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Quality of Life in Pediatric Eosinophilic Esophagitis: What is Important to Patients?

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Abstract

Background and Aims—Current research outcomes in pediatric Eosinophilic Esophagitis (EoE) are directed toward histologic improvement with no attention to health-related quality of

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life (HRQOL). The primary objective of this study was to identify key patient-reported and parent proxy-outcome (PROs) elements of EoE disease-specific HRQOL.

Methods—The research team comprised clinical Allergists and Gastroenterologists with expertise in pediatric EoE as well as two Ph.D. psychologists with extensive experience in qualitative research. Focused interview techniques were adapted from the PedsQL 4.0™ methodology and the consolidated criteria for reporting qualitative research (COREQ). A semi-structured interview guide of open-ended questions was developed, and extensive review of audiotaped transcripts was performed.

Results—A total of 42 focus interviews were conducted. Child self-reports were obtained for patients in the 5-7, 8-12, and 13-18 year old age groups, and parent proxy-reports were obtained in the 2-4, 5-7, 8-12, and 13-18 year old age groups. We discovered that patients and parents often had different concerns, illustrating unique aspects of EoE-specific HRQOL that were not captured in generic HRQOL instruments. Specific themes that emerged from these interviews included, but are not limited to: feelings of being different than family and peers, diet and medication adherence, difficulties with eating food, and worry about symptoms and illness.

Conclusion—Pediatric EoE patient and parent proxy interviews revealed many EoE-specific aspects of HRQOL that are not captured in generic HRQOL instruments. Outcome measures that reflect patient and parent proxy-reported HRQOL are a critical need in pediatric EoE.

Keywords

Quality of life; Focus interviews; Eosinophilic Esophagitis; EoE; children; patient reported outcomes

Introduction

Patient-reported outcomes (PROs) are a critical component in the successful treatment of any chronic condition. Pediatric EoE has evolved over the past 30 years from isolated case reports of patients with prominent esophageal eosinophilia to a recognized clinical disorder. In 2007, the first consensus guidelines defined EoE as an isolated esophagitis with a predominance of eosinophils on endoscopic tissue biopsy, which does not respond to acid suppression therapy and includes upper GI tract symptoms (Furuta *et al.* 2007). In current practice, clinical outcomes in EoE are directed toward histologic and symptomatic improvement with little or no attention to health-related quality of life (HRQOL). Outcome measures that reflect patient and parent proxy-reported concerns would provide valuable information regarding the efficacy of treatment strategies utilized for children with Eosinophilic Esophagitis (EoE).

In an effort to improve patient health and well-being, as well as to determine the value of healthcare services, there has been a significant increase in the development and utilization of pediatric HRQOL measures over the past 10 years (Matza *et al.* 2004, Varni *et al.* 2005). As an initial investigation into the HRQOL of children with eosinophilic gastrointestinal disorders (EGID), we recently utilized the Pediatric Quality of Life Inventory™ (PedsQL™) 4.0 Generic Core Scales to investigate generic HRQOL in pediatric patients across several pediatric chronic conditions, as well as in comparison to healthy controls (Ingerski *et al.*

2010). In addition to demonstrating significantly impaired generic HRQOL from the perspective of both the patients and their parents when compared to healthy controls, patients with EGID had a decreased HRQOL when compared to children with obesity, inflammatory bowel disease, epilepsy, type 1 diabetes, sickle cell disease (SCD), post-renal transplantation, and cystic fibrosis.

In addition to the PedsQL™ 4.0 Generic Core Scales, Varni and colleagues have developed numerous disease-specific modules to be used in conjunction with the generic core scales, including: asthma, cerebral palsy, cancer, diabetes, cardiac disease, end stage renal disease, and rheumatology (Varni *et al.* 2004, Varni *et al.* 2006, Varni *et al.* 2002a, Varni *et al.* 2008, Berkes *et al.* 2010, Goldstein *et al.* 2009, Varni *et al.* 2002b). Disease-specific measures may enhance measurement sensitivity for health domains germane to a particular chronic condition (Patrick and Deyo 1989, Varni *et al.* 1999). Currently, there are no validated and reliable measurement instruments for EoE-specific HRQOL outcomes. Studies that specifically address patient-reported measurement of EoE-specific HRQOL are urgently needed and would address an important gap in the literature on pediatric patients with EoE. Consequently, the primary objective of this study was to conduct focus interviews of pediatric patients with EOE and their parents to identify the key EoE disease specific HRQOL concerns.

Methods

Participants

Participants were identified from local and referral populations at Cincinnati Children's Hospital Medical Center (CCHMC). Informed consent was obtained from each parent and patient assent was obtained for children eleven years of age or older. The study protocol conformed to the ethical guidelines of the 1975 Declaration of Helsinki and was approved by our Institutional Review Board. Pediatric patient participants were restricted to those with a confirmed diagnosis of EoE and the presence of upper gastrointestinal (GI) symptoms. Patients were treated with currently established therapies consisting of dietary restriction or topical steroids. We felt that it was critical to assess patients' and their families' concerns that were specific to EoE, not those related to other co-morbidities. Therefore, we excluded all patients with additional diagnoses that included: Inflammatory Bowel Disease, Celiac disease, a psychiatric disorder and/or therapy with psychiatric medication, eosinophilic gastritis, eosinophilic enteritis, eosinophilic colitis, eosinophilic gastroenteritis, or eosinophilic enteropathy.

Using previously-established sample size estimates and age groups for disease-specific instrument development focus interviews, we recruited a total of 42 subjects that included parents for each child age range (Ages 2-4, 5-7, 8-12, 13-18) and pediatric patients for each of the 5-7, 8-12, and 13-18 years of age groups (Kruger *et al.* 1994, Morgan *et al.* 1993, Sudman *et al.* 1996, Varni *et al.* 2005, Varni *et al.* 2007, Varni *et al.* 2009, Walsh *et al.* 2008, Tong *et al.* 2007). Gift cards were provided to children and adult participants in the amount of \$15 upon completion of interviews.

Procedures

The methodologies for focus interviews and instrument development qualitative research have been described previously by Varni and colleagues (Walsh *et al.* 2008, Goldstein *et al.* 2008). The research team comprised experts in the field of EoE, including specialty physicians in the fields of Allergy and Gastroenterology. In addition, there were two Ph.D. psychologists with specific expertise in qualitative research methodologies. All interviewers were trained by an experienced qualitative researcher and provided with a semi-structured interview guide of open-ended questions. *A priori* domains of food and eating, symptoms, activities and school, treatment, worry, and communication were developed based on the existing literature and the experience of the research team. The hypothesized EoE-specific HRQOL domains were distinct from the generic Peds QL 4.0™ domains and are summarized in Table 1.

Open-ended interviews lasted between one and a half to two hours. Interviewers were directed to remain neutral and non-evaluative, while ensuring that participants were continuing to address targeted questions. Children ages 8-18 year olds were interviewed separately from their parent. Parents were present for the 5-7 year old interviews but the interviewer asked the child questions to gather his/her thoughts without the parent's input. After, the interviewer asked the parents their opinion on what the child reported. The specific open-ended questions utilized for the Focus Interviews are listed in Table 2.

Data Analysis

All sessions were audio-recorded, transcribed verbatim, and analyzed by the lead investigator and the research team. Responses were grouped according to open-ended questions, domains of interest, and age ranges. Parent proxy responses were compared to patient responses. Once data was sorted around *a priori* domains and common themes it was reviewed by the research team. Common domain themes were elicited when two or more participants described a particular concern or issue. Content and themes were then derived by consensus among the research team. Disagreements were resolved by further discussion. The focus interviews were terminated when theme saturation was achieved.

Results

There were a total of 70 eligible patients screened of which 24 parents and 18 children agreed to participate. The demographics of the participating children were 88% Caucasian and 50% male. We discovered that the importance of asking not only the parents of patients, but also the children themselves, cannot be overemphasized. Often their concerns were different and reflected different aspects of disease-specific HRQOL. For each of the specific domains, general themes were identified and are detailed below, with specific representative patient and parent by proxy direct quotations summarized in Table 3.

Food & Eating Domain

Children with EoE and their parents had many concerns regarding how EoE affects their disease-specific HRQOL in the domain of food and eating. They expressed concern about the social impact of not being able to eat what both their peers and other family members

could eat. In addition, children and their families described the difficulties of restricted diets, and at times, of not adhering to their dietary restrictions. Social issues centering on feelings of being different than peers and adhering to specific dietary restrictions were much more apparent in children in the 8-12 and 13-18 year old groups.

Symptoms Domain

Emerging as common themes, children with EoE often had concerns about pain in their chest or abdomen, nausea, vomiting, feeling unwell with eating, having trouble swallowing, and difficulties eating or maintaining weight. Children with EoE frequently talked about how pain, nausea, or vomiting might be associated with certain foods and not improved with their current medication, or both. For the toddlers (ages 2-4) and young children (ages 5-7), parents' concerns often focused around challenges with feeding and not eating enough. In the older age groups, abdominal pain, chest pain, and dysphagia were the most important symptoms. Of interest, children with dysphagia described this in several different ways, including: trouble with swallowing, having to drink more liquids when swallowing foods, avoiding particular foods because they were afraid these foods would get stuck, and taking a longer time to eat than their friends and family.

Activities and School Domain

Common themes emerged including: being able to participate in the same activities as their friends, a sense of fatigue, having trouble in school, difficulty with school work, and missing school. In addition, many participants felt that their EoE made them different from many of their peers because many social activities are often centered on food. Some children and teens also expressed that their peers teased them as a result of their EoE. Parent of young children expressed being different at social functions such as birthday parties where their child could not eat birthday cake because of their diet restrictions.

Treatment Domain

Regarding treatments, a variety of responses emerged. In addition to dietary restrictions, medication regimens and feeding tubes are common treatments for EoE. Frequent trips to the hospital or physician's office are also common. It became clear that children and their families had distinctly different perceptions of their diet restrictions or use of medications. Parents of young children were often worried about going to the doctor or hospital out of concern for how their child would react to the medical encounter. Although being a picky eater or not wanting to take medication were concerns, actual adherence to diet restrictions or medications for the young children themselves was not a significant issue because the parents were in control of these respective restrictions or administrations. Teenagers often spoke of forgetting to take their medications or cheating with their diet.

Feelings Domain

Second only to the food and eating domain, worry was a big component from both the patient and parent perspective. In addition to immediate concerns about eating and visiting the doctor, among teens and all parent groups, there were also general stresses regarding long-term medication usage and being different than their family or peers. Teens in

particular were concerned about how they would be able to adhere to their diet or medications. A concern frequent expressed by parents in of children ages 2-4 and 5-7 as well as some other parents and teens was how EoE would affect their child or them in the future. Several participants expressed worry about getting sick or vomiting in front of others.

Communication Domain

There was a wide range of responses for many subjects regarding communication. Some did not have any trouble communicating, while others had explicit and implied concerns in this area. These concerns centered on talking to friends, family, and care providers about their health concerns and needs. Children and teens also found it difficult to explain EoE to others. Parents of young children expressed difficulty in knowing when their children were having concerns.

Discussion

EoE is a condition without any known risk of malignancy or reduced life expectancy, and therefore HRQOL needs to be a primary outcome in determining the success of both current and new therapies. By implementing a qualitative approach to patients with EoE, we have identified disease-specific domains deemed important to patients and their parents. The domains of food and eating, symptoms, activities and school, worry, treatment, and communication are unique disease-specific quality of life domains that will be critical to the development of a validated and reliable EoE-specific HRQOL measurement instrument. Our results highlight the impact of EoE beyond the esophageal mucosa, and we suggest that the appropriate assessment of HRQOL is an important consideration for future clinical trials conducted in children with EoE.

The concept of patient- and family-focused outcomes has become an active area of investigation across all disease states. Care providers who treat families with EoE are keenly aware of the potential disease complications and symptoms that patients can develop. However, it is the patients who are best suited to speak to the impact of this condition on their HRQOL.

During our focus interviews, several important themes became readily apparent that might have otherwise been missed. Prior to beginning our individual interviews, we debated the use of focus groups versus focus interviews. Given our experience with prior support groups and EoE educational meetings, we were concerned that the diversity of patient and parent concerns and symptoms might not be fully elicited in a larger group setting. Based on our prior qualitative research experience, our group decided on the focus interview technique to allow more individual feedback and avoid consensus effects on data integrity. The open-ended questions gave patients and their families an opportunity to explain in their own words opinions and concerns regarding the impact of EoE on their family. In addition, we were able to develop patient-centered vocabulary and thinking patterns that will allow us to generate items for the next step in instrument development.

Our future goal is to develop an EoE-specific HRQOL measurement instrument that has undergone rigorous qualitative and quantitative testing for instrument reliability, validity,

and responsiveness. We anticipate that this new HRQOL instrument will address the identified gap in the empirical literature on pediatric EoE, as well as address the urgent need to assess the HRQOL of children with EoE in future clinical trials. As care providers, it is always important to remember that health is “a dynamic state of complete physical, mental, spiritual and social well-being and not merely the absence of disease and infirmity” (Grad 2002).

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Key Messages

1. Pediatric EoE-specific aspects of Health Related Quality of Life (HRQOL) are not captured in generic HRQOL instruments
2. Outcome measures that reflect patient and parent proxy-reported HRQOL are a critical need in pediatric EoE
3. Patients and parents often have different EoE-specific HRQOL concerns
4. Pediatric EoE-specific HRQOL outcome measures need to be a primary determinant of successful EoE therapies

Table 1

A Comparison of the PedsQL and EoE-Specific Domains

PedsQL Generic Domains	EoE-Specific Domains
Health and Activities	Food & Eating
Feelings	Symptoms
Peer Interactions	Activities & School
School	Treatment
	Worry
	Communication

The generic PedsQL does not encompass the specific health-related quality of life aspects that are important to patients and their families with EoE.

Table 2**Focus Interview Questions**

<u>General</u>	<u>Treatment</u>
What do you think is your child's (your) biggest concern (stress) about his or her (your) health with EE? Why?	Is taking medication (medicine) or dietary restriction (not eating foods) a problem for your child (tough for you)? How? Explain.
	Is it hard or easy for your child (you) to take their (your) medication? Why?
	Is it hard or easy for your child (you) to limit or restrict their (your) diet (to not eat some foods)? Why?
	Is there anything about your child's (your) current treatment (medicine or diet) plan that bothers them (you)?
	What parts, if any, of your child's (your) treatment (medicines) do you think bothers your child (you) the most?
<u>Food & Eating</u>	<u>Feelings</u>
How does your child (you) feel about the food they (you) eat? Their (your) meals?	What kinds of things does (do) your child (you) worry about? Related to EE?
Can your child (you) eat the things they (you) want to?	Do you think he/she (you) worry about taking medications (medicines)? Diet (not eating some foods)? Going to the doctor? Getting tests done?
How does your child's (your) health with EE affect how s/he (you) eats (eat)?	
How does it make them (you) feel when their (your) friends or family can eat things they (you) can't?	How do you think your child feels (how do you feel) about how s/he (you) eats (eat)? EE? Medications?
<u>Symptoms</u>	<u>Communication</u>
What symptoms does your child (you) relate to EE?	Do you think your child (you) can communicate (talk about) their worries (stressors) to you (your parents, friends, doctors, nurses, others)?
What is the most frequent symptom? How often does this occur?	
What is the worse symptom? How often does this occur?	Is there someone your child (you) feels comfortable telling their (your) worries to?
What trouble does your child (you) about eating food?	Is your child (are you) able to tell someone if they (you) think they (you) need to see a doctor?
How often do you call your child's (your) doctor? For What?	How do you know when your child (you) needs (need) medical attention (to see a doctor or go to the hospital)?
How does EE affect the kind of pain your child has? (Do you have pain because of EE)?	
<u>Activities & School</u>	<u>Miscellaneous</u>
How does EE affect your child's (your) activities? School? Playgroups? Family? Friends?	Is there anything else that is important to you about your child (you) having EE?
Can your child (you) do the things that they (you) want to do? If not, why? How is this related to EE?	Is there anything else about your child's (your) health that is important?
	Any additional comments? Anything else that you would like to share?

Open ended questions asked to parents of children with EoE (ages 2-18), and separately to children and teens (ages 5-18) during focus interview sessions.

Table 3

Focus Interview Representative Quotations Reflecting Common Themes

Domain	Patients (5-18)	Parent Proxy (2-18)
General	"It's very difficult to live with. It takes a lot of adapting." "I can't really eat the things that I want"	"His quality of life has been sad... I mean you have a little 3-year-old dancing to the music of an ice cream truck and can't have it... It's hard for him to go to birthday parties because there is food."
Food & Eating	"If I go out, half the stuff there I can't eat."	"It was a big deal when snacks would come into preschool he could not have it"
Symptoms	"I got nauseous and I ended up throwing up" "Food gets stuck once in a while."	"stomachaches" "Her appetite was not good" "Burning in chest"
Activities & School	"It went to where I just could not even get up for work because I was throwing up before work." "Missing so much school almost caused [me] to fail."	"Having to sit at the allergy table at school... You have to sit at your own table with mixed grades, 2 to 3 kids from each grade level"
Treatment	"I'm forgetful so I probably take it about a quarter of what I'm supposed to." "The process of figuring out what you can and can't eat. You get to trial so many foods and then you get a scope and if it's bad they don't know what foods did it. So they have to take all your food away."	"getting my child to take Pulmicort® without food and drink afterward was very difficult." "He had to get the NG tube, and it was a big problem at first."
Feelings	"[worrying about] throwing up at someone else's house." "[waking] up and [worrying whether I'm] going to have an attack." "[thinking that] if I eat this is this gonna make my belly hurt."	"He worries about having reactions." "He worries about birthday cake" "[He worries] about having his scope done."
Communication	"It's kind of hard to tell what kind of sick it is."	"He is not very good about understanding his own [symptoms]."

From 42 interviews that were conducted with patients ages 5-12 and parents of patients ages 2-18 common themes emerged that are reflected in these patient and family quotations.