Type 1 diabetes, the United States and God

A three-year-old female was admitted to the hospital with a diagnosis of new-onset type 1 diabetes and diabetic ketoacidosis. Her past medical history was unremarkable. She lived with her parents who had immigrated to the United States as refugees from the Middle East three months before. After resolution of diabetic ketoacidosis, the process of diabetes education started with the help of a professional interpreter from the hospital. The mother rejected diabetes education, telling the paediatric endocrinology team that, since the patient is living in the United States, there should be a cure for diabetes so that her daughter would not need insulin injections.

The aetiology, pathology, diagnosis and management of diabetes in children were explained to the mother, including the fact that it is not a curable condition but is a treatable one that requires testing blood glucose and giving daily insulin injections. The mother burst into crying spells whenever she tried to obtain a finger blood stick on her child. The father was more able to accept the situation and slowly started learning the process of care. The mother suggested not using insulin and preferred asking God to cure her daughter. We explained that insulin is necessary for survival. The paediatric team - which included physicians, nurses, diabetes educators, a social worker and a psychologist - visited the family on a daily basis to help with diabetes education and management.

Finally, a paediatrician who spoke the native language of the family, and who shared their religious and cultural roots and had experienced immigration, volunteered to help. The paediatrician finalised the education process translating the medical advice into terms compatible with the family's cultural and religious beliefs. He was able to temper the mother's exaggerated hope for cure. The father was found to be reliable in managing diabetes at home as he had a realistic vision about his daughter's condition. After nine days of inpatient admission (comparable to our usual average of three days), the family was discharged home. When seen one week later on the outpatient clinic, the parents were coping better with the diagnosis.

Discussion

The diagnosis of type 1 diabetes in children places a huge psychological and emotional burden on the family. The diabetes-related stress of this mother can be associated with psychological distress and family conflict.¹ Discomfort, anxiety, depression and post-traumatic stress symptoms can occur in mothers of children with type 1 diabetes.^{2,3}

Interfering with traditional feeding patterns and activities can cause a lot of stress and family conflict. Needle fear and catastrophising pain by both patients and parents remain a major dilemma in the field of paediatric diabetes.⁴

Socio-demographic considerations play a major role in the delivery for care of type 1 diabetes in youth.⁵ Culturally dictated lifestyles of the family may determine response to 'scientific' recommendations.

It is well known that the delivery of diabetes care can be more efficient in ethnic minority groups when culturally competent interventions are utilised.⁶

Many studies have shown that the immigrant status of children can be a risk factor in the timing and diagnosis of type 1 diabetes in children⁷ as well as the progress of the development of complications of the disease.⁸

Understanding cultural, educational and economic factors of immigrant and ethnic minority children with type 1 diabetes in any society is very crucial to improve their metabolic outcome.⁹

Proper diabetes education programmes and materials should be used when dealing with any family from an ethnic minority group with type 1 diabetes children. Respect for language barriers, strong different cultures and health beliefs should be always exercised.¹⁰

Finally, the religious beliefs of the family should be respected as long as they do not seem to pose an imminent danger to the life of the child with type 1 diabetes. There are a few case reports of children with type 1 diabetes who have died at home while parents did not perform expected therapy because of their religious beliefs. Health care providers need to be observant of warning signs of dangerous beliefs that may result in the death of a diabetic child while parents are praying for a cure.¹¹

Conclusion

Exercising tolerance, sympathy, and respect for cultural diversity factors should help in improving the delivery of paediatric diabetes care with utilisation of available cultural, linguistic and personnel resources.

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