DIABETES AND GLYCEMIC OUTCOMES AFTER PANCREATECTOMY FOR DIFFUSE CONGENITAL HYPERINSULINISM

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INTRODUCTION

- **Congenital Hyperinsulinism (HI) is a rare life-threatening condition that results in severe hypoglycemia and can lead to neurological damage.**
- In HI, the dysfunction of pancreatic beta-cells leads to excessive insulin production and severe hypoglycemia.
- In medically unresponsive diffuse HI, subtotal pancreatectomy may be pursued but is not curative and can lead to long-term health complications, including diabetes.
- **Objective: This study characterized post-pancreatectomy diabetes and glycemic outcomes using patient-reported and continuous glucose monitoring (CGM) data from the HI Global Registry (HIGR).**

METHODS

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

- Participants with **diffuse HI who had ≥75% pancreatectomy** were included.
- All participants completed the *Surgical Management* survey in HIGR, and some completed individual research interviews about their pre- and post-surgical experiences with pancreatectomy, which included participants and/or their caregivers.
- 13 participants shared their Dexcom CGM (any generation) data with HIGR.
- CGM metrics were evaluated for up to the most recent 30 days available.

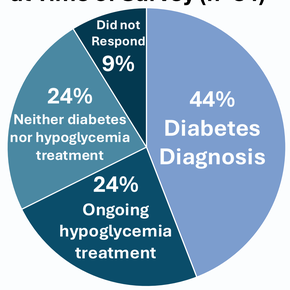
RESULTS

323 Participants completed the *Surgical Management* survey in HIGR

34 Participants were included in the pancreatectomy study

13 Individuals connected their Dexcom CGM to the registry

Patient-Reported Diagnosis Status at Time of Survey (n=34)



In research interviews, challenges with **rapid-onset hypoglycemia**, commonly triggered by **exercise**, changes in **weather**, **hormonal changes**, **growth spurts**, and **illnesses**, were commonly discussed by individuals who had a pancreatectomy and their caregivers.

> If my blood sugars were within a normal range and I went to go exercise, even something as simple as going for a walk, my blood sugars would just plummet. They would just go straight down. That's still the case. We haven't really been able to figure out a way to stop that happening without my blood sugars being high to start with. – *Adult with diabetes*

Patient-Reported Medical Status	Time Since Surgery	Average Glucose (mg/dL)	Coefficient of Variation (CV, %)	Time in Level 2 Hypoglycemia[a] (%)	Time in Level 1 Hypoglycemia[b] (%)	Time in Range[c] (TIR, %)	Time in Level 1 Hyperglycemia[d] (%)	Time in Level 2 Hyperglycemia[e] (%)
Diabetes	6-7 years	154	40.5	0.4	1.8	67.8	20.4	9.5
Diabetes	7 years	183	35.4	0.2	0.8	52.8	28.6	17.7
Diabetes	10 years	150	34.4	0.0	0.4	73.0	21.8	4.7
Diabetes	11 years	194	33.3	0.1	0.3	52.7	26.4	20.5
Diabetes	11 years	156	44.8	0.1	0.6	67.0	22.1	10.2
Diabetes	11.5 years	296	31.5	0.3	0.5	12.0	17.7	69.4
Diabetes	22 years	176	26.6	0.0	0.1	60.5	31.6	7.8
Diabetes	29 years	163	27.2	0.0	0.2	71.6	23.9	4.4
HI medication	2 years	108	33.9	2.0	11.9	82.3	3.8	0.0
HI medication	9 years	149	33.3	0.0	0.0	76.8	19.1	4.1
No medication, uses feeding tube	2 years	147	37.4	0.8	2.8	71.3	19.5	5.5
No medication, no diabetes	14 years	172	38.4	0.2	0.7	62.5	24.6	12.1
No medication, no diabetes	14 years	171	38.0	0.2	1.1	62.2	23.6	12.8
Summary or additional info	**Range: 2-29 yrs post-surgery**	**Mean: 171**	**Mean: 35.0**	**Fear of hypoglycemia was prominent in the interviews, which may contribute to the low frequency of hypoglycemia.**		**5 participants met ADA-defined TIR goals.**	**All but one individual experienced substantial hyperglycemia based on their latest month of CGM data.**	

[a] Level 2 hypoglycemia: < 54 mg/dL
[b] Level 1 hypoglycemia: 54-70 mg/dL
[c] Time in range: 70-180 mg/dL
[d] Level 1 hyperglycemia: 180-250 mg/dL
[e] Level 2 hyperglycemia: > 250 mg/dL

> "Every day is different. Literally, you could do the same thing from day one to day two, and she could eat exactly the same things, and her blood sugars would be totally different. It was like a shot in the dark every day. There was no continuity to this disease and how it reacted in her body. It was wild."—*Caregiver to 14 year-old transitioning to diabetes*

> "It was very difficult trying to manage his medical condition when he had hyperinsulinism. It was very difficult, and doctors didn't know. When he changed to diabetic, it was, I guess, easier, but again, he's not full-blown type 1. He is a little different. It's a different diabetic, but then it's easier for the doctors to manage him now."—*Caregiver to a 9 year-old with diabetes*

CONCLUSIONS

- Subtotal pancreatectomy for diffuse HI is associated with glycemic dysregulation, including insulin-dependent diabetes and high glucose variability.
- The glycemic range of all but one participant suggests fear of hypoglycemia should be studied as a potential cause of higher than ideal average glucose.
- There is a need for improved long-term monitoring and tailored treatment strategies for people with HI, especially following pancreatectomy.

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Learn more about HIGR!

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