



**Parental Distress in Caring
for Children with
T1 and T2 Diabetes:
Oklahoma Choctaw**

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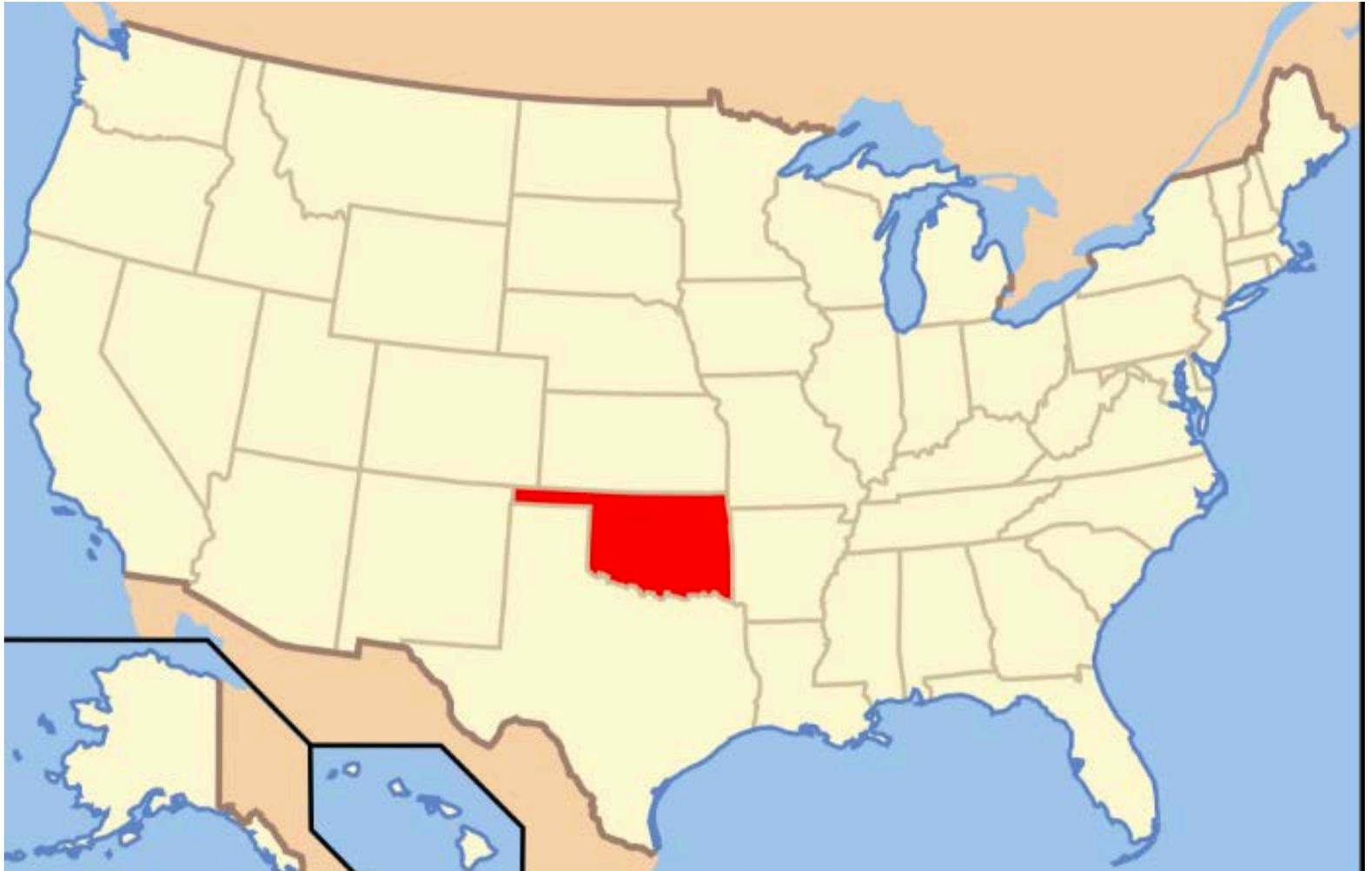
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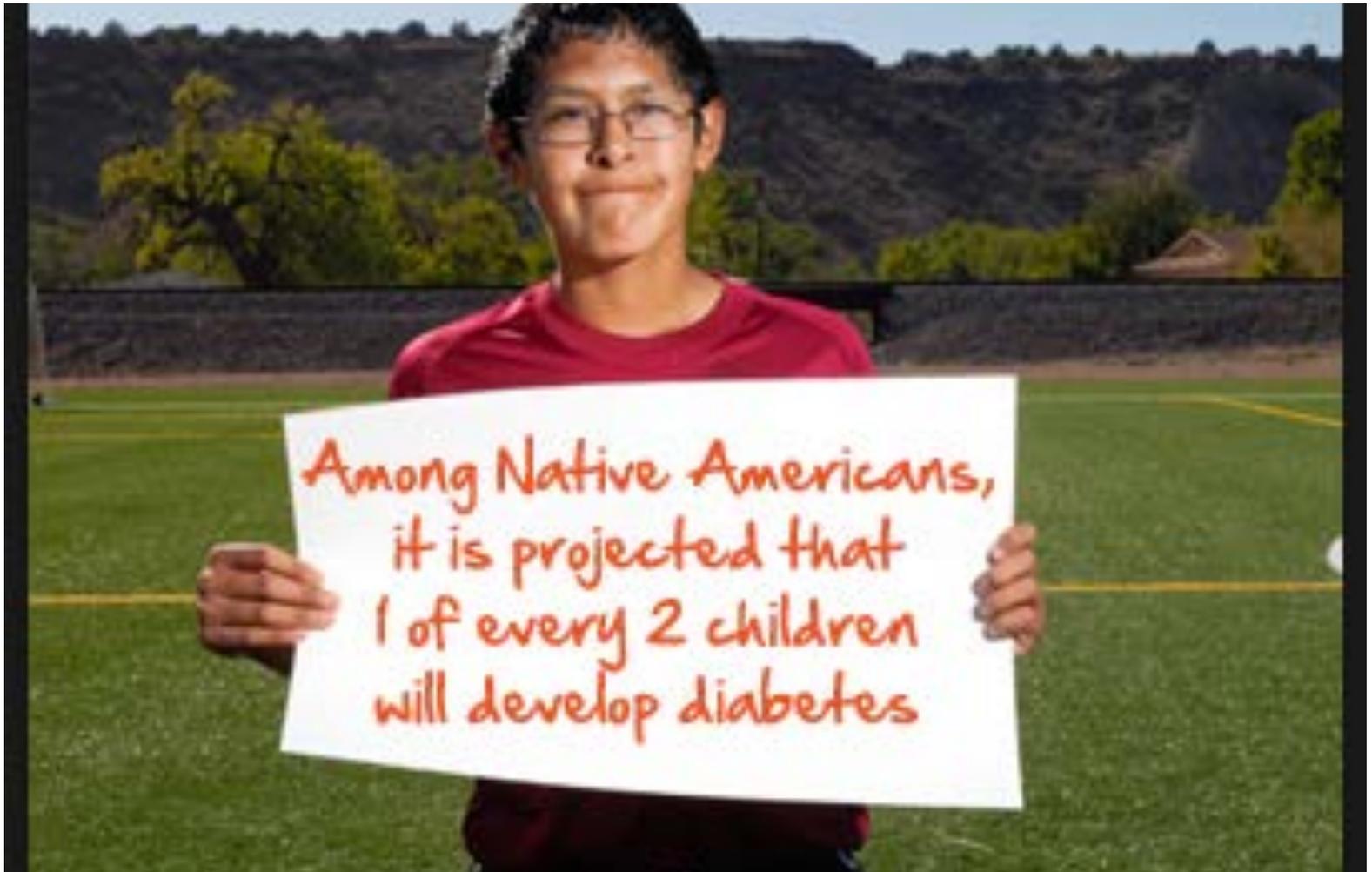
Oklahoma

Choctaw: “Okla” = people; “Humma” = red

Oklahoma is former Indian Territory (1830’s-1907)



Too Much Diabetes



Diabetes by Race/Ethnicity

People with Diabetes by Race and Ethnicity, 2004–2006*



Non-Hispanic whites	6.6%
Asian Americans	7.5%
Hispanics	10.4%
Non-Hispanic blacks	11.8%
^AIAN	16.5%

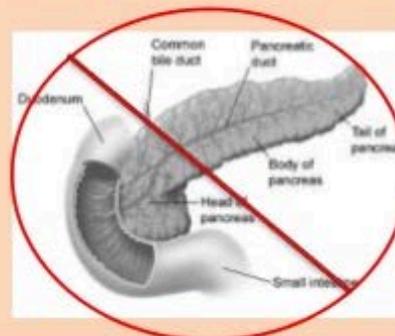
*Adjusted by age

^American Indians and Alaska Natives

T1D

Type 1 Diabetes

- Also known as T1D
- Autoimmune disease
- Pancreas stops producing insulin
- Causes unknown
 - ****NOTHING TO DO WITH LIFESTYLE**
- No prevention, no cure (currently)
- Affects three million in U.S.
- 80 people per day



T2D

Diabetes in Native Americans

2.3 times higher

likelihood of Native American adults to have diagnosed diabetes compared with non-Hispanic whites.

9 times higher

likelihood of Native American youth aged 10-19 to have diagnosed type 2 diabetes compared to non-Hispanic whites.

110%

increase in diagnosed diabetes from 1990 to 2009 in Native American youth aged 15-19 years.

1.6 times higher

death rate due to diabetes for Native Americans



Numbers are good, but

***What is the LIVED EXPERIENCE
of diabetes?***

FOR THE PARENTS!!!!

The Study

3.5 years

24 Parents, grandparents, a brother

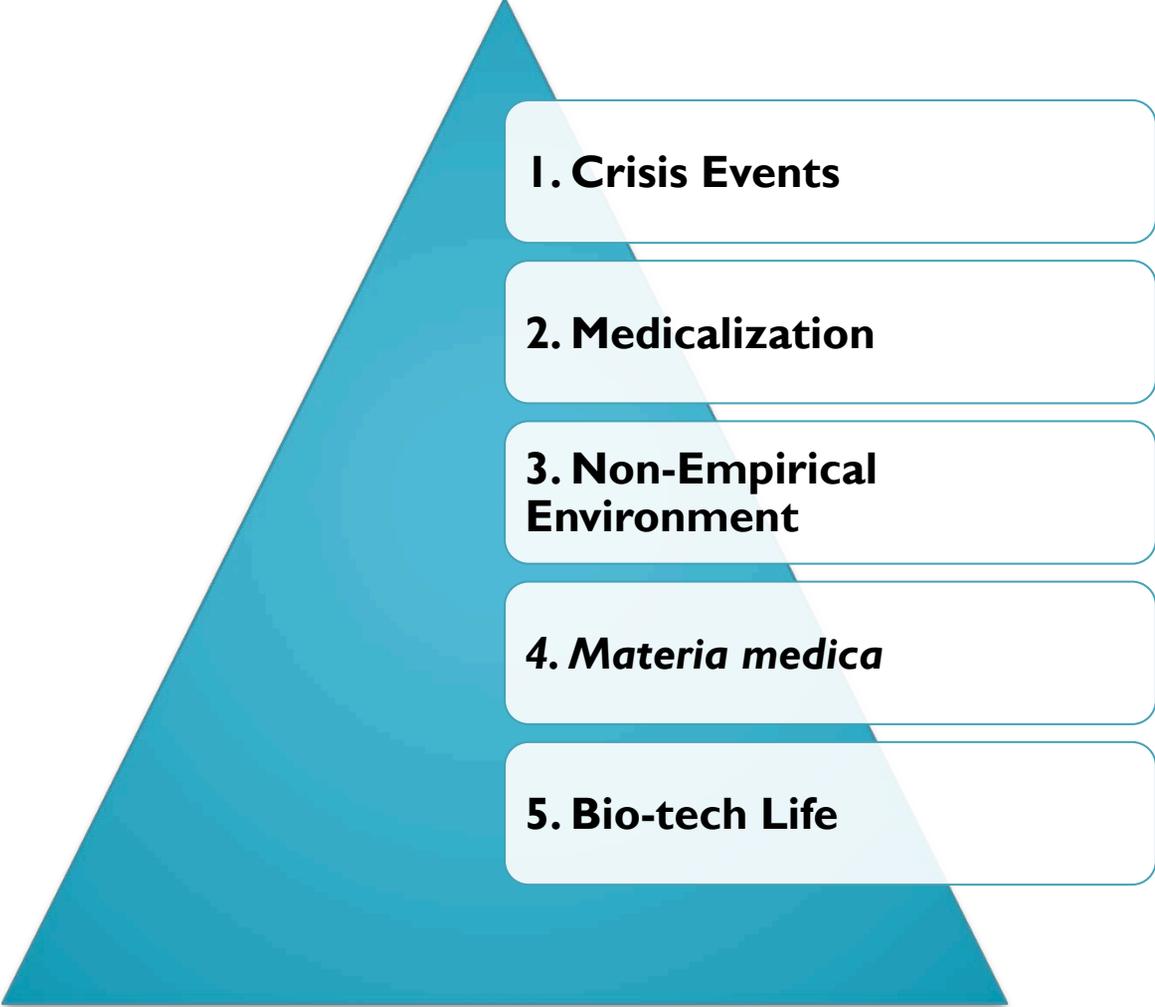
101 intensive semi-structured evolving interviews (3-5 per family) for more than 100 hours of discovery

Average age of children = 12

Average age of parent = 50

Face to Face Interviews

10 Deductive Analytic Themes



1. Crisis Events

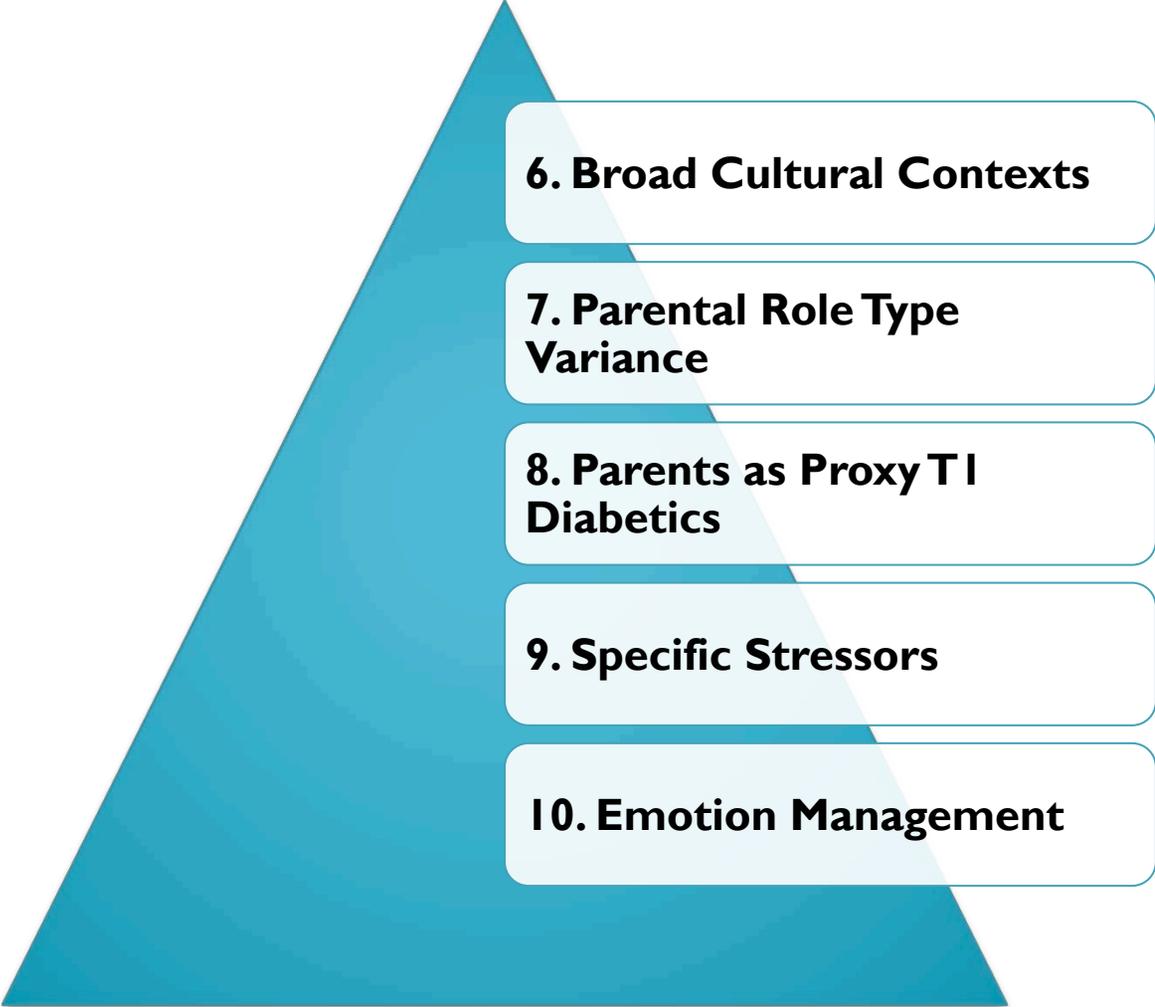
2. Medicalization

**3. Non-Empirical
Environment**

4. *Materia medica*

5. Bio-tech Life

10 Deductive Analytic Themes



6. Broad Cultural Contexts

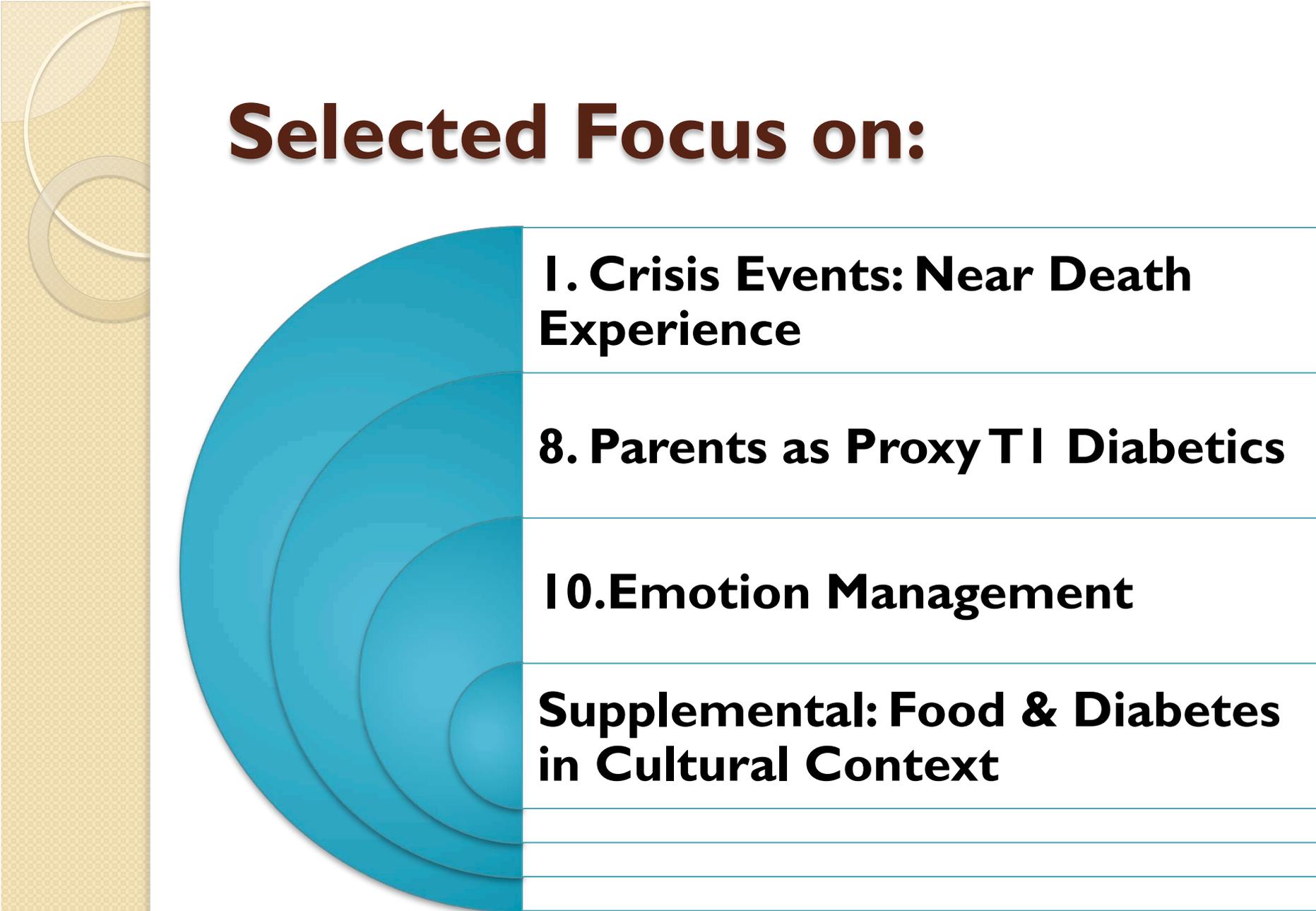
**7. Parental Role Type
Variance**

**8. Parents as Proxy T1
Diabetics**

9. Specific Stressors

10. Emotion Management

Selected Focus on:



1. Crisis Events: Near Death Experience

8. Parents as Proxy T1 Diabetics

10. Emotion Management

Supplemental: Food & Diabetes in Cultural Context

Night Terrors



For the parents!



CRISIS EVENTS

Near Death Experience:

Case DMI.FM3.SW.IVI.012314 Code: NDE.SZS

- **We were in bed asleep in the middle of the night and his blood sugar wasn't severely low. It was low. I mean, he's had them that low before. ... because his pump had quit working during the day and his blood sugar had gotten so high during the day that the meters couldn't even read it.**
- **And we had finally gotten it down around 590 or 580 when he went to bed and, apparently, for whatever reason, it started dropping and it dropped so quick, it dropped down in the mid-30s in less than an hour. It just threw his body into some... like a shock.**
- **He woke up because his body started jerking, like his limbs started jerking and his head was jerking and you go to tunnel vision, so he couldn't see and he screamed.**
- **So, we woke up to like a blood-curdling scream in the middle of the night.**

Case continued...

- **And they can't talk, so they can't tell you what's wrong and I just... You know, it's scary as a parent.**
- **And he's jerking on the bed and you know he's trying to talk because you hear noises and their mouth is moving and so...**
- **Thank God I'm married because I'm able to have somebody there with him while I run to go get supplies. Yeah, I run and get supplies because I'm the level-headed one. (Laughs) Yeah.**
- **So, my husband stayed there like, trying to talk to him and keep him calm, and you know, I think maybe a soothing voice or something. I try to always stay calm whenever something is going wrong.**
- **(Side story) Even at the doctor's office when he had a pretty bad low. All the nurses were running around frantically and I'm still sitting there talking to him in my normal voice and trying to at least put out a façade that I'm calm. Inside, I'm in complete turmoil, but I went and got some juice and we got it brought up. (Back to main story) Then, the rest of the night, I was too terrified to let him be in bed alone, so he slept with us.**



Case continued...

- **The thing that scared me the most is when I walked down there, he was, his eyes were fixed and he was set and I thought, it has happened, he is dead.**
- **And I made one giant leap and I was on top of him. I knew he had a pulse immediately and the way our house is set up, very strategically, the kids are on the complete opposite end of our house.**
- **I screamed out for _____ but he had the Thunder rolling on TV. We were watching the game and he didn't hear me and so I made it down the hallway and yelled for him again and he came so fast that he nearly knocked me down...**

Crisis Events: Near Death Experience



Parents new to the physiology and management of TID
Received classroom training on symptom recognition and appropriate treatment steps
Have not personally seen the range of symptoms, yet
Near death event: nighttime during sleep
Some report supernatural intervention caused awakening to check on child

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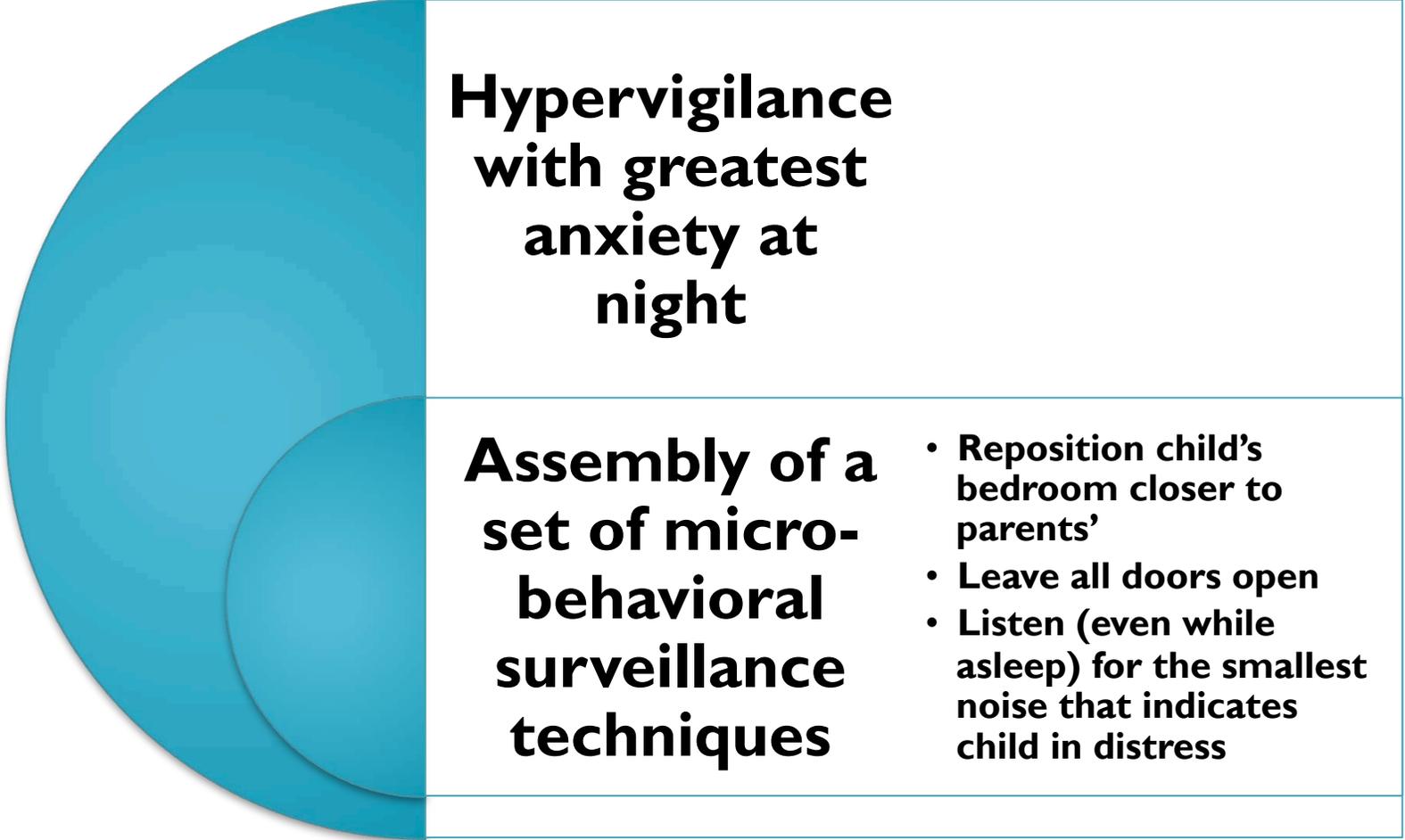
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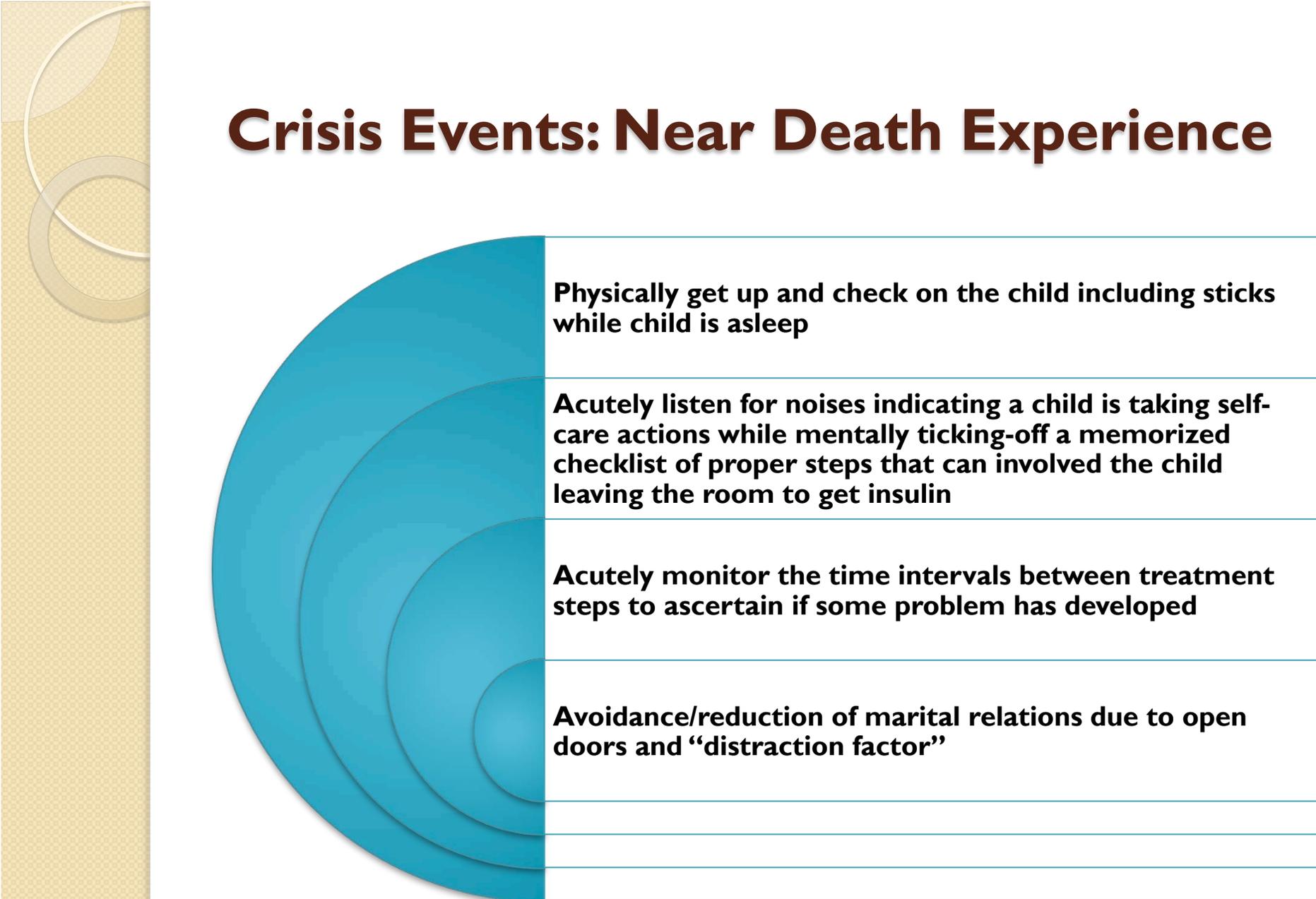


**Hypervigilance
with greatest
anxiety at
night**

**Assembly of a
set of micro-
behavioral
surveillance
techniques**

- **Reposition child's bedroom closer to parents'**
- **Leave all doors open**
- **Listen (even while asleep) for the smallest noise that indicates child in distress**

Crisis Events: Near Death Experience



Physically get up and check on the child including sticks while child is asleep
Acutely listen for noises indicating a child is taking self-care actions while mentally ticking-off a memorized checklist of proper steps that can involved the child leaving the room to get insulin
Acutely monitor the time intervals between treatment steps to ascertain if some problem has developed
Avoidance/reduction of marital relations due to open doors and “distraction factor”

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Parents as Proxy Diabetics: *Being Their Child*

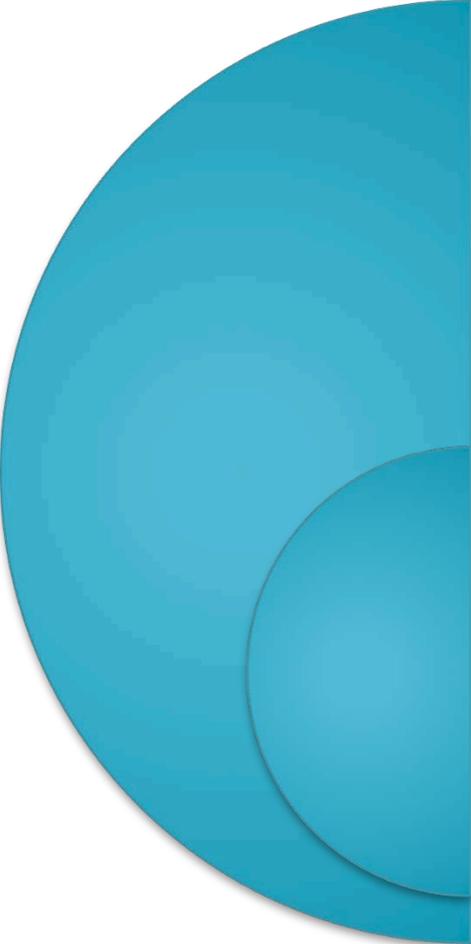
Hypervigilance = the fervent wish to face the diabetes for the child

Parents wish they could live in the child's body to know the early signs of problems

But, parents can't see through the skin and are frustrated & frightened by having to use the child's behavior as a rough indicator of a developing problem



Parents as Proxy TID: Similar to Spirit Possession



This is a type of bodily possession wish, the impossibility of which is a source of frustration, fear, guilt, and anxiety

No matter how hard parents wish, their fantasy of a fix will not come to be

- **The fantasy is never the fact.**
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Parental Guilt



Emotion Management: Parental Guilt

- **Research Partner:** You know, I've been overweight my entire life and I can't control my weight yet alone my daughter's weight. That's the guilt. If I were a better parent, I would get up, I would take control over my eating pattern first. I can't tell you how many times I've gone, "(God), Why did you give me someone with a problem that has to do with their weight? Why couldn't you have given me a child with cancer or a child with seizures or anything except diabetes?"



Emotion Management: Being a Non-Model

- **Interviewer:** So you then are thinking when you go to the store, you think ahead to foods that are going to be friendly to the condition?
- **Research Partner:** We try to. I don't do as good a job as I should do. Um, because, I do buy snack cakes and those kinds of things too. I can't say that I have a completely sugar free environment. I don't.
- **Interviewer:** Okay. Can you tell me some more about that?
- **Research Partner:** I think that if you have a child with diabetes, to be really successful, the whole household has to have diabetes. You have to treat everyone the same. I think to be really successful the whole family has to buy into it.
- **Interviewer:** Okay. Would you describe your household that way?
- **Research Partner:** No, we have not been very successful with that.

DM2.FM1.LI.IV3.081315, LN 242-255



Emotion Management: Denial/Indifference to Modeling Behavior

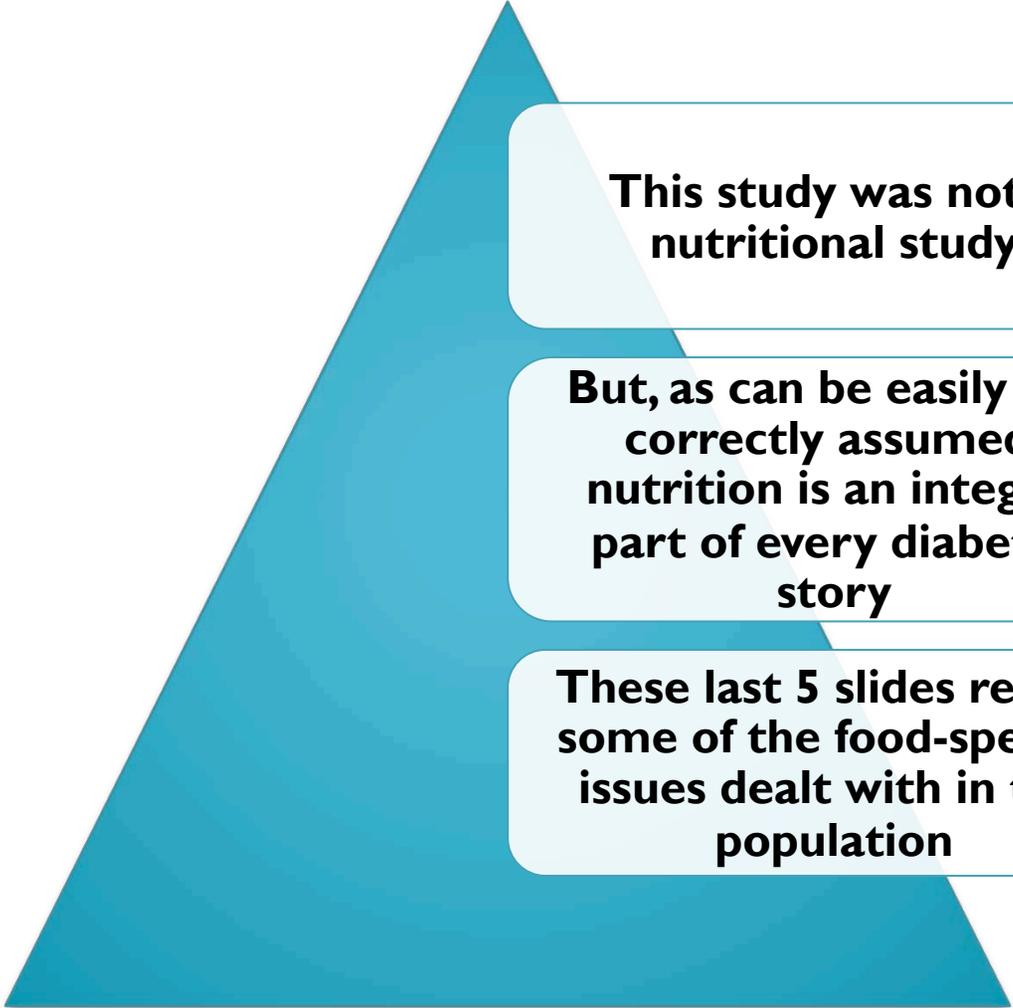
- **Interviewer:** What has having a child with diabetes concerns allowed you to learn about your life?
- **Research Partner:** Um, actually being having prediabetes or diabetes it was the way of eating, um, the way of living, um, that's about mainly, eating, living and exercising. They realized the exercise was a big part of not having diabetes. Especially the eating, what you eat and the way you live.
- **Interviewer:** What is having a daughter who has diabetes concerns allowed you to learn about children?
- **Research Partner:** About her? Um, being prediabetic or having diabetes at an early age, I hate it cause, you know she is not actually taking medication at this time but they are watching her and it has to do with the eating habits she has, exercising which she tries to, which she does a lot and health issues that she does have if it continues to keep growing, you know, the insulin, the medications, you know what that does to your body, you know, just health issues. You know, I hate.
- **Context:** Mother and two adolescent daughters are prediabetic. Mother is visibly obese. The interview was conducted at her place of employment where she had a honey bun and large soda on her desk.

Emotion Management: Self-perceived Failure

- **Research Partner:** Those times that are highly volatile and emotional like, his A_{1C} , that was horrible and I fell to pieces. It just shocked me beyond belief, I didn't understand it. Normally we don't have like a lot of crisis and that wasn't a crisis I know, but to me it was, it was a failure. With everything that has been going on the last two months, our diet has been horrible. There has been so much fast food in our home. We were going to Dallas two to three nights a week (to care for an ailing parent), you just, you don't have time for anything else.



Food & Diabetes in Cultural Context



**This study was not a
nutritional study**

**But, as can be easily and
correctly assumed,
nutrition is an integral
part of every diabetes
story**

**These last 5 slides report
some of the food-specific
issues dealt with in this
population**



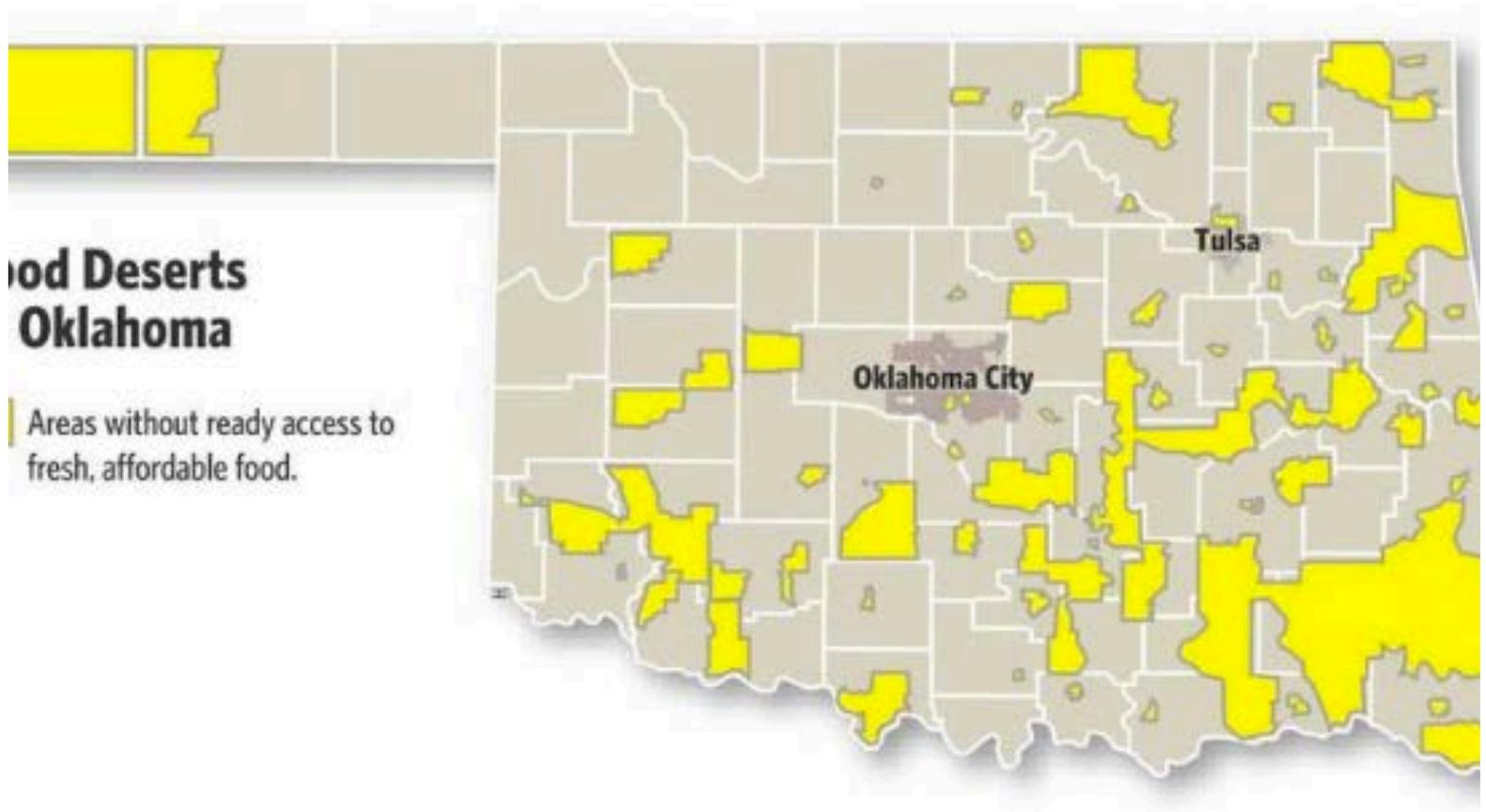
Lack of Resources to Purchase Healthy Food

- **Research Partner:** I really don't do my shopping here. I go to Poteau. It's a 45 minute drive.
- **Interviewer:** How often do you go?
- **Research Partner:** Not very often. Um, probably twice a month or maybe once a month and it just varies.
- **Interviewer:** So, you buy in bulk then, when you go?
- **Research Partner:** Yes.
- **Interviewer:** Get a week supply or a couple weeks supply?
- **Research Partner:** Yeah, I try to get enough that I know it is going to last for two weeks.
- **Context:** Single mom with 3 kids, employed but living paycheck to paycheck. Doesn't have means to regularly travel the distance to purchase perishable produce.

Lack of Access to Fresh Produce

- **Interviewer:** How has your daughter with diabetes affected finances in the household?
- **Research Partner:** It is more expensive to buy healthy foods. Um, but it's the availability also because in Talihina, we are actually losing our grocery store and so that leaves us with the Dollar Store for groceries and there are no fresh fruits or vegetables. There are no fresh meat products. It's a lot, it's just really a lot of processed.
- **Interviewer:** So, where would you go for a better selection of food if you were going to do that?
- **Research Partner:** Poteau or McAlester.
- **Interviewer:** So both ways are about an hour?
- **Research Partner:** Yeah.
- **Context:** Supervising Nurse at local hospital who has financial means but demanding job and other family care responsibilities that make a 2-3 hour shopping trip difficult.

Food Deserts: Oklahoma



JRCE: USDA Economic Research Service

JASON POWERS/Tulsa World

Rural Poverty





Extreme Poverty and Isolation

- Grandmother, mother, and adolescent daughter live together in rural Indian housing.
- Grandmother is severely chronically depressed and unmedicated.
- Mother has double BKA and transradial amputation.
- Daughter is noncompliant T1DM.
- Totally dependent on state and tribal assistance for food, housing, and medical care.
- Tribe provides transportation once a month to purchase food and pick up commodities at tribal center 45 minutes away.
- Nutritional intake consists almost completely of highly processed, nonperishable foods.

DMI.FMI0.DD & DMI.FMI0.LD

**“TAKE
HOMES”**



Parental distress is ubiquitous and a serious emotional and physical health hazard

Parental distress is born from the fear of their child's death and frustration at curative impotence

Caregivers don't recognize themselves as doing anything extraordinary, so help them understand that they are enmeshed in a stressful lifestyle

Task-behaviors are often over-simplified by caregivers and clinicians: think micro-behavioral analysis to elicit all task behaviors = closer to real

Who is the patient?? Parents have “TID by proxy”

**“TAKE
HOMES”**



Cultural construction of diabetes: T2D not viewed as a serious condition

Huge amounts of health education about diabetes pathology permeates tribal life, yet little attention given to it

Normalized out of existence

Perception that nothing can be done about it

Observation that others with T2 “seem” to do ok w/o a lot of self-care

END





Minnesota Food Deserts

