The Impact of the COVID Pandemic on Dietary Changes and Gastric Symptoms in People with Ehlers-Danlos Syndromes

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INTRODUCTION

Evidence suggests that there is a link between gastric symptoms and connective tissue disorders.[1-7] The impetus for this study originated with the Penn State EDS Patient Research Advisory Group, a group of patients who have been diagnosed with Ehlers-Danlos Syndromes (EDS). A principal function of this group is to engage in research design and implementation, and represent the patient's perspective.

This study included patients with Ehlers-Danlos Syndromes (EDS) and Hypermobility Spectrum Disorders (HSD). These are groups of heritable disorders of connective tissue that share a myriad of symptoms, including joint hypermobility and gastrointestinal (GI) conditions.[8-10] The most common GI symptoms reported include abdominal pain, nausea, constipation, heartburn, irritable bowel syndrome (IBS), gastroesophageal reflux, vomiting and diarrhea. GI physiological studies have shown abnormal gastric emptying, abnormal colonic transit, and rectal evacuation disorder.[5]

The patient advisory group discussed the impact of the COVID pandemic and the consequences of the pandemic on their community. The group was particularly interested in the disruption of the food supply chain and its ultimate impact on GI symptoms. Because many members have gastric issues that require specialized diets, they were able to identify challenges with accessing food. They were also interested in understanding whether others in their community had similar experiences. The purpose of this research was to measure the impact of the pandemic on food acquisition, dietary changes, and GI symptoms.

METHODS

A survey questionnaire, *"Ehlers-Danlos Syndrome (EDS) Food Access and Dietary Changes"* was designed to discover how access to food during the pandemic may or may not have caused dietary changes among the EDS population. Survey questions included: food acquisition, food availability and price comparisons, and changes in GI symptoms. A description and link to the online survey questionnaire was published by the Ehlers-Danlos Society on November 5, 2020 in its *Connect* international newsletter (https://www.ehlers-danlos.com). The link to the survey remained open until December 31, 2020. The survey invited people with EDS or HSD to participate voluntarily and anonymously. Study data were collected and managed using REDCap electronic data capture tools hosted at Penn State College of Medicine.[11] REDCap (Research Electronic Data Capture) is a secure, web-based software platform designed to support data capture for research studies. The data were analyzed using descriptive statistics using Stata/IC 15.1 (http://www.stata.com). The study was approved by the Penn State Institutional Review Board.

RESULTS

Two hundred sixteen people participated in the survey. The majority identified as White (88.4%), non-Hispanic (90.7%), female born (95.8%), North American (78.2%); between the ages of 25 and 54 years (75.0%).

Approximately, sixty five percent were in possession of a college degree. Self-reported diagnostic classifications are shown in Table 1.

Table 1. Participant Self-reported Diagnostic Classification

Classification	N, %
Hypermobile EDS (hEDS)	156, 72.2%
Hypermobility Spectrum Disorders (HSD)	25, 11.6%
Vascular EDS (vEDS)	5, 2.3%
Classical EDS (cEDS)	9, 4.2%
Other EDS type	2, 0.9%
More than one EDS type	10, 4.6%
Not sure of diagnosis	9, 4.2%

Food Acquisition

Most survey takers bought food without assistance (62.0%). Of the 35.2% who were assisted by a caregiver, the vast majority reported that a family member served in that role. The most common modes of transportation to buy food were personally owned motorized vehicles (84.3%), walking (15.7%), and public transportation (12.0%). Figure 1 below shows the percentage change in methods survey takers or their caregivers used to acquire food.

Shopping patterns changed. For example, before the COVID pandemic, 88.5% of survey takers or their caregivers went to a food store at least once a week, compared to 54.7% during the pandemic.

Food Prices

The majority of survey taker households consisted of 1-2 members. Almost 67% of survey takers indicated that the price of food in their area had increased during the pandemic, and 76.8% were experiencing some level of financial hardship purchasing food. Of those experiencing financial hardship, 15.7% relied on a food bank/pantry, food service, food assistance program, or donations.

Food Availability

During the COVID pandemic, 87.0% of survey takers experienced some level of apprehension to do with their ability to get the foods they needed. Compared to before the pandemic, survey takers were buying fresh perishable foods less often (45.3%), and were buying foods with a longer shelf life, such as canned (39.9%) and frozen (46.9%) more often. Fresh produce and meats/seafood, along with frozen, canned, and specialized foods (gluten free, etc.) became more difficult to obtain. However, of the 19.3% of survey takers who rely on nutritional products needed for IVs and feeding tubes, the majority saw no change obtaining what they needed.

Dietary Changes

The vast majority (95.3%) of survey takers reported having one or more GI comorbidities related to their EDS/HSD as listed in Table 2.

Many, but not all, people with EDS and GI comorbidities follow a specialized diet. About two-thirds of the survey takers indicated that they were on one or more of these specialized diets (Table 3).

Table 2. Participant Self-reported Gastrointestinal Comorbidities

GI Comorbidity	N, %
Irritable Bowel Syndrome (IBS)	128, 59.5%
Gastroesophageal Reflux Disease (GERD)	125, 58.1%
Temporomandibular Joint Dysfunction (TMJ)	115, 53.5%
Mast Cell Activation Disorder (MCAD)	83, 38.6%
Chronic Constipation	71, 33.0%
Gastroparesis (GP)	51, 23.7%
Other	42, 19.5%
Eosinophilic Esophagitis (EoE)	8, 3.7%
Median Arcuate Ligament Syndrome (MALS)	6, 2.8%
Defacatory Dyssynergia	5, 2.3%

Table 3. Specialized Diet, Before and During the Pandemic

Type of Diet	Before: N, %	During: N, %
Low-FODMAP Diet	44, 20.6%	30, 14.2%
Low-histamine Diet or Mast Cell Diet	48, 22.4%	41, 19.4%
Gluten-Free Diet	73, 34.1%	65, 30.8%
Vegetarian Diet	20, 9.3%	18, 8.5%
Liquid Diet	6, 2.8%	6, 2.8%
Tube Feeding Diet	0, 0.0%	1, 0.5%
Blended Diet (food that has been blended for easy-eating)	9, 4.2%	9, 4.3%
Supplemented Diet (foods supplemented with Ensure)	25, 11.7%	17, 8.1%
Total Parenteral Nutrition (TPN) Feedings	1, 0.5%)	1, 0.5%
Gastroparesis or Low-Residue Diet	20, 9.3%	17, 8.1%
Other	50, 23.4%	50, 23.7%

Changes in GI Symptoms

As a result of difficulties in acquiring food due to the COVID pandemic, 50.0% of survey takers indicated that they changed their usual diet and reported the following changes in their gastric symptoms (Figure 2).

Figure 1. Change in Method of Acquiring Food

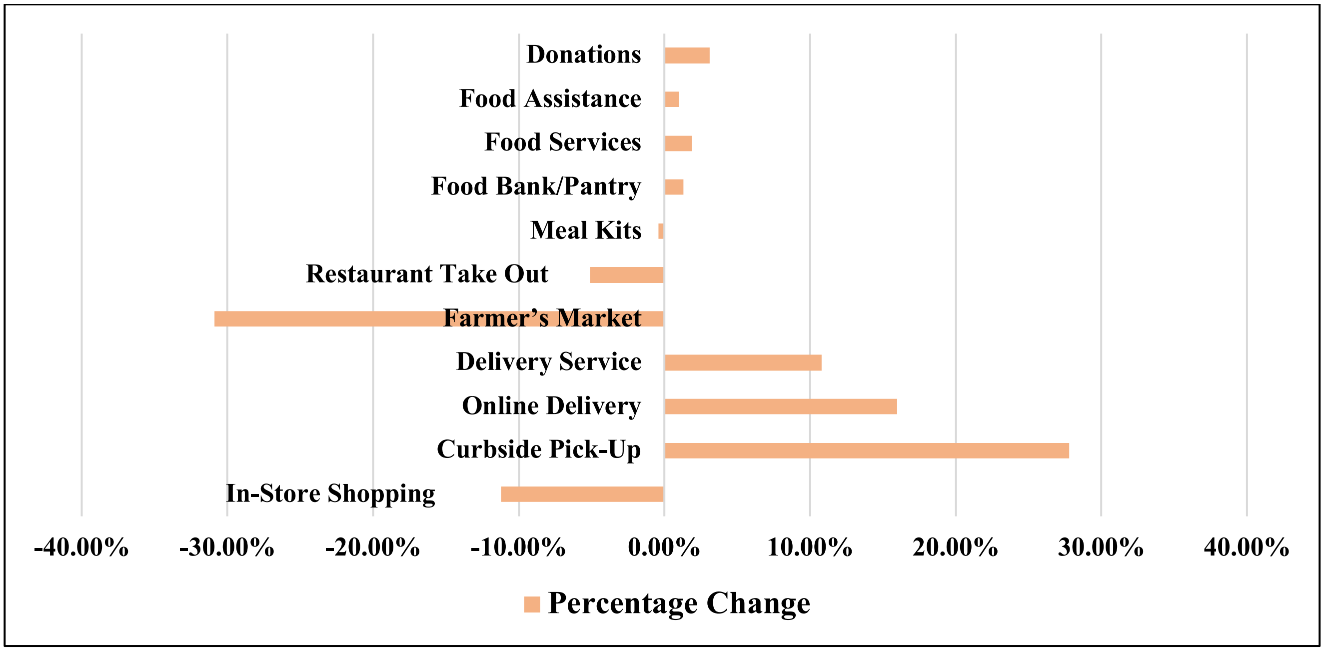
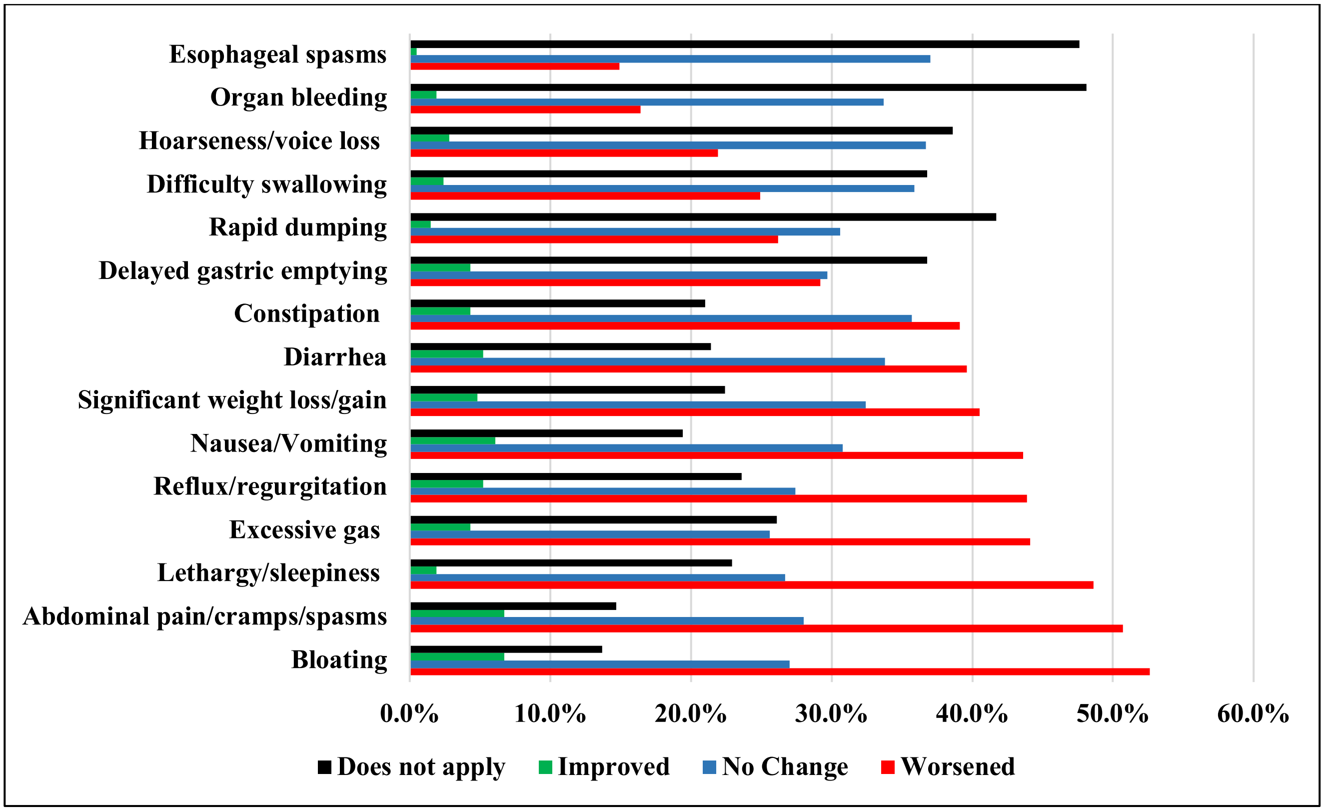


Figure 2. Change of Gastric Symptoms



Discussion

This survey was designed to determine the extent to which access to food during the pandemic contributed to both dietary changes and GI symptoms. The majority of survey takers reported difficulty in access to their usual foods, increase in food prices, and some level of financial hardship in food acquisition. When compared with fresh produce, foods with a longer shelf life were acquired more often. Fifty percent of survey takers reported dietary changes. A large proportion reported worsening of their GI symptoms.

More survey takers reported following a Low-FODMAP Diet before the COVID pandemic. People with EDS/HSD often experience IBS symptoms, including diarrhea, excessive gas, bloating, and abdominal pain/cramps/spasms. The overall worsening of these symptoms reported by survey takers could be explained by an increase in consumption of foods with a longer shelf life. This food type tends to contain sweeteners and additives, including high fructose corn syrup, which should be avoided when following a Low-FODMAP diet. The survey takers who were following a gluten-free diet before the pandemic reported a worsening of their gastric symptoms, including reflux/regurgitation, bloating, excessive gas and abdominal pain/cramps/spasms. Survey takers who were following a low-histamine diet for mast cell activation disorder reported a worsening of their symptoms, for example, lethargy/sleepiness, reflux/regurgitation and abdominal pain/cramps/spasms.

The pandemic created an unusual opportunity to measure the impact of diet changes and resulting gastric symptoms in an unpredictable environment. The study findings shed light on the consequences of not maintaining specialized diets for people with GI manifestations of connective tissue disorders.

Limitations of this survey include a convenience sample of people who were self-selected, had access to the internet and were proficient in the English language. The survey was time limited to a 2-month period during the pandemic. Diagnoses and GI symptoms were self-reported by survey takers.

Conclusion

The survey findings were consistent with the EDS Patient Research Advisory Group's concerns that people with EDS/HSD were negatively impacted by pandemic-related disruption in acquisition of foods. The findings suggest that unavoidable dietary changes contributed to worsening GI symptoms.

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