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Impact on Health-Related Quality of Life in Adults with Eosinophilic Gastritis and Gastroenteritis: A Qualitative Assessment

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Abstract

Background—Eosinophilic gastritis (EG) and eosinophilic gastroenteritis (EGE) are chronic immune-mediated conditions of the digestive tract, which affect the stomach only, or the stomach and small intestines, respectively. Though these disorders are uncommon, they are being increasingly recognized and diagnosed. While health-related quality of life (HRQOL) has been evaluated in other eosinophilic gastrointestinal diseases, this study is the first to describe HRQOL impacts unique to EG/EGE.

Aims—This study aims to qualitatively describe experiences of adults diagnosed with EG and EGE. We aim to identify impacts on HRQOL in this population in order to inform clinical care and assessment.

Methods—Seven patients diagnosed with EG or EGE participated in semi-structured interviews assessing common domains of HRQOL.

Results—Four distinct themes emerged from qualitative analyses, which represent impacts to HRQOL: the psychological impact of the diagnosis, impact on social relationships, financial impact, and impact on the body. These generally improved over time and with effective treatment.

Conclusions—This study demonstrated that patients with EG/EGE experience impacts to HRQOL, some of which differ from HRQOL of other eosinophilic gastrointestinal diseases. These results support the development of a disease-specific measure, or adaptation of an existing measure, to assess HRQOL in EG/EGE.

Keywords

Eosinophilic gastritis; Eosinophilic gastroenteritis; Health-related quality of life; Patient-reported outcomes

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Conflict of interest The authors have nothing to disclose and no competing interests.

Introduction

Eosinophilic gastrointestinal diseases (EGIDs) are chronic immune-mediated conditions of the digestive tract characterized by eosinophil-predominant tissue inflammation [1]. Common symptoms of eosinophilic gastritis (EG) and eosinophilic gastroenteritis (EGE) include abdominal pain, nausea, vomiting, early satiety, and diarrhea. Specific symptoms are based on the anatomic region (i.e., stomach and small bowel) and layer of bowel wall involved. In severe cases, patients may develop disease complications that include malabsorption, anemia, weight loss, gastric outlet obstruction, ulceration, perforation, and bowel obstruction [2]. Treatments for EGIDs are limited and include oral corticosteroids, topical corticosteroids, elimination diet, or sometimes immune modulators [1]. All therapies are being used off-label as none have yet been approved for in the indication of EGIDs. Although EG/EGE are uncommon, they are becoming increasingly recognized and diagnosed [3], and better understanding of patient needs in these disorders is needed.

Health-related quality of life (HRQOL) is a construct that accounts for the social, emotional, occupational, and functional impacts of chronic health conditions often used as a metric for patient-reported outcomes (PROs) [4]. Due to limited treatment options and significant side effects with currently used medications, a significant burden falls on the patient in managing their EG/EGE, resulting in stress and a reduced HRQOL. In fact, these treatments, including elimination diets, are known to be associated with reduced HRQOL in related disease groups, including food allergy [5] and eosinophilic esophagitis (EoE) [6]. HRQOL has been studied in many chronic GI conditions including celiac disease [7], inflammatory bowel disease (IBD) [8], and EoE [9] using either generic measures of HRQOL such as the MOS Short Form-36 [10], or disease-specific such as the IBSQOL [11]. In all of these conditions, a reduction in HRQOL has been identified [7, 8, 12]. Patients with celiac disease have described how symptom management and psychological distress related to long-term risks can negatively impact their HRQOL [7]. However, multiple studies determined that adherence to a gluten-free diet is associated with an increased HRQOL [13, 14]. Similarly, IBD patients have reported that symptoms and behavioral modifications, such as staying close to a bathroom, can negatively impact their HRQOL [15, 16]. Unlike those with celiac disease, patients with IBD suffer chronic and unpredictable symptoms that require lifestyle changes beyond diet [15, 16]. Given the disease-specific effect on HRQOL of IBD, an IBD-specific measure for HRQOL was created, the IBDQ [17]. Finally, patients with EoE also experience chronic relapses that can negatively impact their psychosocial and physical well-being and thus decrease HRQOL [18]. Adults with EOE have identified that the social and emotional burdens, often associated with difficulty swallowing and symptom severity, were associated with decreased HRQOL [12]. In 2011, our group created a disease-specific measure of HRQOL for adults with EoE (EoE-QOL-A) [18, 19], using FDA guidelines for a three-stage, mixed methods process [20]. The EoE-QOL-A was created because the disease-specific concerns EoE patients face were not adequately addressed by other instruments [19]. It is clear that a chronic GI condition can decrease HRQOL. However, each condition may bring unique and disease-specific challenges that can impact patient care and determine healthcare decisions. Thus, it is important that measures of HRQOL are appropriate for the disease group in which they are used.

No study to date has evaluated HRQOL in patients with EG/EGE, and it is unclear whether the impacts to HRQOL in these patients will differ from those with EoE. The present study is an initial step in the development of a PRO measure of HRQOL in EG/EGE. In this study, qualitative research methods [21] are used to characterize and describe patients' experiences with EG/EGE.

Materials and Methods

Participants aged 18–70 with a physician-confirmed diagnosis of EG/EGE were recruited from a university-based gastroenterology practice. Patients had previously been diagnosed with endoscopy and biopsy showing characteristic endoscopic changes as well as histologic abnormalities. Due to the rare nature of EG/EGE and the specific nature of the study's aim/limited scope of the study, purposeful sampling was used to achieve an appropriate study sample. Purposeful sampling is one preferred approach for smaller sample sizes and in populations with limited selection criteria (i.e., a rare disease). This sampling method helps ensure the sample will be rich in characteristics so that saturation can be achieved [22, 23]. Eligible participants were identified via medical record review and called to inquire about study participation. Participants were excluded if they had primarily esophageal symptoms and concomitant EoE that confounded the impact of their EG/EGE symptoms on HRQOL. This study was approved by the Northwestern Institutional Review Board. After providing informed consent, participants completed the following questionnaires.

Demographic information collected included age, gender, race, ethnicity, relationship status, employment status, and education level. As cultural differences can affect how individuals perceive HRQOL and differences in prevalence have been previously reported in EoE, race and ethnicity were collected through a categorical question.

Additional clinical information included was diagnosis duration (years), symptom duration prior to diagnosis (years), current EG/EGE treatment, self-identified food triggers, dietary treatment, and prior psychotherapy treatment for EG/EGE.

Following completion of the questionnaires, participants engaged in an in-depth, semi-structured interview about how living with EG/EGE has impacted several aspects of their lives across established domains of HRQOL [4]. Interviews were conducted by trained graduate students (A.B., L.G., M.C.) either face-to-face or by phone and ranged from 30 to 90 min. Questions were pre-constructed, open-ended, and focused on the various social, emotional, occupational, and functional impacts of living with EG/EGE (i.e., "How has living with EG/EGE affected your relationships with friends?" "How has living with EG/EGE impacted your mood?" "Does living with EG/EGE impact your ability to do your job?"). See Table 1 for interview questions.

Statistical Analysis

All questionnaire responses were entered into SPSS v. 24 (IBM-SPSS, Inc., Chicago IL, USA) for analysis. Descriptive statistics (means, standard deviations, frequency, and percentage) were used to evaluate the participants' demographic and clinical characteristics.

Individual, audio-recorded interviews with EG/EGE patients underwent qualitative analysis using a phenomenological reduction approach [24], which consisted of the following steps: (1) transcription of audio-recorded files into text by authors A.B., L.G., and M.C.; (2) review of individual transcripts to assess for broad themes related to HRQOL; (3) identification of significant statements and phrases relevant to the EG/EGE experience; (4) clustering of similar statements and phrases into units of meaning; (5) deriving HRQOL themes from the clusters of meaning; (6) integration of individual themes into composite textural and structural description of the EG/EGE experience; (7) identification of the fundamental structure of the HRQOL phenomenon via content reduction.

Results

Sample Characteristics

A total of 26 patients were called via telephone with nine successfully recruited (34.6% response rate). Upon screening, two were excluded due to comorbid esophageal predominant symptoms. In total, seven were interviewed. Demographic and clinical data are presented in Table 2. Participants tended to be male, married or in a committed relationship, and employed, with a mean age of 37.9 years. All participants identified as White, reported receiving a college education, endorsed seeing a dietician for EG/EGE and just over a quarter (28.6%) reported visiting a therapist for EG/EGE.

Qualitative Analysis

Analysis of the participants' interview data identified four distinct themes that reflected the impact of EG/EGE on HRQOL. A commonality throughout the themes was a positive change in HRQOL over time since diagnosis. Results are detailed below. See Table 3 for representative quotations.

Theme 1: Psychological Impact of Diagnosis

Emotional functioning and mental functioning are two dimensions of HRQOL that can be impacted by a chronic illness [25]. The diagnostic phase has been reported as the most stressful time of an illness [26]. Indeed, receiving a diagnosis has been described as a "relief" [27]. This was the case in our sample, with many experiencing the pre-diagnostic phase and its associated symptoms as stressful. All participants described an emotional impact of receiving the diagnosis, with one describing depression but many experiencing relief.

Although most participants experienced a sense of relief upon diagnosis, all participants described the way EG/EGE negatively impacted their overall emotional and mental well-being. As EGIDs are thought to be food antigen-driven disorders, 71.4% of patients were on a form of dietary elimination or elemental diet. Not surprisingly, all participants had strong emotions related to food, including anxiety of cross-contamination and the associated symptoms, and feeling overwhelmed due to the constant planning around food and sadness over loss of favorite foods. Fifty-seven percent described the challenges of balancing urges and sticking to their food regimen. Yet, all experienced more acceptance of the food limitations and increased self-efficacy around planning over time.

Relief was also discussed when participants were matched with a clinician that was knowledgeable about EG/EGE, as most participants had to visit multiple providers before receiving a diagnosis. In addition to providing the correct diagnosis, the healthcare team was viewed as an important source for increasing patient self-efficacy about EG/EGE, leading to feelings of ease. All participants viewed their diagnosing provider as knowledgeable, with many describing positive interactions.

All participants reported taking medication for EG/EGE and discussed a range of emotions associated with the treatment. While the medications were viewed as helpful and were associated with improved mood over time, all but one of the participants described concern and worry about the long-term impacts of medications.

Theme 2: Impact on Social Relationships

One dimension of HRQOL is social functioning [25]. Chronic illnesses can impact social functioning through experiences of stigma and symptom burden [28, 29]. All participants described ways in which EG/EGE impacts their social functioning, including social isolation, stigma, and compensatory behaviors, particularly when engaging in social activities involving food. However, all participants described an improvement in their ability to navigate social relationships over time following diagnosis.

Many found that EG/EGE impacted family or cultural traditions (43%). Participants described not wanting to offend other cultures by turning down food and challenges with their own family's expectations around food. Additionally, all participants described either feeling like a burden on their family or experiences of family members expressing concern. Finally, 86% of participants were married or in a committed relationship. All but one described receiving a strong degree of support from their partners, and half described a sexual impact due to experiencing symptoms or feeling self-conscious about them.

All participants shared different strategies they use to navigate social situations, particularly when food is involved. These included eating beforehand, making their own food, or avoiding the situation.

Theme 3: Financial Impact

In addition to the social impact, chronic conditions have been found to be costly [30]. All but one participant reported experiencing a financial impact due to EG/EGE, either through food-, healthcare-, or insurance-related costs. Eighty-six percent described experiencing an impact on their job or education due to EG/EGE, ranging from difficulty finding a job, not eating at work, to not completing graduate school. Yet, the majority described finding a financial balance through saving money in other ways, going on disability or changing insurance.

Theme 4: Impact on the Body

Individuals with gastrointestinal disorders often experience physical changes which can impact their body image and self-image [31, 32]. Eighty-six percent of our participants described losing weight initially, 71% described difficulty gaining weight post-diagnosis,

one participant described weight gain due to treatment, and one experienced fluctuation due to difficulty in adhering to the restrictive dietary regimen. All participants described symptoms, such as diarrhea and vomiting, negatively impacting sleep or leading them to feel lethargic. Although all participants experienced physical changes, the impact on physical activity was diverse with one participant describing becoming more athletic post-diagnosis, four decreasing their physical activity, and two finding a balance of exercise and diet.

The physical changes often led to concerns and changes in the way participants felt about themselves. All described concerns of how EG/EGE impacts their body and the way it changes their perceptions of their body, with one person describing feeling too thin, one person describing feeling damaged, one reporting feeling unable to describe herself as healthy, and two feeling less sexually attractive. All except one expressed worries related to the long-term impacts of EG/EGE. Despite their worries, all described a sense of acceptance of the disease and its physical impact.

Discussion

The present study represents the first step in the development of a PRO measure of HRQOL in EG/EGE, as recommended by FDA guidelines [20], by utilizing qualitative methods to describe patients' experiences. Although a measure of HRQOL in EoE exists (EoE-QOL-A) [19] and some overlap in EoE/EG/EGE impacts is clear, our findings demonstrate patients with EG/EGE have additional, unique impacts to HRQOL. Thus, potential next steps are the development of a new EG/EGE-specific measure or the evaluation of an existing measure for adaptation. We found individuals with EG/EGE experience psychological, social, financial, and body image impacts; these are most significant before and early on in diagnosis and appear to diminish significantly over time and with adequate treatment.

Patients in our sample described a range of psychological impacts related to their EG/EGE. These ranged from a sense of relief at receiving a diagnosis, emotional distress related to dietary restrictions, and depression following development of their disease. Feeling relief upon diagnosis is consistent with prior research, including in a qualitative study of patients with EoE where 74% of participants endorsed a sense of relief when given a diagnosis [18]. Similar feelings of relief are present in patients living with celiac disease [7].

Illness uncertainty is a well-known, measurable construct that refers to the inability to cognitively process illness-related stimuli or structure meaning that results when patients have (a) ambiguity regarding the state of their illness, (b) complexity regarding treatment, (c) lack of information about the diagnosis and its severity, and (d) unpredictability of the course of the disease and its diagnosis [33]. In our sample, patients reported high levels of satisfaction with their current physician's level of understanding of their diagnosis and ability to manage their condition, which was likely related to their sense of relief. However, it should be noted that patients in this study attend a university-based gastroenterology practice specializing in the treatment of EGIDs. Participants cited prior frustrations with obtaining a diagnosis with some seeing several gastroenterologists, suggesting that increased awareness about EG/EGE is needed.

In the IBD literature, psychological distress is strongly related to reduced HRQOL [34, 35]. Patients report embarrassment over IBD symptoms and disease-related concerns such as long-term treatment effects [15]. Those with Crohn's disease report feeling negative emotions such as guilt and depression due to missing out on social activities due to their symptoms [16]; similar findings exist in patients with celiac disease [7]. In our study, all EG/EGE patients discussed similar concerns, experiences, and psychological distress. All participants reported negative emotional reactions related to their disease, such as fear of cross-contamination while on dietary elimination or worry about long-term medication side effects.

Some patients in our sample reported instances of receiving negative comments or insults (e.g., enacted stigma) in adolescence; however, this abated during adulthood. A recent study found that disease-related stigma perceptions are present in adult patients with EGIDs, and those with EoE reported less stigma perceptions than those with EG and EGE [36]. No study to date evaluates stigma in youth with EG/EGE, and this is an important area for future research.

Social situations involving food and eating caused significant challenges in our sample, mostly due to adherence to complicated dietary regimens. Importantly, most discussed adaptive ways of coping, such as looking at a menu online before a dinner out or preparing a diet-friendly dish to pass at get-togethers. Though these types of behaviors require significant planning, our sample seemed to have adjusted to this "new normal" and did not find it overly distressing. This tendency to plan ahead in anticipation of food-related social events closely mirrors findings from celiac disease HRQOL research [7], where dietary restrictions also make spontaneous eating nearly impossible. Most participants in our sample expressed having strong sources of social support, and this combined with improved participant and family/friend knowledge of EG/EGE allowed for a minimal impact on social functioning over time. Though this finding is consistent with EoE, it should be noted that embarrassment associated with a public choking episode, endorsed by 38% of EoE patients in a prior study [18], is not a symptom of EG/EGE and was not present in our sample.

Most patients reported some financial impact due to EG/EGE, either directly through cost of special foods, or indirectly through inability to work or complete school. A range of financial impacts existed with the majority indicating significant costs of treatment. These findings differ from EoE, where a financial impact was not reported in equivalent interviews [18]. The EoE-QoL-A [19] has a single item for spending money on food, but this item is only asked of patients on an elimination diet. Similarly, in celiac disease, financial concerns are not reported in a qualitative study [7] or in the celiac disease-specific Quality of Life Scale (CDQOL) [37].

Patients with EG/EGE may develop negative perceptions of their bodies, changes in their ability to carry out normal activities, and an impact on their sexual activity. Many participants recalled significant impairment in their ability to engage in physical activity prior to effective EG/EGE treatment, with an eventual return to normalcy. Interference with sexual activity was minimal, with some participants stating if they are symptomatic they are less interested in sex, but most denied any impact. Body image was impacted by weight loss,

due to dietary restriction, or weight gain due to steroids. Again, these findings differ from EoE, where physical or bodily impacts were not reported in equivalent qualitative interviews [18] or in the EoE-QoL-A [19]. Our findings more closely resemble those in Crohn's disease [16] where some participants described concerns about their physical appearance as well as a lack of interest in sex due to fatigue.

There are limitations to consider when interpreting this study's findings. The small sample, while meeting the general guidelines for studies of this design [38], is entirely White, college educated, and predominantly male. As such, caution should be used when extrapolating the findings to other cultural groups. A recently published large-scale study of EGE suggests a prevalence of 5.1/100,000 in the USA, with a slight female predominance [39] and higher rates in White individuals than Asians or Blacks. Similar data are not available for EG. Our sample was also recruited from an urban hospital gastroenterology clinic with physicians who specialize in EG/EGE; thus, it is possible that their experiences will not mirror those of patients treated in other settings.

However, our findings suggest that accurate and early diagnosis and effective treatment are the first steps in improving HRQOL in patients with EG/EGE. While many patients may achieve a normal HRQOL following treatment, providers should assess for areas in need of additional support. To do this most effectively, an existing measure should be adapted, or a new measure should be developed and validated, to assess HRQOL in EG/EGE.

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Table 1**Semi-structured interview questions**

Please briefly tell me about how you discovered that you have EG/EGE.	
How long did it take you to get diagnosed? Did you have to see many doctors?	
How long have you had EG/EGE?	
Had you heard of EG/EGE before being diagnosed?	
What kind of information did you get from your doctor when you were diagnosed?	
Did you look for information from online or other sources?	
How are you currently treating your EG/EGE? (e.g. meds, diet)	
Tell me about how EG/EGE has affected your relationships with your family - this can include immediate and extended family members.	
How has EG/EGE affected your relationships with friends?	
Are you currently working? How has EG/EGE affected your work relationships?	
Does living with EG/EGE affect your ability to do your job?	
Are you currently in school? How has EG/EGE affected your school relationships?	
Does EG/EGE affect your school work?	
Do you feel like you socialize less now that you have EG/EGE?	
Tell me about navigating social engagements, like eating out or going to someone's house for a party or meal.	
How would you describe your interactions with healthcare providers who treat your EG/EGE?	
Has living with EG/EGE impacted you financially?	
How has living with EG/EGE impacted your mood? Do you feel more down or worried than before you got sick?	
Are you able to participate in activities (e.g. exercise, hobbies) that you liked to do before you got sick? Which ones have been affected?	
Have people ever treated you differently or said negative things to you because you have EG/EGE?	
Does EG/EGE impact your sleep at all?	
Have you noticed any changes in your feelings about sex since being diagnosed with EG/EGE?	
Does living with EG/EGE impact how you view yourself?	
Has EG/EGE affected how you see your body (e.g. sense of being defective, too thin from weight loss, weight gain from steroids, etc.)?	
Does living with EG/EGE impact your relationship with food? (harder to find things to eat, anxiety about cross-contamination, worry about food bringing on symptoms, etc.)	
Do you have any worries or concerns about your EG/EGE or its treatment(s)?	
Is there anything else you think is important for us to know about living with EG/EGE that we didn't cover?	

Table 2

Demographic and clinical characteristics of study sample

Demographic/clinical variable	(N = 7)
Male	71.4%
White	100%
Age (mean $\pm$ SD)	37.9 $\pm$ 14.5
Married or in committed relationship	85.7%
College educated	100%
Employed	85.7%
Seen a dietician for EG/EGE	100%
Seen a therapist for EG/EGE	28.6%
Current treatments *	
None	0%
Topical corticosteroids	71.4%
Montelukast	14.3%
Systemic steroids	28.6%
Clinical trial	0%
Elimination diet	42.9%
Elemental diet	28.6%
Supplemental/alternative treatments (e.g., acupuncture and OTC herbal remedies)	14.3%
Other	57.1%
Self-identified food triggers *	
Milk/diary	85.7%
Eggs	85.7%
Soy	57.1%
Wheat/gluten	71.4%
Peanuts	85.7%
Tree nuts	71.4%
Fish	57.1%
Shellfish	42.9%
Other	57.1%

* Participants could select more than one

Table 3

Representative quotations grouped by theme

Theme	Constructs	Sample quotes
Psychological impact of diagnosis	Pre-diagnostic phase	"Before I was diagnosed, if I didn't believe in God I would have committed suicide because of the pain. Because I couldn't eat anything, it caused me great pain" (34 y-old Male)
	Relief upon diagnosis	"Once I understood what it was, before that I was apprehensive. But I deal with it, I keep finding out more" (66 y-old Male) "I got the call from [name of clinician]...that this was the diagnosis and she basically answered all my questions, totally put me at ease, and got a game plan for my case in order and that's kind of what I needed" (30 y-old Female) "From a diagnosis point to going back to work, it was almost a 3 year period for me to get through the depression [and] anxiety" (37 y-old Female)
Emotional impact of diagnosis and treatment	Emotions related to food	"Side effects from medications, long term, I think is what is a worry.... So I'm just sort of wondering what is my, realistically, what is my life expectancy?" (34 y-old Male) "...It may over the long term cause certain things to happen, like I don't know, like cancer... maybe I'm at a greater risk for that. But, um, I don't worry—it's not something I constantly worry about.... I think there's a pretty even chance that something else will get me before this does (laughing)" (27 y-old Male) "You're having that anxiety kick in, that feeling that my diet has completely gone out the window" (37 y-old Female) "It can be tough sometimes to be on a strict diet and balance the urge to eat food that I know I'm not supposed to eat due to the allergies with the better feeling mentally and physically that I get from not eating it" (47 y-old Male) "Going out to dinner at first I was just terrified of it because I didn't know what types of things I couldn't eat... Now I kind of know it's okay if I could just have grilled chicken, steamed vegetables you know there are just things you kind of know to ask for at the time. So it's been a pretty decent transition" (37 y-old Female)
	Improvement over time	"People in high school didn't understand, they always just thought I was being a picky eater. And they'd always make comments about me eating the same few foods. So I mean, that bothered me at the time" (27 y-old Male) "I secluded myself at first because so much social dynamic is around food and I just couldn't—it was hard for me to say no. And then I still—a lot of friends didn't understand, I've lost friends because they just didn't understand, because I didn't understand" (34 y-old Male) "In a professional setting, it's hard to figure out, okay, do I tell them everything so they are not wondering why I'm not coming to the company lunch, or why when we ordered pizza on Friday I'm not eating it" (30 y-old Female) "I grew up in a very Midwestern home...every night you had meat for dinner...and just a tiny bit of vegetable. And now my plate is 100% vegetable. I think that's hard for them to understand" (30 y-old Female) "I come from an Italian family and food's very important...so coming from that cultural stance, that cultural aspect it was hard, it was hard for my mother to understand and even if it has a little in it, 'well it just has a little', it doesn't matter" (34 y-old Male)
Impact on social relationships	Experiences of stigma or social isolation	"So if I get invited to a dinner, this is how far I've come, in the past I would have been like paralyzed, like I can't go. But now, I go, I review the menu prior, so I'm not like, short-sighted, and everyone who is in my friend group knows I do like to do this" (30 y-old Female) "...Upon diagnosis, I was paralyzed to be in social settings...., to come here, and Chicago's a drinking city... [and] to not be able to order a drink embarrassed me...Now I feel like I have like a core group of friends that are so solid. So it doesn't affect me now" (30 y-old Female)
	Familial or cultural impact	
Improvement over time	Compensatory behavior	
	Improvement over time	

Theme	Constructs	Sample quotes
Financial impact		<p>"I'm comfortable with it. At first it was a little bit frustrating. I felt like I had to keep explaining it over and over again. But then I realized... I can understand why they don't understand" (47 y-old Male)</p> <p>"Yeah over time it gets better.... I host Thanksgiving, granted I cook up a storm because I can cook what I can eat, and then I cook for everybody else too" (34 y-old Male)</p> <p>"I think last year we paid like 10 or 12 thousand dollars in medical stuff... So the doctors' visits, and the tests, those are super expensive" (27 y-old Male)</p> <p>"Insurance does cover part of the Neocate, and you know I'll hit my deductibles every year but I also figure I'm saving money on food, on regular food (laughing). So I think that kind of balances out, or evens out" (47 y-old Male)</p> <p>"I would say I go out to dinner less than I did before I was being strict about my diet. But um, you know I never turn away, if a friend wants to meet at a restaurant I never turn that down" (47 y-old Male)</p>
	Healthcare-related costs	"I can't get a job because of this, I have already contacted, a while back, social security to try to get disability" (24 y-old Male)
	Food costs	"I didn't finish grad school because of it, because of medical bills. And just food, food is god-awful. I got a bag of groceries...just one bag and it was over 100 bucks" (34 y-old Male)
	Job or education costs	"But now I am just skin, bones and organs. I see myself as a skin-wrapped skeleton" (24 y-old Male)
	Impact on the body	<p>"I guess you're just a little more self-conscious and a lot of things trigger different emotions and it's such an emotional time for you and your spouse...you know you'll start out in a romantic moment and you'll end up bawling your eyes out because of, you know, other thoughts" (37 y-old Female)</p> <p>"I mean I do think about it and how it affects my body... but I think most people have challenges one way with their body anyway, so I don't think I'm different in that way" (47 y-old Male)</p>
Level of activity	Physical changes	<p>"I put on weight because of steroids. I'm trying to work it off, you know, it's mainly because it raises my blood pressure. And that image I don't like. I don't like being 20 lbs heavier than I should be, but besides that not too much, I don't have too many body issues, self-esteem with bodies issues" (34 y-old Male)</p> <p>"When I was transitioning to the formula I'd be up a lot at night having diarrhea. I think the depression and the worry and anxiety severely impacted my insomnia" (37 y-old Female)</p>
		"I used to do triathlons, for me right now the distance is too far. Like my biggest concern is what if I have to use the bathroom" (37 y-old Female)
		"I run. I've done triathlons since I've been diagnosed with it. It hasn't negatively affected any of that in any way" (47 y-old Male)