well as parents of children with IBD, want to be actively involved in decision making[13,16,18,27] and desire close collaboration with their clinician.[13] Such involvement in decision making has been associated with increased satisfaction[18] and activation[15] among patients with IBD. Furthermore, patient engagement in treatment decisions has been associated with a greater likelihood of treatment adherence and decreased health care costs.[15] Clinicians report similar enthusiasm for SDM,[14,19] mitigated in part by reimbursement and time barriers.[14,18] Here too, several SDM tools exist that target both medical[20,26] and surgical[28] decisions, but their efficacy has not been reported.

Barrett Esophagus

Patients with Barrett esophagus with low-grade dysplasia can receive care with SDM as they consider whether annual endoscopic surveillance or radiofrequency ablation is best for them. An SDM tool for use during the clinical encounter, BE-Choice, was prospectively assessed in a before/after study with 29 patients, 8 of whom received usual care and 21 care with the SDM tool.[21] Despite its small size, this pilot study documented that the use of the SDM tool significantly improved patient knowledge and involvement in SDM.

SDM IN FUNCTIONAL DISORDERS

Functional gastrointestinal disorders are a heterogeneous group of disorders sharing in part the common characteristics of central sensitization and visceral hypersensitivity. Comorbidities such as diabetes and neuropathy with gastroparesis or fibromyalgia and migraine with IBS are common. Irritable bowel syndrome is the most commonly diagnosed gastrointestinal condition, affecting up to 1 in 5 people in the community at some point in their lives.[29] It reduces patients' quality of life and leads to lost productivity and high health care utilization. Management of IBS often requires eliminating exacerbating factors (eg, certain drugs, stressors, foods) and using symptom-specific medications such as antispasmodics and antidepressants, although these treatments have limited effectiveness, potential adverse effects, and increasing costs.[30] These limitations have increased the appeal of mind-body complementary and integrative approaches, including hypnosis, mindfulness, yoga, meditation, and acupuncture.[31] The limited evidence of effectiveness for these interventions prevents their routine inclusion in IBS guidelines. In addition to offering participation in clinical trials of these interventions, clinicians could review these options with patients, particularly those who have experienced harmful effects from evidence-based alternatives.

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CHALLENGES TO SDM IN GASTROENTEROLOGY PRACTICE

Gastroenterologists and other clinicians are facing increasing time pressures during consultations. Particularly troubling is the distraction from patient-clinician interactions brought by fulfilling requirements for documentation for reimbursement and billing. For clinicians who consider SDM as an add-on to their care process, there may not be more time, attention, or energy available to implement SDM, even though the use SDM tools has been associated with only a 2- to 3-minute increase in discussion time.[32] For clinicians who conceptualize SDM as a way of caring for patients, however, another challenge is making themselves available intellectually and emotionally to notice each patient and to cocreate a treatment plan that makes sense to that individual patient. Yet, clinicians may be increasingly unavailable, as they personally struggle with empathy loss, depersonalization, and symptoms of burnout.[33,34] Paradoxically, meaningful patient interactions, typical of SDM, could themselves protect clinicians from burnout.[35]

The proceduralist's mind-set may represent another challenge to SDM. This mind-set calls for identifying a fix or definitive solution to the problem, which can be counterproductive in patients with functional disorders. This issue may explain the myriad patients with IBS or chronic abdominal pain exposed to too many computed tomographic scans, endoscopic interventions, and even surgical explorations looking for something to fix or to remove. Concerns exist that financial incentives—typically greater for procedures than for clinical conversations—may drive proceduralists and their functional patients inappropriately to testing and invasive therapy. In support of this concern, Longstreth and Yao[36] found that "health examinees with physician-diagnosed IBS report rates of cholecystectomy 3-fold higher, appendectomy and hysterectomy 2-fold higher, and back surgery 50% higher than examinees without IBS." A diagnosis of IBS was independently associated with these surgical procedures.

Clinicians willing to engage with their patients in SDM benefit from using tools able to support patient involvement and the cocreation of treatment programs. These tools may also help correct biases in the presentation of options and their features. Kunneman et al[25] found that radiation oncologists discussed fewer than 50% of the recommended risks and benefits of radiation and were more likely to discuss its benefits than its harms with patients with rectal cancer considering preoperative radiotherapy. Shared decision-making tools may also help patients engage in decision making, particularly those who may be reluctant to ask questions or challenge clinician recommendations for fear of being perceived as difficult or a bother. This issue was documented by the work of Henselmans et al[23] assessing information needs of patients postoperatively after resection of esophageal cancer. Few SDM tools are available for gastroenterological concerns, even fewer have been studied in practice, and none, to our knowledge, are implemented routinely in the care of patients.

WHAT HAPPENED TO SARAH

After a thorough conversation, and with an eye to her upcoming wedding, Sarah and her gastroenterologist codeveloped a treatment plan. Building on Sarah's growing interest in mindfulness, something that arose in conversation, the plan included training in diaphragmatic breathing to aid in managing her anxiety. Because of her dry mouth, the nortriptyline was discontinued. After considering venlafaxine, an antidepressant capable of reducing gastric motility and mitigating anxiety, and alosetron, a selective 5-hydroxytryptamine receptor 4 antagonist useful in diarrhea-predominant IBS, they decided to try the latter. After 6 months, Sarah reported having fewer and milder IBS symptoms. After stopping the nortriptyline, she became quite anxious, however, and the medication was restarted at a lower dose. She was able to eat 3 meals a day with less fear of class interruptions or social interactions to use the restroom. She also was able to implement a daily 2- to 3-mile walk without having to keep the nearest bathroom in sight. She lost 4.5 kg and felt healthy at her wedding. Sarah's IBS has improved, albeit not completely, and she is certainly doing better at coping and thriving with IBS.

CONCLUSION

Shared decision making enriches the clinical interactions that we have with our patients, allowing us to see them more fully as multidimensional people. By participating in SDM, we are better able to bring into focus the problem that needs fixing and how that solution may fit into a patient's life and lifestyle. In the field of gastroenterology and especially in caring for patients with functional gastrointestinal tract disorders, we often find ourselves in the situation in which there is not a black-and-white answer to the problem but rather several reasonable solutions. It is our opinion that this not only likely uncovers misunderstandings or misconception on the part of both the clinician and the patient with regard to disease burden and treatment but also leads to a more fulfilling clinical practice.

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SUPPLEMENTAL ONLINE MATERIAL

Supplemental material can be found online at: http://www.mcpiqojournal.org. Supplemental material attached to journal articles has not been edited, and the authors take responsibility for the accuracy of all data.

Abbreviations and Acronyms: **CRC** = colorectal cancer; **IBD** = inflammatory bowel disease; **IBS** = irritable bowel syndrome; **SDM** = shared decision making

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