

Perspectives Of Patients And Caregivers On The Use Of Elemental Formula For Eosinophilic Gastrointestinal Disease

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ABSTRACT

INTRODUCTION: Patients with eosinophilic gastrointestinal disease (EGID) frequently require elemental formula (EF) as a nutritional supplement or as part of their therapy.

HYPOTHESIS: The goal of this study was to identify perspectives of patients/caregivers on EF use.

METHODS: An online survey was administered to EGID patients prescribed EF or their caregivers. Data collected included demographics, indications for EF, duration of use, potential benefits, cost, and quality of life.

RESULTS: Data from 207 respondents were analyzed. Mean age of EGID patients was 14.0 years (range 1-61). 79.2% had eosinophilic esophagitis. 85.0% were on dietary therapy, 45.4% on corticosteroids, 45.4% on proton pump inhibitors. 48.3% had been using EF for ≥5 years, 46.4% for full nutrition. 43.5% received EF via feeding tube (fully/in combination with oral feeds). Most common reported EF benefits were ease of digestion (51.2%), decreased pain/inflammation (18.8%), and meeting nutritional needs (15.9%), with high rate of satisfaction with its benefits (mean score 4.2, scale 1-5). Overall experience with taking EF was variable. EF had the most positive impact on patients' relationships with parents (34.3%) and the most negative impact on travel (60.9%). 36.7% stopped EF for some time or missed/skipped feeds, with resultant weight loss (29.0%) and incomplete nutrition (21.1%). Most common barriers to accessing EF were insurance coverage problems (68.8%) and out-of-pocket cost (67.3%).

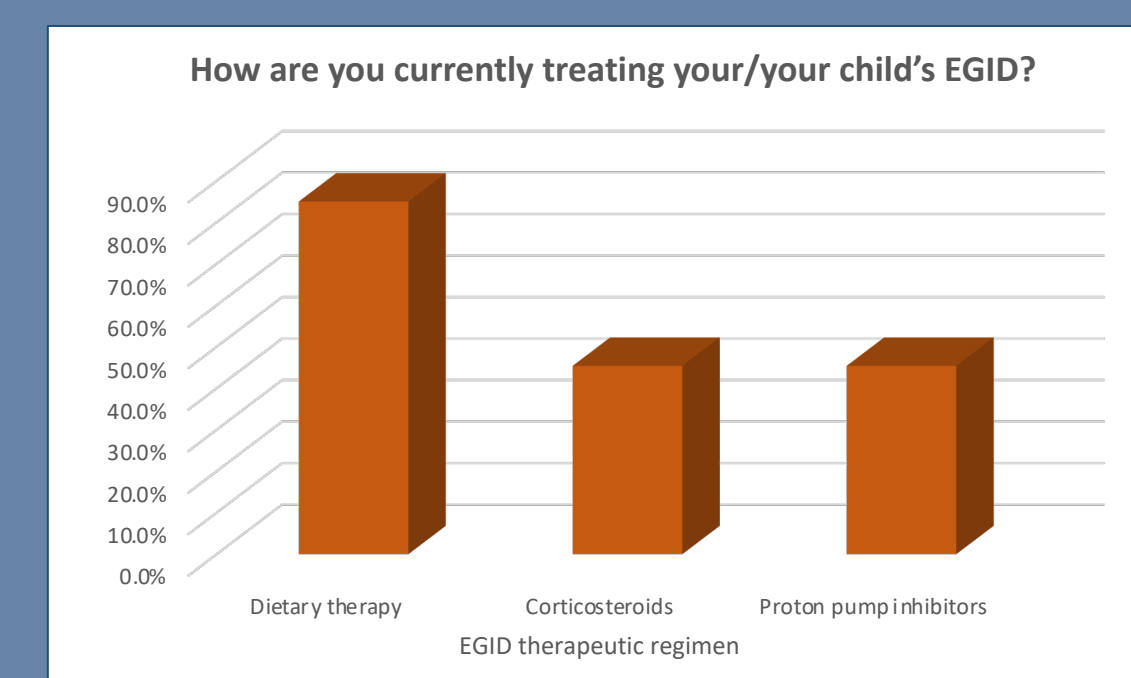
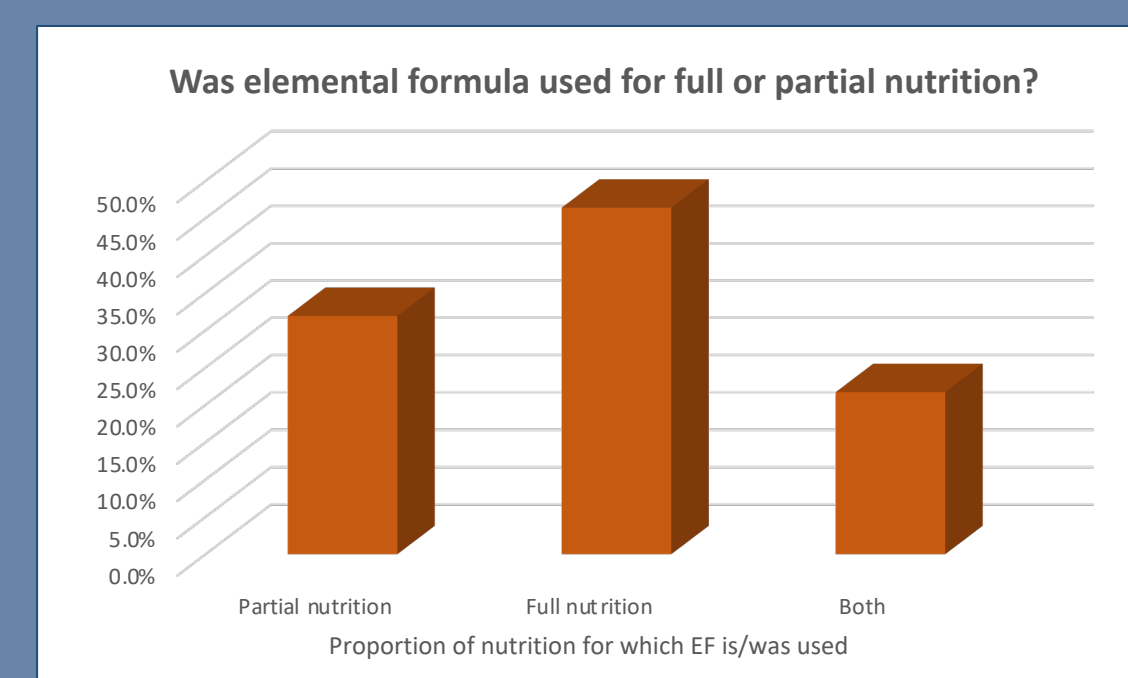
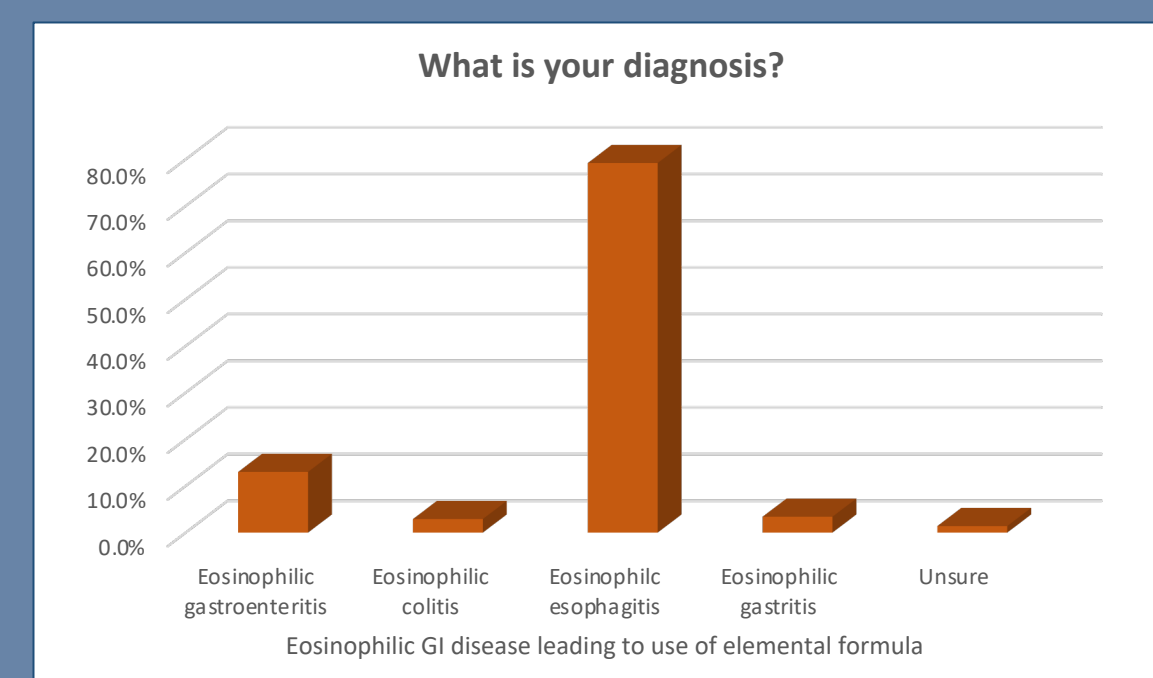
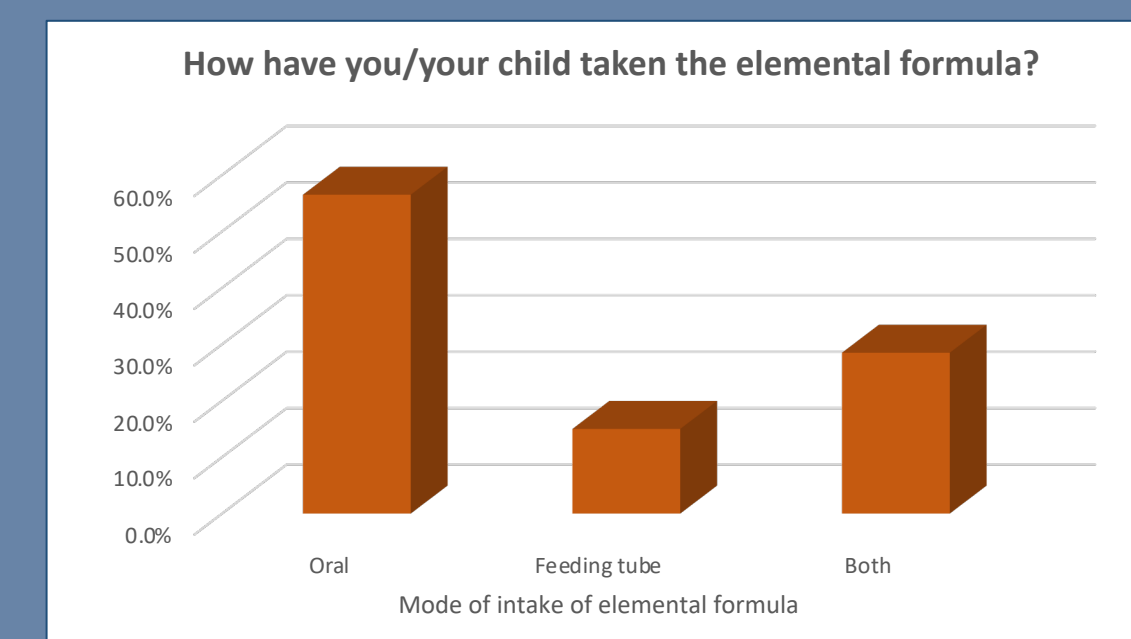
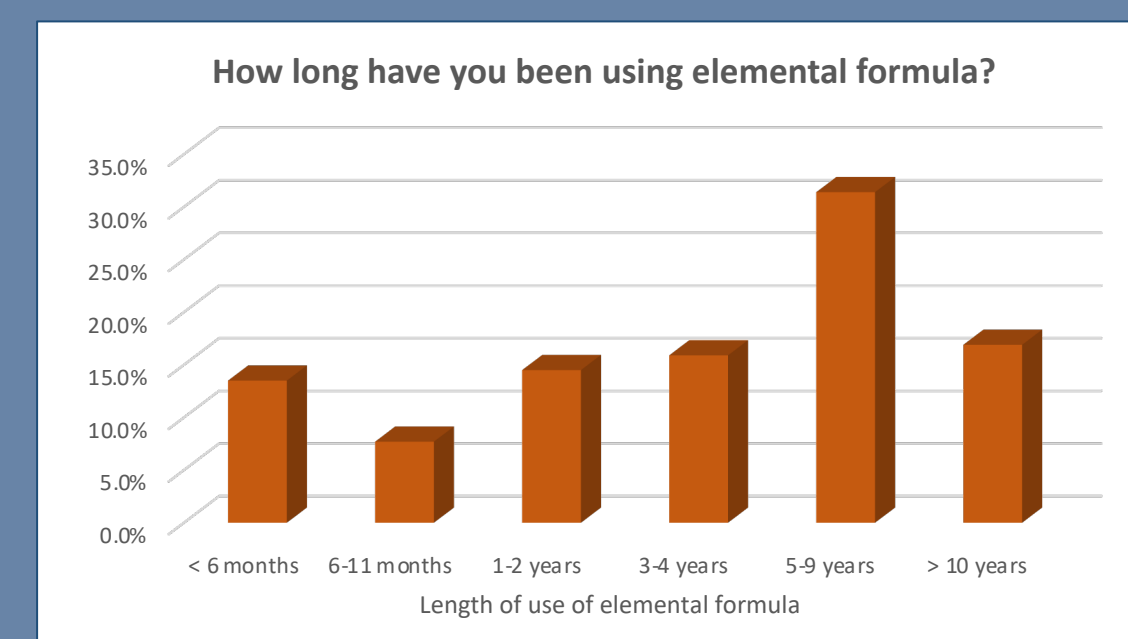
CONCLUSIONS:EF is a mainstay nutritional supplement in the management of EGID patients. EF is medically beneficial but costly to families, with detrimental consequences when interrupted. Ways to improve access to EF need to be addressed in the future.

INTRODUCTION

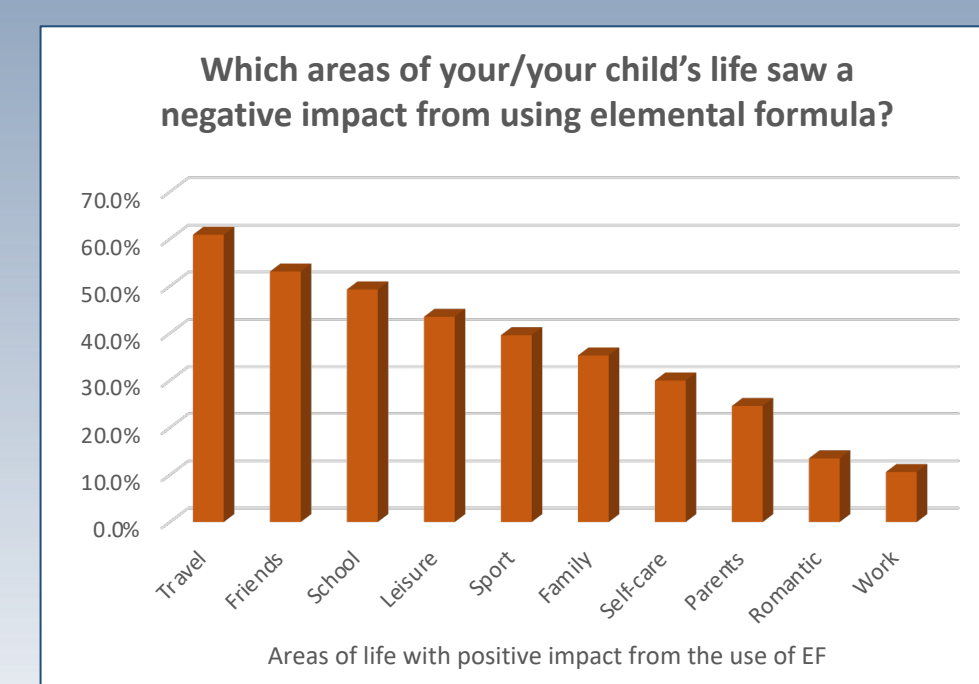
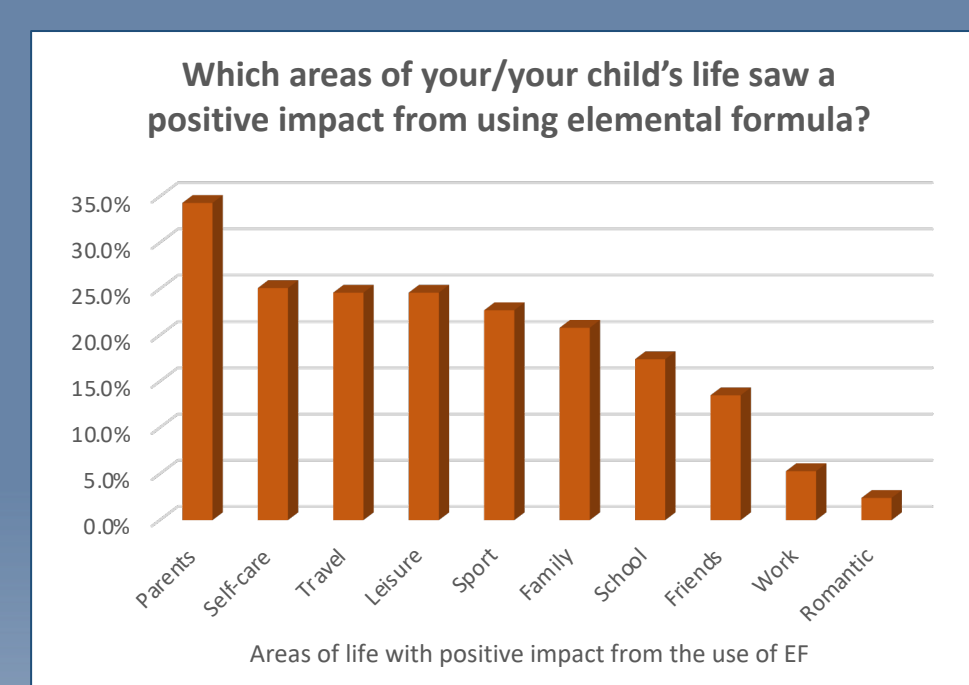
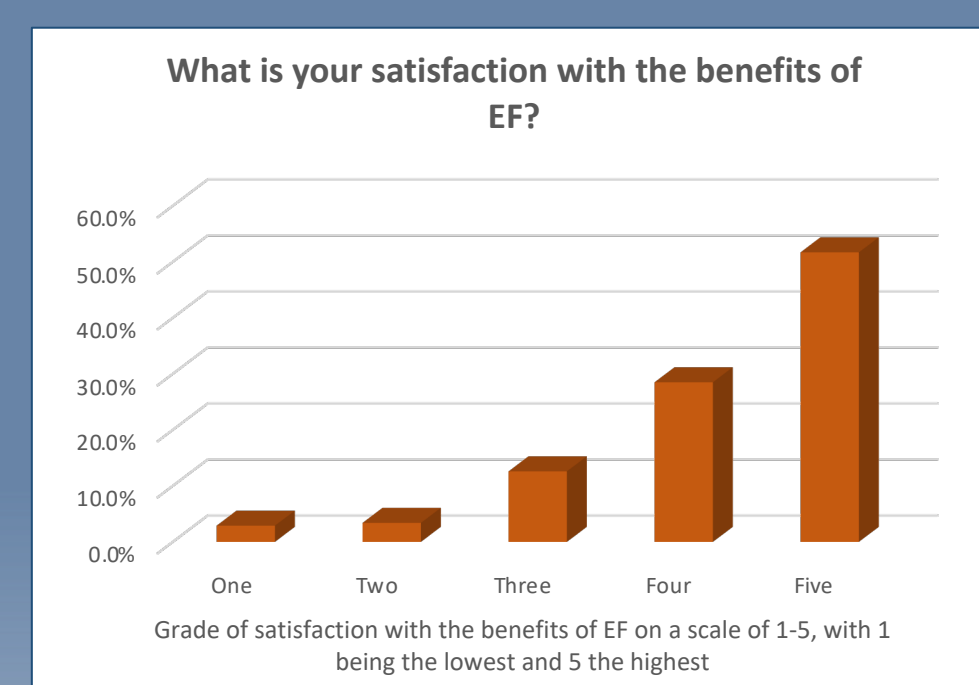
- Eosinophilic gastrointestinal disease (EGID) has a range of presentations that can affect any part of the gastrointestinal tract, with the infiltration of eosinophils in those different areas associated to degrees of inflammation that can be quite severe
- EGID patients frequently require the use of elemental formula (EF), either as a nutritional supplement or as a part of their therapeutic management
- Access to elemental formula for those in need may face several barriers, from costs, to insurance coverage, to impacts in the quality of life
- In this study we attempted to identify, through an online survey, the perspective of EGID patients that were prescribed EF, or their caregivers, regarding the use of elemental formula

RESULTS

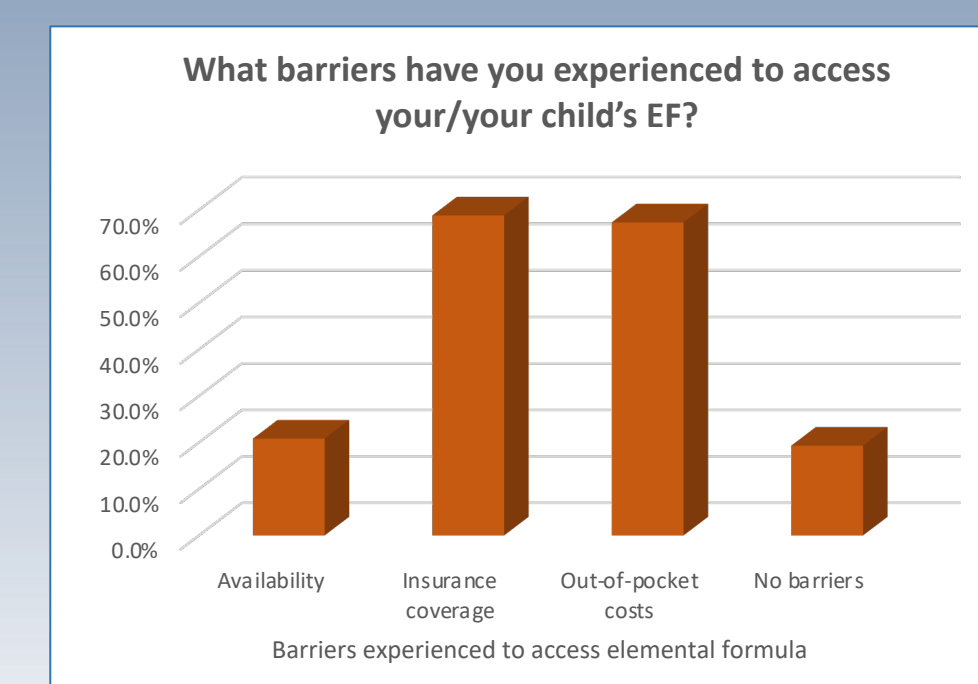
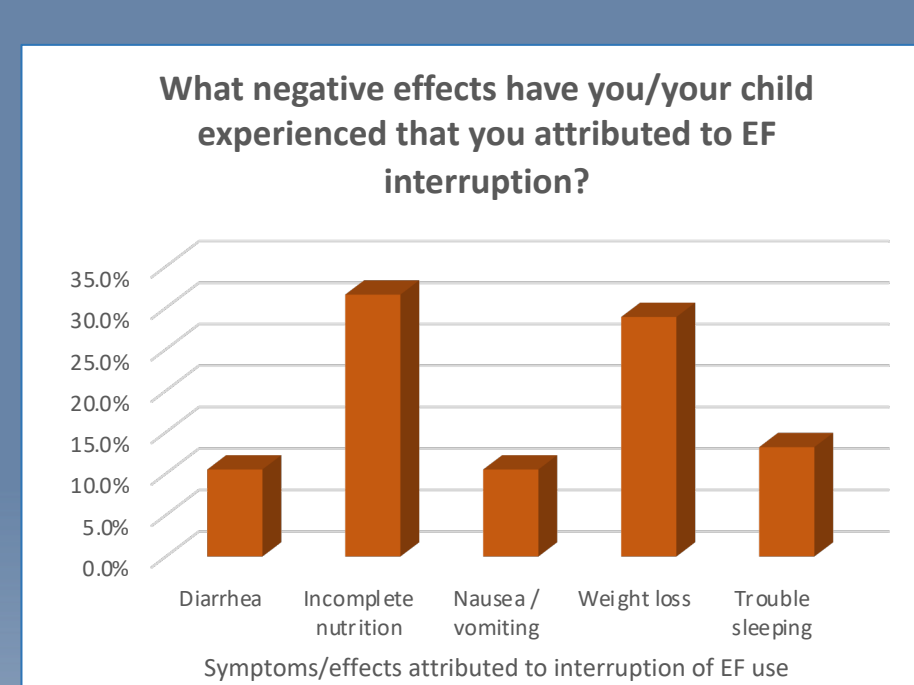
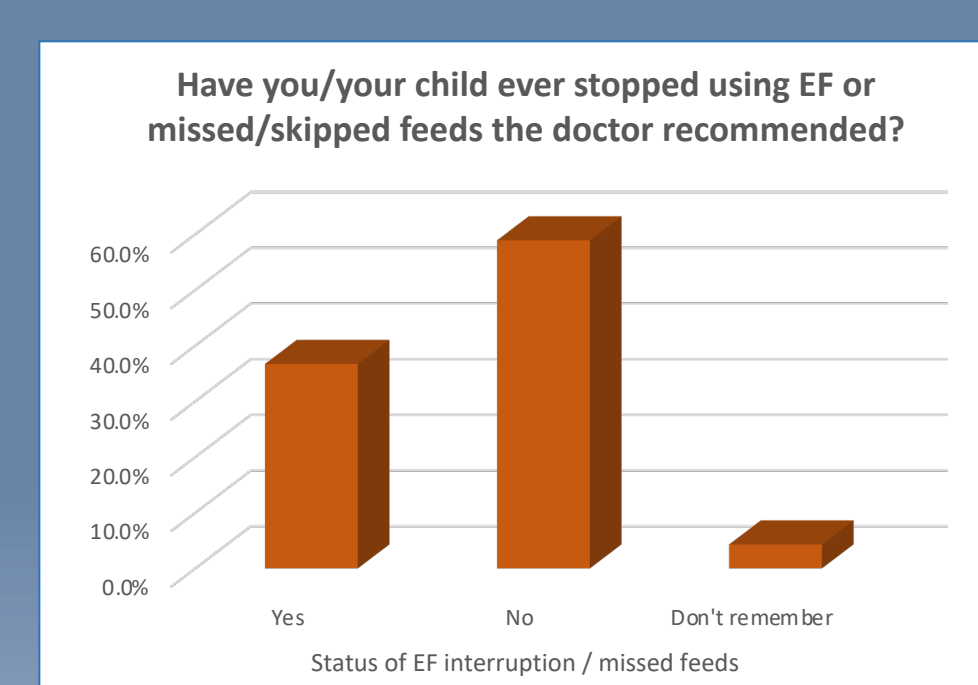
Survey demographics	
Respondents	207
Age (mean, years-old)	14
Age (range, years-old)	1-61



Wide age range of respondents to the survey, with a mean age of 14 years-old. Nearly half of the respondents have used EF for more than 5 years and also nearly half of them have used for full nutrition, with a high frequency of dietary therapy (85.0%).



The majority of the respondents were satisfied or very satisfied with the benefits of EF. Relationship with parents, self-care and travel were the most reported positive impacts, while impacts on travel, relationship with friends, and school were the most reported as negative impacts.



More than one-third of the respondents (36.7%) stopped their EF for some time, with several reported negative effects, incomplete nutrition and weight loss the most common. Lack of insurance coverage and out-of-pocket costs are the most reported barriers to access EF.

METHODS

- An online survey was administered to EGID patients prescribed elemental formula or their caregivers
- Data was collected including demographics, indications for EF, duration of use, potential benefits, cost, and quality of life
- Data was organized through Microsoft® Excel and analyzed using IBM® SPSS Statistics

DISCUSSION

ELEMENTAL FORMULA AS A MAINSTAY OF NUTRITION FOR EGID PATIENTS

- The current work analyzed the perspectives of EGID patients who were prescribed EF or their caregivers, showing, amongst other things, that EF is medically beneficial, but costly to families, with detrimental consequences when interrupted
- The surveyed group has large experience in EF use (more than 5 years for nearly half of them) and with a clear need (nearly half using it as a form of full nutrition)

SATISFACTION WITH ELEMENTAL FORMULA

- There was a high rate of satisfaction with the benefits of EF (a mean score of 4.2 in a scale of 1-5), with percept benefits impacting quality of life (easy digestibility, decreased pain and inflammation), but also critical goals such as meeting nutritional needs

EXPERIENCE WITH ELEMENTAL FORMULA

- The overall experience with taking EF itself was more variable and dependent on individual patient perception, with the most positive impacts described on the relationship of the patients with their parents and the most negative impacts of using EF related to its impact on travel
- The variable character is reflected on travel being also reported as the third most common positive impact (likely due to portability), while its negative character may depend on the extra arrangements related with carrying EF while traveling
- Additional studies will help refine additional reasons for patient and caregiver perceptions of the significant positive and negative impacts of EF on different areas of their life

ELEMENTAL FORMULA INTERRUPTION AND BARRIERS TO ACCESS

- Almost 40% of the group had to interrupt EF or skip feeds at some point, with patients reporting weight loss and inability to fulfill nutrition needs as a result, a concerning feature, with insurance coverage and out-of-pocket costs listed by nearly 70% as a barrier to access
- Ways to improve access to EF need to be addressed in the future

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