

# **The Psychosocial Implications of Hereditary Diffuse Gastric Cancer**

Master's thesis

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The Faculty of the Graduate School of Arts and Sciences  
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## ABSTRACT

### The Psychosocial Implications of Hereditary Diffuse Gastric Cancer

A thesis presented to the Department of Biology,  
Program in Genetic Counseling

Graduate School of Arts and Sciences  
Brandeis University  
Waltham, Massachusetts

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The unique journey families face with hereditary cancers warrants investigation as it impacts quality of life and survival in ways that are different from experiences in families with sporadic cancer. With hereditary diffuse gastric cancer (HDGC), this stems from the discovery of a mutation known to predispose to gastric cancer as well as the prophylactic total gastrectomy (TG) necessary to reduce risk. Few studies have looked at the psychosocial ramifications of the identification of a hereditary predisposition for gastric cancer in a family and the necessary prophylactic surgery that follows.

The purpose of this qualitative study was to explore the psychosocial journey facing families with members found to carry the mutation known to cause a predisposition for HDGC. Eighty-four individuals completed a survey, offering advice for those stepping into the experience and for the professionals guiding them. We used qualitative content analysis to interpret responses to five open ended questions.

From the 84 survey respondents, the following should be considered in the guidance of individuals and families facing the experience of HDGC: (1) Physicians need to be better educated about the physical and emotional aspects of dealing with HDGC. (2) Dieticians need information about the unique dietary requirements associated with TG. (3) Genetic counselors should be prepared to educate and provide resources for entire families, including those individuals who are not at risk.

This study shows those dealing with HDGC are in need of help from the medical community, including genetic counselors. This highly motivated group is eager to educate and share their experiences with others. The implications for genetic counseling services and also for pre and post surgical services for those facing a TG will be discussed.

Keywords: hereditary diffuse gastric cancer, psychosocial implications, total gastrectomy

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## INTRODUCTION

The hereditary nature of cancer was feared long before accepted as fact. In 1938, Dr. Boris Sokoloff explored the possibility of hereditary transmission of a predisposition to cancer through his analysis of the Bonaparte family. Napoleon Bonaparte was reportedly obsessed by the fact that his father died of stomach cancer at the age of 39. In fact, he ordered a copy of his father's autopsy and took private "anatomy lessons" from his court physician. He was sure he was destined for an untimely death similar to his father's. Napoleon died of stomach cancer, as did his father, grandfather, and four siblings. (Sokoloff, 1938)

Through analysis of the Bonaparte family history, Dr. Sokoloff came to some telling conclusions. In the following passage, he reveals how far we have come since the first half of the 20<sup>th</sup> century.

*An analysis of Bonaparte's case may convince one that human predisposition to cancer is a phenomenon of an unstable variable nature, which is easily broken by marriage. It is therefore of doubtful practical value in the prognosis of malignancy. Although familial predisposition should be taken into consideration, its importance must not be overestimated. (Sokoloff, 1938, pg 678)*

We have indeed come a long way in our understanding of a hereditary predisposition to cancer. The story of hereditary diffuse gastric cancer (HDGC) is one of remarkable discoveries, extreme measures, and tangible successes. It is also a story of incredible struggles, triumphs for survival, and sometimes defeat. The story of the science behind and treatment for HDGC is well documented. What has yet to be told is the story of



the people who have lived the experience.

The unique journey families face with hereditary cancers warrants investigation as it impacts quality of life (QOL) and survival in ways that are different from the experiences in families with sporadic cancer. When a mutation is found in an individual, there is a ripple effect that spreads immediately across generations. The focus is not solely on the individual. Instead it becomes a distinct and very personal experience for every individual in the family. In the case of HDGC, it stems from the discovery of an identifiable gene mutation known to predispose to gastric cancer as well as the radical measure necessary to reduce risk. Because gastric cancer is typically discovered at a late stage, the survival rate is very low. Consequently the only effective method of risk reduction for HDGC to date is having a total gastrectomy. Few studies have looked at the psychosocial ramifications of the identification of a hereditary predisposition for gastric cancer in a family and the necessary prophylactic surgery that follows.

Braga et al, compared the QOL in patients who had a total gastrectomy (TG) to those who had a subtotal gastrectomy (SG), finding a more positive outlook among those having SG (Braga et al, 1996). Ishihara considered the physical and emotional experience of TG among patients and their families. She suggested the need for education regarding the surgery and recovery associated with TG before and ongoing after surgery (Ishihara, 1999).

These research endeavors focused on gastric cancer, comparing the physical, and sometimes emotional recovery of patients who underwent TG versus those who had SG. They did not distinguish between intestinal and diffuse type cancers, or between hereditary and sporadic cancers. In thinking about these studies, one must consider that SG is not a viable option for someone testing positive for a mutation causing the predisposition

for diffuse gastric cancer. Another important issue is the mean age of subjects. Taking a random look at gastric cancer patients with no focus on HDGC yields an older group than would be expected with HDGC. For example, the mean age of patients at the time of surgery in Ishihara's study was 66.9 years (Ishihara, 1999). However HDGC has a striking occurrence among individuals under the age of 40 (Koea et al, 2000).

Lynch et al (2000) provided an account of the experience of one family facing HDGC. After two information sessions educating a total of 30 family members, Lynch and his colleagues reported three common reasons for testing. These included concern about risk to children, personal health management, and relief from the anxiety of the unknown. (Lynch et al, 2000)

In 2008, Lynch and others looked at four other families to consider, again, the influences that come into play in the decision making process with regard to HDGC. They found two factors that made the decision more difficult: the high variability in age of onset, and the need for removal of the entire stomach. However witnessing a close relative suffer from gastric cancer and education about the inadequacies of screening made the decision easier for the family members. And finally, group therapy and family commitment made the choice for surgery more likely. (Lynch et al 2008)

Pandalai et al also focused exclusively on individuals found to have a germline mutation in the CDH1 gene, which causes HDGC. This group limited participation to those who chose total gastrectomy. They found the bulk of these individuals already had foci of noninvasive or invasive gastric cancer by middle age. An important result of this study was support for total gastrectomy as the best option for risk reduction in those carrying a CDH1 mutation. (Pandalai et al 2011)

In 2013 Onitilo et al provided an account of one patient's experience with HDGC, the price he paid, and the lives he ultimately saved. While this story is familiar among families in the HDGC community, it is eye opening to many. In this paper, researchers describe the progression of HDGC in a 56-year-old male. As with many people who manifest HDGC, his was not found via esophagogastroduodenoscopy, ultrasound, gastric biopsy, or laparoscopic cholecystectomy. When symptoms did not go away, they did further testing via an exploratory laparotomy. A later biopsy, taken during an upper endoscopy showed signet ring adenocarcinoma leading to the diagnosis of metastatic gastric cancer. With this information, a PET/CT scan was done, and was negative for metastatic disease. Because his mother had died of gastric cancer at 51, the patient underwent genetic testing. The result was heterozygosity for the CDH1 gene mutation. Remarkably, it was 19 months after the diagnosis of metastatic gastric cancer, that a CT scan showed positive cytology for adenocarcinoma, highlighting the inadequacy of surveillance. Having been diagnosed with terminal cancer at the age of 56, the patient became an advocate for genetic testing among his family members. These included his two children, both of whom were found to be carriers. They both chose prophylactic total gastrectomy. Laboratory analysis of postoperative specimens from both revealed gastric cancer. (Onitilo et al 2013)

While the information gathered through these studies is important, it does not provide a complete description of the physical and emotional toll these families with HDGC experience. The primary aim of our study was to explore the unique psychosocial journey facing families with members found to carry the mutated gene (CDH1) known to cause a predisposition for diffuse gastric cancer, the condition known as hereditary diffuse gastric cancer (HDGC). Families having survived this experience offer advice for those stepping

into the experience and for the professionals guiding them. The implications for genetic counseling services and also for pre and post surgical services for those facing a TG will be discussed.

## METHODS

We used an anonymous qualitative-based online survey utilizing conventional content analysis to analyze the data from open response questions. The survey gathered demographic information such as age, gender, and level of education as well. The Brandeis University IRB approved the survey, which was available to participants for approximately two weeks. In appreciation for completion of the survey, respondents had the opportunity to enter a raffle for one of three \$50 gift certificates.

In 2005, Hsieh and Shannon defined qualitative content analysis as “...a research method for the subjective interpretation of the content of text data through the systematic classification process of coding and identifying themes or patterns” (Hsieh and Shannon, 2005, p. 1278). The hope in this process is to elucidate the phenomenon under investigation. These authors identify conventional content analysis as one of three approaches to qualitative content analysis. It is useful when the topic under study is largely unknown. (Hsieh and Shannon, 2005)

Conventional content analysis begins by simply reading the text. In our case this entailed reading the responses to open ended questions. The next step is to chronicle thoughts and impressions of the text, highlighting important words and phrases. Through this process, labels for codes emerge organizing responses into themes. With each theme clearly defined, examples are chosen directly from the text for discussion. (Hsieh and Shannon, 2005)

We recruited participants through [www.nostomachforcancer.org](http://www.nostomachforcancer.org), an organization whose mission is "to support research and unite the caring power of people worldwide affected by stomach cancer." Although they help people facing all types of stomach cancer, they work with many families and individuals facing gastrectomies, including those with HDGC. Inclusion/exclusion criteria were set as follows:

- Participants were 18 years of age or older.
- Participants were part of a family in whom a mutation in the gene causing the condition known as HDGC has been identified.
- Biological relationship was not required. For example, spouses and adopted family members were eligible for participation.

Respondents identified themselves in connection to the following experiences and/or roles in their family's journey through the experience of HDGC.

- CDH1 mutation carrier who elected to have a total gastrectomy/prophylactic total gastrectomy
- CDH1 mutation carrier who has not yet had a TG
- Had genetic testing and found not to be a carrier of the CDH1 mutation
- Candidate for testing but delayed testing for now
- Candidate for testing but decided not to proceed
- Caregiver for someone who elected to have a TG
- Non-biologically related family member

With codes in place and respondents identified in this way, we used SPSS to search for statistical significance among the themes in relationship with the respondents. In addition, we identified those who had the perspective of multiple roles, for example someone who had a TG and also served as a caregiver for someone who had a TG. SPSS allowed us to search for correlations between experience, age, and/or gender and type of response/advice given.

## RESULTS

One hundred and four individuals began the online survey. Eighty-four respondents completed the survey. Of those 78 (93%) took time to answer open response questions regarding advice for individuals facing the possibility of HDGC and for the professionals guiding them. The majority of respondents were female (74%). More than half of the total responses (58%) came from adults between the ages of 41 and 60 years old. The level of education showed a bell curve with the range between high school and graduate level degrees. Responses came primarily from within the United States, but also came from Canada, Europe, Australia, and Iran. See figures 1 - 4 below.

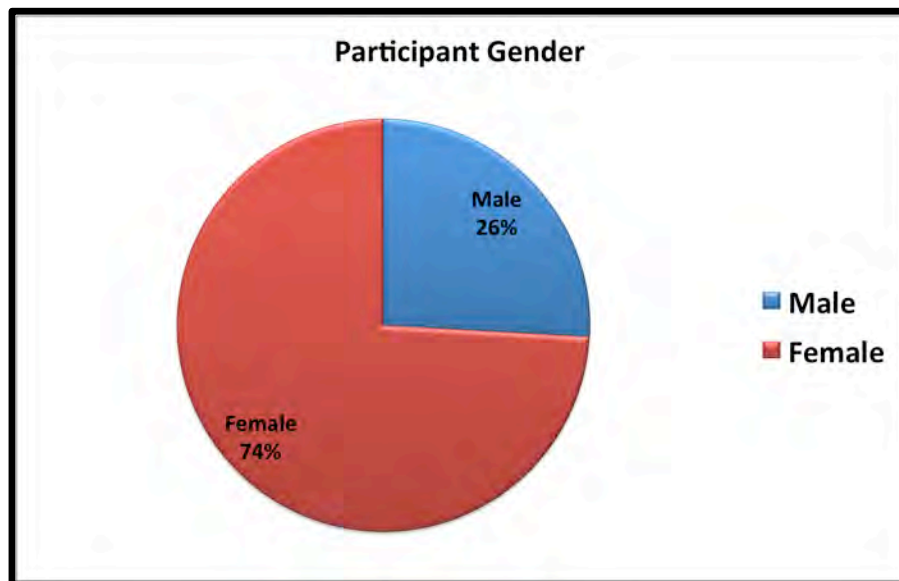


Figure 1: Of the 84 completed surveys... 62 females, 22 males

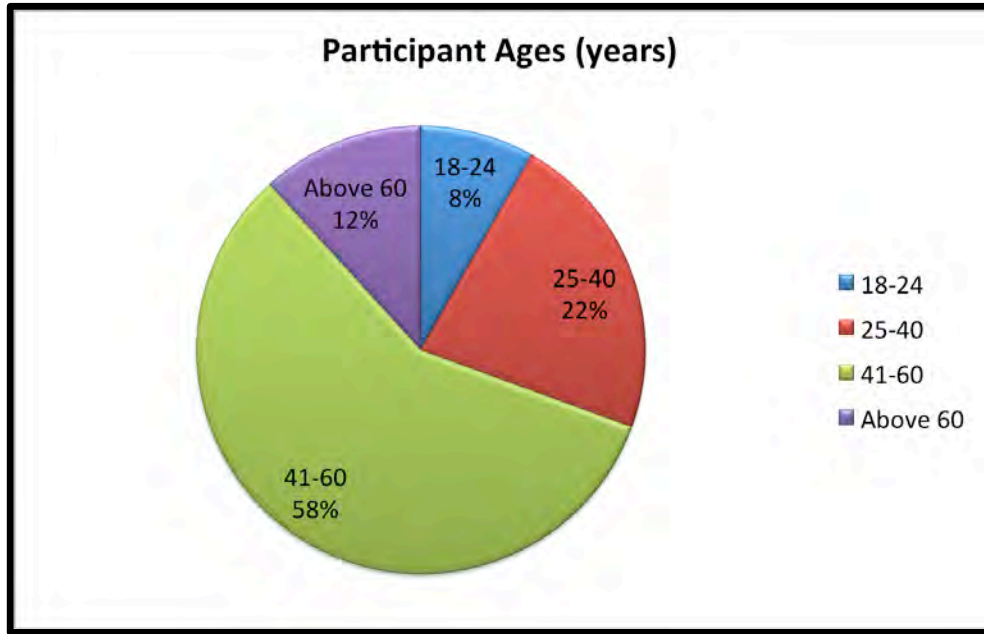


Figure 2: Respondents' ages (among the 84 completed surveys)

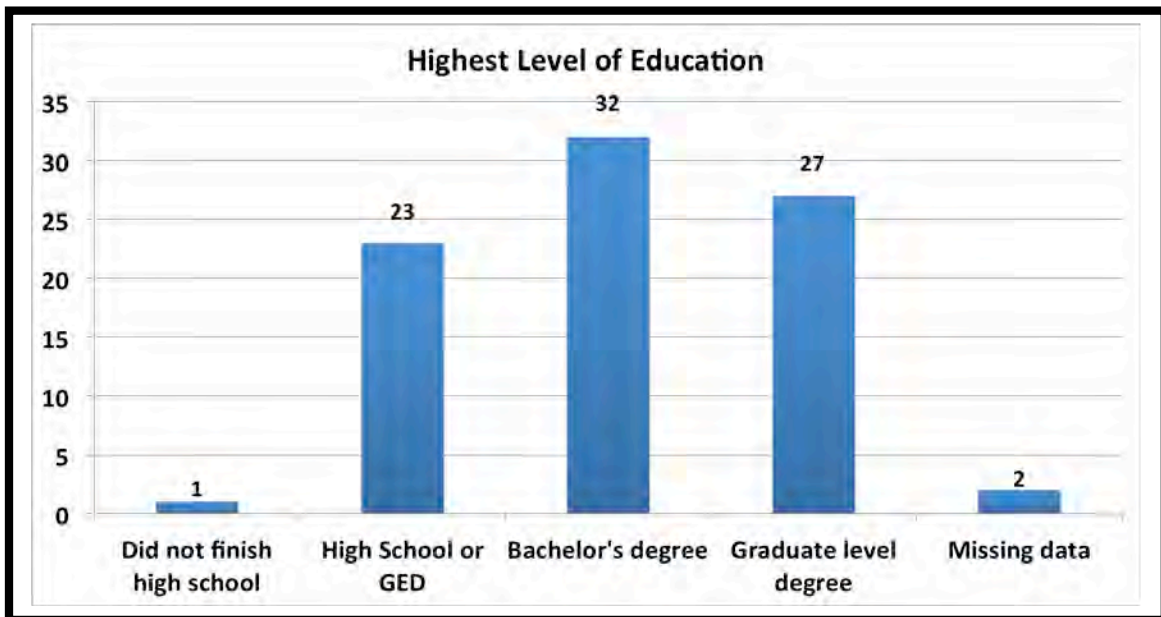


Figure 3: Respondents' levels of education



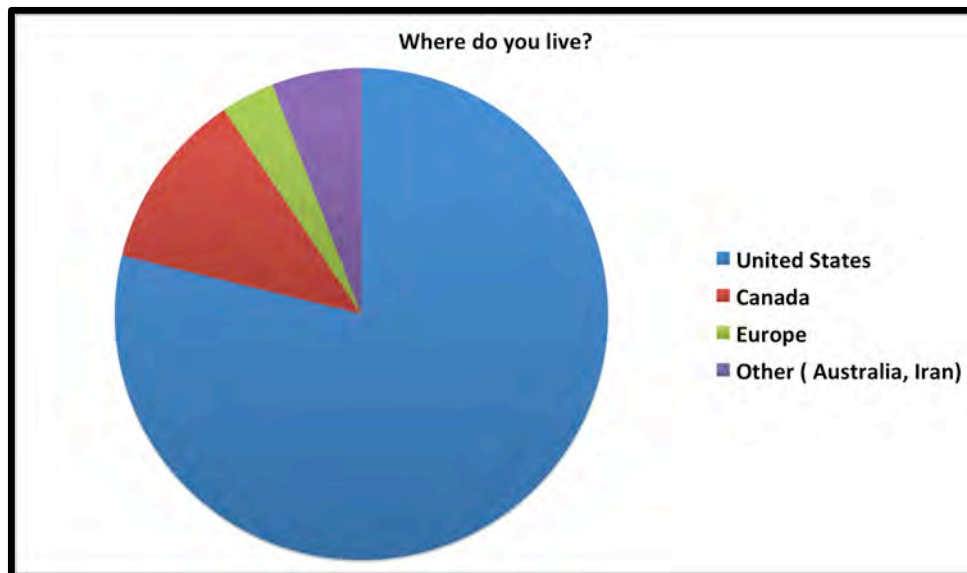


Figure 4: Respondents' location

Among the 84 individuals who completed the survey, the greatest number came from those who had had a total gastrectomy. Fifty-one respondents identified themselves as having had a TG. Of those, 18 reported they also served as caregiver to someone else who had a TG. A total of 13 responses were from non-biologically related family members, ten of whom served as caregiver to someone who had a TG. We heard from four people who identified as carriers of a CDH1 mutation, but who had not yet elected for a TG. Eight respondents had been found not to carry a CDH1 mutation, two of whom served as a caregiver. Four individuals reported being a candidate for testing, but had delayed testing at the time they completed the survey. One of these respondents also served as a caregiver. And finally, our total number of caregivers who completed the survey was thirty-five, thirty-one of whom fit into one of the other categories as well. See figure 5.

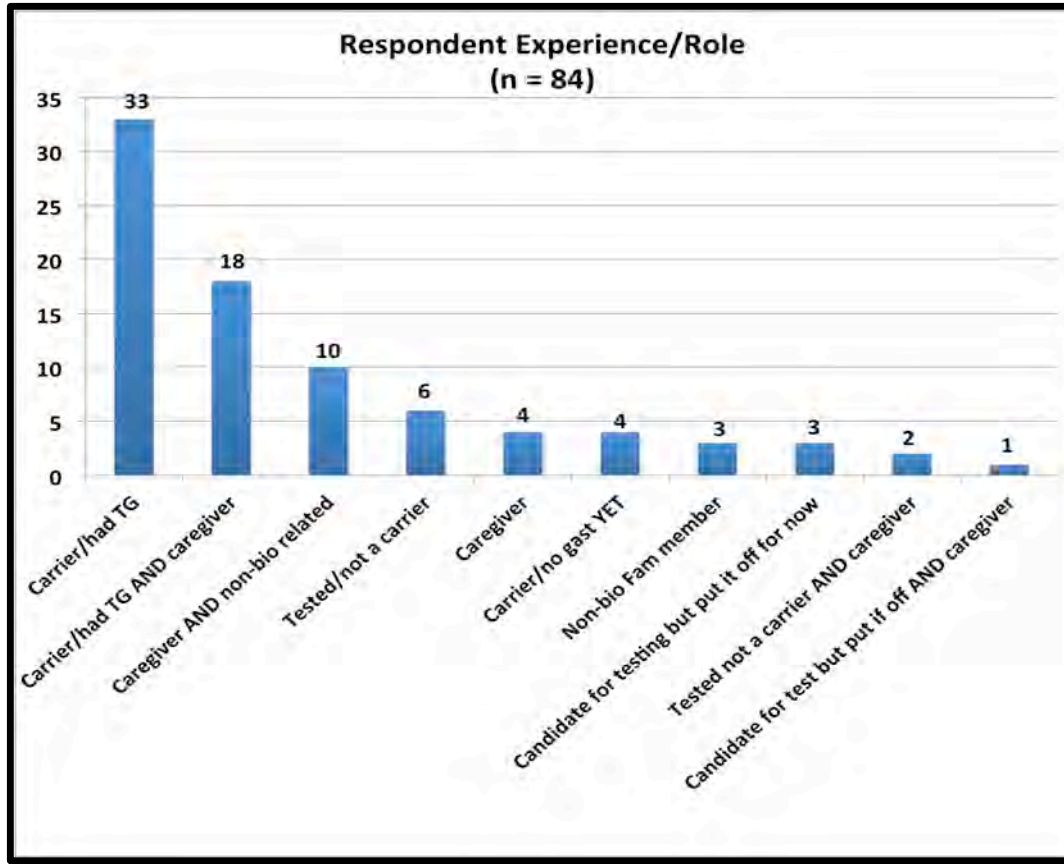


Figure 5: Respondent role in HDGC experience

In analyzing the data, we considered age, gender, and respondent experience/role as described above. Open response questions used for analysis included the following.

1. What advice might you give to someone considering genetic testing for HDGC?
2. What advice might you give to someone considering a total gastrectomy?
3. What advice might you give to family members of those having a total gastrectomy?
4. What advice might you give to someone about to step into the role of caregiver to someone who has just gotten a total gastrectomy?
5. What advice might you give to medical professionals (genetic counselors, physicians, surgeons, dieticians) who are trying to help families deal with HDGC?

Through the process of conventional content analysis, as previously described, we looked at responses to each question individually. As themes emerged, we used Statistical

Product and Service Solutions (SPSS) to seek trends among the different demographics of our respondents (gender, age, and experience/role). We also used SPSS to ascertain statistical significance as part of the process in drawing conclusions. The results of the analysis of each question will be addressed independently. We chose quotes to represent not only the themes that emerged, but also to represent the range of experience, age, and gender of respondents.

***What advice might you give to someone considering genetic testing for HDGC?***

In analyzing responses to this question, two themes emerged: encouragement and advice. Messages of encouragement focused on empowerment and what there is to gain through testing. Some individuals also shared personal stories. The theme of encouragement predominated among the surveys, accounting for 63% (n=53). The message came from both males and females and from all age groups. Respondents representing six of the seven designated family roles (carrier who had a TG, carrier who has not yet had a TG, tested and found not to be a carrier, candidate for testing but delayed for now, caregiver, and non-biological family member) provided messages of encouragement when answering this question.

*“Looking back I would tell them that even if you do test positive for the gene having a total gastrectomy to save your life is still a better outcome than if you don't have the surgery and then get the cancer. My youngest son age 23 just went through the process of being tested and although I prayed he not have the gene I also tried to be a positive role model and be honest about my struggles as well as my victories and that as time passed each month gets easier. I am so happy to be alive. His test came back negative and he does not have the CDH1 gene (mutation). Now my older son hopefully will choose to go through with the testing.”* (41 – 60 year old female CDH1 mutation carrier, who elected to have a TG)

*“You can save your own life, as well as your future children's by undergoing PGD\*.”* (18 – 20 year old female CDH1 mutation carrier, who had a gastrectomy and also served as caregiver to someone else who had a TG)

\*Preimplantation genetic diagnosis

Thirty-seven percent of those surveyed responded by giving specific advice. We define “advice” in this context as things to do and/or think about before or after testing. Some of the messages are thought provoking, while others express concerns. Again they came from men and women as well as all age groups and most of the designated family roles.

*“You may be uninsurable if you test positive...get your insurances in place...Ask yourself what you will do with the results once you know them. Do you have a good support system? Can you handle the decision process(s) or will you need a professional to help you.” (41-60 year old female CDH1 mutation carrier, who had a TG)*

*“...It is very important that the older generations do not feel responsible for their role in passing on this genetic mutation. For example, my wife discovered it through random genetic testing and had to ask both of her parents to get tested. We know her father is negative and are awaiting her mother’s results” (41 – 60 year old male, who is a non-biologically related family member who served as caregiver)*

The following individual warns of the change in perspective that can result from testing positive for the CDH1 mutation. He describes what could be interpreted as a transition from optimism to pessimism.

*“...be aware that once you find out it changes how you view things. Prior to testing you would say to yourself, I might have cancer, but I might not. If you find out you’re positive, the thoughts become MIGHT have cancer.” (41 – 60 year old male CDH1 mutation carrier, who elected to have a TG, and served as caregiver to someone else)*

### ***What advice might you give to someone considering a total gastrectomy?***

Respondents’ answers to the question, “What advice might you give to someone considering a total gastrectomy?” were more varied. Encouragement was again the predominant theme. Forty-nine percent of our 84 subjects expressed encouragement by focusing on what there is to gain from having the TG. The word empower could be used to describe the apparent message behind this theme.

*"If you can prevent any chance of getting stomach cancer (which you are highly likely to get at some point in your life, if you test positive), it makes sense to do so... I understand the reasons why someone would not want to get a gastrectomy (I will be getting one in the near future), but the benefits seem to outweigh the costs. From what I've read, recovery is not extremely difficult, and while the surgery will require some lifestyle changes, they might even be for the better! (Studies show that it's healthier to eat several small meals throughout the day than three larger meals, anyway!)" (18 – 24 year-old female found to be a carrier, but has not yet had a TG)*

*"It is life changing but it extends your time with loved ones." (41 – 60 year-old male who tested and was found not to be a carrier)*

Practical advice also emerged in response to this question. Thirty-six percent of our 84 respondents gave practical advice. The word practical can be defined as "of or concerned with the actual doing or use of something rather than theory and ideas". Practical advice as defined in this context had a focus on things to DO around having a total gastrectomy. The advice was as diverse as the individuals giving it. What most had in common were the focus on food, nutrition, and eating.

*"...research, talk to others, join "No Stomach for Cancer", find out what the experience is really like from those who have lived it. Find the best possible doctor experienced in TOTAL gastrectomy and meet with him/her armed with information and questions. Know that this is a life-changer. Develop a follow-up plan that includes regular check-ups, B-12 shots, and meetings with a nutritionist. ... Be gentle and good to yourself-- eat small meals throughout the day... Develop a good support system -- have people you can contact with questions at any time." (41 – 60 year old female who is a non-biologically related family member who served as a caregiver)*

*"... Take time before surgery to enjoy eating." (18 – 24 year old male was found to carry the mutation, had a TG, and also served as a caregiver to someone else)*

*"My advice is to eat soft food, eat several times but small portions, don't eat dinner late." (25 – 40 year-old male who is a non-biologically related family member)*

"What to expect" surfaced as a third theme in response to this question. Sixty-eight percent (n=22) of these comments came from individuals who had had a TG. They talk about the physical toll, the emotional toll, and lifestyle change associated with a TG. Again this theme was not limited to any age group, experience/role, or gender.

*"Be prepared for a significant readjustment that will have social and relational consequences, not just physical. Understand that you will likely have to work at readjusting. ..."* (41-60 year old male who is a non-biologically related family member and also served as a caregiver)

*"... Individual experiences are very different...Know that most people go into the hospital because they are sick, have surgery and get better. We are almost opposite of that. For most of us, having a TG is for prophylactic reasons; we walk in feeling great, have surgery and then expect to be on the mend. In fact, most of us will likely go down a long road, sometimes into a depression because we have trouble doing things that seemed so easy before. Boiling my first egg at home exhausted me and I had to take a two hour rest after that. Be patient, things will get better and you will get used to your "new normal".* (41 – 60 year-old female who was found to be a carrier and had a TG)

*"... From personal experience the mental aspect of having the surgery tends to be over looked."* (25 – 40 year old male who was found to be a carrier and had a TG)

### ***What advice might you give to family members of those having a total gastrectomy?***

This question gave survey respondents a chance to address the importance of the actions and reactions of family members surrounding those facing this prophylactic surgery. The processes of conventional content analysis led us to empathy as the central theme in responses to this question. Words like “supportive”, “patient”, and “understanding” prevailed in 51% (n=84) of answers. Seventy-seven percent of these came from caregivers and individuals who had a TG.

*"be supportive of whatever and whenever they decide and let them decide. Offer love and support and don't tell them what to do but be there to encourage and try to walk with them, get them out, etc. in a loving, encouraging way as they may need a loving push too, to do and eat more. Don't fret over their weight loss--it will come back!"* (41-60 year old male found to be a carrier, chose TG, and who served as caregiver)

*"Don't ever minimize their emotional needs...their fear...understand that this is far more than just a surgery to save their life. For me, cancer was already found...twice. For my daughter, she knew she was a carrier and did everything she could to save her own self from getting cancer, but like so many others, it was already there. Let them grieve. Let them be fearful, but be supportive and encouraging. Stay upbeat when you need to, but allow them to express everything they are feeling."* (41 – 60 year old female found to be a carrier, chose TG, and who served as a caregiver)

*"Be brave for your family, we need your support and your strength."* (25 – 40 year old female found to be a carrier, chose TG)

Others gave more practical advice, focusing on things to do, plan, or think about before or after surgery. Thirty-one percent (n=84) of responses contained this advice. All (100%) came from people who either had a TG, or who served as a caregiver to someone.

*"... Practice personal self-care to help yourself manage your own emotions about witnessing a loved one's challenges. Stay optimistic but don't sugarcoat things for the loved one. Listen more than talking. Take cues from the loved one. Go to medical appointments if they are comfortable with that, and keep notes on everything."* (>60-year-old female non-biologically related family member who served as a caregiver)

*"Tell family members to pull their calendars together so that they can provide an hour break for the spouses at the hospital who sleep with the spouse every night..."* (41 – 60 year old male non-biologically related family member who served as a caregiver)

*"This is a lifestyle change that will affect everyone. Nutrition and hydration are very important. The patient needs reminding of this because the usual body cravings aren't there. You can really get into trouble if you don't stay in tune with your body. Listen to your body. Rest also as needed."* (41 -60 year old female who served as a caregiver)

Encouragement was less predominant, but still present. 7% (n=84) of the responses focused on this, promoting solidarity and a positive outlook.

*"It isn't anything to fear. People have gastric bypass all the time and they are doing well. Also, people have done relatively well post gastrectomy and you will be okay as well."* (25 -40 year old female found to be a carrier, and who has not yet elected TG)

***What advice might you give to someone about to step into the role of caregiver to someone who has gotten a total gastrectomy?***

For this question, we elected to ask those who served the role of caregiver to give advice. In all thirty-five people reported serving as caregivers to someone who had a TG. Of those thirty-one responded to this question. Among them, sixteen had also had a TG, nine were non-biologically related family members, two reported having been tested and

found not to carry a CDH1 mutation, and one reported delaying testing. Empathy surfaced as the most prevalent theme, elicited from 49% of caregivers, half of whom also reported having had a TG themselves. In the context of this question, we define messages of “empathy” as those encouraging emotional support, positive attitude, and in some cases using the actual word empathy in describing how caregivers can best help their loved ones.

*“... Be patient. Listen. It's difficult sometimes to ascertain what the patient needs because they are in new territory. The patient's experience is completely alien to them. Extreme pain can be simple gas or it could be the wearing off of an important pain killer.” (41 – 60 year old male non-biologically related caregiver)*

*“Be patient and supportive, but don't be condescending or phony about it. You will eventually figure out what your relative can/cannot eat, but it will be a trial and error process. Be patient. Your relative may very well be tired much or all of the time after the surgery and beyond. Again, be patient.” (41 – 60 year old male non-biologically related caregiver)*

*“Don't ever minimize their emotional needs...their fear...understand that this is far more than just a surgery to save their life.” (41-60 year old female who had a TG and also served as caregiver)*

Six caregivers expressed the need for education, encouraging future caregivers to be knowledgeable. They recommend talking with others who've had the experience, meeting with professionals, and doing research. Five caregivers wrote of the support needed throughout this experience, mentioning family/friend support, professional support, and the importance of self-care to ensure the strength necessary in helping loved ones. And finally four caregivers highlighted the need for a focus on food intake and planning ahead.

*“Talk to as many people who have had this surgery as possible. Join “No Stomach for Cancer” and read everything on their website. Know that life is not going to be the same again - it is not just a matter of recovering from a surgery and getting back to normal ---there is now going to be a new “normal.” Meet with the doctor(s) fully armed with as much information as you can find. Keep snacks and quick nutritious meals on hand ALWAYS. Make sure you have an electric blanket or heating pad and a functioning thermometer.” (41-60 year old non-biologically related caregiver)*

*“Continue to worry about yourself as well as your loved ones. You can get very caught up in caring for others and lose a large part of yourself!” (41 -60 year old female caregiver)*



***What advice might you give to medical professionals who are trying to help families deal with HDGC?***

Respondents considered their experiences with the professionals who guided them into and through their journeys. Some are still in the midst of the experience. Others are years past. Their answers provide insights into direction for improvement in all areas of their experience. Most prevalent was a call for education. Forty-eight percent (n=84), of subjects made a plea for education in at least one of three areas. They see a need to educate doctors. They see a need to educate dietitians. And finally, from genetic counselors, they ask for balanced information regarding the surgery, and for attention to mental health in the recovery process. The appeal for education came from both genders, all age groups, and every representative experience/role.

*"... When you leave the care of your cancer doctors, other doctors have very little experience with the issues that go along with having no stomach, for example, what kind of pills to take. My daughter was on one medication, but it took almost 4 months to realize that it wasn't working because it wasn't being absorbed correctly. Similarly, knowing which vitamins we need and how best to take them is an issue. (41 – 60 year old male who had a TG and also served as caregiver)*

*"...GIVE MORE NUTRITIONAL ADVICE! - Yet be aware that not everything will work for everyone, and foods that work one week may not be tolerated the next. Discuss the possibilities for conceiving children. We have run into doctors that did not understand the importance of B-12 shots --THEY ARE CRUCIAL. Insurance companies tend to lump total gastrectomy in with partial (for weight loss). This needs to be clearly defined that this surgery is NOT for "cosmetic reasons!" Alcohol addiction is a serious issue for those without a stomach -- more research needs to be done on this and patients advised of the danger of drinking. Research also needs to be carried out to determine the effectiveness of orally taken medicines. (41-60 year old female non-biologically related family member who served as a caregiver)*

*"There is little to no practical knowledge of nutrition for a post-surgery gastrectomy patient. The information I was given was very general stuff I already knew (eat more frequent and smaller meals) or for people who had difficulty chewing and/or swallowing (the dysphagia soft diet). We don't have difficulty swallowing. We have difficulty digesting! Much more work needs to be done to inform doctors and hospital staff of the gastrectomy patient's unique dietary requirements."(41-60 year old female who had a TG and also served as a caregiver)*

*"I believe a focus needs to be given on the mental aspect of things and the effects the surgery can have on you emotionally and mentally. So much focus is given on the physical changes by doctors that it is*

*often over looked that this is a major change that needs to be handled mentally as well.” (25 – 40 year old male who had a TG)*

*“Present the facts and pros and cons and be aware that each person can be so different with regards to healing and recuperation.” (41 – 60 year old female who had a TG)*

The process of conventional content analysis also yielded connecting patients as a theme. Respondents expressed a need for connecting patients with each other and with support groups. Those who have had a TG were most vocal in this theme. Of the 15 responses, 12 came from individuals who had had a TG. The remaining 3 came from non-biologically related family members who served as caregivers.

*Contact people who have been through it. Professionals may not understand that there is no feeling of fullness until one bite too late and then it feels miserable - almost as if the food will come right back up. In the beginning I watched the volume I consumed so I knew my limit. I then very gradually increased the volume to avoid the miserable feeling from overeating that last bite. (41-60 year old female who had a TG)*

*I would tell medical professionals to encourage their patients to seek out survivor stories, and read up on the personal experiences of others who have gone through the procedure. Obviously, all of this is anecdotal and personal and would not under any circumstances be considered professional medical observations. But, there is something about the personal nature of reading or hearing another survivor's personal experience that is emotionally/mentally more powerful than any 'life after a gastrectomy' brochure that a hospital dietitian could give you. Immediately after my own surgery I was terrified every time I tried a new food. I thought each culinary 'adventure' would be the one that just makes me feel ill and sets me back. After reading others' stories, I gained so much confidence to try new foods and get eating and get back to normal quickly. I am convinced that my ability to stabilize my weight and get off of my feeding tube was due in large part to reading those stories and realizing that I could be more adventurous in my food choices. Again, this is just me and my anecdotal experience, but I think combining the medical/diet professionals' recommendations with hearing about real people's experiences goes a long way during recovery. (25-40 year old female who had a TG)*

Empathy emerged as a third theme, accounting for 17% of the responses to this question. Both genders, all age groups, and individuals representing most experience/roles in the family (with the exception of a candidate for testing who delayed for now) expressed the need for empathy from all professionals.

“...Have a caring and nurturing attitude towards both the patient and spouse or primary caregiver ... know that your patient will be dealing with both pain and anxiety in the initial stages...” (41-60 year old male who is non-biologically related and who served as caregiver)

“be sympathetic. Don’t be shy to express sympathy for all they are going thru... be supportive and encouraging that they will be ok and you will help them but let them be sad, scared and cry too so they don't try to just muster through it all. It's not healthy and those stuffed feelings will ooze out in other ways some day otherwise.” (41-60 year old female who had a TG and also served as caregiver)

## DISCUSSION

Through qualitative analysis of the information gathered, we began to elucidate the challenges facing families affected by HDGC. Hearing directly from patients and their family members, concerns about how the experience of HDGC affected them as a whole is an important component of the complete picture. By gaining an understanding of their struggles and their triumphs, genetic counselors and other medical professionals are better able to prepare and guide future patients and their families. This survey provided information from both genders, and from all age ranges beyond the age of 17. It drew subjects from the spectrum of experiences and roles in the families, with the exception of someone who is at risk, but decided not to have the testing. These individuals may be less likely to have exposure to the No Stomach For Cancer website, and therefore be less likely to have access to the survey. While the numbers are too small to show statistical significance, the range in representation along with the time required to respond in a thoughtful way to the open ended questions make it clear this is a population that is eager to educate/share but is also asking for help.

These families have an extraordinary story to tell. They have information that can help professionals and families alike. Stories about what went well along with accounts of dissatisfaction, sometimes approaching exasperation can all have a positive impact on the care and guidance we provide in the future. The range of emotions was especially apparent in responses to the question eliciting advice for professionals.

*“Encourage patients to connect with others that can really talk about the process, especially if there are specific common events in some patients. For example, I spoke with another HDGC patient after being connected by my doctor to let her know I too had gone through the same vomiting stage she had and that it had lessened over time. She was miles away but we were so close during that call. She was thrilled to hear she was not alone and that it does or can get better! In my instance, having a Team approach to my doctor visits before and after the surgery helped SO much...We met every 2 weeks, then 1 time a month, then every 2 months and there was a type of gradual release on both our parts. I could always come sooner if I felt 6 months or a year was too long. By then, I felt I had such a strong relationship with my team that I could come or just call with questions knowing they knew me and would help me with whatever was going on or help answer any questions.” (41-60 year old female who was found to be a carrier and had a TG)*

*“Remember that this diagnosis does not only affect one person but it potentially affects multiple family members. That can be devastating... Nutritionists need to do a better job helping patients with eating. Although we are similar to those with gastric by-pass surgery, it is not the same. We need to determine how to coordinate care after the surgery. Who monitors our blood work? Levels? Nutrition? Testing for other risk factors such as breast cancer and colon cancer? After the surgery is behind us, there is a sense of not so much sadness but as aloneness..... It feels like we just went through this intense event with so many emotional aspects..... and then it feels like we are on our own to navigate our way through life .... It would be nice to have follow up appointments to check on us not only physically but emotionally too.....” (41-60 year old female who was found to be a carrier and had a TG)*

*As younger people are testing positive, more information needs to be available for in vitro fertilization and embryo testing. In addition, the nutritionists in the hospital are NOT really knowledgeable about total gastrectomy diets. They give out pamphlets but have no true knowledge of vitamin absorption. I am still trying to figure out a good source of calcium citrate for my loved ones. (41 – 60 year old female who served as a caregiver)*

*“Research. There isn’t enough information for families...” (41-60 year old male candidate for testing who chose to delay for now)*

As genetic counselors we spend significant time speculating about how to help our patients. In that process we decide what may help them, and what may harm them. We work very hard to balance their need for the facts without giving them more information than they want or can handle in a given moment. Having direct information from patients regarding their emotional and physical needs is invaluable. Content analysis of surveys or interviews with people who have had a particular experience can aid in the process by validating or discrediting our approach. The individuals quoted above had very different

experiences. Their realities can serve as a piece of the puzzle in preparing professionals to guide families through the experience of HDGC.

Consider also the non-biologically related family member quoted previously, who commented how important it is to avoid making earlier generations feel guilty for having passed on the gene mutation. This did not come from someone experiencing HDGC in the physical sense. He is not himself at risk. His comment speaks more to the emotional toll this experience can have on families as a whole. Based on responses to the question eliciting advice for families members of those facing TG and for caregivers, the well being and successful recovery of individuals having had a TG is connected in part to the emotional well being of those around them. Being aware of issues like this can help professionals in the successful treatment of their patients.

There are few moments in life that ultimately become a dividing line, distinguishing life prior to and after a particular moment. The genetic counseling session introducing an individual and family to HDGC has the potential to be, for some individuals, one such instance. In a relatively short time, the genetic counselor can help set the tone on how this life changing experience will start. Based on responses to our survey, the magnitude of the experience encompassing both that initial visit and all that follows is quite varied, but several important commonalities recur regarding what variables influence the experience and/or recovery process. Respondents impart the importance of knowledgeable genetic counselors, medical doctors, and dieticians. They also convey the necessity of having the support of family and friends. The key components necessary for all involved is the knowledge and understanding of their struggle.

In pursuing the career of genetic counseling, we choose to accept the very important responsibility of educating, guiding, and supporting individuals and families through unfamiliar and sometimes traumatizing experiences. One effective way to fulfill this responsibility is to understand the needs and struggles of those living the experience. Although our survey included responses from a relatively small sampling of those dealing with HDGC, their collective voice articulated clearly ways that medical professionals can better guide individuals and families through their experience. We can say from the 84 individuals who took the time to share their journey, the following statements are important and should be considered in the guidance of individuals and families into and through the experience of HDGC.

- Primary care physicians need to be better educated about both the physical and emotional aspects of dealing with HDGC, not only at the time of diagnosis but in the patient's long-term care.
- Dieticians need information about the unique dietary requirements of someone who has undergone a total gastrectomy.
- Genetic counselors need to be prepared to educate and provide resources for entire families, including those individuals who are not at risk (ie non-biologically related family members).

In the face of daily discoveries and advances in the world of genetics and medicine, it is implausible to think we can educate all medical doctors and dieticians everywhere about the unique needs of this small population. Therefore, the responsibility falls on genetic counselors to educate and communicate on behalf of individual patients and families facing HDGC. It is our hope that the results of this study will draw attention to HDGC, inspire further qualitative research, and ultimately aid in the production of practical, concise information for patients stepping into a genetic counselor's office to learn about HDGC for the first time.

## CONCLUSION

Dialogue with patients should be an integral part of the quality assessment in the field of medicine in general. Surveys such as ours can provide a way of gathering, saving, and analyzing that dialogue in large quantity. This approach can be used to explore any experience in the genetic counseling settings.

However, in any qualitative study, there are several general limitations. First the qualitative approach is subjective. It is difficult to know if/when the full extent of any particular experience is understood. Second the results are very specific to the particular experience being studied. Therefore, they are not generalizable to other experiences. For example, the results of this study cannot be generalized to other hereditary cancer experiences.

This study also had some unique limitations. We did not distinguish multiple people from the same family. Therefore, we cannot say how many families were represented in our study. Additionally the sample size is small and skewed toward those who have been through a gastrectomy, and who have been caregivers. It does not adequately represent the people who experience other aspects of this journey, for example those who had genetic testing and were found not to carry a CDH1 mutation, or those who are not part of the No Stomach For Cancer community.

The response to this study shows that those dealing with HDGC are in strong need of help from those in the medical community, including genetic counselors. This highly



motivated group is eager to educate and share their experiences with others. It is our hope that the results of this study will serve as a springboard for future research.

## RESOURCES

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## APPENDIX A

### Recruitment Notice

#### Do you have a personal and/or family history of hereditary diffuse gastric cancer?



My name is Marcie Casey, and I am a graduate student in the Genetic Counseling Program at Brandeis University. For my master's thesis, I am seeking volunteers to participate in a research project. The goal of this research study is to explore the impact that hereditary diffuse gastric cancer (HDGC) has on families. If you have experience with HDGC in your family, I invite you to participate in this research study. If you meet the following criteria, you are eligible to participate:

- Participants must be 18 years of age or older.
- Participants must be part of a family in whom a mutation in the gene causing the condition known as hereditary diffuse gastric cancer has been identified.
- Biological relationship is not required. For example, spouses and adopted family members are eligible for participation.

Participation in this study is completely confidential and voluntary. It will involve completing an online anonymous survey. The time commitment for completion is estimated to be between 20 and 30 minutes. To participate in this study, please follow the link below to access the online survey:

<https://brandeis.qualtrics.com/XXXXXXXXXXXXXXXXXXXX>

Upon completion of the survey you will be eligible to enter a raffle for one of three \$50 Amazon.com gift cards.

If you have any questions or comments, please feel free to contact me at [mlbcasey@brandeis.edu](mailto:mlbcasey@brandeis.edu). Thank you in advance for your participation.

Sincerely,  
Marcina Beaston-Casey  
Brandeis University Genetic Counseling Student, Class of 2014

## APPENDIX B

### Family Letter



Dear Family Member,

You are receiving this letter because your family member believes you may be willing to participate in a research project designed to explore the impact hereditary diffuse gastric cancer (HDGC) can have on families.

My name is Marcie Casey, and I am a graduate student in the Genetic Counseling Program at Brandeis University. For my master's thesis, I am seeking volunteers to participate in a research project. The goal of this research study is to explore the impact that hereditary diffuse gastric cancer (HDGC) has on families. If you have experience with HDGC in your family, I invite you to participate in this research study. If you meet the following criteria, you are eligible to participate:

- Participants must be 18 years of age or older.
- Participants must be part of a family in whom a mutation in the gene causing the condition known as hereditary diffuse gastric cancer has been identified.
- Biological relationship is not required. For example, spouses and adopted family members are eligible for participation.

Participation in this study is completely confidential and voluntary. It will involve completing an online anonymous survey. The time commitment for completion is estimated to be between 20 and 30 minutes. To participate in this study, please go to [www.nostomachforcancer.org](http://www.nostomachforcancer.org), where you will find an invitation to participate with a link to the online survey. Or you can go directly to the online survey using the following URL.

<https://brandeis.qualtrics.com/XXXXXXXXXXXXXXXXXXXX>

Upon completion of the survey you will be eligible to enter a raffle for one of three \$50 Amazon.com gift cards.

If you have any questions or comments, please feel free to contact me at [mlbcasey@brandeis.edu](mailto:mlbcasey@brandeis.edu). Thank you in advance for your participation.

Sincerely,  
Marcina Beaston-Casey  
Brandeis University Genetic Counseling Student, Class of 2014

## Appendix C

### Online Survey

Thank you for accepting the invitation to participate in this research study. The purpose of this study is to explore the impact that hereditary diffuse gastric cancer (HDGC) has on families. The estimated time commitment in taking the survey is 20 – 30 minutes. Please answer all of the questions to the best of your ability and knowledge. The Brandeis University Committee for Protection of Human Subjects (IRB) has approved this research study. Your participation is completely anonymous and voluntary. By completing the survey, you are consenting to participate in this research study. You may discontinue participation at any time for any reason. Should you feel the need to speak with someone about thoughts or feelings that may arise as a result of this survey, please feel free to contact Devanshi Patel, MS, CGC at [DPATEL5@PARTNERS.ORG](mailto:DPATEL5@PARTNERS.ORG) or by phone at 877-726-5130. Upon completion of the survey, you will have the opportunity to be entered into a drawing for one of three \$50 Amazon.com gift certificates. Please feel free to contact me with any questions or if you need assistance accessing the survey. I greatly appreciate your participation.

Marcie Casey

Brandeis University Genetic Counseling Program, Class of 2014

[Mlbcasey@brandeis.edu](mailto:Mlbcasey@brandeis.edu)

**Before beginning this survey, please verify that you meet the following requirements:**

- I am 18 years of age or older.
- I am part of a family in whom a mutation in the gene causing the condition known as hereditary diffuse gastric cancer has been identified.

**Demographic questions (for everyone):**

1. How old are you?
  - a. 18 – 24
  - b. 25 – 40
  - c. 41 – 60
  - d. Above 60
2. What is your gender?
  - a. Male
  - b. Female
3. Do you have biological children?
  - a. Yes
  - b. No
4. What is your relationship status?
  - a. Married
  - b. Common law
  - c. Domestic partner
  - d. Never married
  - e. Separated
  - f. Divorced
5. What is your **highest level of education**?
  - a. Did not finish high school
  - b. High School or GED
  - c. Bachelor's degree
  - d. Graduate level degree
6. Where do you live?
  - a. United States
  - b. Canada
  - c. Europe
  - d. Other \_\_\_\_\_
7. **Who was the first person in your family to be diagnosed with a cancer related to HDGC. (diffuse gastric cancer, lobular breast cancer, colon cancer)?**
  - a. I am the first person in my family
  - b. My Mother/Father was the first in our family
  - c. My brother/sister was the first in our family
  - d. Another relative was the first in our family. Please specify \_\_\_\_\_
8. Who was the first person in your family found to carry a mutation causing HDGC?
  - a. I am the first person in my family
  - b. My Mother/Father was the first in our family
  - c. My brother/sister was the first in our family
  - d. Other relative. Please specify \_\_\_\_\_
9. Into which of the following categories do you best fit? Please choose all that apply.  
I was the first in my family found to carry a mutation in the CDH1 gene.

As a result of my family member's HDGC diagnosis...

- I learned that I am a carrier of a mutation in the CDH1 gene, and I elected to have a total gastrectomy.
- I learned that I am a carrier of a mutation in the CDH1 gene, but have not yet elected to have a total gastrectomy.
- I was tested, and found NOT to carry a mutation in the CDH1 gene.
- I am a candidate for genetic testing, but put it off for now.
- I am a candidate for genetic testing, but decided not to get tested.

I am (or have been) a caregiver of someone who was found to carry a mutation in the CDH1 gene, and who chose to have a total gastrectomy.

I am a non-biologically related family member (for example, spouse or adoptive child) of someone who was found to carry a mutation in the CDH1 gene.

**To this point, all questions were asked of everyone. Based on their response to question #9, the software sent them to a more specific set of questions. They are divided into sections below.**

***I was the first in my family found to carry a mutation in the CDH1 gene.***

1. Were you diagnosed with diffuse gastric cancer, lobular breast cancer, or colon cancer before you were found to carry a mutation in the CDH1 gene? Yes/No

If yes, please specify which type of cancer \_\_\_\_\_

2. Did you have a total gastrectomy? Yes/No

**If NO**, do you plan to have a total gastrectomy? Yes/No  
If not, why?

- My doctor advised against having a gastrectomy.
- It is a personal decision.
- Other: \_\_\_\_\_

**If YES**, how much time passed between learning of your CDH1 gene status and having a total gastrectomy?

- Fewer than 2 months
- 2 months – 6 months
- Greater than 6 months

**If YES**, how much time passed since your gastrectomy?

- Fewer than 2 months
- Between 2 months and 1 year
- Between 1 and 5 years
- Greater than 5 years

**If YES**, what factors were important to you in deciding to get tested and have surgery? Choose all that apply.

- I wanted to do everything I could to reduce the risk of gastric cancer.
- I wanted to do everything I could to help my loved ones.
- I was following my doctor's medical recommendations.
- Other Please specify \_\_\_\_\_

**If YES**, did you have concerns about the impact a total gastrectomy would have on your life? YES/NO

- If YES, what were you concerned about? (choose all that apply):
  - My life at home
  - Relationships with my family members
  - My professional life
  - Relationships with my colleagues
  - My social life
  - Relationships with my friends
  - I had financial concerns
  - I had insurance concerns
  - I had other concerns. Please explain. \_\_\_\_\_

**If YES**, regarding your relationship with food ...

- Prior to surgery, did you struggle with maintaining a healthy weight? Yes/No  
If YES, Please explain \_\_\_\_\_
- Since having surgery, have you struggled with maintaining a healthy weight? Yes/No If YES, Please explain \_\_\_\_\_
- Were you ever diagnosed with an eating disorder? Yes/No
- Were/are you an emotional eater? Yes/No
- Are there any particular social situations that you find difficult as a result of your gastrectomy? Yes/No Please list \_\_\_\_\_
- In the following table, please select what best describes your **emotional** state when you ate prior to surgery, immediately after surgery, and when you eat today:

Anxiety/fear about eating	None	A little bit	Moderate	Quite a bit	Extreme
YOUR LIFE PRIOR TO SURGERY					
IMMEDIATELY AFTER SURGERY					
TODAY					

• I

In the following table, please select what best describes your **physical** state when you ate prior to surgery, immediately after surgery, and when you eat today:

Physical symptoms associated with eating	Nausea	Vomiting	Bloating/cramping	Diarrhea	Dizziness	Sweating	Fatigue
YOUR LIFE PRIOR TO SURGERY							
IMMEDIATELY AFTER SURGERY							
TODAY							

	Anxiety/fear about eating	None	A little bit	Moderate	Quite a bit	Extreme
3. Did you inform your family members that you were found to carry a mutation in the CDH1 gene? Yes/No						
If yes, how did you inform your immediate family? (Choose all that apply)	YOUR LIFE PRIOR TO SURGERY					
	<ul style="list-style-type: none"> <li>Family meeting</li> </ul>					
	IMMEDIATELY AFTER SURGERY					
	<ul style="list-style-type: none"> <li>Individual in person conversation</li> <li>Phone conversation</li> <li>Email</li> <li>Letter</li> <li>Social media</li> </ul>					
	TODAY					
	<ul style="list-style-type: none"> <li>Other _____</li> </ul>					

If yes, how did you inform your extended family? (Choose all that apply)

- Family meeting
- Individual in person conversation
- Phone conversation
- Email
- Letter
- Social media
- Other \_\_\_\_\_

Looking back, would you change anything about the way you informed your immediate family?

Yes/No If yes, how? \_\_\_\_\_

Looking back, would you change anything about the way you informed your extended family?

Yes/No If yes, how? \_\_\_\_\_

4. What advice might you give to someone considering genetic testing for HDGC?
5. What advice might you give to someone considering a total gastrectomy?
6. What advice might you give to family members of those having a total gastrectomy?
7. What advice might you give to medical professionals (genetic counselors, physicians, surgeons, dieticians) who are trying to help families deal with HDGC?

**As a result of my family members HDGC diagnosis, I learned that I am a carrier of a mutation in the CDH1 gene, and I elected to have a total gastrectomy.**

1. How did you learn about HDGC in your family?

- Family meeting
- Individual in person conversation
- Phone conversation
- Email
- Letter
- Social media
- Other \_\_\_\_\_

2. Looking back, would you change anything about the way you were informed about the HDGC in your family?

Yes/No If yes, how? \_\_\_\_\_

3. How much time passed between learning of your family member's HDGC diagnosis and choosing to have testing yourself?

- a. Fewer than two months
- b. 2 month – 6 months
- c. Greater than 6 months

Was there a delay in your testing? Yes/No

If YES, why? Choose all that apply

- I needed time to prepare
- I needed to make arrangements at work.
- There was a delay at the medical facility
- I had insurance issues
- I had emotional concerns
- Other Please specify \_\_\_\_\_

d. I never had genetic testing. I knew I was positive based on my child's result.

4. Were you diagnosed with diffuse gastric cancer, lobular breast cancer, or colon cancer before pursuing genetic testing? Yes/No  
If yes, which type?

- a. Diffuse gastric cancer
- b. Lobular breast cancer
- c. Colon cancer

5. How much time passed between learning of your CDH1 status, and having a total gastrectomy?

- a. Fewer than two months
- b. 2 months – 6 months
- c. Greater than 6 months

6. How much time has passed since your gastrectomy?

- a. Fewer than 2 months
- b. Between 2 months and 1 year
- c. Between 1 and 5 years
- d. Greater than 5 years

7. Which of these factors, if any, were important to you in making decisions about testing and/or preventative surgery (gastrectomy)?  
Choose all that apply.

- I wanted to do everything I could to reduce the risk of gastric cancer.
- I wanted to do everything I could to help my loved ones.
- I was following my doctor's medical recommendations.
- Other Please specify \_\_\_\_\_

8. Prior to having surgery, did you have concerns about the impact a total gastrectomy would have on your life? YES/NO

If YES, what were you concerned about? (Choose all that apply):

- My life at home
- Relationships with my family members
- My professional life
- Relationships with my colleagues
- My social life
- Relationships with my friends
- I had financial concerns
- I had insurance concerns
- I had other concerns. Please explain. \_\_\_\_\_

9. Regarding your relationship with food prior to surgery...

- Prior to surgery, did you struggle with maintaining a healthy weight? Yes/No If YES, Please explain \_\_\_\_\_
- Since having surgery, have you struggled with maintaining a healthy weight? Yes/No If YES, Please explain \_\_\_\_\_
- Were you ever diagnosed with an eating disorder? Yes/No
- Were/are you an emotional eater? Yes/No
- Are there any particular social situations that you find difficult as a result of your gastrectomy? Yes/No Please list \_\_\_\_\_
- In the following table, please select what best describes your **emotional** state when you ate prior to surgery, immediately after surgery, and today:

Anxiety/fear about eating	None	A little bit	Moderate	Quite a bit	Extreme
YOUR LIFE PRIOR TO SURGERY					
IMMEDIATELY AFTER SURGERY					
TODAY					

- In the following table, please select what best describes your **physical** state when you ate prior to surgery, immediately after surgery, and today:



Physical symptoms associated with eating	Nausea	Vomiting	Bloating/cramping	Diarrhea	Dizziness	Sweating	Fatigue
YOUR LIFE PRIOR TO SURGERY							
IMMEDIATELY AFTER SURGERY							
TODAY							

10. What advice might you give to someone considering genetic testing for HDGC?
11. What advice might you give to someone considering a total gastrectomy?
13. What advice might you give to family members of those having a total gastrectomy?
14. What advice might you give to medical professionals (genetic counselors, physicians, surgeons, dieticians) who are trying to help families deal with HDGC?

**As a result of my family member's HGDC diagnosis, I learned that I am a carrier of a mutation in the CDH1 gene, but have not yet elected to have a total gastrectomy.**

1. How did you learn about HDGC in your family?
  - Family meeting
  - Individual in person conversation
  - Phone conversation
  - Email
  - Letter
  - Social media
  - Other \_\_\_\_\_
2. Looking back, would you change anything about the way you were informed about the HDGC in your family?
 

Yes/No \_\_\_\_\_ If yes, how? \_\_\_\_\_
3. How much time passed between learning of your family member's HDGC diagnosis and choosing to have testing yourself?
  - a. Fewer than 2 months
  - b. 2 month – 6 months
  - c. Greater than 6 months

Was there a delay in your testing? Yes/No \_\_\_\_\_  
 If YES, why? Choose all that apply.

  - I needed time to prepare
  - I needed to make arrangements at work.
  - There was a delay at the medical facility
  - I had insurance issues
  - I had emotional concerns
  - Other Please specify \_\_\_\_\_

d. I never had genetic testing. I knew I was positive based on my child's result.
4. Were you diagnosed with diffuse gastric cancer, lobular breast cancer, or colon cancer before pursuing genetic testing? Yes/No \_\_\_\_\_  
 If yes, which type?
  - a. Diffuse gastric cancer
  - b. Lobular breast cancer
  - c. Colon cancer
4. Which of these factors, if any, were/are important to you in making decision about testing and/or preventative surgery (total gastrectomy)? Choose all that apply.
  - I want to do everything I can to reduce the risk of gastric cancer.
  - I want to do everything I can to help my loved ones.
  - My doctor's medical recommendations are important to me.
  - Other Please specify \_\_\_\_\_
5. Do you have concerns about the impact a total gastrectomy will have on your life? Yes/No \_\_\_\_\_  
 If YES, what are your concerned about? (Choose all that apply):
  - My life at home
  - Relationships with my family members
  - My professional life
  - Relationships with my colleagues
  - My social life
  - Relationships with my friends
  - I had financial concerns
  - I had insurance concerns
  - I had other concerns. Please explain. \_\_\_\_\_
5. Do you plan to have surgery? Yes/No \_\_\_\_\_  
 If not, why? (Choose all that apply)
  - My doctor advised against having a gastrectomy.
  - It is a personal decision.

- Other: \_\_\_\_\_
6. What advice might you give to someone considering genetic testing for HDGC?
  7. What advice might you give to someone considering a total gastrectomy?
  8. What advice might you give to family members of those having a total gastrectomy?
  9. What advice might you give to medical professionals (genetic counselors, physicians, surgeons, dieticians) who are trying to help families deal with HDGC?

**As a result of my family member's HDGC diagnosis, I was tested and found NOT to carry a mutation in the CDH1**

1. How did you learn about HDGC in your family?
  - Family meeting
  - Individual in person conversation
  - Phone conversation
  - Email
  - Letter
  - Social media
  - Other \_\_\_\_\_
2. Looking back, would you change anything about the way you were informed about the HDGC in your family?
 

Yes/No	If yes, how? _____
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3. How much time passed between learning of your family member's HDGC diagnosis and choosing to have testing yourself?
  - d. Fewer than two months
  - e. 2 month – 6 months
  - f. Greater than 6 months

Was there a delay in your testing? Yes/No

If YES, why? (Choose all that apply)

  - I needed time to prepare
  - I needed to make arrangements at work.
  - There was a delay at the medical facility
  - I had insurance issues
  - I had emotional concerns
  - Other Please specify \_\_\_\_\_
4. Which of these factors, if any, were important to you in making a decision about testing? Choose all that apply.
  - I wanted to do everything I could to reduce the risk of gastric cancer.
  - I wanted to do everything I could to help my loved ones.
  - I was following my doctor's medical recommendations.
  - Other Please specify \_\_\_\_\_
5. Prior to receiving your test results, did you consider the possibility of having a total gastrectomy should your result come back positive for the CDH1 mutation? Yes/No
 

If YES, which of these factors, if any, were important to you in considering the possibility of having a total gastrectomy? Choose all that apply.

I was concerned about the impact a total gastrectomy would have on...

  - My life at home
  - Relationships with my family members
  - My professional life
  - Relationships with my colleagues
  - My social life
  - Relationships with my friends
  - I had financial concerns
  - I had insurance concerns
  - I had other concerns. Please explain. \_\_\_\_\_
6. If you had been found to carry the CDH1 mutation, would you have had a gastrectomy? Yes/No/I don't know.
7. What advice might you give to someone considering genetic testing for HDGC?
8. What advice might you give to someone considering a total gastrectomy?
9. What advice might you give to family members of those having a total gastrectomy?
10. What advice might you give to medical professionals (genetic counselors, physicians, surgeons, dieticians) who are trying to help families deal with HDGC?

**As a result of my family member's HDGC diagnosis. I am a candidate for genetic testing, but put it off for now.**

1. How did you learn about HDGC in your family?
  - Family meeting
  - Individual in person conversation
  - Phone conversation
  - Email
  - Letter
  - Social media
  - Other \_\_\_\_\_

2. Looking back, would you change anything about the way you were informed about the HDGC in your family?  
Yes/No \_\_\_\_\_ If yes, how? \_\_\_\_\_
3. Are you still considering genetic testing? Yes/No \_\_\_\_\_  
**If YES**, which of these factors, if any, are important to you in deciding whether to get tested? Choose all that apply.
  - I want to do everything I can to reduce the risk of gastric cancer.
  - I want to do everything I can to help my loved ones.
  - My doctor's recommendations are important to me.
  - I have other considerations. They are \_\_\_\_\_**If YES**, are you considering the possibility of having a total gastrectomy in the event that you are found to be a carrier of the CDH1 mutation? Yes/No \_\_\_\_\_  
**If YES**, which of these factors, if any, are important to you in considering the possibility of having a total gastrectomy? Choose all that apply.  
 I am concerned about the impact a total gastrectomy would have on...
  - My life at home
  - Relationships with my family members
  - My professional life
  - Relationships with my colleagues
  - My social life
  - Relationships with my friends
  - I had financial concerns
  - I had insurance concerns
  - I had other concerns. Please explain. \_\_\_\_\_
4. What advice might you give to someone considering genetic testing for HDGC?
5. What advice might you give to someone considering a total gastrectomy?
6. What advice might you give to family members of those having a total gastrectomy?
7. What advice might you give to medical professionals (genetic counselors, physicians, surgeons, dieticians) who are trying to help families deal with HDGC?

***As a result of my family member's HDGC diagnosis, I am a candidate for genetic testing, but decided not to get tested***

1. How did you learn about HDGC in your family?
  - Family meeting
  - Individual in person conversation
  - Phone conversation
  - Email
  - Letter
  - Social media
  - Other \_\_\_\_\_
2. Looking back, would you change anything about the way you were informed about the HDGC in your family?  
Yes/No \_\_\_\_\_ If yes, how? \_\_\_\_\_
3. What factors were important to you in making your decision? (Choose all that apply)
  - I am too old to consider the preventative surgery (total gastrectomy).
  - I was concerned about the impact a total gastrectomy might have on my life...
    - My life at home
    - Relationships with my family members
    - My professional life
    - Relationships with my colleagues
    - My social life
    - Relationships with my friends
    - I had financial concerns
    - I had insurance concerns
    - I had other concerns. Please explain. \_\_\_\_\_
4. What advice might you give to someone considering genetic testing for HDGC?
5. What advice might you give to someone considering a total gastrectomy?
6. What advice might you give to family members of those having a total gastrectomy?
7. What advice might you give to medical professionals (genetic counselors, physicians, surgeons, dieticians) who are trying to help families deal with HDGC?

***I am (or have been) a caregiver of someone who was found to be a carrier of the CDH1 mutation, and who chose to have a total gastrectomy.***

1. How did you learn about HDGC in your family?
  - Family meeting
  - Individual in person conversation
  - Phone conversation
  - Email
  - Letter
  - Social media
  - Other \_\_\_\_\_

2. Looking back, would you change anything about the way you were informed about the HDGC in your family?  
Yes/No If yes, how? \_\_\_\_\_
3. What is your relationship with the person for whom you care/cared?
4. What is/was the most difficult part of your role as caregiver?
5. Which of the following best describes your responsibilities as caregiver? Choose all that apply.
  - o I provided practical help on a daily basis (such as but not limited to administering medicine, preparing meals, helping with children, transportation to appointments, etc)
  - o I provided practical help several times per week.
  - o I provided practical help occasionally.
  - o I provided emotional support
  - o I would like to be more specific about the help I provided. \_\_\_\_\_
6. Please describe any support system you had during your role as caregiver.  
Did the support you received meet your needs? Yes/No  
If no, please explain. \_\_\_\_\_
7. Was there any other support you would like to have had? Yes/No Please describe \_\_\_\_\_
8. Did your relationship with food change as a result of your experience providing support for someone with HDGC? Yes/No  
**If YES**, please describe how it changed.
9. What advice might you give to someone about to step into the role of caregiver to someone who has just gotten a total gastrectomy?
10. What advice might you give to someone considering genetic testing for HDGC?
11. What advice might you give to someone considering a total gastrectomy?
13. What advice might you give to family members of those having a total gastrectomy?
14. What advice might you give to medical professionals (genetic counselors, physicians, surgeons, dieticians) who are trying to help families deal with HDGC?

***"I am a non-biologically related family member (for example, spouse or adoptive child) of someone who was found to carry a mutation in the CDH1 gene."***

1. How did you learn about HDGC in your family?
  - Family meeting
  - Individual in person conversation
  - Phone conversation
  - Email
  - Letter
  - Social media
  - Other \_\_\_\_\_
2. Looking back, would you change anything about the way you were informed about the HDGC in your family?  
Yes/No If yes, how? \_\_\_\_\_
3. Did your relationship with food change as a result of your experience with HDGC in your family? Yes/No  
**If YES**, please describe how it changed. \_\_\_\_\_
4. What advice might you give to someone considering genetic testing for HDGC?
5. What advice might you give to someone considering a total gastrectomy?
7. What advice might you give to family members of those having a total gastrectomy?
8. What advice might you give to medical professionals (genetic counselors, physicians, surgeons, dieticians) who are trying to help families deal with HDGC?

Thank you for taking the time to complete this survey. To enter for your chance to win one of three \$50 Amazon gift cards, please follow the link below to register. Contact information for the gift card entries will not be linked to completed surveys.

Should you feel the need to speak with someone about thoughts or feelings that may arise as a result of this survey, please feel free to contact Devanshi Patel, MS, CGC at [DPATEL5@PARTNERS.ORG](mailto:DPATEL5@PARTNERS.ORG) or by phone at 877-726-5130.

If you have a family member who you feel may be willing to participate in this study, please direct them to [www.nostomachforcancer.org](http://www.nostomachforcancer.org), where they can find the information and link to the survey. Alternatively, we are providing a "family letter" explaining the study. Please forward the letter to family members you feel may be interested, or print it and give it to them.

Again, I truly appreciate your participation and your help in including others who may be interested.

Link to enter for a chance to win one of three \$50 Amazon gift cards: XXXXXXXX

Marcie Casey

Brandeis University Genetic Counseling Program, Class of 2014

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