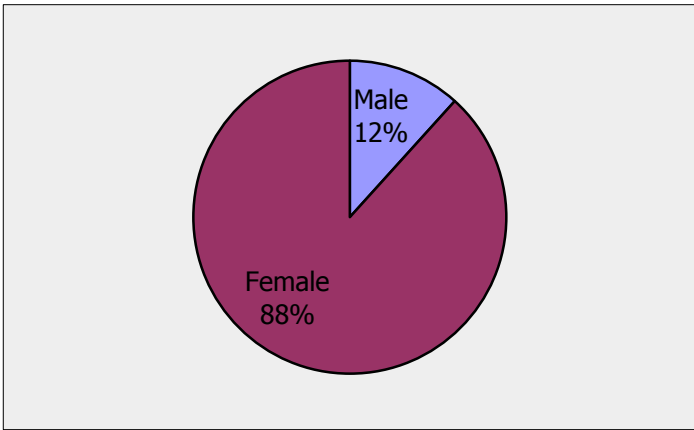


Survey Results: Personal Experience with Gastroparesis

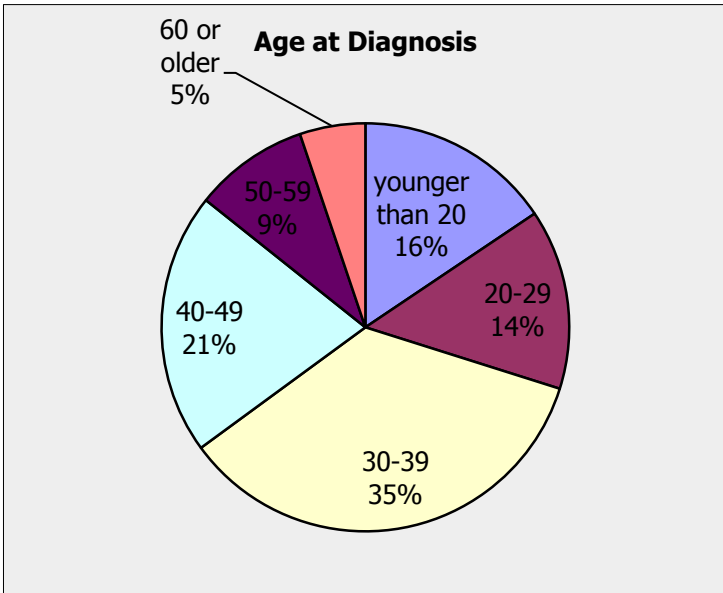
Question 1: Please indicate:

Answer Options	Response Percent	Response Count
Male	11.7%	9
Female	88.3%	68
<i>answered question</i>		77
<i>skipped question</i>		0



Question 2: How old were you when you were diagnosed?

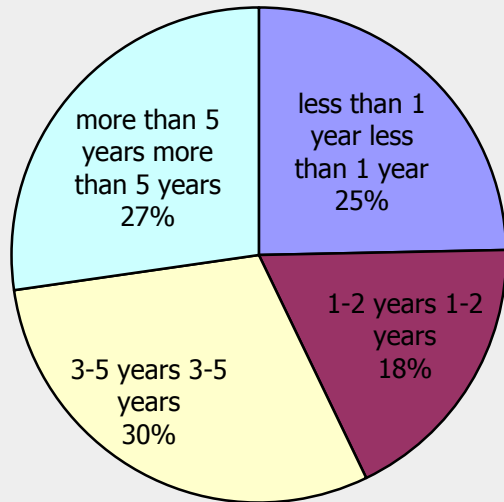
Answer Options	Response Percent	Response Count
younger than 20	15.6%	12
20-29	14.3%	11
30-39	35.1%	27
40-49	20.8%	16
50-59	9.1%	7
60 or older	5.2%	4
<i>answered question</i>		77
<i>skipped question</i>		0



Question 3: How long have you had Gastroparesis?

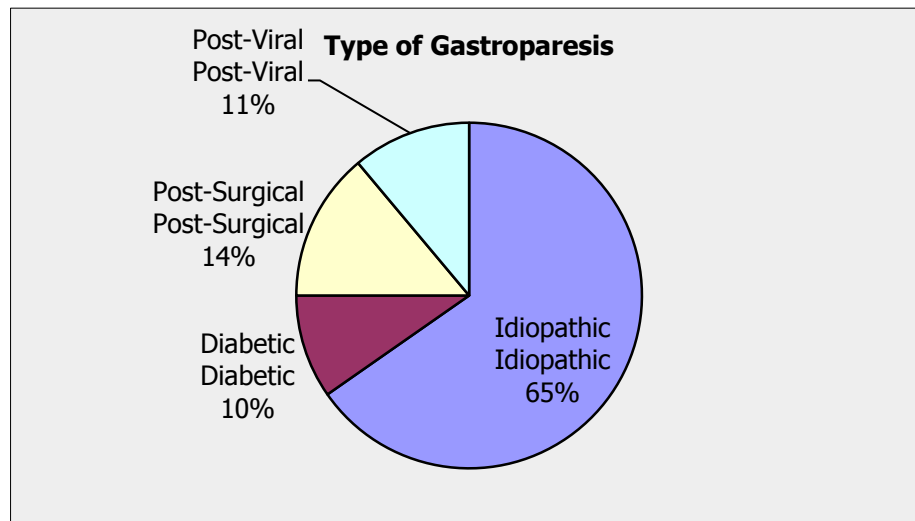
Answer Options	Response Percent	Response Count
less than 1 year	24.7%	19
1-2 years	18.2%	14
3-5 years	29.9%	23
more than 5 years	27.3%	21
answered question		77
skipped question		0

How long have you had Gastroparesis?



What "kind" of Gastroparesis do you have?		
Answer Options	Response Percent	Response Count
Idiopathic	65.3%	47
Diabetic	9.7%	7
Post-Surgical	13.9%	10
Post-Viral	11.1%	8
Other (please specify)		8
answered question		72
skipped question		5

Number	Other (please specify)
1	don't know really
2	from autonomic neuropathy
3	caused by a congenital defect and possibly the surgery to correct it.
4	query if related to thoracic spine fractures
5	With Scleroderma
6	also diagnosed with autonomic dysfunction which causes gastroparesis
7	MSA
8	Spinal syrinx

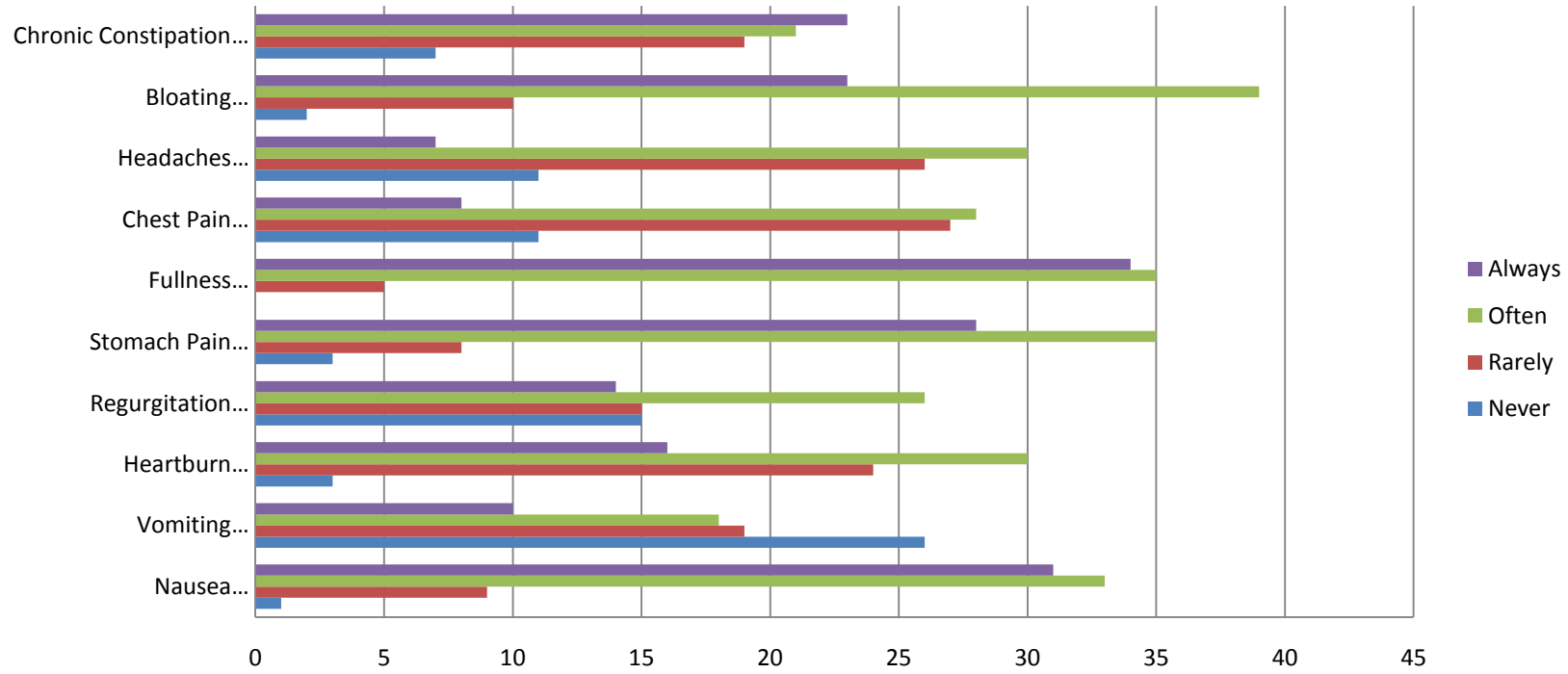


How often do you experience the following symptoms?

Answer Options	Never	Rarely	Often	Always	Rating Average	Response Count
Nausea	1	9	33	31	3.27	74
Vomiting	26	19	18	10	2.16	73
Heartburn	3	24	30	16	2.81	73
Regurgitation	15	15	26	14	2.56	70
Stomach Pain	3	8	35	28	3.19	74
Fullness	0	5	35	34	3.39	74
Chest Pain	11	27	28	8	2.45	74
Headaches	11	26	30	7	2.45	74
Bloating	2	10	39	23	3.12	74
Chronic Constipation	7	19	21	23	2.86	70
Other (please specify)						11
<i>answered question</i>						74
<i>skipped question</i>						3

Number	Other (please specify)
1	interstitial cystitis
2	fatigue
3	esophageal spasms
4	diarrhea, weight loss, aversion to food
5	She is 16 months old so these are a bit difficult to answer
6	backache from constipation always
7	I would vomit if I could but because of surgery I cannot any longer.
8	afternoon fatigue (severe)
9	Dizziness
10	diarrhea
11	diarrhea

Symptom Frequency

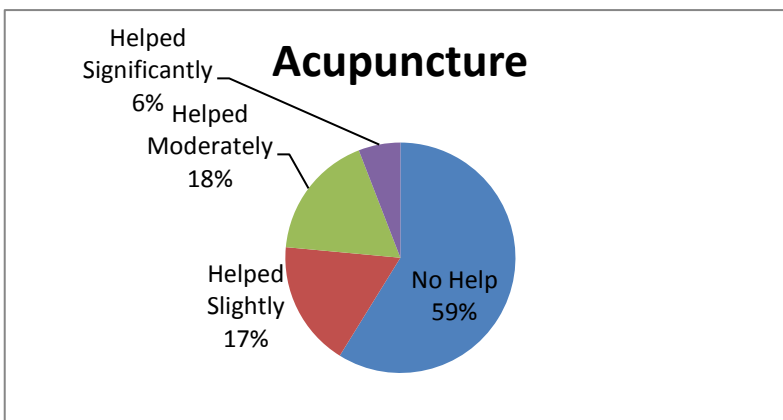
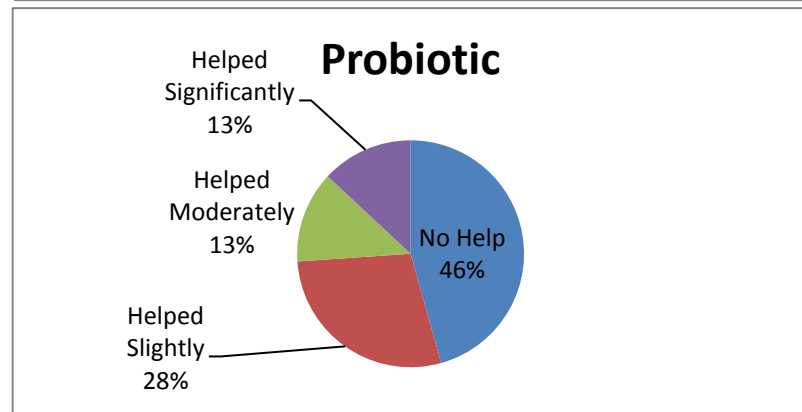
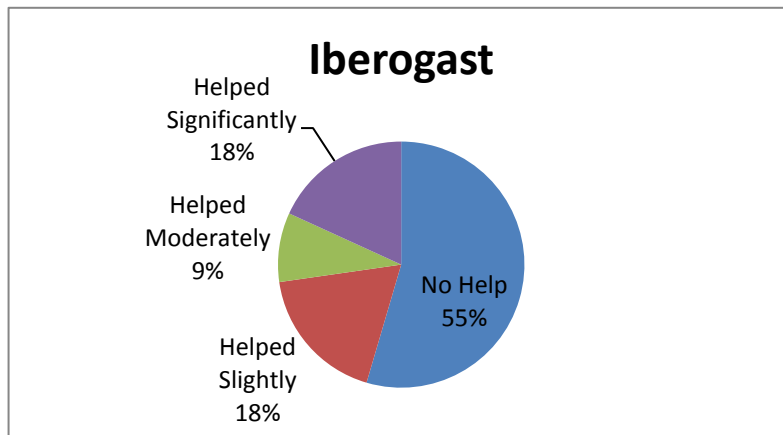
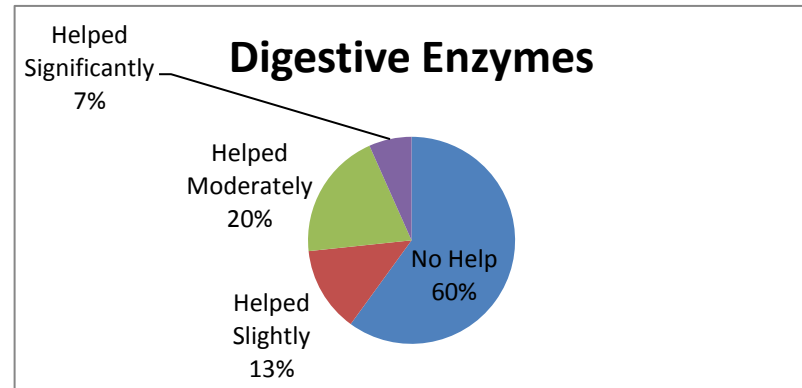
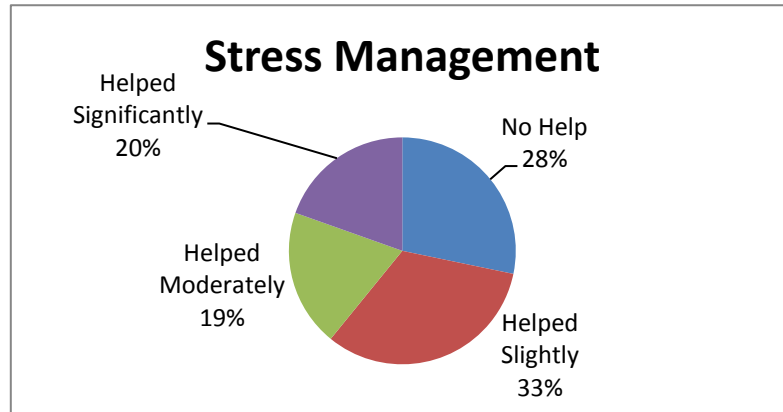
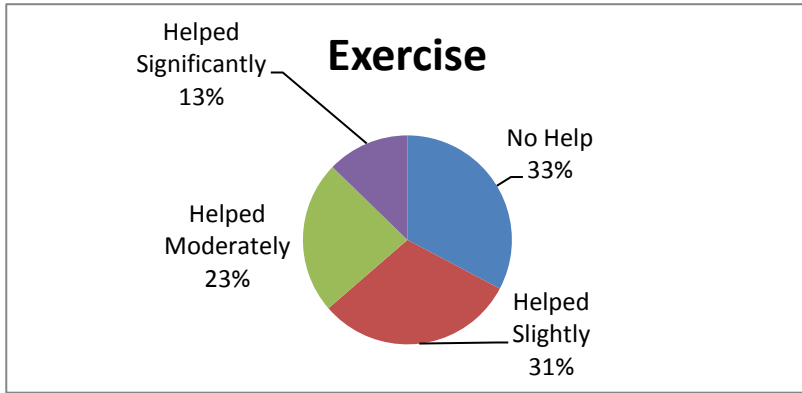


**For each of the following treatments, please indicate how helpful you found each one.
(Choose N/A if you haven't tried it.)***

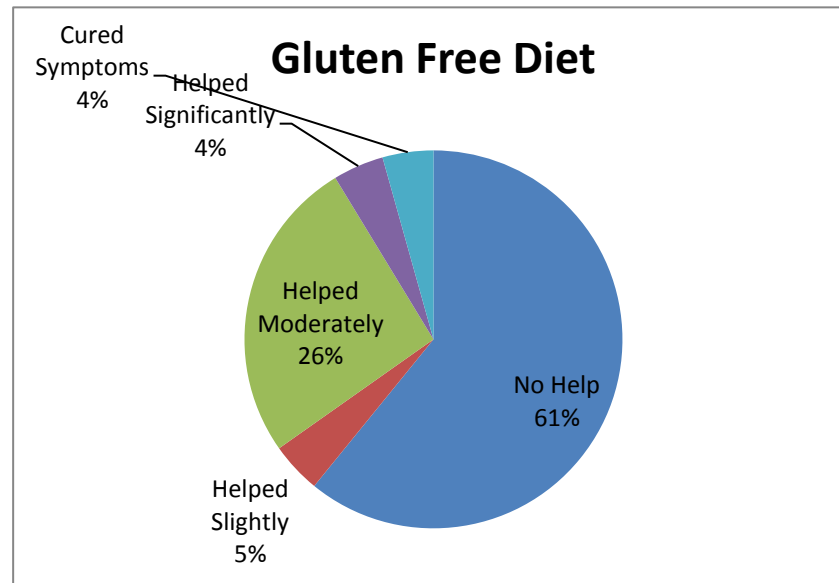
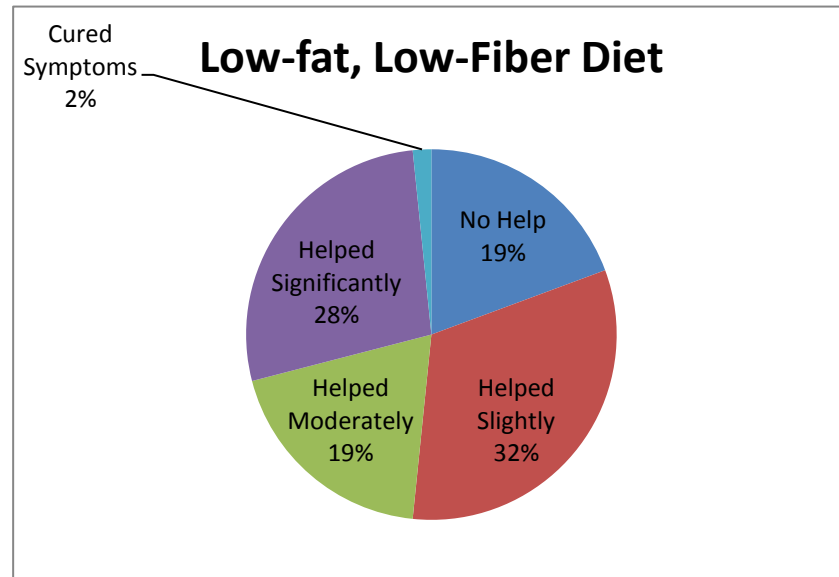
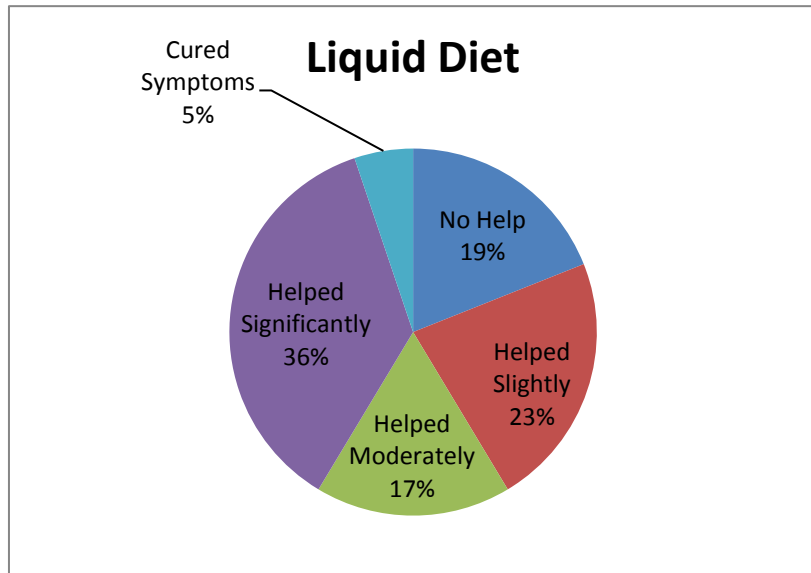
Answer Options	No Help	Helped Slightly	Helped Moderately	Helped Significantly	Cured Symptoms	N/A	Rating Average	Response Count
Reglan	31	6	7	8	1	17	1.91	70
Domperidone	13	5	4	8	0	42	2.23	72
Prescription Nausea Meds	9	12	19	17	0	14	2.77	71
Digestive Enzymes	18	4	6	2	0	40	1.73	70
Iberogast	6	2	1	2	0	56	1.91	67
Probiotic	21	13	6	6	0	25	1.93	71
Low-fat, Low-Fiber Diet	12	20	12	17	1	10	2.60	72
Liquid Diet	11	13	10	21	3	14	2.86	72
Gluten Free Diet	14	1	6	1	1	47	1.87	70
Botox Injections	3	2	4	0	1	58	2.40	68
Gastric Neurostimulator	0	1	1	3	1	60	3.67	66
Exercise	18	17	13	7	0	17	2.16	72
Stress Management	13	15	9	9	0	25	2.30	71
Acupuncture	10	3	3	1	0	53	1.71	70
Other (please specify)								7
answered question								75
skipped question								2

Number	Other (please specify)
1	cisapride - helps significantly <input type="checkbox"/> tramadol - helps significantly
2	Correctly balancing supplements and nutrition
3	Allergic to the nausea meds I tried
4	Nutritional supplement for weight gain, very helpful. (Now at maintenance.)
5	She is starting Pancreatic Enzyme Replacement Therapy and is on Zantac which does help her motility for an unknown reason
6	Erythromycin - helped for about a year, but built up a tolerance
7	Regular amounts of fats, zero fiber (fiber = polysaccharides - sits in our guts and ferments due to slow digestion), zero sugar, and vegetable juicing stopped all symptoms.

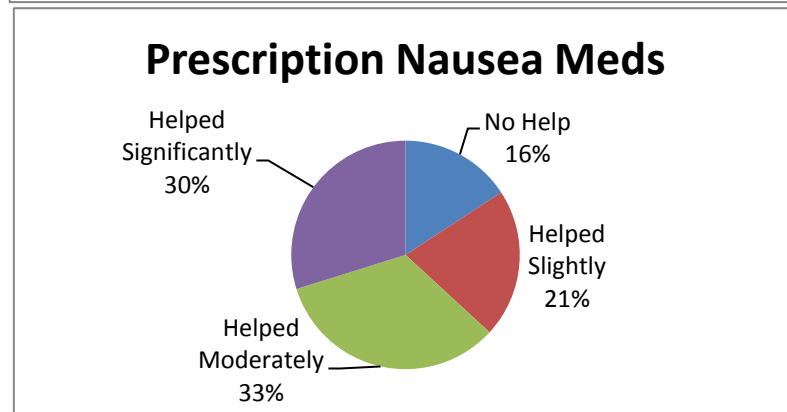
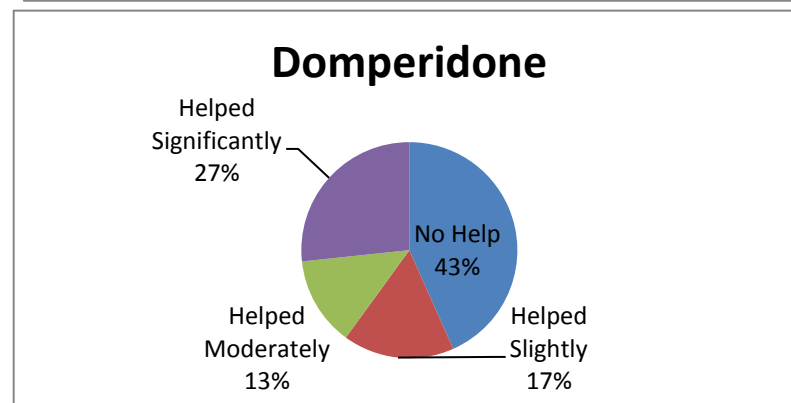
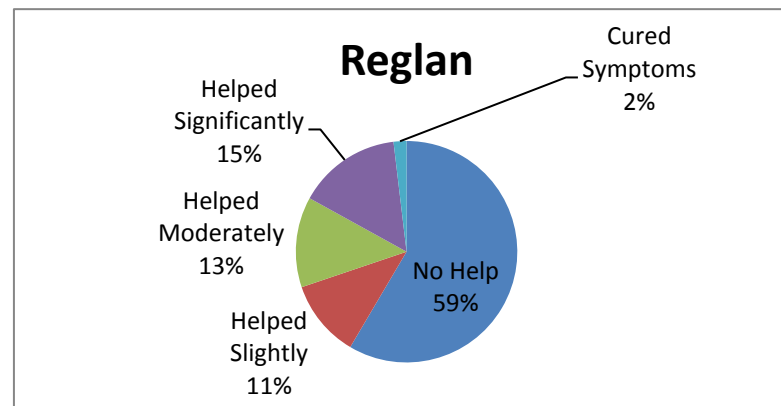
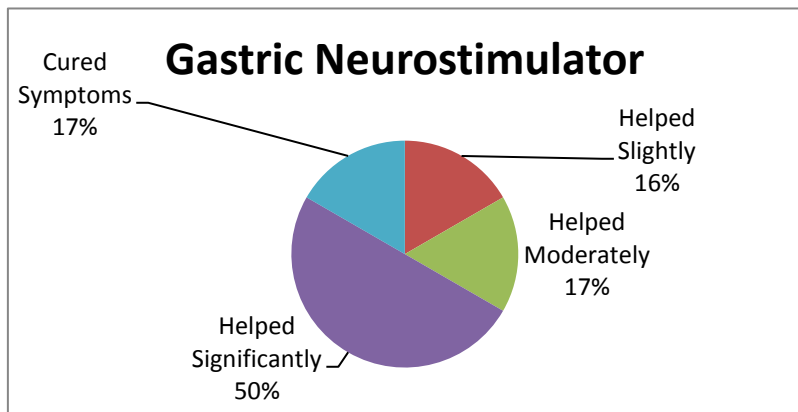
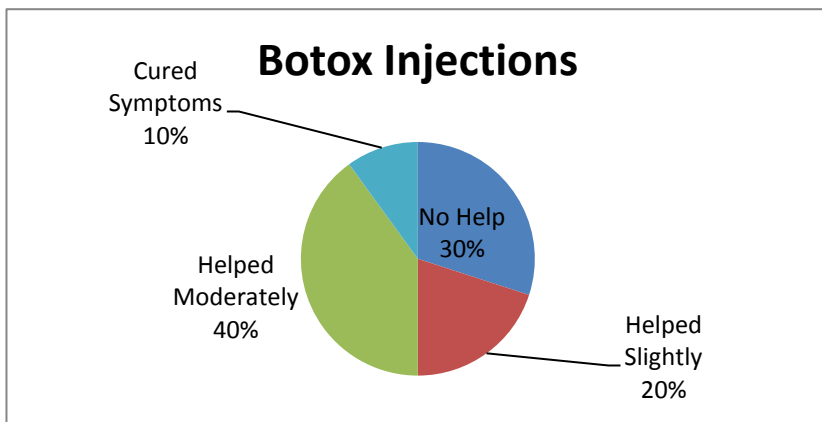
Lifestyle Changes & Alternative/Complimentary Medicine



Dietary Modifications



Prescription Medication & Medical Procedures

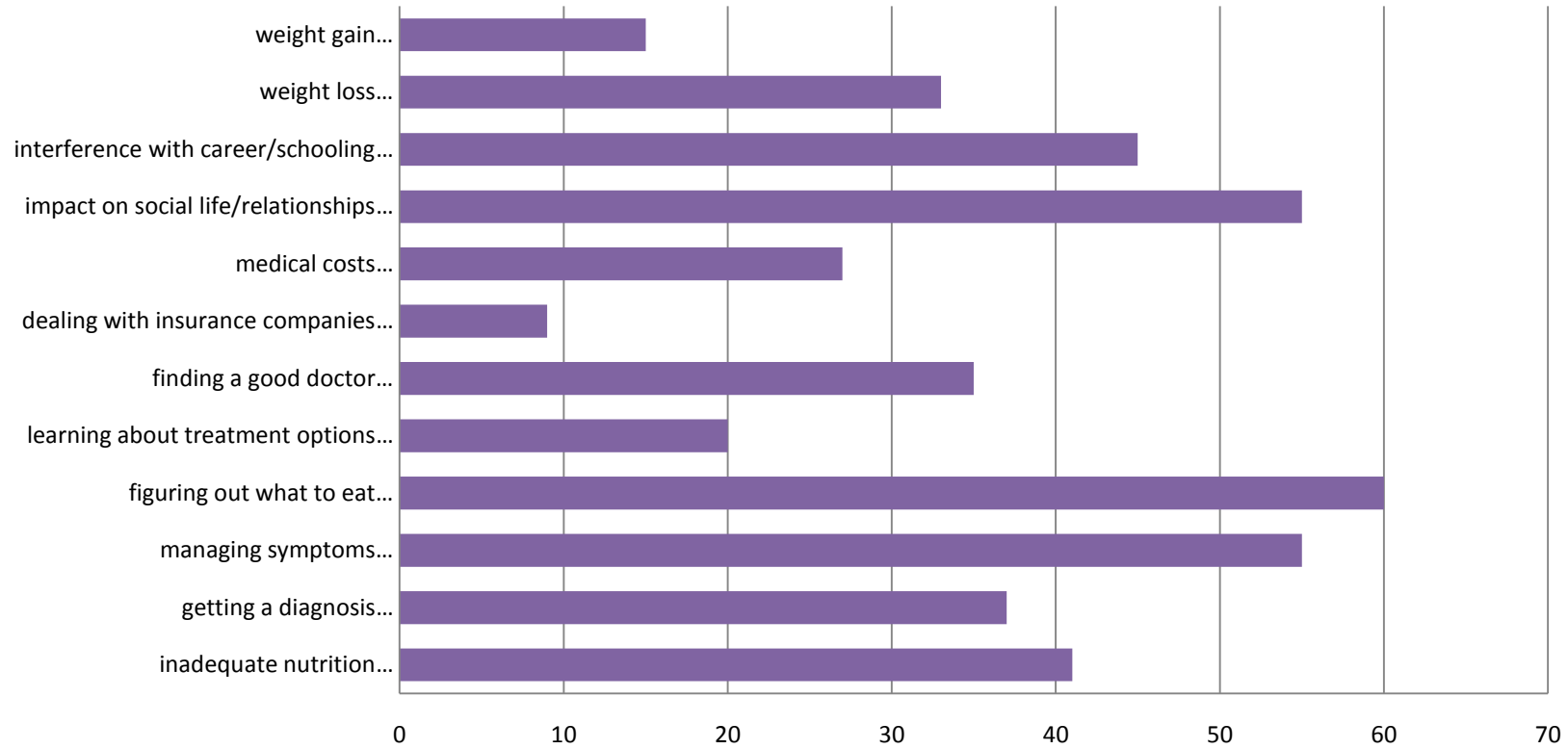


Which aspects of living with GP have caused you the most difficulty?

Answer Options	Response Percent	Response Count
inadequate nutrition	54.7%	41
getting a diagnosis	49.3%	37
managing symptoms	73.3%	55
figuring out what to eat	80.0%	60
learning about treatment options	26.7%	20
finding a good doctor	46.7%	35
dealing with insurance companies	12.0%	9
medical costs	36.0%	27
impact on social life/relationships	73.3%	55
interference with career/schooling	60.0%	45
weight loss	44.0%	33
weight gain	20.0%	15
Other (please specify)		6
answered question		75
skipped question		2

Number	Other (please specify)
1	fatigue
2	development.
3	Managing the pain - or inability to manage the pain
4	Depression
5	people thinking I have an eating disorder
6	feeling alone, coming across drs. who don't believe or understand

What do you have the most difficulty with?



What are the "staples" of your current diet?*

1	low-fiber cereal, boost, applesauce, baby food, 100 calorie packs, hot chocolate
2	Ensure muscle milk light light cheese baby food
	Doing well on the "Stage 3" GP diet <input type="checkbox"/>
3	Mostly starches & dairy plus small amounts of chicken, fish, ground meat, a few cooked vegetables & low fiber peeled fruits.
4	granola bars in small amounts many times each day
5	glucerna drinks, carnation drnks, otherwise small portions of regular food
6	Mostly on tube feedings but when have to have something by mouth can do best with mashed potatoes, baked potato, toast
7	liquid protein shakes, mashed potatoes, anything runny
8	rice, pudding, toast, juices, mostly soft diet
9	crackers
10	Now that I have the gastric stimulator, I am able to eat anything I want.
11	I use a j-tube most of the time. Sometimes I can have broth, flat soda, juice
12	Whatever I feel like eating
13	whey protein, almond milk, fat-free yogurt, carnation instant breakfast, peanut butter, canned or fresh pureed fruit, fresh fruit smoothie bases, pumpkin, squash soup, quinoa, ground meat
14	Protein smoothies, gluten free hot cereal, well cooked veggies
15	I am on tube feedings (Jevity 1.2)
16	tube feeding liquid diet
17	Not sure yet.
18	Tube feeding via a j-tube
19	Carbohydrates
20	meat, cheese and lactose free milk - everything else causes rapid emptying and blood sugar complications because she is intolerant of all sugars.

21	tube feeding
22	slimfast(like the taste better than other liquids) carnation instant breakfast, soup, egg beaters, smart water, chewable vitamins,smoothies
23	Chesse-itz, pedilite pops , homemade fruit/veggie sluslues
24	Oatmeal, Chicken(bland) and Ice tea
25	I'm tube fed. I can sometimes take a little food orally but it needs to be fairly soft as I have trouble swallowing. I try to eat chocolate regularly!
26	nothing
27	egg whites, quinoa, crackers, cheese sticks, broths, v 8, bread sometimes, salmon sometimes
28	Muffins, pretzels, waffels, cereal, bread
29	I dont eat until finished work around 2pm then I eat anything my body craves and crash for the rest of the day. Not good, I know, but only diagnosed 3 days ago.
30	rice, cream of wheat, potatoes, coffee
31	TPN
32	Low fat!
33	Not much! I try liquids, soft foods, even feeding tube liquids and I still can't keep them down.
34	I have fructose and lactose intolerance so I can't have fruits or vegetables. My diet consists of fish, poultry, rice, potato, and bleached wheat products. It is low-fat and low-fiber. I take supplemental vitamins, calcium, vitamin B12 and vitamin C.
35	Bananas, Cheerios, protein shakes, lite yogurt. I can tolerate potatoes and rice. I can eat chicken but not other meats very well.
36	V-8 mixed with water, homemade chicken spread, salmon, supplements enteric coated or liquid.
37	Things that are easy to digest; avoid anything raw, acidic, or fried
38	protein, almond flour, eggs, coconut milk, almond butter for baking breads
39	shakes, smoothies, yogurt, pudding, mashed potatoes, pasta
40	Small Portions.
41	Soy protien powder, fruit juice, V8, crackers, gummy vitamins
42	Simple carbs, Low fat proteins, Fruit juice.

43	tube feed and small amounts of liquids i feel full very fast
44	liquids and crackers with low fat cheese and boost helps
45	applesauce, gatorade, animal crackers, vanilla wafers, ginger ale, yogurt
46	Noodles and plain bread.
47	Basic starches, soup, soda.
48	i eat very little. mabe once or twice a day, if i eat more than i have more abdominal pain and more naseua.
49	boiled skinless potato
50	boost, soup, baby food, dry cereal
51	chix noodle soup, cereal, frozen yogurt, sorbet, english muffin, potatoes, carrots, bananas
52	TPN, dried cereal, yogart
53	When bad I ate baby food and drank liquids. Now I am eating normally and long may it continue.
54	I am tube fed
55	yogurt;turkey meatballs; protein drinks;crackers;
56	jello, water, popsicles
57	Shredded chicken and rice, lowfat/fiber cereal, puddings, custard, toast, fat free yogurt, fat free frozen yogurt, fat free cheese, fat free cottage cheese, baked potato without skin, baked haddock
58	ENSURE HP, BRYERS ICE CREAM, STICKY RICE (SOLUBLE FIBER)
59	soups, and low fat carbs
60	Cheerios, low-fat milk, fruit smoothies, baby food stage 2 carrots and squash, potatoes, sweet potatoes, well cooked and skimmed ground beef, lean chicken, lean pork, non-fat yogurt, low-fat cold cuts, white bread, apple sauce, pear sauce, peeled grapes, peeled pears, Quakers rice snacks, pretzels, Special-K Bliss bars.

Is there any additional information or advice that you would like to share with others who have Gastroparesis?*

1	Study the internet for any and all information you can find. Take questions to your doctor and ask if you can try treatments you read about. If he isn't taking you seriously, change docs.
2	Are there other kinds of conditions commonly associated with Gastroparesis? I also have IBS & GERD
3	Although my gp is officially considered "idiopathic", it began following many GYN surgeries. At that time I was also diagnosed with chronic pancreatitis, chronic intestinal psuedo obstruction, severe small bowel dysmotility, severe bacterial overgrowth, all making life very limited. I appreciate the effort you have made to conduct this survey.
4	god bless
5	Continue to educate yourself about GP. Educate your doctors so they can help you and others.
6	Don't take Reglan, especially if you are prone to depression. The allergy symptoms are also awful, and the steroids....it's just a disaster waiting to happen
7	keep your hydration up
8	If any medications are prescribed, get a second opinion. If anyone tells you it's "in your head," run like mad!
9	Having the PEG to drain/vent is somewhat helpful. Using suction with it is helpful. The j-tube and TPN have saved my life.
10	Continue to push your doctors for the latest treatment options. Be your own advocate! And most importantly take care of yourself when symptoms are bad.
11	I wish.
12	I try not to take any meds that I can do without, thats me. I do stay with liquids as much as possible, it helps with pain management. I also have colonic anertia, so my colon doesn't work, so with liquids it helps everything work a little better. You just have to figure out what works best for you and stick to it as best you can till that step goes bad and than figure it out again.....
13	Go to the mayo and learn how to breathe correctly☐ Please share my answers as I hope they can be of help to someone
14	find the actual cause, as it's bound to be a symptom in itself
15	I have found that you have to be your own advocate. I have taken to keeping a journal in which I record my weight every morning, when and what medications I take, what I eat, and what symptoms I experience and their severity. It sounds time-consuming, but it wasn't so bad once I got into the habit of keeping it.
16	Trust your GUT don't let anyone tell you that you are not really sick! Believe in how you feel and don't stop until you get answers!

17	Get your nutrition!
18	I'll be praying for some kind of breakthrough of relief for us all.
19	I was told to avoid chocolate, tea, and coffee. These foods were making me very sick. Thank you for doing this survey. I wish you had included tube feedings and TPN in your treatment question.
20	TONS. I will help anyone who contacts me because the doctors are missing it when it comes to diet. Plain and simple. If you look at this disease from a chemistry standpoint, it makes sense to immediately stop all sugar/starch intake because it ferments in our guts, furthering the debilitation by candida overgrowth. Anyone can contact me. Most people who do, don't want to hear me because of the self-denial involved in the dietary guidelines I propose, but they work. People are addicted (really) to carbs and can't imagine life without them.
21	Sticking to a liquid diet really helps. 3 flax seed oil caps really help. miralax really helps. drinking lots of liquids really helps.
22	Keep going until someone listens to you. You're not crazy, there is really something wrong. Find a Dr that will help/listen. Seek support. Get as educated as you can about this.
23	Get a family member to go to DR app with you to help fight for what you want. Keep a log of every thing you do as this will help to let the DRs know what is going on and help you to remember as well.
24	It takes courage and strength to face our diagnosed but we will overcome. We are not alone we always have support from loved ones. Yes times are hard and get us down we must fight to survive!!! Thanks to sites like this that makes us live for a new beginning. Lots of love and hope to all.....
25	I'm still early in my GP experience, and would love information or advice from others!
26	Botox is a new thing and it worked for me for a while...so i would recommend anyone to try it.
27	Believe it won't last forever - I have had two major episodes and pray I will have no more.
28	FIND A DOCTOR WHO HAS EXPERIENCE WITH "END OF LIFE ISSUES" BECAUSE THEY ARE THE ONES WHO HAVE EXPERIENCE WITH THE SAME PROBLEMS WE HAVE.
29	Have your last food at least three hours before bedtime. I have found the new Metamucil soluble fiber to be effective and easy to tolerate.
30	Don't engage in groups that promote negativity or complaining. Instead surround yourself with a community that supports each other by offering information and hope.

****NOTE: These comments are the opinions of the survey respondents only and are not meant as medical advice. I DO NOT endorse or discourage any particular treatment or diet. Check with your doctor before starting or stopping treatment.***