

Exploring childhood diabetes in American Indian populations

Chronic conditions, such as type 1 diabetes, are becoming more prevalent in children. However, it is not just the children themselves who are affected. Many parents become so knowledgeable and hypervigilant about their child's care that they essentially develop "diabetes-by-proxy". Dr J. Neil Henderson, at the time working at the University of Oklahoma Health Sciences Centre but now affiliated with the University of Minnesota Medical School, explored experiences of parents of children with diabetes amongst American Indians over a four-and-a-half-year period. The study highlighted the need for focus on parent caregiver stress, as well as on the medical management of diabetes.

Globally, the incidence of diabetes is increasing. This means that the number of children with diabetes is also increasing and this is mostly due to diagnosis of type 1 diabetes (T1D). Around 90% of young people with diabetes have T1D, with the remaining 10% diagnosed with type 2 or other forms of diabetes.

The International Diabetes Federation estimates that over 98,000 children under 15 years develop T1D annually. Globally, there are an estimated 600,900 children under 15 years who have T1D.

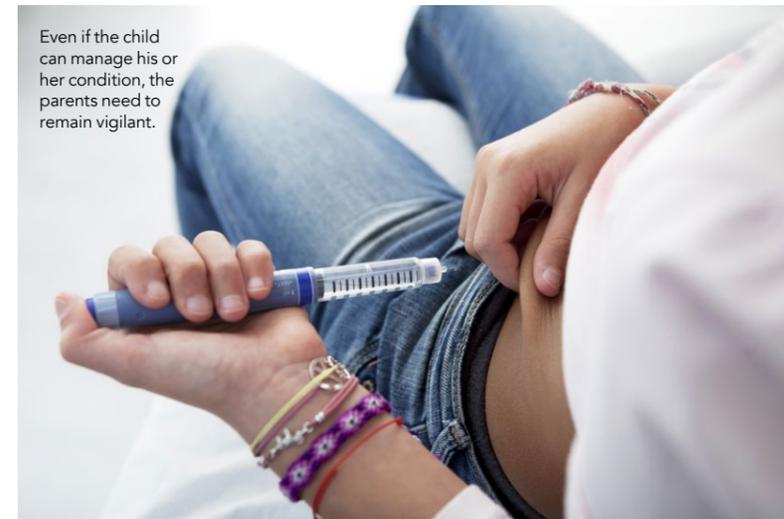
Type 1 diabetes is an autoimmune condition that occurs when the body attacks the cells of the pancreas that are responsible for making a hormone called insulin. Insulin helps the body's cells use glucose (sugar) for energy and in doing so, ensures that the levels of glucose circulating in the blood are kept under control. The absence of insulin

production by the pancreas means that people with T1D must administer their own insulin via injection, and the amount of insulin required depends on blood sugar levels.

While adults may be more aware of drops in their blood sugar levels and how to address them, this is often not the case in childhood T1D. There is a risk associated with night-time drops in blood sugar levels that are not noticed by the child or parents. Even when the child is able to independently test their blood sugar levels and take the appropriate action, parents must remain vigilant. Furthermore, it is already well known that being a caregiver for someone with a chronic condition is associated with persistent and sometimes extreme stress.

In the case of childhood T1D, the parents must learn how to manage the condition. Dr J. Neil Henderson comments that they "essentially have type 1 diabetes-by-proxy". "Diabetes-by-proxy" refers to the virtual internalisation of the child's behaviours, mood and metabolic physiology by the parents, but an absence of actual physiological symptoms of diabetes. Although this work was done while Dr Henderson was at the University of Oklahoma Health Sciences Centre, he is now at the University of Minnesota Medical School.

Dr Henderson emphasises the clinical need to better understand that parents require support beyond practical management of T1D; parental fears



generally a severe condition, although in the extremes, there is a profound fear of amputations. Dr Henderson also identified that AI elders may hold the strongest views around type 2 diabetes, including denial, avoidance and non-adherence to treatment, and these can influence the beliefs and practices of others.

PARENTS EXPERIENCES OF CHILDHOOD DIABETES

Dr Henderson's research team followed the experiences of 19 families in the Choctaw Nation of Oklahoma over four and a half years. The Choctaw Nation is the third-largest recognised tribe in the United States, with over 200,000 enrolled members.

also need to be acknowledged and appropriate help must be offered to ensure a high quality of life for the child and their parents.

DIABETES IN AMERICAN INDIAN PEOPLE

There are many disparities in healthcare for American Indian people compared to other populations in the United States. For example, American Indians (AIs) are 2.2 times more likely than non-Hispanic white people to develop type 2 diabetes; 16.3% of AI have diagnosed type 2 diabetes. The rate of complications is also higher than in

other populations. These differences may partly be due to genetic influences, but psychocultural variables also play a major role.

Dr Henderson's previous work has shown that the main categories of patient's concern about type 2 diabetes centre around mechanical acts, such as

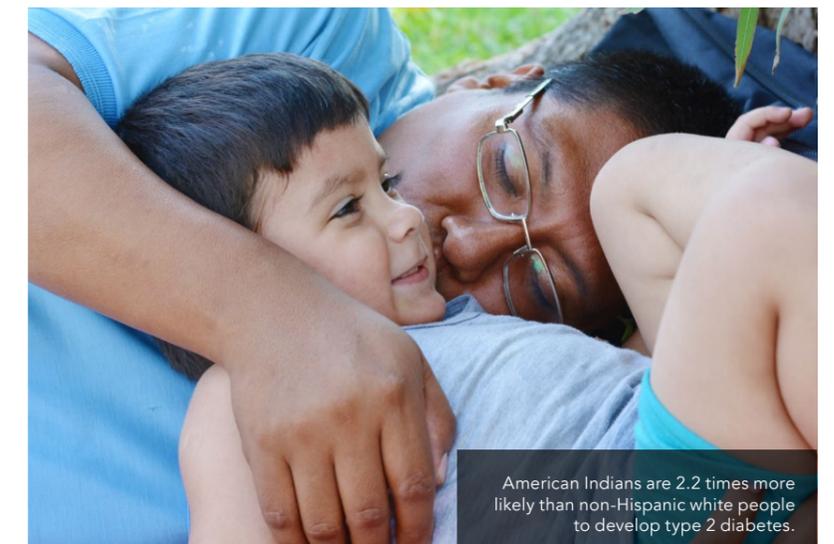
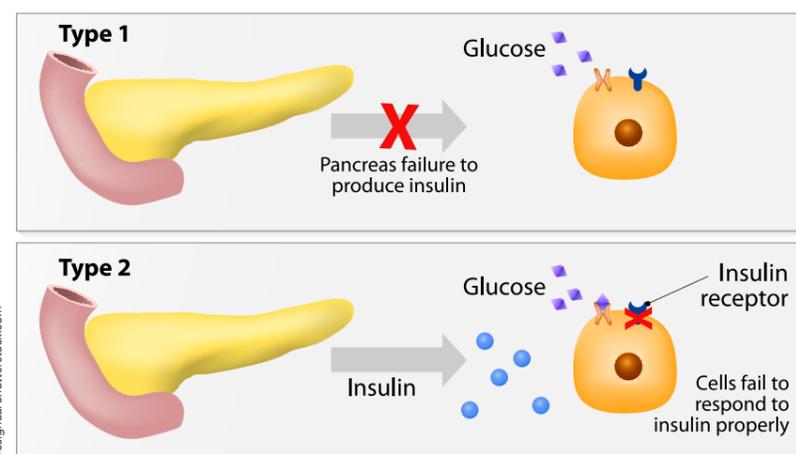
Each of the 19 recruited families had a child under 18 years with T1D and they provided Dr Henderson with almost 100 hours of semi-structured interview data over this time period. This allowed the researchers to track changes in the caregiver stress and distress, as well as exploring the child's transition into young adulthood with T1D. In particular, they

noticed that increased levels of stress within the family were present between the ages of 18 and 25 years. This was due to a combination

The parents' hypervigilance can be associated with chronic sleep deprivation, increased depression and anxiety, and physical illness.

injecting insulin, medical complications and the perception that diabetes is not

of factors such as concern over the child being able to manage their own





Whilst caring for their child, parents also need to monitor and recognise their own stressors to avoid caregiver burnout.

care, repeated hospitalisations and approaching the time at which the child would be leaving their parental home.

This exemplifies the extent to which a childhood condition directly effects the mental and physical health of the parents.

DIABETES-BY-PROXY

The families involved in the study had access to free insulin and equipment as well as clinical diabetes specialists. Most

constant vigilance and as a result, parents behaved as if it was them that had diabetes. Dr Henderson interprets this as psychological embodiment of the disease by parents. This hypervigilance, especially when linked to checking the child's blood sugar levels overnight, can be associated with chronic sleep deprivation, increased depression and anxiety, and physical illness.

The study used qualitative methods to explore categories of interest that arose

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of the families did not have continuous glucose monitors (apart from two families). These are devices which can track and monitor blood sugar levels throughout the day and night, allowing trends to be identified and patients to be alerted to high or low blood sugar levels.

Without continuous blood glucose devices, parents must monitor the blood glucose levels of children who are too young to do so themselves. This requires

from the answers to the questionnaire and interviews. Serial interviews occurred at intervals of six to ten months over the whole span on the four-and-a-half-year study.

The first common theme identified was extreme stress relating from the potential for severe drops in blood sugar levels at night-time, something which can be a real or perceived risk of death for the child. The second theme followed from this and included the

subsequent hypervigilance of parents to prevent episodes of nocturnal low blood sugar levels. For example, parents may start becoming more anxious before bedtime and post-traumatic stress-type responses may be seen in parents who have experienced extreme diabetic events.

Both of these factors contribute towards the parents' developing "diabetes-by-proxy" as they are impacted by the condition as much as the child – if not more.

Parental personality traits can also impact the stressors they experience. Depending on their socio-economic backgrounds, parents may have different approaches to managing their child's conditions, ranging from more relaxed approaches to more structured, proactive approaches.

CLINICAL NEED TO ADDRESS PARENTAL STRESS

While parents of children with chronic health conditions are dedicated to saving the lives of their children, they also put themselves at risk of caregiver burnout at the same time.

In order to achieve the best outcomes for both parents and child, there is a need for the parents to recognise their own stressors, rather than focusing solely on the child. This places additional pressure on the child as they may feel that their diabetes is responsible for changes to their parents' health and wellbeing. Thus, the balance between caring for the child and enabling them to manage a chronic health condition, and ensuring the parents are in the best possible place emotionally and physically to facilitate this, is key.

Dr Henderson emphasises it is not only the child with T1D who is a patient; a household made up of others who are also impacted by the condition should be included under this title as well.

Furthermore, by recognising "diabetes-by-proxy" as a real, meaningful phenomenon, Dr Henderson hopes that clinical frameworks may start to explore options for treatment, improvement and legitimisation of parents' experiences and concerns.



Behind the Research

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Research Objectives

Dr Henderson studies parents' experience of their child's type 1 diabetes.

Detail

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Bio

Dr Henderson is a medical anthropologist using a syndemic analytic framework to explore the intertwined nature of diabetes and dementia among American Indian people. He developed the earliest minority Alzheimer's support groups and biocultural dementia research with American Indians. He is a voting member of the Choctaw Nation of Oklahoma.

Funding

National Institute on Minority Health and Health Disparities

Collaborators

- Amanda Hass
- Alisa Tomette

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Personal Response

What can parents of children with chronic illnesses do to prevent caregiver burnout?

Parents can become well informed regarding the nature of T1D and its many metabolic manifestations, identify a hotline for immediate help with questions, join a support group, teach family, friends, and teachers about the condition and its best management, and ask for their cooperation. As the child matures, parents should provide age-appropriate information in a factual manner that does not scare the child but empowers them. Last, like many things, the task is communication, communication, and, yet again, communication. //

