

Feeding Issues: An Under-Recognized Complication in People with Hyperinsulinism



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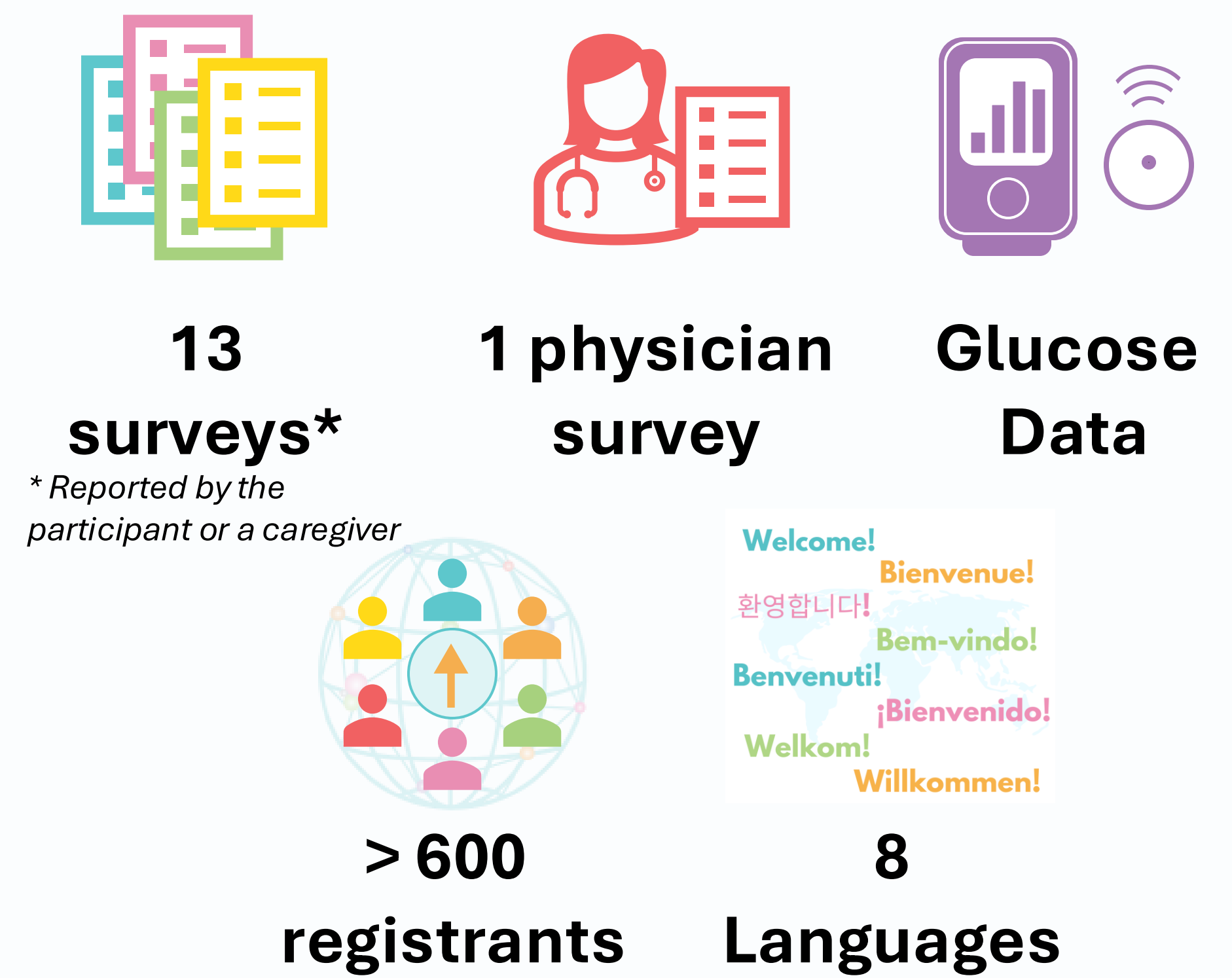
Congenital Hyperinsulinism International,
Glen Ridge, New Jersey, USA



INTRODUCTION & METHODS

- Congenital Hyperinsulinism (HI) is the most common cause of persistent hypoglycemia in newborns and children.
- In HI, dysregulated pancreatic beta-cells produce too much insulin, leading to severe hypoglycemia and, in many cases, irreversible neurological damage.
- An under-studied and under-recognized feature of HI is **feeding issues**.
- This study's aim was to characterize the presence of feeding issues in individuals with HI and the impact on their families.

The HI Global Registry (HIGR) is the only international patient-powered registry for people with HI.



People with HI (18+ years) or their parent/caregiver consented to participate in HIGR

N = 246 Respondents completed the Diet & Feeding survey

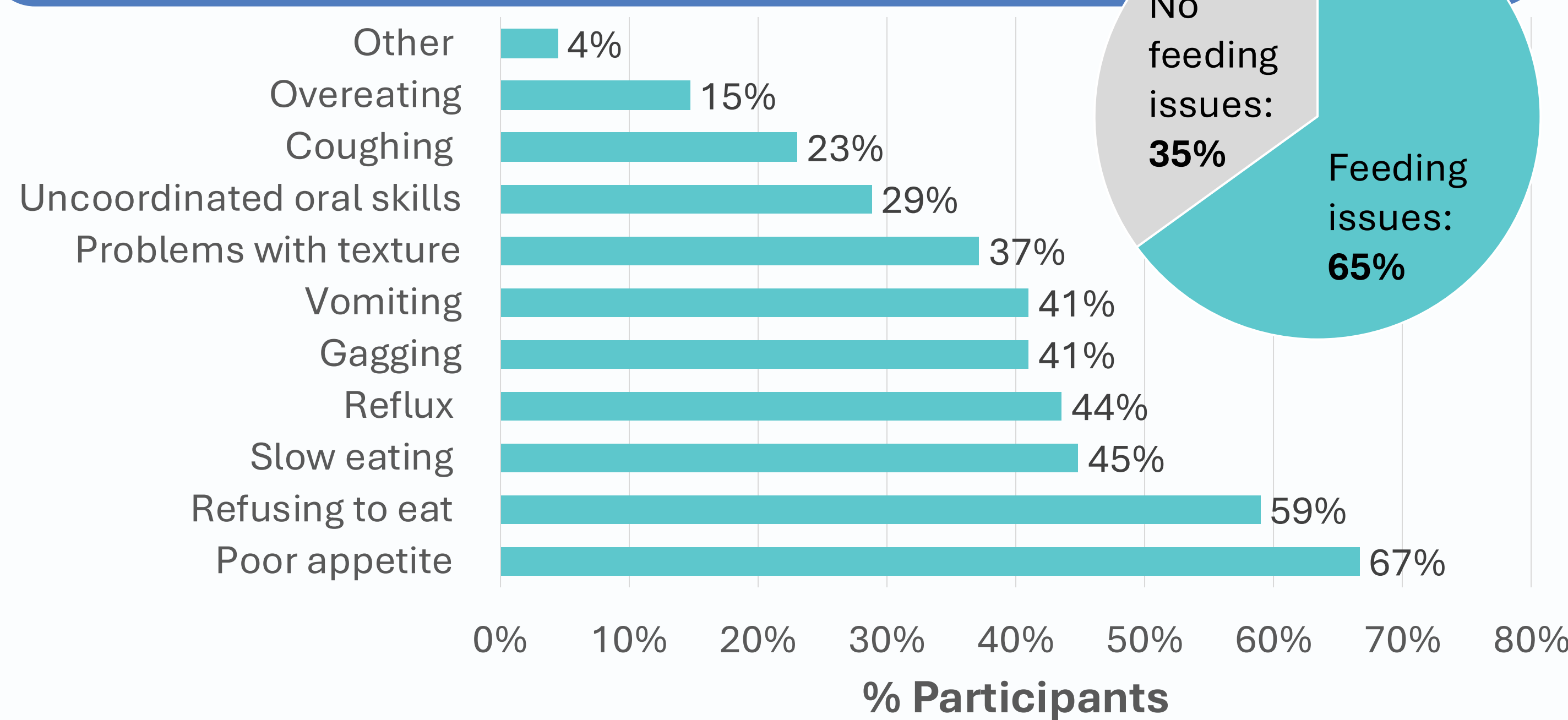
Categorical data reported using descriptive statistics

RESULTS

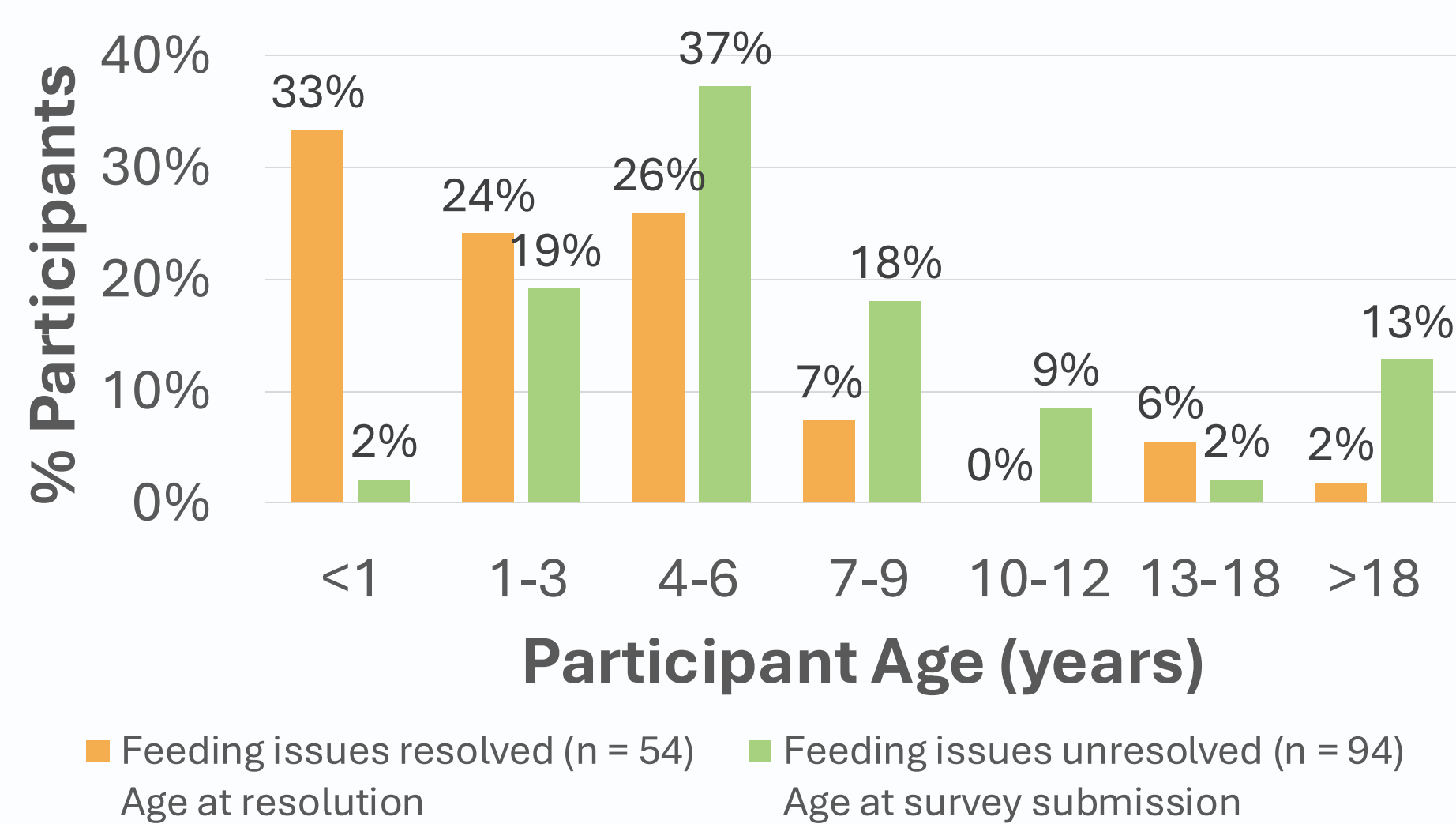
Of 246 people with HI, 65% reported experiencing feeding issues

"[NAME] has severe eating aversions and as such has an extremely limited/ very poor diet - largely ignored by all professionals as long as his blood sugar levels remain manageable."

- Parent of a child with HI



63% reported feeding issues had not fully resolved, and 41% of those individuals were 7 years or older.



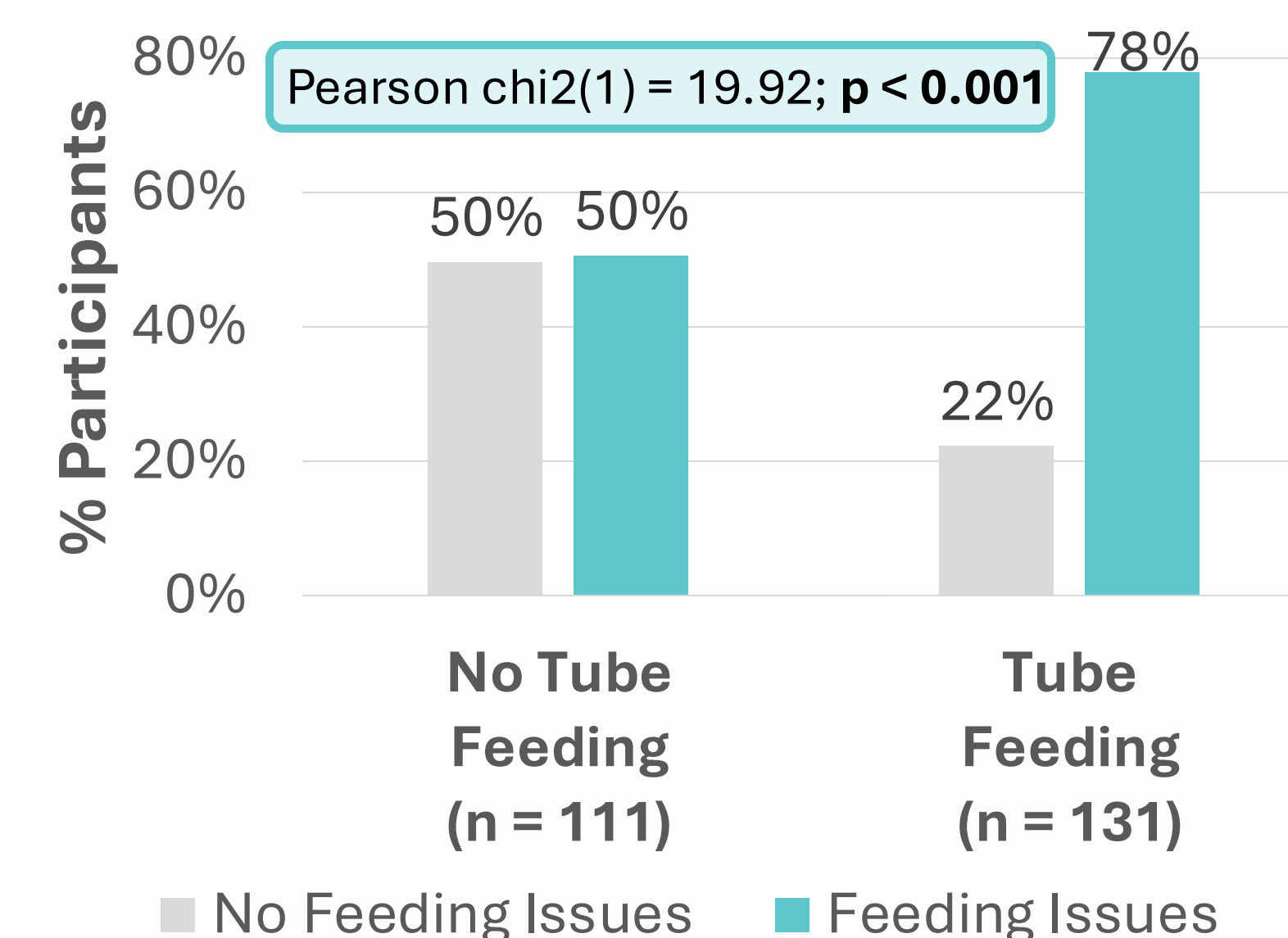
"Learning to eat was a very long and (mentally) painful process. It took 9 years before I could eat solids. It impacted my social life and self-esteem in a negative way."

- Adult with HI

Individuals who reported tube feeding were more likely to have experienced feeding issues than those who did not use tube feeding

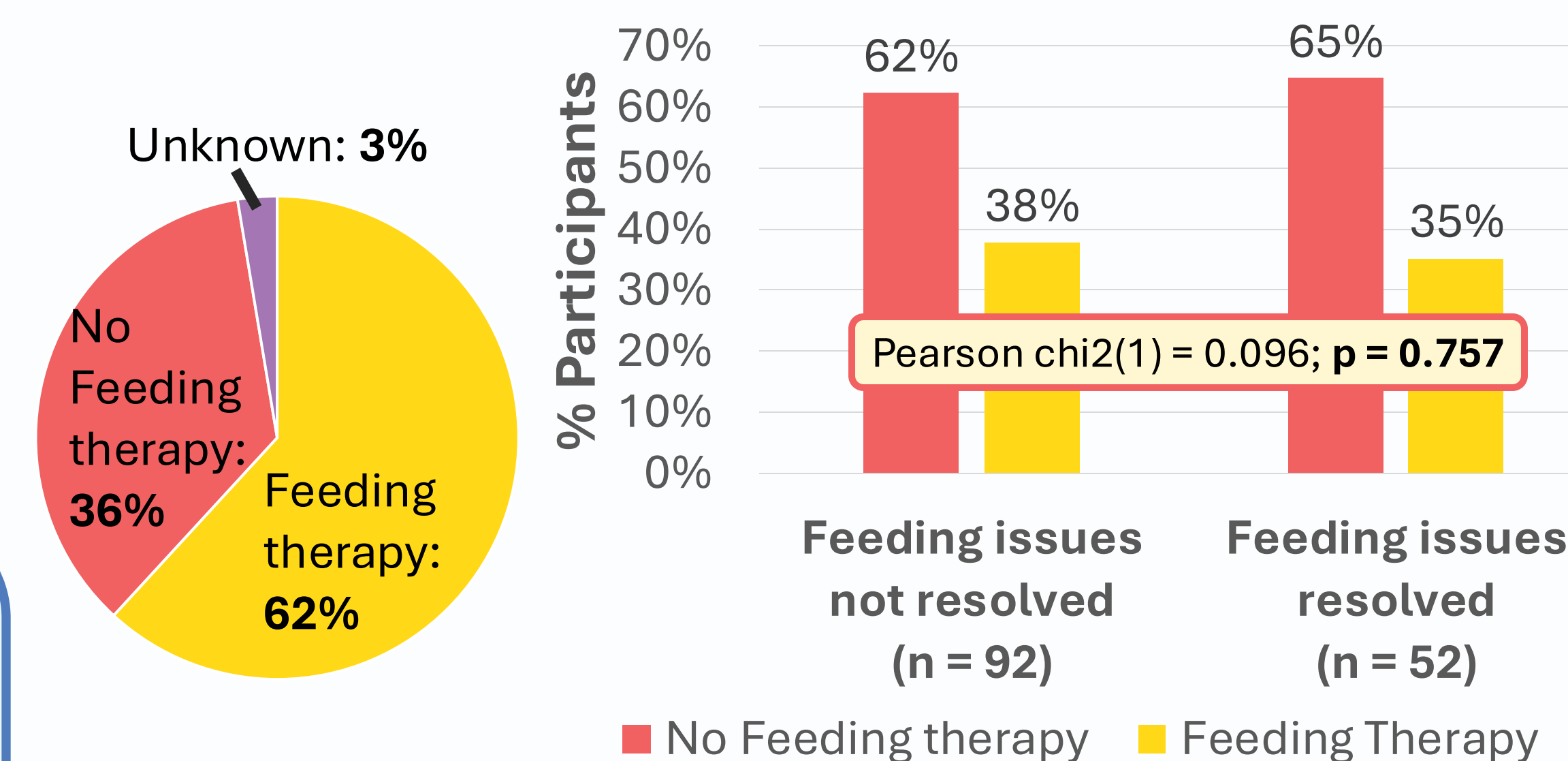
"Speech and Language therapists felt they were unable to help ... due to having heard that HI babies are 'poor feeders' and discharged with no resolution because patient was not aspiring so left to continue using NG [nasogastric tube] indefinitely."

- Parent of a child with HI



Amongst HIGR participants, feeding therapy did not have a significant impact on whether feeding issues resolved*.

* However, note that details such as the type or duration of feeding therapy were not collected in this survey.



"Every time that we go with the feeding therapy they said they don't see a problem with the way that he eats; that the poor appetite looks more like a GI problem that cause him get full faster or loss of appetite."

- Parent of a child with HI

"When we realized that our anxiety was affecting his relationship with food ... we embarked on a psychological journey to cope with the illness and therapy management. As we eased the pressure on him, his relationship with food gradually improved."

- Parent of a child with HI [translated from Italian]

DISCUSSION

Feeding issues are poorly understood within the context of HI. It is unknown exactly what leads to feeding issues, although factors such as direct pathophysiology of HI, the effects of HI medications, and the psychological impacts of the heightened importance of feeding and over-feeding to prevent hypoglycemia may play a role. Many individuals with HI and their caregivers feel that feeding issues represent a major gap in the clinical management of HI. **More research into the causes of feeding issues and the most effective therapies for people with HI are urgently needed.**

"Management of feeding issues is something which I feel is horrendously lacking in HI and lack of attention and mismanagement has caused my son far more difficulties and trauma than should have needed to be the case. This continues on a daily basis."

- Parent of a child with HI

"With the prevalence of feeding problems in HI kids documented I feel there needs to be more education of endocrinologist and that feeding therapy should be part of the treatment plan when the patient is discharged from hospital."

- Parent of a child with HI

Learn more about the HI Global Registry!

The authors would like to thank the patients and caregivers for their contribution to HIGR and the HIGR Steering Committee for their guidance.

