

Challenges Experienced by Families With a Child With Diabetes in Rural Nebraska

Vanessa Jewell, PhD, OTR/L¹, Emily Knezevich, PharmD, CDE¹, Amy Abbott, RN, PhD¹, Kameran Ulferts¹, Benjamin Feiten, Amanda Wise, OTR/L¹

¹Creighton University, Omaha, Nebraska, United States

DOI: 10.5014/ajot.2022.76S1-PO183

Date presented: April 1, 2022

Primary Author and Speaker: Vanessa Jewell, vanessajewell@creighton.edu

PURPOSE: In rural and medically underserved communities, children with type 1 diabetes and their families can struggle to get care matching current diabetes practice guidelines potentially resulting in an increased risk for health complications. Due to a dearth of pediatric endocrinologists in rural Nebraska and Iowa families are forced to travel extensively to receive care increasing the financial impact for families (Oser & Oser, 2020). Although these factors contribute to challenges for rural families, it is not clear if families living in rural Nebraska and Iowa experience similar or additional challenges in the quality and accessibility of health care, in daily management of the disease, and successful return to families' previous daily routines. Therefore, the aims of this qualitative study were to identify the specific, unique needs of rural families affected by type 1 diabetes.

DESIGN: Utilizing a phenomenological approach, a team comprised of healthcare providers, researchers, and community partners conducted four focus groups (n = 23) across Iowa and Nebraska. Informants were aged 8-80, were diagnosed or had a close connection to type 1 diabetes, and lived a minimum of a one-hour commute from a pediatric endocrinologist.

METHOD: All community partners participated in a series of research capacity building training prior to study implementation. Focus groups lasted 60-90 minutes and utilized a semi-structured questionnaire that allowed for in-depth exploration of the informants lived experiences related to challenges and barriers of access to specialized endocrinology healthcare services and health management routines. Phenomenological analysis guided the coding process that included the researchers and community partners (Moustakas, 1994). Trustworthiness was established through member checking, researcher triangulation, reflexivity, a thick description of the process, and an audit trail (Curtin & Fossey, 2007).

RESULTS: Four themes emerged: dramatic family and lifestyle changes after diagnosis, lack of access to specialized care resulted in complications, isolation improves resourcefulness in health management, and technology improves health management and flexibility.

CONCLUSION: Findings suggested a need to increase accessibility and training of healthcare providers in remote settings or creative strategies to improve access to care. Stakeholders across Nebraska and Iowa are resourceful and committed to utilizing technology to improve quality of life and health. Finally, improved support after diagnosis may improve the transition to managing a chronic disease. Specifically, occupational therapy may be a beneficial healthcare service for families as they are able to support the family's transition to caring for a young child with a chronic condition, such as type 1 diabetes. Services to improve the family's quality of life through providing support and strategies to return to family roles and routines are necessary.

IMPACT STATEMENT: Occupational therapy has a unique opportunity to support families after a child's diagnosis of type 1 diabetes to potentially improve child health outcomes, access to care, and health management routines.

References

- Oser, S.M., & Oser, T.K. (2020). Diabetes technologies: We are all in this together. *Clinical Diabetes*, 38(2), 188-189. <https://doi.org/10.2337/cd19-0046>
- Curtin, M., & Fossey, E. (2007). Appraising the trustworthiness of qualitative studies: Guidelines for occupational therapists. *Australian Occupational Therapy Journal*, 54(2), 88-94. <https://doi.org/10.1111/j.1440-1630.2007.00661.x>
- Moustakas, C. (1994). *Phenomenological research methods*. Sage Publications.