



ISSUES OF COST AND ACCESS IN GASTROPERESIS

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ABSTRACT

The gastroparesis community experiences many setbacks. The inability to eat and digest normally prevents them from thriving in society in a conventional sense. Working a job, attending spiritual services, and attending functions are all impacted by the disability their disease presents. The disease is debilitating, progressive, and has no cure.

In looking at the issues of access and affordability that the [gastroparesis community](#) faces, it became apparent that more needed to be known about their unmet needs. In cooperation with the patient support organization [G-PACT](#) (Gastroparesis Patient Association for Cures and Treatments), Patients Rising developed a survey to further investigate.

The survey indicated the gastroparesis community had a relatively negative view of their health status, and that their out-of-pocket costs ranged widely (median of \$350/month). For the majority of patients for whom health insurance did not cover consumable medical supplies, their monthly out-of-pocket costs could be noticeably higher. We also found that about half of the surveyed population had experienced step therapy; of these, over 80% expressed that it either worsened their condition or prolonged their suffering. We learned a great deal about what the community felt were the obstacles between them and accessing the quality care they needed.

INTRODUCTION

Gastroparesis, also called delayed gastric emptying, is a disorder that slows or stops the movement of food from the [stomach](#) to the [small intestine](#). Normally, after food is swallowed, the muscles in the wall of the stomach pulverize food and move it into the small intestine to continue [digestion](#). In gastroparesis, the stomach muscles work are “paralyzed,” working poorly or not at all, and the stomach takes too long to empty its contents. Gastroparesis can delay digestion, which can lead to various [symptoms](#) and complications. Signs and symptoms of gastroparesis include:

- feeling full soon after starting a meal ([early satiety](#))
- feeling full long after eating a meal
- [nausea](#)
- [vomiting](#)

- Increased bloating
- Increased belching
- Abdominal pain
- [heartburn](#)
- poor appetite

Complications gastroparesis can cause include:

- [dehydration](#)
- [malnutrition](#) due to poor absorption of [nutrients](#)
- [blood glucose](#) levels that are harder to control
- low [caloric](#) intake
- [bezoars](#)
- losing weight without trying
- lower quality of life

BUILDING THE SURVEY MODEL

[Patients Rising](#) provides support and education to people with chronic and life-threatening illnesses. We work with patients to advocate for access to the treatments, innovations, and timely care they need. [G-PACT](#) provides services and reliable information to and advocacy for the both gastroparesis and the community of greater digestive tract paralysis (DTP) diseases, such as colonic inertia, chronic intestinal pseudo obstruction, and others.

We came together to raise awareness in advance of the August 2019 gastroparesis awareness month to investigate what some of the access issues for DTP patients might be. Together we devised a 9-question survey. G-PACT shared the link to that survey in the [G-PACT Facebook Group](#) and just over 100 people voluntarily and anonymously completed it.

FINDINGS

Age and Race

The people who participated in the survey came exclusively from the G-PACT Facebook Group. They ranged in age from under 18 to over 65, but the majority – about 77% – fell between 25-64. They were primarily Caucasian (94%), the rest being a mix of Black, Native American, and refused-to-identify.

Household Income and Insurance

Nearly a quarter of responders (22%) reported a total household income of under \$20,000 annually. Of these, 77% were on some form of public insurance (Medicare, Medicaid), while 18% had some form of private insurance (work, spouse, exchange plans) and 4% had no insurance at all.

Reporting Current Health Status

Responders were asked *“How would you rate your current health status, as of today?”* and were given the following standard scale of responses: 1 – Poor; 2 – Fair; 3 – Good; 4 – Very Good; and 5 – Excellent.

Self-reporting of current health status				
<i>Poor</i>	<i>Fair</i>	<i>Good</i>	<i>Very Good</i>	<i>Excellent</i>
29%	49%	23%	none	none

Half of all responders (49%) reported their current health status to be FAIR (a score of 2 out of 5). Nearly a third (29%) scored their current health as POOR (1 out of 5), and 23% scored it as GOOD (3 out of 5). Out of 100 responders, no one scored their current health as VERY GOOD (4 out of 5) or EXCELLENT (5 out of 5).

Monthly Out-of-Pocket Costs

Ninety-nine responders answered the question: *“How much money, in US dollars, do you spend on healthcare in a typical month?”* Participants were instructed to take their time to *“consider health insurance premiums, deductibles, copays, co-insurance fees, transportation, child/pet care during doctor visits / hospitalization, and any other out-of-pocket expenses for medical, dental, or vision services and medications.”*

The range of out-of-pocket healthcare spending was vast. The median amount was \$350.00 per month, which translates to \$4200 annually. For perspective, according to Healthinsurance.org, the 2019 out-of-pocket-maximum is \$7900 for an individual.

Coverage and Cost for Consumable Medical Supplies

We asked specifically about insurance coverage and out-of-pocket costs for medical supplies and equipment. We defined “medical supplies and equipment” as items like needles, tubing, sharps containers, ostomy bags, test strips and other items that would be considered by the industry term [“consumable medical supplies.”](#) Of note, these items are **not** the same as [durable medical equipment](#).

More than three-quarters (76%) of responders said they had coverage for medical supplies and equipment, while 24% had none. Of those **with** medical supplies coverage, the average monthly out-of-pocket cost was \$167.70. Of those **without** medical supplies coverage, the average monthly out-of-pocket cost was \$437.50.

All those who utilize consumable medical supplies had some kind of monthly cost. We saw no noticeable differences between public, private or some-combination of insurances.

Medical Supplies and Equipment: Coverage and Out-of-Pocket Costs		
Insurance coverage for medical supplies & equipment		Average monthly out-of-pocket cost
SOME COVERAGE	76%	\$167.70
NO COVERAGE	24%	\$437.50

Step Therapy: Exposure and Impact

The practice of insurers intervening in a patient’s treatment for non-medical reasons goes by a few different names – [non-medical switching](#), [fail first](#), or [step therapy](#). But the practice can be defined as the overruling of a doctor’s judgement by the insurer for reasons other than medical efficacy.

Participants were asked, *“Has your insurer for any reason ever influenced you to try a medication or treatment other than the one you and your doctor agreed on (“fail first” “step therapy” or some other non-medical switching)?”* and all participants responded (n=100).

Fifty three percent (53%) reported that YES they had been subjected to Step Therapy, and 44% reported, NO, they had not. The question did not apply to 3% of the responders, because they did not have insurance.

Of those who said YES, they had been subjected to Step Therapy (53 people), there were 37 who talked about the consequences of having been subjected to it.

Consequences of Step Therapy	
Prolonging my suffering	49% (n=18)
My condition got significantly worse	32% (n=12)
I paid out-of-pocket to access the original treatment or an alternative treatment	14% (n=5)
My doctor was able to fight the insurer, and won	5% (n=2)

These findings tell us that slightly more than half of all patients had, at some point, been told by their insurance that they could not get access to the treatment that their doctor decided

would be best. Furthermore, this was more than an inconvenience or a waste of time. The use of step therapy extends a patient’s suffering, or delays effective treatment long enough that conditions progressed or worsened. Of note, currently [several States have laws](#) restricting the practice of step therapy.

Primary Issues Getting in the Way of Quality Care

Lastly, we wanted to know what kinds of access issues patients were facing. We asked, “*What are the obstacles you face between your healthcare needs and getting that care?*” Responders were told to write out their answers so we could capture responses that we might not predict. Eighty-seven (87) responders answered this question and we categorized their responses as follows:

Access Issues for People with Digestive Tract Paralysis Diseases		
Responses (categorized)	# of people out of 87 who mentioned issue	% out of 87 who mentioned issue¹
Lack of expert providers	49	56%
Insurance interference ²	31	36%
Financial ³	28	32%
Doctor is too far away	23	26%
Lack of family support	16	18%
Medical prejudice ⁴	7	8%
Complications with transportation	7	8%
Takes so long to get an appointment	6	7%
Complications from co-morbidities	6	7%
My doctors don’t talk to each other	3	3%
<p>1: Because responders were able to mention multiple concerns, the percentages listed do not add up to 100, but are instead the rate at which responders mentioned each concern. For example, the Lack of Expert Providers of 56% means 49 out of the 87 responders cited this concern.</p> <p>2: Insurance interference: examples include: <i>denying coverage for “experimental” treatments, step therapy, delays due to authorizations, lack of coverage for specialists, high out-of-pocket costs, doesn’t cover my meds, in-network limitations.</i></p> <p>3: Financial: we separated “financial” concerns from “insurance” concerns whenever a responder mentioned finances outside of the context of insurance. Some examples of financial concerns include: <i>poor finances, lack of money, on Social Security Disability Income, forced to work despite illness, can’t afford out-of-pocket.</i></p> <p>4: Medical prejudice: responders mentioned issues like, <i>treated like a drug seeker, providers not willing to listen, doctor has given up on me.</i></p>		

CONCLUSION

Based on these findings, Patients Rising will work with G-PACT to create educational materials on the following issues:

- Strategies for reducing monthly out-of-pocket costs
- How different states view step therapy and how patients can work with doctors to avoid step therapy
- Finding reliable sources of affordable medical supplies and equipment
- Finding or creating a listing of motility specialists

As for the obstacles to access, [Patients Rising University \(PRU\)](#) has already developed several resources as follows:

- PRU January 2020 webinar entitled "[Getting Your Treatments Covered](#)"
- PRU panel-discussion "[Navigating the Cost of Care: A Financial Planner](#)" featuring experts like oncology financial navigator Clara Lambert, health and wellness coach (and DTP patient) Samantha Smith, and Terry Wilcox
- PRU presentation "[Managing Chronic Illness: A Guide to Organizing Your Care](#)", which includes a section on financial management presented by Whitney Morrison, the principal financial advisor at LegalZoom

This conversation between organizations will continue and is vital to understanding the full picture of the patient challenges. You can keep up with educational information and events by following [G-PACT on Facebook](#) and by [Subscribing to the Patients Rising newsletter](#).