Management of gastroesophageal reflux disease: Patient and physician communication challenges and shared decision making

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Abstract

Gastroesophageal reflux disease (GERD) is a common upper esophageal condition and typical symptoms can include heartburn and sensation of regurgitation while atypical symptoms include chronic cough, asthma, hoarseness, dyspepsia and nausea. Typically, diagnosis is presumptive given the presence of typical and atypical symptoms and is an indication for empiric therapy. Treatment management can include lifestyle modifications and/or medication therapy with proton pump inhibitor (PPI) class being the preferred and most effective. Complete symptom resolution is not always achieved and long-term PPI therapy can put patients at risk for serious side effects and needless expense. The brain-gut connection and hypervigilance plays an important role in symptom resolution and treatment success, especially in the case of non-PPI responders. Hypervigilance is a combination of increased esophageal sensory sensitivity in combination with exaggerated threat perception surrounding esophageal symptoms. Hypervigilance requires a different approach to GERD management, where continued PPI therapy and surgery are usually not recommended. Rather, helping physicians and patients understand the brain-gut connection can guide and improve care.
Education and reassurance should be the main pillars or treatment. However, it is important not to suggest the symptoms are due to anxiety alone, this often leads to patient dissatisfaction. Patient dissatisfaction with treatment reveals the need for a more patient-centered approach to GERD management and better communication between patients and providers. Shared decision making (SDM) with the incorporation of patient-reported outcomes (PRO) promotes patient adherence and satisfaction. SDM is a joint discussion between clinician and patient in which a mutually shared solution is explored for GERD symptoms. For SDM to work the physician needs to capture patients’ perceptions which may not be obtained in the standard interview. This can be done through the use of PROs which promote a dialogue with patients about their symptoms and treatment priorities in the context of the SDM patient encounter. SDM could potentially help in the management of patient expectations for GERD treatment, ultimately positively impacting their health-related quality of life.

**Key words:** Gastroesophageal reflux disease; Psychosocial; Patient-physician communication; Shared decision making; Patient-reported outcomes; Patient satisfaction

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Core tip: Gastroesophageal reflux disease management can be complex and is affected by psychosocial factors. Physician-patient communication improvement and shared decision making are two approaches that could improve patient-reported outcomes and patient satisfaction.

**DEFINITION**

GERD is defined as a group symptoms or a presence of mucosal damage caused by abnormal reflux of highly-acidic gastric content into the esophagus or beyond, including into the oral cavity or respiratory pathways[8]. The symptoms of GERD are classified as typical symptoms that include heartburn, sensation of regurgitation and atypical symptoms which are associated with chronic cough, asthma, hoarseness caused by laryngitis, dyspepsia and nausea[9]. Another group of symptoms are defined as alarm symptoms since they can be potentially associated with life-threatening conditions (chest pain/myocardial infarction, dysphagia/esophageal stricture or malignancy)[10]. About 70% of GERD patients have non-erosive reflux disease (NERD). These patients report symptoms related to acid exposure, but do not have mucosal damage[11]. Untreated and chronic GERD may lead to serious complications including peptic stricture, Barrett’s esophagus and esophageal adenocarcinoma[12].

**DIAGNOSIS OF GERD**

In most cases the diagnosis is presumptive. The accurate diagnosis of GERD relies on the careful questioning of the patient by the provider. Many patients do not report their symptoms of GERD and receive no treatment[13]. Facilitating effective communication between patient and provider at the beginning of treatment has been shown to improve patient experience and satisfaction. The presence of typical and atypical symptoms and the absence of alarm symptoms is considered an indication for empiric therapy[14]. A positive response to PPI therapy is used as a conformation of initial GERD diagnosis[15]. This approach to diagnosis of GERD has a high specificity with low sensitivity. Counterintuitively, studies have demonstrated that patients are consciously aware of only 2 to 3 percent of acid reflux events[16]. Additionally, many...
patients present with atypical symptoms that are not used as clear markers for diagnosis\textsuperscript{[15]}. The frequent lack of clinical correlation between the patient’s perception of typical symptoms and episodes of reflux points to the complex nature of GERD symptom production which will be explored in detail in later sections. The older proactive testing with barium contrast radiography has fallen out of favor due to low sensitivity and specificity. The most reliable method of diagnosis remains direct visualization and identification of esophageal injury obtained by endoscopy of the upper GI tract including tissue biopsy demonstrating mucosal damage\textsuperscript{[8,16]}. This diagnostic method is not, however, bulletproof. Most patients with typical symptoms of GERD do not present with abnormal findings on the upper gastrointestinal endoscopy exam. The upper GI endoscopy is usually reserved for evaluation of GERD-associated complications and placement of wireless pH probes. Wireless pH probes are used in ambulatory 24-h pH monitoring allowing direct measurement of esophageal exposure to gastric acid. This diagnostic method can be used to quantify a reflux frequency and provide information on the association between the timing of symptoms and actual reflux episodes\textsuperscript{[8]}. The widespread use of 24-h pH probes has led to the identification of a subset of patients with typical GERD symptoms who do not respond to PPI\textsuperscript{s}. These PPI-refractory symptoms have been shown, with the use of pH-impedance testing, to be related to continued episodes of reflux\textsuperscript{[20]}. This testing method has also demonstrated that only 5%-15% of reflux events correspond to patient symptoms\textsuperscript{[27]}. One advantage of this diagnostic procedure is that it is associated with very little discomfort to patients allowing them to resume their normal lives during the testing period\textsuperscript{[17-19]}. The most common complication associated with this method are poor data reception, dysphagia, increased number of reflux episodes, early capsule detachment and failure of scheduled detachment\textsuperscript{[20]}. The more traditional method of ambulatory esophageal acid monitoring is through the placement of transnasal catheter with pH sensor capability. The method is shown to be a very accurate, however, its utilization is hindered by patient discomfort and limitation of daily activity\textsuperscript{[21]}.  

**THERAPY**

The initial treatment of GERD should include lifestyle modifications with education about the factors precipitating physiological and pathological reflux\textsuperscript{[22,23]}. This includes advice on diet, alcohol and tobacco use, sleep position and weight loss. Although many patients are advised to avoid certain foods, there is little evidence this is helpful. Rather losing weight, stopping smoking, elevating the bed headrest and avoiding late evening meals can substantially reduce symptoms\textsuperscript{[24]}.  

The next step in treatment of GERD is initiation of acid suppression therapy. Several classes of medications are used for acid suppression: antacids, histamine-receptor antagonists and PPIs. The PPIs are the preferred medication for treatment of GERD. They have been shown to be a highly effective tool against injuries associated with erosive gastritis and their effect is achieved much faster than other medication alternatives\textsuperscript{[25]}. Proven effectiveness and wide popularity of PPIs has resulted in FDA approval of over-the-counter sale of this group of medications.  

Surgical therapy is usually reserved for patients who do not respond well to acid suppression medication, patients who prefer surgical approach, and patients who present with complications due to GERD\textsuperscript{[15]}. Prior to recommending surgery, it needs to be established heartburn is due to GERD and not another reason. The majority of these patients undergo Nissen fundoplication, however, several alternative techniques such as endoscopic radiofrequency energy delivery technique and minimally invasive surgical procedures have also been used\textsuperscript{[26]}. Long-term complications of these surgical procedures include bloating and gas-bloat syndrome, dysphagia, diarrhea, recurrent heartburn and recurrent atypical symptoms\textsuperscript{[27]}. Bariatric surgery for weight loss has been evaluated for its effect on GERD. Evidence shows improvement of GERD symptoms, mostly due to weight loss, although some patients develop GERD symptoms after surgery\textsuperscript{[28,29]}. The majority of patients will not require surgery. Acid suppression such as PPIs remains the most common treatment for GERD. However, emerging studies indicate a presence of side effects with long-term use of these drugs. The chronic usage of PPIs has been associated with malabsorption of calcium, magnesium and Vitamin B\textsubscript{12} which can ultimately lead to an increased risk for bone fractures\textsuperscript{[30,31]}. Various studies have also indicated a potential link between PPI use and increased incidence of community acquired pneumonia\textsuperscript{[32]} and enteric infections\textsuperscript{[33,34]}. PPIs are also found to interact with cytochrome P450 isozyme 2C19 which can result in interference with metabolism of other co-administered drugs (clopidogrel) prompting an FDA warning\textsuperscript{[32]}. Recent studies have found increased risk of chronic kidney disease with PPI use\textsuperscript{[35-40]}. Finally, a Nationwide study in Denmark found an association between PPI use and microscopic colitis\textsuperscript{[41]}. Hence, use of these medications, especially over the long-term, may need to be weighed against their potential risk of side effects. Patients who have a positive response to PPI therapy can be reluctant to taper off and stop treatment. Limiting unnecessary PPI exposure should therefore a treatment goal to reduce risk of the above mentioned side effects. In observational primary care and community-based studies, 45% of participant reported persistent, troublesome heartburn symptoms despite PPI therapy\textsuperscript{[3]}. One study noted that 42% of PPI non-responders remained on a PPI with no clinical benefit even after showing they had no acid reflux\textsuperscript{[42]}. Up to 50% patients with GERD symptoms do not respond to a double-dose\textsuperscript{[15,43]}. These numbers suggest that many patients are taking PPIs without any clinical benefit. Effective communication with patients should
include discussion of persisting troublesome symptoms. Providers and patients often do not explicitly address these concerns. Even in patients who have responded to PPIs, long term use is often unnecessary. The majority of PPI responders can successfully step-down their use of PPIs without negatively affecting their quality of life (QOL)[44,45]. Overuse and misuse of PPIs leads to needless expense, increased risk, and no benefit to patient experience or satisfaction. Providers must take the time to communicate the relative risks and benefits of PPI treatment, especially the benefits of discontinuation.

PSYCHOSOCIAL FACTORS CONTRIBUTING TO PATIENT OUTCOME AND PATIENT SATISFACTION

Understanding the factors associated with PPI treatment non-response continues to be a challenge. Possible factors conjectured include persistent or weakly acid reflux, and an impaired esophageal mucosa. However, there is more going on here than just acid exposure and tissue damage. Taken from another perspective, one study found that more than half of a general population sample reported symptoms of heartburn, and severity of their symptoms was the same as reported by patients seen in a gastroenterology[1]. This suggests that care seeking for GERD is not related to symptoms or mucosal damage alone, and should be considered within a wider context.

The central importance of the brain-gut bi-directional communication pathway cannot be overstated. The central nervous system (CNS), through neural, hormonal, and immunological bi-directional communication with the gut, maintains normal gastrointestinal functioning and helps modulate disease activity[46]. Psychological factors, such as stress, can influence gut functioning and also influence perception of peripheral gut nerve input to the CNS all of which may impact clinical outcomes in GERD[46]. Thus, there is a continuous feedback loop between the brain and the gut and it is increasingly recognized that you cannot treat one without the other.

The brain-gut axis can be helpful in explaining why symptoms can persist despite treatment. Hypervigilance to gut input is thought to play a central role in understanding why some patients continue to report symptoms despite healing of the esophageal mucosa. Hypervigilance is a combination of increased gut sensory sensitivity in combination with exaggerated threat perception surrounding gut symptoms. Kahrilas and colleagues defined it as the “cognitive-affective process that stems from hyperawareness of discomfort. This heightened awareness or sensitivity is coupled with behavior that is out of proportion to the prior symptom experience, serving to amplify the ‘threat-level’ of symptoms and their potential consequences”[47]. In other words, some patients are highly sensitive to gut inputs. These patients feel discomfort at levels where other people may not notice and/or be bothered by it (visceral hypersensitivity). Hypervigilance is the combination of increased symptoms due to visceral sensitivity as well as a high level of threat associated with these symptoms (“In order to be in this much pain, there must be something really wrong”). Hypervigilance often leads to avoidance of situations that may trigger symptoms, such as eating certain foods, restaurants and even sleep[1,48,49]. These patients strictly monitor their symptoms and become caught in a negative feedback loop of discomfort, pain and anxiety. Indeed, anxiety has been associated with persistent reflux symptoms despite PPI therapy and increased visceral hypersensitivity[50].

In one study, hypervigilance accounted for 50% of patient-reported symptom severity while psychological distress (depression, anxiety, somatization) was found to be within normal limits in the treatment refractory group[51]. More medicine and more diagnostic procedures will not help these patients. Similarly, avoiding surgery in these patients is critical as outcomes may be poor in this patient population. Rather, helping physicians and patients better understand and appreciate the brain-gut connection can guide and improve care.

Physicians have to treat the whole person and focus on the patient experience. Physicians must recognize these underlying patient dynamics and not ignore or discount them. More PPI, more testing or surgery is not the answer. However, suggesting their symptoms are due to their anxiety is not helpful either. Patients as a rule do not react well to being told that their symptoms are “all in their head” as it communicates their doctor is not taking them seriously or minimizing their suffering. Instead, physicians should provide education and assurance. Education about the origin of the symptoms should include an explanation of the brain-gut axis and an explanation on how hypersensitive gut nerves can be responsible for their symptoms. Usually pain and discomfort are symptoms that warn us for harm, but in this case, the nerves may be over responding and the signal (pain) is not useful anymore. Reassurance that there is no need for continued testing, surgery or even PPI or other medication treatment is needed as well. Low-dose imipramine has shown initial promise in this patient population[52], but only improved QOL, not symptoms nor visceral hypersensitivity. Better success has been found with behavioral interventions[46]. These focus on increasing their coping skills and resilience while reducing disability[53]. Some approaches may even target hypersensitivity directly. Given the complexity of the origin and treatments of GERD symptoms and potential reluctance of patients to entertain the influence of the brain-gut axis, effective physician-patient communication is important in the treatment of GERD.

PATIENT-CENTERED COMMUNICATION

Meaningful and effective physician-patient communication can be influenced by many factors including medical, ethical, and socioeconomic issues[54]. Differing opinions, patient autonomy, cost and truthful assessment could
potentially cause conflict. A physician should be able to identify pitfalls and learn how to navigate these circumstances in order to provide optimal patient care.

Physician-patient communication should be patient-centered[55]. Epstein and Street defined patient-centered communication as: “(1) Eliciting, understanding, and validating the patient’s perspective (e.g., concerns, feelings, expectations); (2) Understanding the patient within his or her own psychological and social context; (3) Reaching a shared understanding of the patient’s problem and its treatment; and (4) Helping a patient share power by offering him or her meaningful involvement in choices relating to his or her health.”

Patient-centered communication positively affects patient satisfaction, recall, understanding, and adherence and health outcomes[55]. Increase in malpractice and in missed opportunities to empower patients to self-manage their illness are two negative consequences of not employing patient-centered communication[56].

A limited earlier review of studies on verbal and nonverbal physician behaviors during a patient interview found several to have a positive effect on health outcomes[56]. Some of the verbal behaviors include: empathy, psychosocial talk, time spent in health education and information sharing, humor, courtesy, and clarification. Several of the nonverbal behaviors found to be beneficial include: head nodding, arms and legs that are uncrossed and leaning forward.

There is very limited research on physician-patient communication within the context of GERD. Research has shown a disparity between patients and providers regarding GERD management and its impact. Patient satisfaction with prescription treatment for symptom management is often overestimated by providers[57-61]. The severity of symptoms are often underestimated by providers when compared to patients’ reports[60,62]. There is also a disconnect with what providers and patients see as most problematic symptoms for QOL[37]. This evidence supports the need for a more patient-centered approach to GERD management and better communication between patients and providers.

In a study of the impact of patient education and GERD management, a survey of outpatients indicated that only 66% of patients thought they had a comprehensive discussion of factors affecting GERD with their physician[63]. These patients are also significantly more knowledgeable about when to take their medication than those who did not have a comprehensive discussion with their physician. This emphasizes the need for better discussion between physician and patient.

The type of practitioner may also impact a GERD patient’s perception. A study comparing the satisfaction of patients with GERD who saw gastroenterologists to those who saw a family physician indicated that the latter were significantly more satisfied with the care information they received and thought their doctors spent more time with them[64]. This implies that patients form a closer relationship and a more beneficial communication with their family physicians which could lead to a more effective treatment.

Patient-reported outcomes (PRO) tools can help advance physician-patient communication by capturing patients’ perceptions of GERD management via specific targeted questions which patients may not provide in the standard interview to their provider. These tools can facilitate treatment management by measuring the impact of GERD from the patients’ perspectives. Improved communication regarding treatment expectations can also help with a more patient-centered approach. Patients should be educated that treatments may not provide full symptom relief and residual symptoms may persist.

The GERD Impact Scale (GIS) is a commonly used PRO. It has eight questions exploring the frequency of symptoms over the past week: acid-related symptoms, chest pain, extra-esophageal symptoms, and the impact of symptoms on sleep, work, meals and special occasions. Two other tools include the Quality of Life in Reflux and Dyspepsia that informs treatment response and gives a patient-centered measure of progress and the Reflux Disease Questionnaire, a patient-centered self-administered instrument that tracks symptom improvement[65]. Using these PRO’s at the time of diagnosis and at each subsequent visit helps fill the gap in physician appreciation of patient’s ongoing symptoms and suffering.

Physicians have frequently been shown to underestimate the severity and impact of GERD symptoms on their patient’s lives while simultaneously overestimating treatment effects[57,66]. Systematically tracking patient response and patient experience fosters a collaborative discussion between physician and patient. Patients are more likely to be satisfied if they feel they are taken seriously by their physician as well as if the consultation is interactive[67]. Employing validated PRO instruments at diagnosis and during ongoing pharmacotherapy demonstrates physician concern for the GERD patient. Patients feel that their physician is serious about providing enduring symptom relief when they monitor their progress over time. Additionally, if treatment is not successful, physicians recognize treatment failures faster allowing them to adjust treatment strategies. In some treatment refractory patients this may include behavioral health referral for gut-centered cognitive behavioral therapy. Patients may be much more receptive to this discussion and referral if the physician has been employing PRO tools during ongoing care and use these as part of SDM.

**SHARED DECISION MAKING IN THE DIAGNOSIS AND MANAGEMENT OF GERD**

Despite the fact that GERD represents one of the most common diseases encountered by primary care providers as well as gastroenterologists, there remain large gaps in actual clinical practice especially in the areas of patient-
Surprisingly, SDM has not been studied in GERD. The Inflammatory Bowel Disease briefly mentioned SDM Organization’s review on treatment withdrawal in multiple sclerosis relationship of the physician and patient elements of SDM, the concept focuses heavily on the while tools and decision aids and choices are critical that these tools improve care remains low necessary for care to count as SDM - also the evidence such as patient decision or conversation aids are not tools to promote the SDM clinical conversation. Tools care rather than a goal of SDM.

The strongest evidence supports an increase in patient treatment adherence especially in chronic conditions. It has been shown to increase patient satisfaction and care have demonstrated clinicians often overestimate their level of patient engagement and involvement. While the evidence is still growing, the SDM approach has been shown to increase patient satisfaction and treatment adherence especially in chronic conditions. The strongest evidence supports an increase in patient satisfaction when utilizing an SDM approach. It has been more difficult to demonstrate improved health outcomes or decreased levels of health utilization. The latter was thought to be a potential by-product of SDM care rather than a goal of SDM.

Often, providers use decision aids or communication tools to promote the SDM clinical conversation. Tools such as patient decision or conversation aids are not necessary for care to count as SDM - also the evidence that these tools improve care remains low. In fact, while tools and decision aids and choices are critical elements of SDM, the concept focuses heavily on the conversation, evident caring, and mutually respectful relationship of the physician and patient.

SDM has been studied in many conditions including multiple sclerosis, Coronary Heart Disease, and depression. The European Crohn’s and Colitis Organization’s review on treatment withdrawal in Inflammatory Bowel Disease briefly mentioned SDM. Surprisingly, SDM has not been studied in GERD. The SDM approach to GERD treatment management can be a way for clinicians to provide more patient-centered care and improve patient satisfaction. Every step in GERD management - diagnosis, medication trials and adjustments, further work-up for refractory symptoms provides an opportunity for the practice of SDM. Clinicians need to identify which troublesome symptoms matter most to their patients. This will necessarily vary from patient to patient. Without this conversation, clinicians may not focus on what the patient feels is most important. One way for clinicians to gather this information on an ongoing basis employs the use of PROs discussed above. In the absence of decision aids and conversation aids, PRO tools can help the clinician hone in on continuing patient concerns and track treatment progress overtime. Medication adherence and proper dosing including the time of dose also need to be monitored and addressed with patients. The SDM approach encourages patients to share their concerns and includes their experience as a central part of care decisions. Finally, optimal care, which includes SDM approaches, should include basic patient education about the brain-gut bidirectional pain pathway. This educational information can provide the patient with a framework to understand that not all of their symptoms will resolve. Utilizing the SDM process can help clinicians optimize treatment, but may also help the patient understand, accept, and manage residual persisting symptoms potentially avoiding unnecessary invasive testing and expense.

Employing PRO tools as part of the SDM model may help improve the use of PPI therapy in several ways. Patients who have a good initial response to PPIs can be monitored and maintained on the lowest dose necessary to control symptoms. PROs can also help the clinician explore reasons for treatment failure including checking for adherence and proper dosing 30 min prior to eating or the need for dose-escalation. Long-term PPI therapy carries increased risk of enteric infections and community acquired pneumonia, increased hip and vertebral fractures possibly due to the decreased absorption of calcium, and secondary hypergastrinemia and rebound acid hypersecretion. Limiting unnecessary PPI exposure should be a treatment goal and PROs can help guide optimal care. Many patients remain on excessive doses of PPIs exposing them to risk and expense. The majority of PPI responders can successfully step-down their use of PPIs without negatively affecting their QOL.

Overuse and misuse of PPIs leads to needless expense, increased risk, and no benefit to patient experience or satisfaction. PROs can help physicians track this initial treatment response and better engage patients in an ongoing conversation about their troublesome symptoms and QOL. One study revealed that physicians alter their treatment decision 35% of the time based on PRO information gleaned from the GIS (a common PRO). Clinicians need to find efficient, effective ways to gather critical clinical information from patients. PROs may be
one of many tools clinicians can use to promote dialogue with patients about their symptoms and treatment priorities in the context of the SDM patient encounter.

Lifestyle modifications remain a potent but often neglected area of treatment recommendation and disease modification for GERD patients. Providers should return again and again to these proven strategies. Weight loss, smoking cessation, avoiding trigger foods, decreased alcohol use, avoiding late night meals and elevating the head of the bed have all been shown to reduce GERD symptoms and improve QOL[24]. Continued engagement with patients on these conservative, lifestyle management strategies promotes patient self-management and has been shown to improve perceived symptoms[26,37]. The SDM approach can help facilitate a conversation with the patient on lifestyle changes. While a detailed discussion is outside the scope of this article, Motivational Interviewing may also be a supporting technique for use in the SDM patient care approach[78].

By applying SDM principles in the management of GERD, both the generalist and specialist can target specific areas where physicians have frequently been shown not to follow treatment guidelines. It also could decrease the chance of a breakdown in patient-physician communication.

CONCLUSION

GERD management can be complex, involving multiple avenues of trial and error, from lifestyle modifications to medication therapy. PPI therapy can be successful for some, but often does not provide complete resolution of symptoms. Long-term PPI therapy can put patients at risk for serious side effects and needless expense. The brain-gut connection may be important in explaining non-PPI responders. Emerging consensus has focused on the relatively new concept of hypervigilance to best understand this challenging population of patients. Given that the goal of treatment is managing symptoms, patient-physician communication is important. The paucity of literature on physician-patient communication in the treatment of GERD calls for more research in this area. Further, a disparity between patients and providers regarding GERD management can also impact patient satisfaction. This necessitates understanding and validating a patient’s perspectives and values pertaining to his or her illness and choices, in addition to effectively obtaining information. SDM with the incorporation of PROs includes the patient in their treatment, promoting patient adherence and satisfaction. SDM manages patient expectations of GERD management, ultimately impacting their health-related QOL.

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