

# The Impact of Congenital Hyperinsulinism on Family Finances and Time:



## A Report from the HI Global Registry

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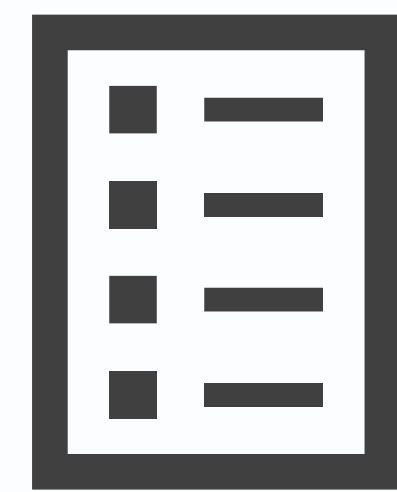
### INTRODUCTION

- Congenital Hyperinsulinism (HI) is a rare life-threatening condition that results in severe hypoglycemia and can lead to neurological damage.
- HI is rare, but it is the most common cause of persistent hypoglycemia in newborns and children.
- In HI, the dysfunction of pancreatic beta-cells leads to excessive insulin production and severe hypoglycemia, which often causes irreversible neurological damage.
- The management of infants and children with HI is intensive, often requiring around-the-clock care and frequent visits to healthcare specialists
- This places a significant burden on the families of affected children.
- This study aimed to describe aspects of the financial burden of HI on the families of people with HI

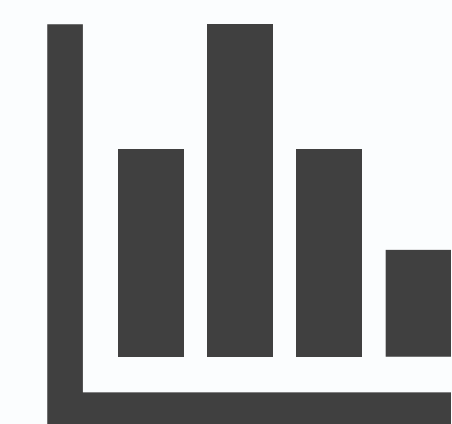
The HI Global Registry (HIGR) is the only international patient-powered registry for people with HI.



Caregivers of people with HI consented to participate in HIGR

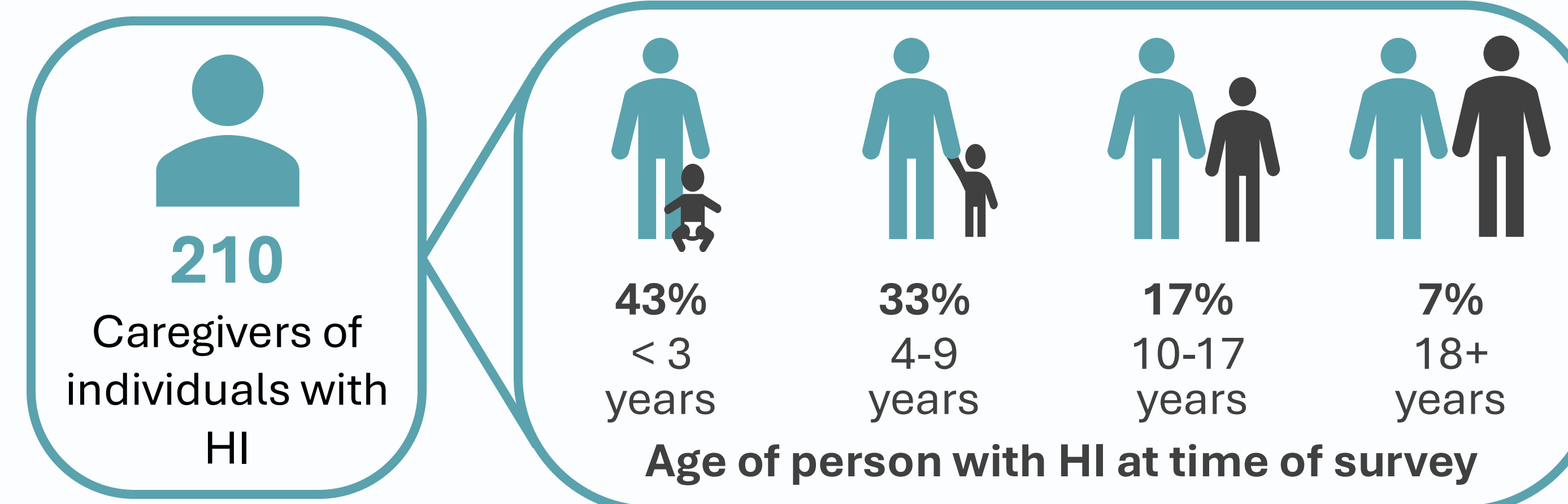


Caregivers completed the Caregiver Quality of Life (QOL) survey

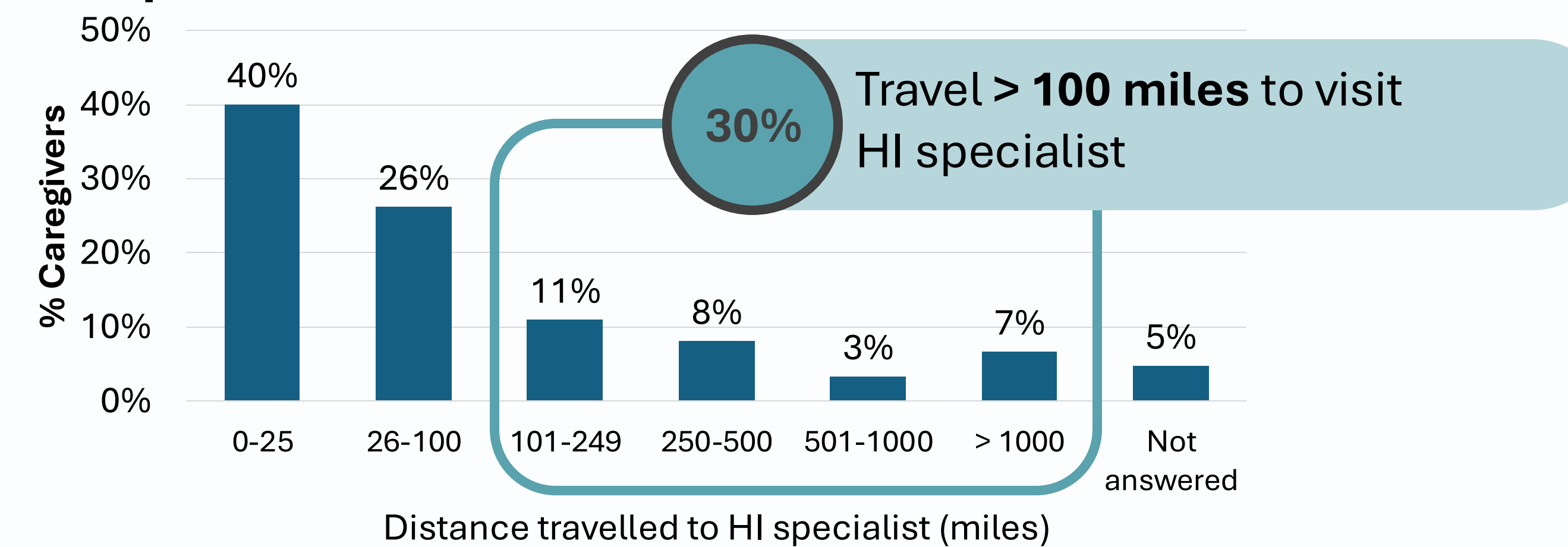


Categorical data reported using descriptive statistics

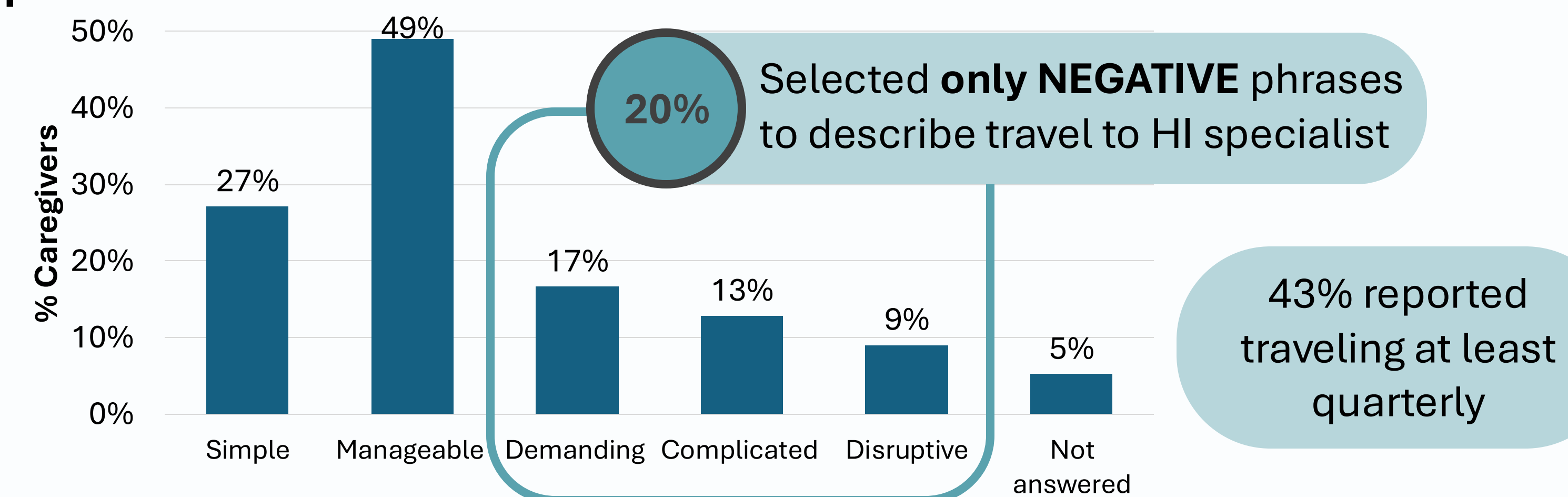
### RESULTS



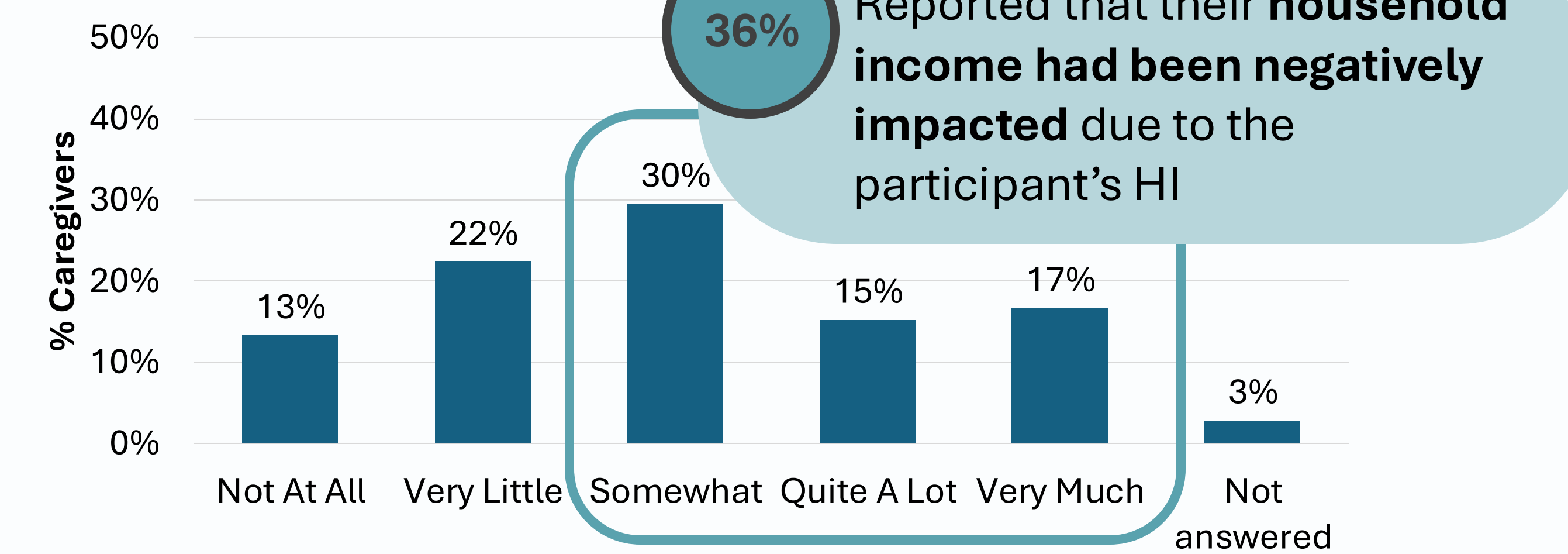
#### How far do you travel to see the specialist that treats the participant's HI?



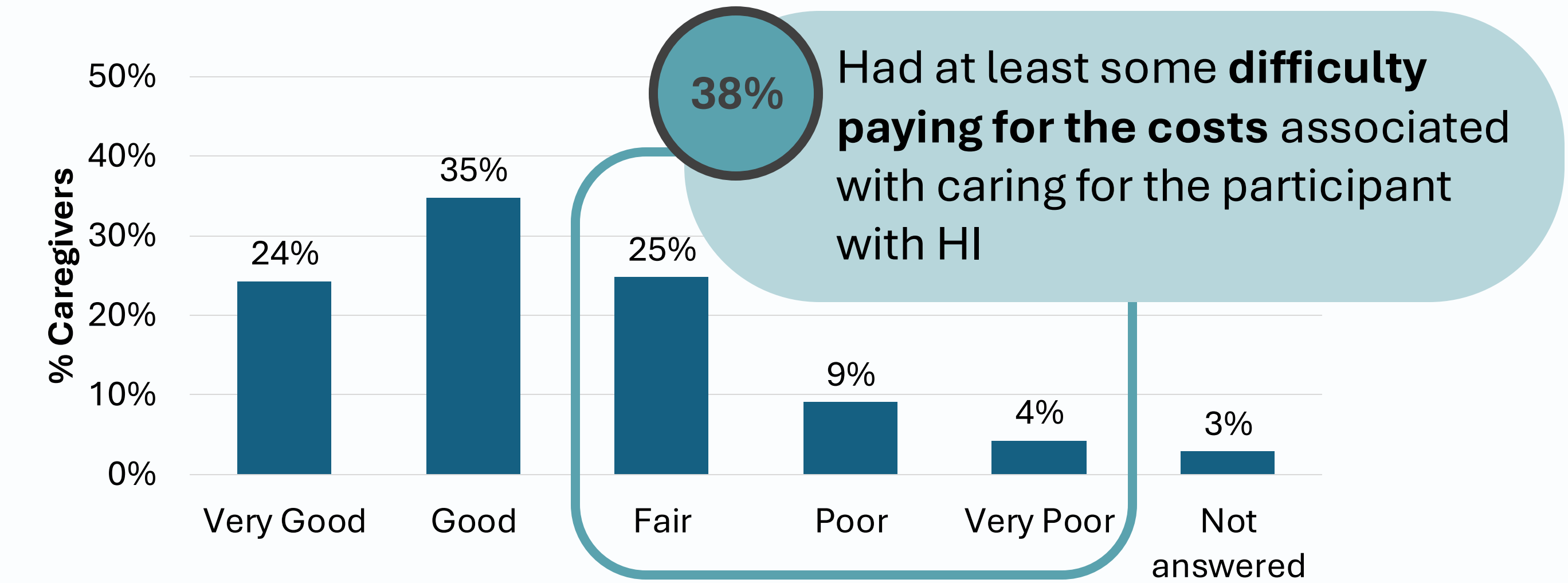
#### How would you describe your travel to the participant's HI specialist?



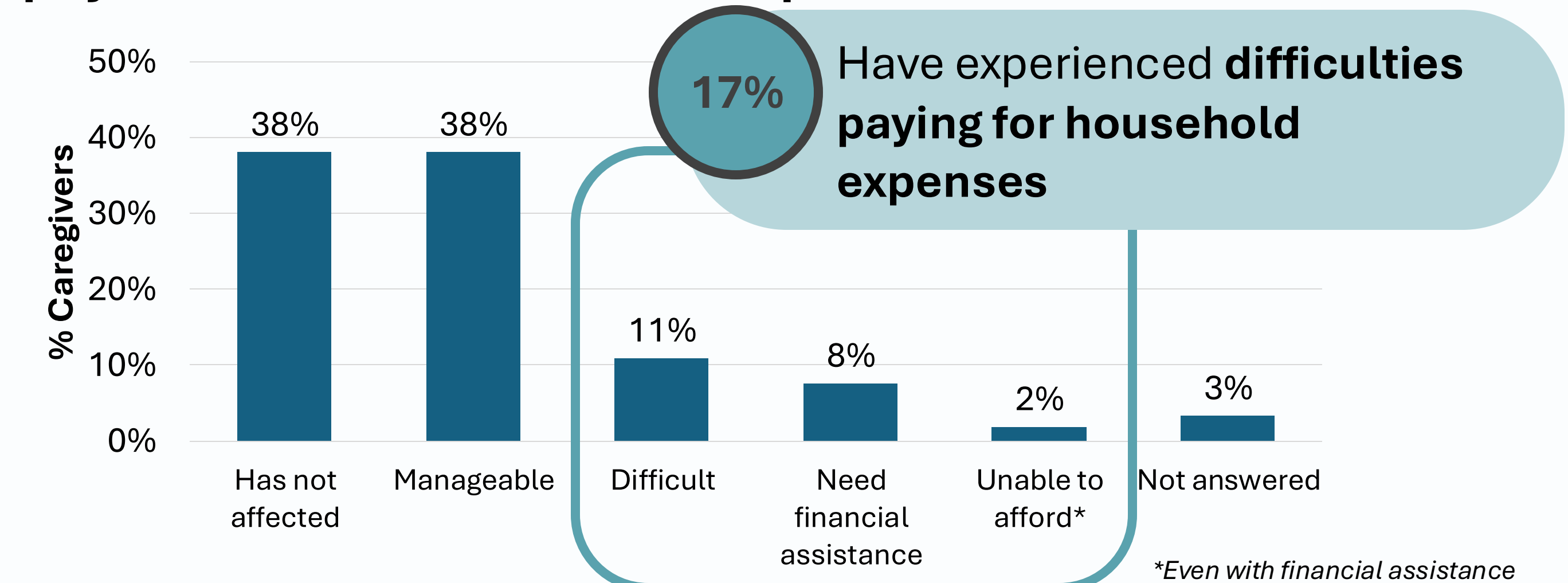
#### Has your household income been negatively impacted due to the participant's HI?



#### How would you rate your ability to pay for the costs associated with caring for the participant with HI?



#### How has caring for the participant with HI affected your ability to pay for household essential expenses?



### DISCUSSION

- HI requires intensive management and frequent healthcare visits to monitor patients and optimize treatment protocols.
- This places a **significant financial and time burden** on the families of people with HI.
- For some families, this leads to difficulties paying for medical and household expenses and reduced time at work or school, which may further impact current income and/or future earning potential.
- Clinicians who manage the care of people with HI should ensure that families are well-supported in all aspects of life beyond clinical management, including:

- ✓ Connection to community and government support programs
- ✓ Coordinating with local physicians
- ✓ Offering telehealth appointments with specialists

Learn more about HIGR!



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

#### In the last year, how often have you missed school/work due to the participant's HI?

