



# Scoping review: the social and emotional impacts of gastroparesis

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**Background:** Patients with gastroparesis experience severe gastrointestinal symptoms including nausea, vomiting, early satiety, excessive fullness and bloating that can have significant negative effects on their mood, relationship with food/eating, and overall quality of life. The aim of this review was to systematically explore the literature on the social and emotional burdens experienced by patients with gastroparesis.

**Methods:** PubMed and Google Scholar were used to identify potential articles for inclusion. The population of interest was those with abnormal gastric emptying. Studies were excluded if they focused on the effects of a particular treatment for gastroparesis. Thirty-one articles were included based on search criteria.

**Results:** Three themes emerged, including healthcare utilization and opioid use, relationship between gastroparesis and mental health, and the impact of gastroparesis on lifestyle factors including sleep, nutrition, and social engagement. Patients experience challenges from a perceived lack of understanding of medical providers and loved ones and difficult to manage symptoms. Symptom specific anxiety, underlying psychiatric history, and symptom severity are associated with distress around symptoms. Self-reported symptom severity and severity of gastric emptying are not highly correlated.

**Conclusions:** Patients with acute onset and gradually worsening of symptoms over time are likely at increased risk of distress related to their disease. Patients commonly experience isolation from their medical providers and in other social relationships. Treatments aimed not only at reducing the severity of symptoms but also helping patients with gastroparesis engage with the enjoyed aspects of life are essential in mitigating the social and emotional impacts of gastroparesis.

**Keywords:** Gastroparesis; quality of life; healthcare utilization; nutrition; mental health

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## Introduction

Gastroparesis is a chronic digestive condition characterized by delays in gastric emptying that are associated with early satiety, excessive fullness, loss of appetite, nausea, vomiting, and abdominal pain. These symptoms can have a significant negative impact on overall quality of life, including mood, social and occupational functioning, and one's relationship

with food and eating.

As is the case with treating many chronic conditions, there is a difference between observable abnormalities (such as the severity of delay in gastric emptying) and subjective symptom reporting. In gastroparesis, the severity of delay in gastric emptying is not generally associated with the severity of nausea (1,2), bloating (3), or pain (1). From a treatment standpoint, then, setting normalization of gastric

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emptying as the treatment target does not always effectively address symptoms, especially if a patient experiences concurrent hind-gut dysmotility. When gastric emptying is normal but symptoms persist, this is more appropriately diagnosed as functional dyspepsia. In recent years, there has been extensive discussion of the possibility that functional dyspepsia and gastroparesis may exist along a spectrum of gastroduodenal neuromuscular disorders as opposed to being distinct clinical entities (4). This may be similar to the discourse around inflammatory bowel disease (IBD) and irritable bowel syndrome (IBS), where a patient may be symptomatic despite evidence of histological remission and we begin to question dysregulation of the gut-brain axis as playing a contributing role in ongoing symptoms.

Higher severity of any one gastroparesis symptom is associated with worse quality of life (1-3,5). Compared to patients with idiopathic gastroparesis, those with diabetic gastroparesis tended to have more severe nausea, vomiting, and retching and reported higher levels of distress overall (2). On average, patients with idiopathic gastroparesis report an average of 3.5 vomiting episodes per day, whereas those with diabetic gastroparesis report an average of 7.3 vomiting episodes per day (6). Forty-one percent of patients reported severe bloating that was associated with worse nausea, fullness, distension, pain, and bowel function (3). In one small study (n=55) the physical sub-score of the Short Form-12 and severity of anxiety and depression were

associated with reported symptom severity (5).

In a large study of gastroparesis patients (n=715), 50% of patients acknowledged poor quality of life (7). Quality of life appears to be influenced by the severity of the symptoms themselves (nausea, vomiting, and abdominal pain), whether symptoms presented acutely and/or progressively worsened, presence of medical and psychological comorbidities, and lifestyle/behavioral factors (including smoking) (7). The purpose of this review was to review the literature on the social and emotional impacts of gastroparesis. Specific recommendations for assessing quality of life in clinical practice are provided. We present this article in accordance with the PRISMA-ScR reporting checklist (available at <https://tgh.amegroups.com/article/view/10.21037/tgh-23-124/rc>).

## Methods

The following electronic databases were searched: PubMed and Google Scholar in October 2023 using search terms “gastroparesis”, “emotional”, “social”, and “quality of life.” We retrieved articles based on subject headings and keywords in both databases and duplicates were removed. The reference lists of articles selected for full-text review were manually screened for additional articles.

The search was limited to peer-reviewed original studies published in English. Conference proceedings, review articles, and theoretical articles were excluded. In this search, the population of interest was adults diagnosed with gastroparesis based on abnormal gastric scintigraphy. Studies involving patients with gastroparesis-like symptoms, who did not have abnormal gastric emptying (e.g., patients with functional dyspepsia), were excluded unless they included a gastroparesis comparator group. Studies evaluating a specific treatment for gastroparesis (e.g., pharmacological, surgical, dietary) were also excluded, as the purpose of this review was to focus on the social and emotional impacts of being diagnosed with gastroparesis.

Our initial searches retrieved 439 results, of which we excluded 375 based on title and abstract review. This left 31 articles for full text review that were appropriate for inclusion (see *Figure 1* for the PRISMA diagram). Included articles were reviewed and major themes were identified. Three major themes emerged: interactions with the medical system including healthcare utilization including opioid use, psychological considerations with gastroparesis, and lifestyle factors including nutrition, sleep, and social functioning. A small group of studies evaluated the role of sociodemographic factors including race/gender with

### Highlight box

#### Key findings

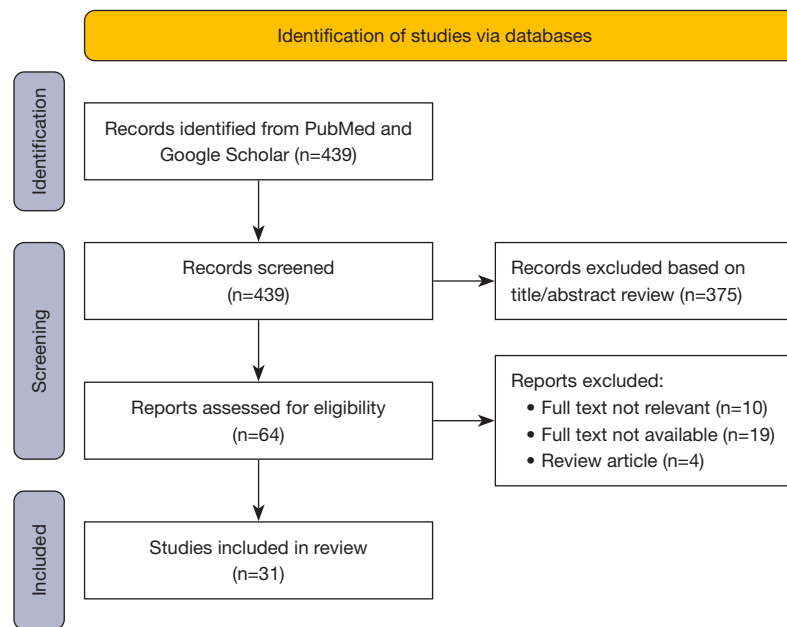
- Patients frequently report a perceived stigma and lack of understanding from medical providers and loved ones about their condition.
- Abdominal pain is a common symptom in gastroparesis but may be particularly challenging to effectively treat.

#### What is known and what is new?

- We know severe gastroparesis symptoms are associated with impairments in quality of life.
- There is likely a reciprocal relationship between symptoms and diet, sleep, and underlying psychiatric conditions that can compound distress associated with gastroparesis.

#### What is the implication, and what should change now?

- Emphasis should be placed on establishing trust in the patient provider relationship.
- Providers should inquire about effects of gastroparesis on lifestyle with the intention of helping patients reconnect with enjoyed activities and loved ones.



**Figure 1** PRISMA diagram reflecting article review process.

symptoms and these studies were aggregated also. These studies are summarized in *Table 1*.

## Results

### *Interactions with the medical system*

On average, there is a nine-year delay from time of symptom onset to being accurately diagnosed with gastroparesis (33). Thirty-three percent of patients with gastroparesis symptoms describe feeling frustrated with their diagnostic journey (30) and “unsatisfied” with their treatment, highlighting pain, nausea, and vomiting as the most important symptoms they would like to see improve (33). In fact, abdominal pain and vomiting are the symptoms most likely to be associated with emergency department (ED) visits and pursuit of additional testing (14). Severe gastroparesis symptoms may increase patients’ willingness to take risks with their healthcare, including agreeing to additional diagnostic tests and use of medications (14,21). More diagnostic testing in the ER did not improve treatment or outcomes, but it was associated with increased financial cost to the patient and increases in overall risk associated with care (14).

As a disease with a relapsing-remitting course, it can be difficult to determine a symptom or quality of life endpoint

as the targets for treatment may change frequently. Similarly, patients can feel frustrated or discouraged by the unpredictable and uncontrollable nature of symptoms (25). In a small pilot study of patients receiving gastric stimulation for gastroparesis, over half of all clinical encounters were associated with a “transition”, where symptoms either improved or became worse from one visit to the next (29). This may reflect the waxing and waning of a particular symptom (e.g., nausea) or the quieting of one symptom during the building of another. When multiple symptoms are present, it can be difficult to identify improvements in a particular symptom when others are worsening.

Despite generally reporting more severe symptoms, females in one study were less likely to be hospitalized for their symptoms than males (34). Anecdotally, female patients describe having their physical symptoms attributed to a psychological cause more often than males. In three separate qualitative studies exploring stigma and quality of life in patients with gastroparesis, patients frequently identified stigma or lack of understanding from their medical providers as a significant source of frustration in their healthcare experience, though gender differences were not explored in these studies (8,25,26). This lack of understanding can become more damaging, progressing even to medical gaslighting or post-traumatic stress.

Table 1 Summary of included studies

Authors	Sample size	Aim of study	Outcomes/measures	Main findings
Bennell and Taylor (2013) (8)	n=9	Social eating experiences in gastroparesis	Qualitative interviews-loss of social eating	Themes: experiences of medical professionals, understanding of mental health/illness, managing social settings, identity and security
Bielefeldt <i>et al.</i> (2009) (5)	n=55	Relationship between pain, affect, and gastric emptying	Symptom severity: GCSI, visual analog pain severity; anxiety/depression: HADS; QoL: SF-12	Physical subscore of SF-12 and HADS, but not gastric emptying delay or symptom duration, associated with disease severity. Combination of vomiting, bloating, and depression predicted impact on quality of life
Burton Murray <i>et al.</i> (2020) (9)	N=288	Avoidant/restrictive food intake disorder in gastroparesis	Symptom severity; NIAS; Feeding/Eating disorder severity	55% of patients with dyspepsia report symptoms of a feeding/eating disorder. These symptoms were associated with the severity of GI symptoms but not the level of gastric retention
Cherian <i>et al.</i> (2010) (10)	n=68 (18 DG and 50 IG)	Abdominal pain in gastroparesis	Symptom severity: PAGI-SYM, McGill pain; QoL measures	90% of patients had abdominal pain and for some it interfered with sleep. Abdominal pain was not associated with GE but was associated with QoL
Cherian <i>et al.</i> (2012) (11)	n=156	Fatigue in gastroparesis	PAGI-SYM; PAGI-QOL; FAI; anxiety/depression: HADS	93% reported fatigue; 51% reported severe fatigue. Fatigue associated with decreased QoL, increased depression, lower anxiety, low hemoglobin
DiBaise <i>et al.</i> (2016) (12)	n=209 patients referred for GES	Relationship between psychological distress, gastric emptying, and dyspeptic symptoms	Depression, anxiety, somatization, stress, positive/negative affect, alexithymia	72% meet criteria for functional dyspepsia. Higher anxiety, depression, somatization, and perceived stress than population norms. No differentiation with gastric emptying, similar degrees of psychological distress whether there was a delay in emptying or not
DiBaise <i>et al.</i> (2016) (13)	n=266 patients referred for GES	Relationship between gastroparesis symptoms, QoL, clinical factors, and gastric emptying severity	GES; health care resource utilization; gastroparesis symptoms; QoL	Delayed emptying more likely to be associated with nausea/vomiting and postprandial fullness but not bloating. Weak correlation between severity of emptying and symptom severity. QoL lower in delayed emptying group
Dudekula <i>et al.</i> (2011) (14)	n=326	Predictors of hospital stay and use of diagnostic testing	EMR review	Pain and vomiting were most common cause for ER encounters and diagnostic testing. Testing did not improve treatment or outcome but associated with increased cost and risk of care
Friedenberg <i>et al.</i> (2013) (15)	n=255	Comparison of etiology, clinical characteristics, healthcare utilization, symptom profile, QoL in white and nonwhite patients	PAGI-SYM; PAGI-QOL	Non-white GP patients with higher rates of GP related ED visits and hospitalizations. QoL lower in nonwhite patients. Nonwhite patients had more severe symptoms, poorer QoL and utilized more healthcare resources; more likely to have diabetic etiology
Hasler <i>et al.</i> (2011) (3)	n=335	Bloating severity in gastroparesis	GCSI bloating subscale	41% report severe bloating, associated with nausea, fullness, distension, pain, and bowel function; severe bloating associated with worse QoL. Bloating not influenced by GE rates
Hasler <i>et al.</i> (2013) (1)	n=393	Differences in pain predominant gastroparesis versus nausea predominant	PAGI-SYM	66% had moderate-severe upper abdominal pain. 21% were pain predominant; 44% were N/V predominant. Predominant pain associated with impaired QoL, more opiate use, reduced antiemetic use. GES and Gastric retention similar across both profiles
Jaffe <i>et al.</i> (2011) (2)	n=59 (20 DG, 39 IG)	Nausea severity and impact	GES; PAGI-SYM; PAGI-QOL; SF-36; nausea profile	Nausea associated with worse QoL; nausea/vomiting similar between DG and IG but DG had more severe retching and more vomiting per week. Nausea and overall distress higher in DG. Nausea was not related to severity of delay in GE
Jehangir and Parkman (2017) (16)	n=233	Opioid use in gastroparesis	PAGI-SYM; pain medicine questionnaires	70% not using opioids, 10% PRN, 19.3% using chronically. 8% using opioids for abdominal pain. Those on scheduled opioids report more severe GI symptoms of nausea, retching, vomiting, early satiety, postprandial fullness, loss of appetite, upper GI pain, heartburn, chest discomfort, regurgitation, bitter/sour/acid taste in mouth. Chronic opioid use associated with longer duration of nausea and more vomiting episodes per day. Pain more frequently woke them up at night, lower employment rate, less working hours, more hospitalizations
Kabadi <i>et al.</i> (2017) (17)	n=76 patients (13 HC, 30 GP, 10 GERD, 23 GERD/GP)	Taste and smell disturbances in gastroparesis	PAGI-SYM; TSS	Taste/smell disturbances higher in GP, GERD, and GP/GERD compared to controls. Taste/smell score correlated with Heartburn/regurgitation and gastroparesis severity
Lacy <i>et al.</i> (2018) (18)	n=398	Impact of GP symptoms on QoL and daily activities	SF-36; McGill pain questionnaire	67.5% had reduced daily activities, 28.5% reduced annual income, 11% disabled d/t GP symptoms
Lee <i>et al.</i> (2022) (19)	n=150	Longitudinal impact of GP symptoms based on GES and Wireless Motility capsule	GES; WMC; PAGI-SYM; PAGI-QOL	Female gender, harder stools (Bristol stool scale), presence of functional dyspepsia associated with more severe upper GI symptoms. Delayed GES or WMC associated with worse symptom severity and QoL. Low gastric and elevated small bowel contractile parameters associated with severe symptoms and QoL
Lee <i>et al.</i> (2023) (20)	n=321	Health related social needs and gastroparesis	GCSI; health related social needs questionnaire; PAGI-QOL	most common health related social need was mental health, financial strain, food security; number of HRSN was correlated to total symptom score and inversely correlated with QoL. People with Mental health HRSN w/ more severe GP symptoms and reduced QoL
Navas <i>et al.</i> (2019) (21)	n=103	Willingness to take risks with medications to treat GP	Medication use; anxiety, depression, impulsivity	Symptom severity and GCSI associated with increased willingness to take risks associated with medications. Anxiety was negatively associated
Parkman <i>et al.</i> (2019) (22)	n=346 (212 IG and 134 DG)	Describe characteristics of abdominal pain in gastroparesis	PAGI-SYM, GCSI; PAGI-QOL; BDI, State Trait Anxiety, PHQ-15	90% of GP patients report abdominal pain, mostly in the upper abdomen or central/midline area. 34% report severe or very severe pain. Pain severity was associated with GCSI severity, depression, anxiety, somatization, use of opiates, and quality of life. Pain was not associated with the severity of delay in GE

Table 1 (continued)

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Authors	Sample size	Aim of study	Outcomes/measures	Main findings
Parkman <i>et al.</i> (2023) (23)	n=971 (579 IG, 336 DG, 51 surgical)	Characteristics of those using enteral/parenteral nutrition	GES; water load satiety testing; gastroparesis symptom severity; QoL	96.7% using oral nutrition only, 1.4% using exclusive PN, 1.9% using EN
Parkman <i>et al.</i> (2019) (24)	n=718	Ethnic, racial, sex variations in etiology, symptoms, QoL, GES, treatments, and symptom outcomes in GP	PAGI-SYM; QoL: SF-36	Non-Hispanic Blacks more likely to have DG GP, more severe retching/vomiting, higher percentage hospitalized; Hispanics less nausea/early satiety; women had lower hospitalizations but more severe symptom scores
Parkman <i>et al.</i> (2021) (7)	n=715	Factors influencing QoL in gastroparesis	PAGI-SYM; QoL: SF-36, PAGI-QOL; anxiety/depression: BDI, State Trait Anxiety	Worse N/V and upper abdominal pain, acute onset of symptoms, higher number of comorbidities, use of narcotic pain medications, IBS. 41% had impairments in physical component; 26% had impairments in mental component. Patient related factors such as smoking also impaired QoL
Raubinger <i>et al.</i> (2023) (25)	n=11 motility patients	Impact of gastroparesis symptoms on daily living	Qualitative interviews	Theme-frustration; 3 subthemes: feeling misunderstood, judged and dismissed; severity and unpredictability of undesirable symptoms; reduced QoL b/c of physical and social limitations
Taft <i>et al.</i> (2022) (26)	n=23	Stigma experiences in gastroparesis	Qualitative interviews	Themes: stigma from healthcare providers, stigma in interpersonal relationships, invisible disease, blame, unsolicited suggestions, disclosure, and stigma resistance
Tanner <i>et al.</i> (2023) (27)	n=100	Symptom specific anxiety and its association with symptom severity and quality of life	Visceral sensitivity index	Symptom anxiety associated with greater severity, beyond depression, anxiety, or somatization. GI anxiety associated with decreased mental health QoL
Teigland <i>et al.</i> (2018) (28)	n=34 patients w/ diabetes and GI symptoms, with/without diabetic GP	Longitudinal follow up of gastroparesis symptoms	Symptom severity: PAGI-SYM; QoL: SF-36, PAGI-QOL; anxiety/depression: HADS	Impaired QoL, 47% anxiety, 38% depression
Velanovich (2009) (29)	n=32	Evolution of quality of life in a waxing/waning condition	Electronic medical record review	Over 50% of clinical encounters are associated with a transition period, can't identify a symptomatic endpoint
Woodhouse <i>et al.</i> (2017) (30)	n=10	Impact of gastroparesis on QoL	Qualitative interviews	Themes: frustration, identity, coping and adaptation
Woodhouse <i>et al.</i> (2018) (31)	n=179	Relationship between symptom severity, illness perceptions, coping styles, QoL, psychological distress	Symptom severity: GCSI; QoL: PAGI-QOL; brief illness perception questionnaire, COPE scale psychological distress: DASS21	GP symptom severity influenced illness perceptions and QoL; illness perceptions influenced maladaptive coping, psych distress and QoL. Maladaptive coping influenced psych distress which influenced QoL. The relationship between GP symptom severity and psych distress was mediated by illness perception
Yekutieli <i>et al.</i> (2023) (32)	n=522 Israeli gastroparesis patients	Healthcare utilization	Electronic medical record review	GP more likely to have cardiovascular disease, lower obesity, higher healthcare resource utilization/hospitalizations
Yu <i>et al.</i> (2017) (33)	n=1,423	Identify burdens/concerns of patients with gastroparesis; relationship between symptom severity and quality of life	Symptom severity: PAGI-SYM; QoL: SF-36	Duration of symptom was 9.3 years; time before diagnosis was 5 years. 33% dissatisfied with treatment; most wanting to address nausea, pain, vomiting

Unless otherwise specified, all samples included patients diagnosed with gastroparesis. GCSI, Gastroparesis Cardinal Symptom Index; HADS, Hospital Anxiety and Depression Scale; SF-12, Short-Form-12; NIAS, Nine Item ARFID Screen; GI, gastrointestinal; DG, diabetic gastroparesis; IG, idiopathic gastroparesis; PAGI-SYM, Patient Assessment of Upper Gastrointestinal Symptom Severity; GE, gastric emptying; PAGI-QOL, Patient Assessment of Upper Gastrointestinal Symptoms Quality of Life; FAI, fatigue assessment instrument; GES, Gastric Emptying Scan; EMR, electronic medical record; ER, emergency room; GP, gastroparesis; ED, emergency department; SF-36, Short Form-36; PRN, pro re nata; GI, gastrointestinal; HC, healthy control; GERD, gastroesophageal reflux disorder; TSS, taste and smell survey; WMC, Wireless Motility Capsule; HRSN, health related social needs; BDI, Beck Depression Inventory; PHQ-15, Patient Health Questionnaire-15; PN, parenteral nutrition; EN, enteral nutrition; N/V, nausea/vomiting; IBS, irritable bowel syndrome; COPE, Coping Orientation to Problems Experienced Inventory; DASS21, Depression, Anxiety and Stress Scale.

### Opioid use

While nausea and vomiting have been the symptoms most traditionally associated with gastroparesis, many patients with gastroparesis also endorse a high level of abdominal pain. In fact, over two-thirds of patients report moderate to severe upper abdominal pain, with pain being the predominant symptom in 21% of patients (1). When pain was the predominant symptom, patients tended to experience reduced quality of life, more opiate use, and reduced use of anti-emetics, despite similar gastric scintigraphy profiles as those with a nausea-predominant presentation (1).

Although opioids have been highly associated with intestinal dysmotility (35), a small number of studies have examined opioid use in patients with gastroparesis. The majority of patients (70%) with gastroparesis denied use of opioids (16). Of those prescribed opioids, 19.3% were using them chronically and 8% were prescribed opioids specifically for their abdominal pain (16). Those who used opioids were likely to report more severe upper gastrointestinal (GI) symptoms, including a longer duration of nausea and more vomiting episodes per day, and the pain was more likely to interfere with social and occupational functioning (16).

### Mental health symptoms

Quality of life in gastroparesis seems to be affected by a combination of symptom severity, depression, symptom anxiety, and coping styles (5,10,13,20,27,31). The most common health related social need expressed by gastroparesis patients was mental health, followed closely by financial strain and food security (20). Patients with gastroparesis appear to experience higher rates of depression and anxiety than what is typical in the general population. In one study, 47% met criteria for generalized anxiety disorder and 38% met criteria for major depressive disorder, compared to 2.7% and 3.8% of the general population respectively (12,28). The level of psychological distress a patient experienced due to their symptoms did not appear to be influenced by the severity of gastric retention; those with functional dyspepsia experienced similar levels of distress as those with gastroparesis (12). However, when mental health needs are high, patients also report more severe gastroparesis symptoms and reduced quality of life (20).

When we consider psychological factors that may influence functioning with a chronic digestive disease, we typically separate generalized anxiety or depression

from symptom specific anxiety or depression, where the primary source or focus of distress is around the symptoms themselves. Consistent with the literature in esophageal conditions, symptom specific anxiety was associated with greater severity of gastroparesis symptoms and was more strongly correlated than depression, anxiety, or somatization (27). Similarly, one study found illness perception to be the mediating factor in the relationship between symptom severity and psychological distress (31). This theme also emerged in qualitative interviews with patients with gastroparesis, where patients who had a more health-focused and resilient identity were better able to adapt to the difficulties of their condition compared to those who were more illness-focused (30).

### Lifestyle factors

#### Nutrition

Gastroparesis symptoms often lead to a loss of normalcy around eating (8), as many patients describe eating as the primary trigger for symptoms. Patients describe their relationship with food and eating to be significantly impacted by their gastroparesis symptoms, including feeling isolated and rejected during social eating opportunities (8). Some patients with gastroparesis also describe alterations in taste and smell, which may impact the desire and ability to eat food orally (17). Severity of heartburn, regurgitation, and gastroparesis symptoms were all associated with taste and smell disturbances (17). Despite the significant negative impact gastroparesis has on eating behaviors and food related quality of life, there is limited empirical literature available on this topic.

The prevalence of avoidant/restrictive food intake disorder (ARFID) has been assessed in one study involving patients with gastroparesis. Based on the Nine Item ARFID Screen, 39.9% of patients with gastroparesis were considered to have possible ARFID based on a conservative scoring system and 23.3% were considered to have probable ARFID based on the presence of psychosocial/medical impairments due to food restriction. Self-reported symptom severity was associated with the likelihood of patients exhibiting signs of a feeding/eating disorder, as well as the severity of the ARFID symptoms themselves, but not the severity of gastric emptying.

In a small group of patients with very severe gastroparesis (23), supportive nutrition may be considered when patients are not able to adequately meet caloric targets via oral food consumption. Parkman *et al.* found

that out of a group of 971 patients, 1.4% used exclusive parenteral nutrition (PN) and 1.9% used enteral nutrition (EN) (23). Characteristics that were associated with the need for supportive nutrition included younger age, lower body mass index (BMI), and more severe gastroparesis symptoms. Overall, the need for PN or EN was associated with a reduction in physical quality of life but not mental or gastroparesis related quality of life. Those dependent on supportive nutrition generally had more impairments in gastric accommodation via the water load satiety test but not more severe delays in gastric emptying. Notably, at 48 weeks follow up for these patients, 50% of those with exclusive PN resumed oral nutrition and 25% of those with exclusive EN resumed oral nutrition (23).

### Sleep

93% of patients with gastroparesis endorse feeling “fatigued”, with 51% of patients reporting severe fatigue (11). Upper abdominal pain and discomfort were most associated with fatigue and fatigue had significant negative association with quality of life (11). Seventy-four percent of patients with gastroparesis report experiencing abdominal pain in the nighttime, with it being severe enough in 66% of patients to interfere with sleep (6,10).

### Social functioning

One of the themes identified in qualitative interviews of patients with gastroparesis is the challenge of managing social situations with gastroparesis (8). More than two thirds of gastroparesis patients report reductions in daily activities and 28.5% report reductions in annual income related to their symptoms (18). Gastroparesis symptoms lead to full disability in 11% of patients (18). There is preliminary evidence that how a person identifies with the illness shapes their pattern of social engagement (31).

### Race

A small group of studies have explored the specific impacts of race and gender on the etiology and symptoms of gastroparesis. Non-Hispanic black individuals were more likely to have diabetic gastroparesis (18) with more severe retching/vomiting and a higher likelihood of hospitalization with symptoms, whereas Hispanic individuals reported less nausea and early satiety (34). A separate study similarly demonstrated higher rates of gastroparesis related emergency room visits and hospitalizations among non-White patients (15). When compared with healthy controls,

Israeli patients with gastroparesis were more likely to have cardiovascular disease but less likely to be obese, with more hospitalizations and emergency room visits (32).

## Discussion

Symptoms of gastroparesis can have a significant negative impact on a patient’s quality of life. Conversely, many lifestyle/behavioral factors have an influential role on a patient’s symptom experience. The areas highlighted by this review include how symptoms affect healthcare utilization, mental health, and lifestyle factors including nutrition, sleep, and social engagement.

We did not include studies that focused on the impact of treatments for gastroparesis on quality of life, as this was not within the scope of this paper and could comprise its own review. However, it is worth bringing attention to the relative dearth of highly effective treatments for gastroparesis, as this significantly influences a patient’s quality of life and hopefulness about the future. Pharmacologic options primarily target symptom control, and can include prokinetics, neuromodulators, or anti-emetics. However, some of the medications used to manage symptoms may compound a patient’s difficulties; for example, although ondansetron can be helpful in reducing nausea and vomiting, it can also be highly constipating and thus result in the same upper GI symptoms. Surgical interventions including per-oral pyloromyotomy may be helpful in normalizing gastric emptying and reducing symptoms of nausea and vomiting, but patients with hind-gut dysmotility may be less likely to benefit from this and it does not typically improve other gastroparesis symptoms including bloating, abdominal pain, and early satiety. Thus, we recognize the effective treatment of gastroparesis often requires a multidisciplinary approach, including a physician, surgeon, behavioral health provider, pelvic floor physical therapist, and dietitian. Of note, patients with gastroparesis were willing to take on a significant number of risks with respect to medication use and procedures they would undergo to find relief from symptoms or a source of their suffering. This is likely a reflection of the severity of the person’s physical and emotional distress with their symptoms. Patients were at risk of greater emotional distress when their symptoms were of acute onset and when they gradually worsened over time. It may be particularly important to screen for these two risk factors when working with patients with gastroparesis to mitigate the effects of symptoms on overall psychological well-being. When

offering treatment options that have risks associated with them (whether pharmacological, surgical, dietary, or behavioral intervention), it is also important for providers to keep in mind patients' susceptibility to taking on excessive risks, helping patients navigate the decision between risks and benefits for their situation.

This review highlighted a couple of specific populations of gastroparesis patients for whom treatment may be particularly challenging, including those using opioids to manage abdominal pain and those requiring enteral/PN because of insufficient oral intake. It also highlighted the significant burden of abdominal pain in gastroparesis, for which we have few effective treatments. This raises two important priorities in gastroparesis research: identification of treatments aimed specifically at reducing abdominal pain and optimizing nutrition status in patients with gastroparesis. Future studies aimed at understanding which patients are at risk of requiring supportive nutrition and their longitudinal outcomes will also be critical in optimizing care.

Dietary modification is considered a critical part of gastroparesis management, as patients are encouraged to eat smaller, more frequent meals, defer to liquid calories as tolerated, reduce particle size of foods consumed, and separate food and drink. Despite the likely significant role of diet in managing GI symptoms, only a small number of studies (included in this review) have evaluated the bidirectional relationship between gastroparesis symptoms and diet, including how gastroparesis symptoms affect the social experience of eating. In more severe cases or during disease flares, patients may be encouraged to consume a primarily soft solid or full liquid diet, especially in the evenings as motility tends to be at its slowest. However, when we consider dietary modification for patients with GI symptoms, it is important to recognize whether the patient can implement dietary change, including the amount of time necessary to prepare different meals, the financial resources to purchase needed foods, and sufficient dietary knowledge to modify intake according to the recommendations. It is also important to assess whether the patient can implement the diet without significantly compromising quality of life by assessing their ability to travel, eat socially, and plan a comprehensive, nutrient dense diet with the recommended restrictions.

Although a single data point, food insecurity, or the lack of regular access to nutritious and sufficient food, was one of the most commonly identified health related social need by patients with gastroparesis (20,36). Patients who are

dependent on oral nutrition supplements or even EN in some cases may be particularly vulnerable to food insecurity. Typically, meal replacement shakes are not inexpensive and they are not likely to be covered by insurance, especially if consumed orally. This can present a significant barrier to maintaining nutrition support that may adequately manage symptoms, as patients may be unable to afford the expense of a full liquid diet. Patients may then defer to consumption of more solid foods that could exacerbate symptoms.

It is worth noting there is likely a reciprocal relationship between sleep quality and GI symptoms including nausea and abdominal pain. Patients with GI conditions tend to report poorer sleep quality than healthy controls (37-39). In patients with IBS, more waking episodes during sleep was predictive of more abdominal pain (38), GI distress, and worse quality of life but not bowel consistency or frequency (37). One study demonstrated that improving sleep quality using prescription sleep aids improved GI symptoms and quality of life in patients with functional dyspepsia (40). Poor sleep quality has been associated with increased nausea, fatigue, and abdominal pain in children and adolescents with disorders of gut brain interaction (41). Of note, the majority of these studies have relied on self-report data of perception of sleep quality. Objective measures of sleep quality, obtained via wearable devices, have so far not been demonstrated to be associated with GI symptoms (38).

Much of the research on the social and emotional impacts of gastroparesis has focused on depression and anxiety as the reciprocal entities. In clinical practice, it is important to distinguish what role these mental health symptoms may be playing in the experience of gastroparesis. For example, the presence of underlying depression may be contributing to overall fatigue or the inability to distinguish/appreciate incremental improvements in symptoms. Similarly, generalized anxiety may contribute to further avoidance of otherwise enjoyed activities, which may compound the distress associated with symptoms. Notably, there has not been a single study, to our awareness, published on the prevalence of posttraumatic stress disorder (PTSD) in patients with gastroparesis. Given active PTSD symptoms can contribute to chronic overactivation of the sympathetic nervous system, we hypothesize this to have a much more closely defined association with gastroparesis symptoms than underlying anxiety or depression. PTSD, whether related to psychosocial trauma or medical trauma, may also impact how a patient engages in treatment and which treatments they agree to. For example, if there is pelvic



floor dysfunction, a history of sexual trauma may reduce a patient's willingness to complete an anorectal manometry or engage in pelvic floor physical therapy. It would be important then to engage the patient in shared decision making about the order of treatments to make them most effective. In these cases, we would be considering treatment of the active PTSD symptoms to likely be paramount in improving the efficacy of pelvic floor physical therapy or other behavioral interventions.

### **Limitations**

There are limitations of this review, which mainly reflect the limitations of the data available. Much of the research in gastroparesis is funded by the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK) Gastroparesis Consortium, which is a multicenter endeavor to expand our knowledge of the etiology and effective treatment of gastroparesis. The strength of these studies is they tend to be quite large and therefore inclusive of many patients with gastroparesis. However, these may not capture the experience of patients presenting to their local or regional hospitals with gastroparesis like symptoms, where treating providers may not have the experience of working with a large enough volume of gastroparesis patients to know how to flexibly adapt treatment.

This review excluded studies focused on patients with functional dyspepsia. Although this homogenizes the data by including only those with abnormal gastric scintigraphy, there are some potential downsides of limiting the included data in this way. Most importantly, this review may not fully account for the presence of a disorder of gut brain interaction on top of a known delay in gastric emptying. This can come up when gastric emptying is normalized per a gastric emptying scan after surgical intervention but the patient remains symptomatic. In addition, many of the conclusions raised from this review are likely applicable to those with functional dyspepsia and, conversely, likely many of the strategies used to manage functional dyspepsia are likely useful in improving quality of life in patients with a known delay in gastric emptying. From a behavioral medicine standpoint, we find this to be true across GI conditions, regardless of affected organ or organic versus functional nature of the condition.

### **Clinical practice recommendations**

Understanding symptoms is only the beginning in assessing

the impact of those symptoms on quality of life in patients with gastroparesis. Providers may choose to use informal conversation or brief questionnaires to assess the impact of symptoms on quality of life. The use of brief, validated screening questionnaires can also help to identify a patient's baseline level of functioning and provide interim measures of treatment effectiveness. *Table 2* includes a list of questions that can be used to assess quality of life in patients with gastroparesis, as well as a list of commonly used quality of life questionnaires. When choosing assessment measures for use in your practice, we recommend choosing symptom specific quality of life assessments (as opposed to those that inquire about generalized quality of life). In *Table 3*, we provide a list of suggested assessments that could be used with new gastroparesis patients to help gain a more comprehensive understanding of their gastroparesis symptoms, quality of life, and cognitive-affective factors that may be affecting their symptom experience.

We recommend providers inquire about the patient's main goal for treatment prior to discussing any treatment options. An example of this question may be: "What symptoms, if they improve, would translate to an improvement in quality of life for you?" The patient's response helps to align the provider and patient in addressing their most distressing symptoms, as the target for treatment will vary significantly based on the patient. For some, reduction in pain or nausea is most important, whereas others may be seeking more dietary flexibility or to be able to socialize with friends again. As the provider, you ultimately want to know the answer to both questions: What symptoms need to improve? And what would you be doing more of if those symptoms were less frequent/severe? The treatment options being proposed should then align with the patient's goals. Although in some cases we can effectively work toward symptom reduction, this also opens the opportunity to discuss where symptom anxiety may be playing a role in decreasing participation in otherwise enjoyed activities. For example, if a patient identifies more engagement with their social community as one of their goals and sees symptom relief/reduction as being critical to this, we may also work to increase social engagement despite the presence of symptoms to improve quality of life.

### **Conclusions**

The presentation of gastroparesis can be highly variable and any one of the symptoms, whether nausea/vomiting, abdominal pain, or bloating, can significantly impair quality

**Table 2** Questions to assess quality of life in patients with gastroparesis

Questions to use in clinical interview	What information may be gained from this inquiry
Once your symptoms start, how do you typically respond?	The patient's response to this question might be behavioral, cognitive, or emotional. For example, patients may respond to nausea or pain by inducing vomiting to try to relieve symptoms. Other patients may describe changes in emotional state associated with symptom flares (e.g. sadness, fear, frustration). In part, you are wanting to know how a patient's symptoms make them feel and what they do to try to manage
How long might you wait before you begin taking medication to try to feel better?	Length of time from symptom onset to intervention may give you a sense of the patient's ability to tolerate distress or the level of anxiety they experience about symptoms, which may amplify the severity of symptoms
How do your symptoms affect your ability to participate in activities you would otherwise enjoy?	Avoidance of otherwise enjoyed activities including increased social isolation is likely to contribute to depressive symptoms. Getting a sense of how patients have withdrawn from their typical activities will help to gauge risk for symptom driven depression and/or anxiety
Do you still feel joy when you do participate in those activities?	Loss of joy with activities patients enjoyed previously is an additional indicator of severity of depressive symptoms, which may or may not be symptom driven. There is a clinical difference between the patient who says: "I can't do the things I enjoy as often, but they're still enjoyable to me" and one who says: "Nothing is really enjoyable for me anymore." For the first patient, we may want to be helping them find flexibility around symptoms to continue to engage in those enjoyable activities and for the second, we may want to incorporate therapeutic or pharmacologic interventions to treat depression
How have your symptoms affected your relationship with food and eating?	Along this line of questioning, you are inquiring both about the actual eating behaviors and a person's thoughts/emotions around the eating experience. With regard to eating behaviors, it is important to know if symptoms have contributed to avoidance of certain nutrients, modification of dietary texture, or alterations in the frequency/volume/timing of foods consumed. Patients may also report changes in appetite, changes in the way food tastes/smells, or even having developed a fear around eating because of their symptoms. If some of these variables are affected, it may be helpful or even necessary to incorporate a psychologist and/or dietitian with specialized GI training as part of a multidisciplinary approach to care
How have your symptoms affected your ability to fall asleep or stay asleep?	The presence of nausea, vomiting, or abdominal pain/discomfort may impact a patient's sleep, especially if meals are consumed too close to bedtime. As sleep disruption can be associated with next day pain/nausea, all efforts should be made to preserve/improve the patient's ability to sleep
What symptoms, if they were to improve, would translate to an improvement in quality of life?	This question is critical in making treatment planning decisions, as different treatments target different aspects of a patient's symptoms. We cannot make assumptions about which of a patient's symptoms are most bothersome to them or most interfering with their functioning. It is often important to ask multiple layers within this question. For example, a patient may answer that one of their goals is to enjoy eating more. There should then be follow up questions including: "What would need to change about your experience to be able to enjoy eating?" For some patients, enjoyment of eating may be centered around less discomfort with the eating experience while for others, enjoyment of eating may mean less cognitive energy spent thinking about/planning around eating

GI, gastrointestinal.

of life. When working with patients with gastroparesis, it is important to assess not only the severity of the symptoms themselves but also how the symptoms have negatively impacted a patient's mood, sleep, relationship with food/eating, and ability to participate and find pleasure in activities they would otherwise enjoy. Patients with

gastroparesis may have higher rates of healthcare utilization and be willing to take risks with procedures and medications to find relief from symptoms. Facilitating a collaborative and empathic relationship between the patient and provider are key steps in providing effective care for patients with gastroparesis.

**Table 3** Questionnaires commonly used to assess symptoms and quality of life in gastroparesis

Measure	Number of items	Main themes
Patient Assessment of Upper Gastrointestinal Symptom Severity Index (PAGI-SYM)	20 items	Symptom severity: Heartburn/regurgitation, fullness/early satiety, nausea/vomiting, bloating, upper abdominal pain, lower abdominal pain
Gastroparesis Cardinal Symptom Index (GCSI)	9 items	Symptom severity: postprandial fullness/early satiety, nausea/vomiting, bloating
Patient Assessment of Upper Gastrointestinal Disorders Quality of Life (PAGI-QOL)	30 items	Symptom specific quality of life: activities of daily living, worry about symptoms, avoidance of activities due to symptoms, negative impacts on mood and social relationships, impacts of and on food/eating
Esophageal Hypervigilance and Anxiety Scale (EHAS)	15 items, 7 items short form	Hypervigilance to physical sensation, anxiety about symptoms

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