

Experiences and Difficulties in Transitioning from Pediatric to Adult Diabetes Clinical Care

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BACKGROUND

- Emerging adulthood (ages 18-25) is a developmental stage characterized by new challenges, responsibilities, and major life changes.¹
- Emerging adults with Type 1 Diabetes (T1D) must also juggle the transfer of healthcare from the pediatric to adult clinical setting.
- The ADA currently recommends that pediatric providers begin transition preparation at least one year prior to planned transfer to minimize lapses in care.²
- Current literature suggests that healthcare transition is associated with an increased risk of acute and chronic health complications for patients with T1D.³⁻⁵
 - Poor glycemic control
 - Deterioration of self-care
 - Acute diabetes-related hospital admissions
 - Vascular complications
- There is limited research regarding ways to optimize the transition process for patients with T1D.

OBJECTIVES

- To highlight patient-focused areas of improvement that could be used to optimize transition of care.

STUDY DESIGN

Barbara Davis Center (BDC) patients with a diagnosis of T1D between ages 17-25 who had completed both a pediatric BDC transfer visit and at least 1 adult BDC appointment were identified.

- Demographic information and diabetes characteristics were obtained via retrospective chart review.

13 patients were randomly selected to complete a "Type 1 Diabetes Transition" questionnaire developed by faculty and staff at the BDC.

- The questionnaire included open-ended questions regarding experiences transitioning to adult diabetes care.

Interviews were conducted over the phone, recorded, and analyzed for themes. Initial broad themes were generated separately by research team members. Members then met to determine a consensus list of finalized themes.

Using finalized themes, members separately analyzed interviews and assigned one or more to each interview question. Final assignments were made by unanimous group vote.

REFERENCES

- Arnett JJ. Emerging adulthood. A theory of development from the late teens through the twenties. *Am Psychol*. 2000;55(5):469-480.
- Chiang JL, Maaha DM, Garvey KC, et al. Type 1 Diabetes in Children and Adolescents: A Position Statement by the American Diabetes Association. *Diabetes Care*. 2018;41(9):2026-2044. doi:10.2337/dci18-0023.
- Helgeson VS, Reynolds KA, Snyder PR, et al. Characterizing the transition from paediatric to adult care among emerging adults with Type 1 diabetes. *Diabet Med*. 2013;30(5):610-615. doi:10.1111/dme.12067.
- Castorena-Seidenfaden R, Jensen AK, Smedegaard H, et al. Clinical, behavioural and social indicators for poor glycaemic control around the time of transfer to adult care: a longitudinal study of 108 young people with diabetes. *Diabet Med*. 2017;34(5):667-675. doi:10.1111/dme.13318.
- Lofstein DS, Seed M, Kingersmith S, et al. Transition from pediatric to adult care for youth diagnosed with type 1 diabetes in adolescence. *Pediatrics*. 2013;131(4):e1062-e1070. doi:10.1542/peds.2012-1450.
- Sheehan AM, White AE, Coyne I. The experiences and impact of transition from child to adult healthcare services for young people with Type 1 diabetes: a systematic review. *Diabet Med*. 2015;32(4):440-448. doi:10.1111/dme.12639.
- Coyne I, Sheehan A, Heery E, White AE. Healthcare transition for adolescents and young adults with long-term conditions: Qualitative study of patients, parents and healthcare professionals' experiences. *J Clin Nurs*. 2019;28(21-22):4062-4076. doi:10.1111/jocn.15006.
- Gray WN, Schaefer MR, Resmini-Rawlinson A, Wagoner ST. Barriers to Transition From Pediatric to Adult Care: A Systematic Review. *J Pediatr Psychol*. 2018;43(5):488-502. doi:10.1093/pepsy/ixx142.
- Vijayan T, Benin AL, Wagner K, Romano S, Ardman WA. We never thought this would happen: transitioning care of adolescents with perinatally acquired HIV infection from pediatrics to internal medicine. *AIDS Care*. 2009;21(10):1222-1229. doi:10.1080/09540120903273004.
- Hillard ME, Peltus JG, Clark LM, et al. Perspectives from before and after the pediatric to adult care transition: a mixed-methods study in type 1 diabetes. *Diabetes Care*. 2014;37(2):346-354. doi:10.2337/dc13-1346.
- Pyatak EA, Sequiera PA, Whitemore R, Vigen CP, Peters AL, Weigensberg MJ. Challenges contributing to disrupted transition from paediatric to adult diabetes care in young adults with type 1 diabetes. *Diabet Med*. 2014;31(12):1615-1624. doi:10.1111/dme.12485.
- Commissariat PV, Wentzell K, Tanenbaum ML. Competing Demands of Young Adulthood and Diabetes: A Discussion of Major Life Changes and Strategies for Health Care Providers to Promote Successful Balance. *Diabetes Spectr*. 2021;34(4):328-335. doi:10.2337/ps21-0009.
- Commissariat PV, Wentzell K, Tanenbaum ML. Competing Demands of Young Adulthood and Diabetes: A Discussion of Major Life Changes and Strategies for Health Care Providers to Promote Successful Balance. *Diabetes Spectr*. 2021;34(4):328-335. doi:10.2337/ps21-0009.
- Raymaekers K, Onis L, Pihlken S, et al. The Role of Peers for Diabetes Management in Adolescents and Emerging Adults With Type 1 Diabetes: A Longitudinal Study. *Diabetes Care*. 2017;40(12):1678-1684. doi:10.2337/dci17-0643.
- Raymaekers K, Onis L, Pihlken S, et al. The Role of Peers for Diabetes Management in Adolescents and Emerging Adults With Type 1 Diabetes: A Longitudinal Study. *Diabetes Care*. 2017;40(12):1678-1684. doi:10.2337/dci17-0643.

RESULTS

- Thirteen (n=13) young adults with T1D (M_{age} 23.09±1.52 years; M_{duration} 13.04±5.35 years) completed the questionnaire (Table 1).
- Five interview questions were thematically analyzed (Table 2).
- Participant responses for each question either (Table 2):
 - Fit into the finalized themes
 - Lacked sufficient information to judge ("insufficient info")
 - Were too infrequent to be considered a theme ("other")
 - Answered "nothing" to the question ("none")

Table 1: Participant Demographics

Sex (%Female)	46%
Age (years; mean±SD)	23.09±1.52
<u>Race/Ethnicity</u>	
%Caucasian	69%
%Hispanic	23%
%Other	8%
<u>Insurance</u>	
%Private	69%
%Public	31%
T1D Duration (Years)	13.04±5.35

Table 2: Thematic Analysis of Transition Questionnaire Responses

Transition Strengths	Transition Challenges	Areas for Improvement	Support Systems	Support Type
Streamlined 66.7% (n=10)	Provider Compatibility 12.5% (n=2)	Distance to clinic 20% (n=3)	Family 68.8% (n=11)	Emotional 25% (n=5)
Clinic Familiarity 20% (n=3)	Lack of Guidance 25% (n=4)	Scheduling 13.3% (n=2)	Significant Other 25% (n=4)	Diabetes Care 35% (n=7)
Other 6.7% (n=1)	Changing Providers 18.8% (n=3)	Other 20% (n=3)	None 6.3% (n=1)	Financial 30% (n=6)
None 6.7% (n=1)	None 37.5% (n=5)	None 46.7% (n=7)		None 5% (n=1)
	Insufficient Info 6.3% (n=1)			Insufficient Info 5% (n=1)

CONCLUSIONS AND NEXT STEPS

- Strengths:** Similar to preexisting literature on the benefits of joint transition clinics, patients in this study highlighted that a streamlined process and previous familiarity with the clinic made transferring care easier.^{6,7}
- Challenges:** Notable barriers to the transfer process included provider compatibility issues, lack of guidance, and difficulty changing providers. These findings are consistent with what has been described in the transition literature for a variety of chronic illnesses, including T1D.⁷⁻¹⁰
- Support:** Young adults in this study highlighted the continued need for financial, emotional, and diabetes-care support as they transition to adult clinical care. Current literature strongly promotes the importance of multifaceted support systems in healthcare transition for young adults with chronic diseases.^{8,9,11-15}
- Future Directions:** These findings may indicate areas where providers at this joint transition clinic can improve the transition process. They also provide valuable considerations for creating a patient-centered, effective transition program.
- Limitations:** Small sample size, recall bias, and limited resources to reinterview participants for additional information and clarification.

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COMIRB Approval #: Protocol #20-165.

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