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## MaineHealth Knowledge Connection

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Costas T. Lambrew Research Retreat 2023

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### Access to Pediatric Type 1 Diabetes Care in Montana

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# Living with pediatric Type I Diabetes in Montana

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## Introduction

Management of Type 1 Diabetes (T1D) requires significant family effort and specialty support. We aimed to understand how living in a rural state impacts families' experiences during and after diagnosis.

## Methods

In an electronic survey publicized through local diabetes clinics and organizations, we asked for demographics, clinical traits, and personal experiences. Qualitative analysis is ongoing.

## Results

Among 116 responses, emerging themes include: Local **healthcare unprepared** to diagnose and treat T1D, **travel** and **financial burdens**, and **provider shortages**, including endocrinologists, mental health experts, and school nurses.

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## On diagnosis and initial education...

"Our son nearly died. [...] I asked for a blood test or urine test and the provider tried to talk us out of it because our son "wouldn't like " an IV. Finally they did; and the doctor came in crying. We thought he was dying. She told us he had Type 1 Diabetes . [...] We found services totally not prepared to care for a child with T1. I have nightmares over this."

"Upon discharge from the hospital/ICU; [the doctor] instructed us to get into our car and drive immediately from Butte to Bozeman and not eat any carbs until we got there."

## On access to care...

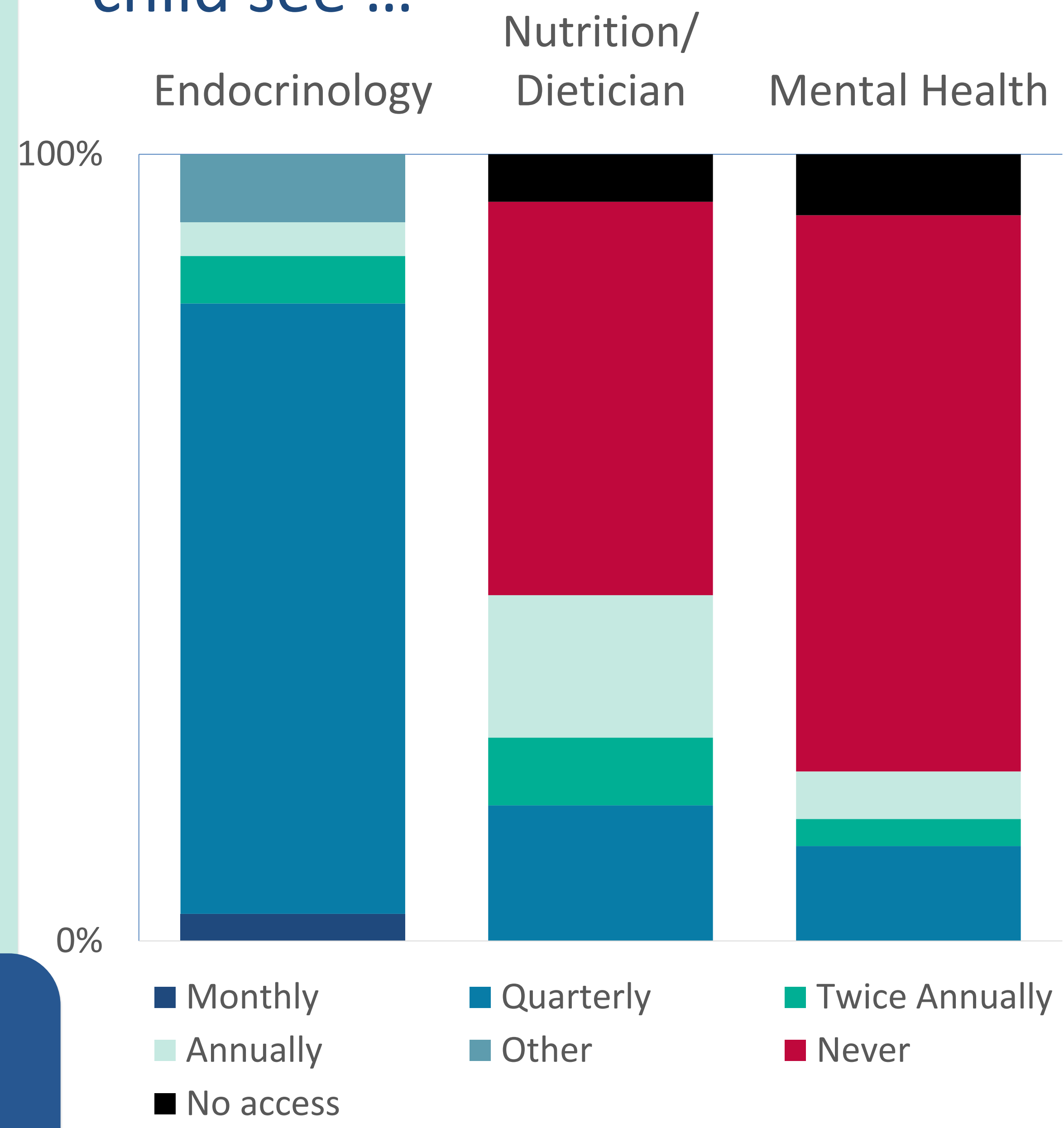
"The nurse has to rotate between four schools so it's not a comfortable feeling if my daughter had an emergency. The chances of the nurse being there are minimal."

"It took us almost a year to find a counselor for my son to speak with. It was very frustrating and sad because he was emotionally hurting."

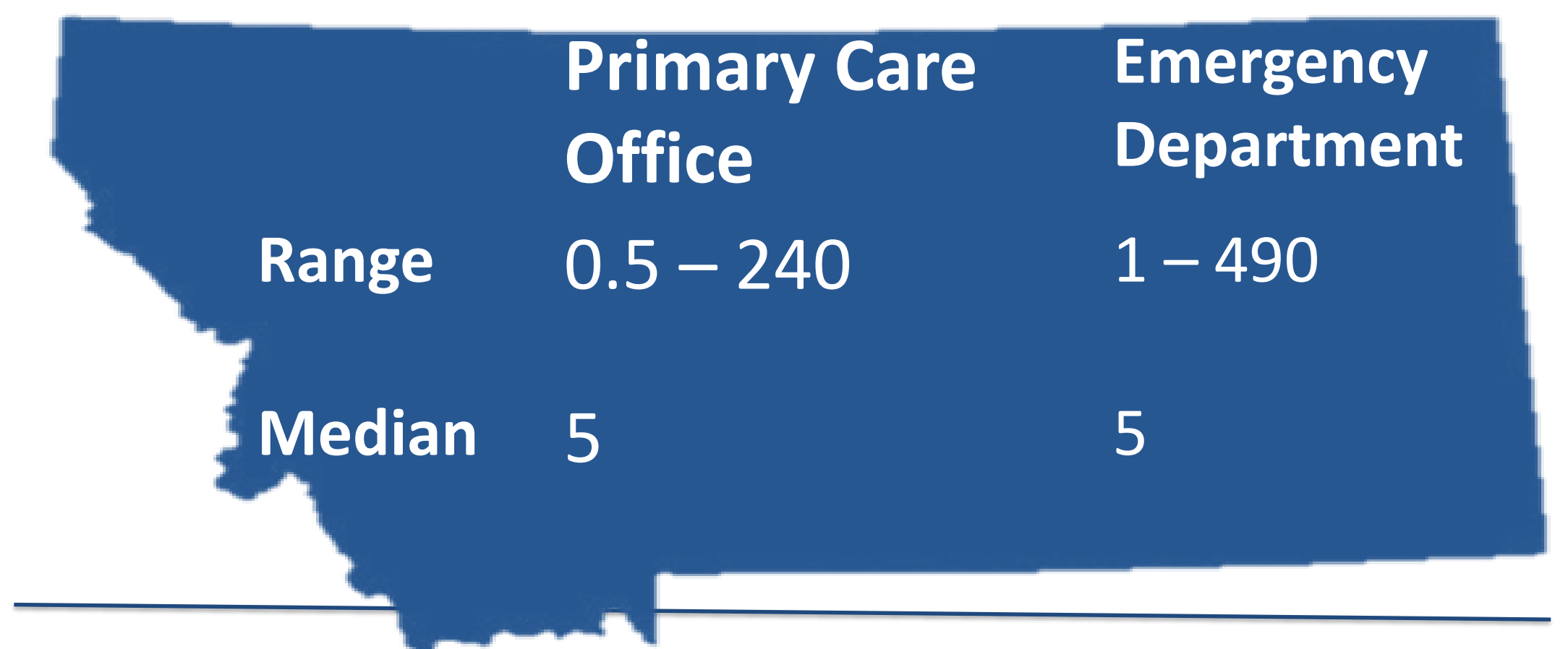
## On cost of care...

"We've had to basically remain in poverty for the past seven years in order to keep his insurance through the state; the alternative is tens of thousands in copays and insurance premiums that would drop us back into poverty again regardless."

## Care: how often does your child see ...



## Travel: how many miles away is your ...



## Technology: does your child currently use a ...

