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Project: *ReshapeT1D: Utilizing patient and clinician led research to uncover new insights on type 1 diabetes lived experiences in Alberta*



Background

For many, living with T1D often leads to burnout and distress and clinicians are under-resourced to provide appropriate emotional and social support. To meet the demand of addressing gaps in how to provide the best care experiences and improve health outcomes, clinicians often survey patients to assess the quality of care and while an efficient tool, surveys often lack important information. In a questionnaire a person might respond by checking

a box labelled 'Satisfied' as an indication of the quality of care received. As has been previously shown, understanding the lived experience through narrative inquiry is more impactful for evaluating processes of care. In a recent Ontario based study, when asked about reflections of care received in a narrative interview a person living with T1D responded:

"I think it is very important to be part of a very active team with your nurse, your doctor, your partner-spouse, all working towards and end goal (...) If you don't think that you've got a good team as part of your treatment with diabetes, then continue looking until you are happy you've got a team you can work with" [26].

The noted patient narrative provides a rich description of the lived experience beyond what is unearthed through checkboxes within a survey. Several studies have explored the lived experiences of people with T1D, yet the majority have focused on T1D in

children and how those experiences are related to transitions of care [27–30]. To date, research into understanding the adult T1D lived experience in Canada is nearly non-existent. The DAWN2 study remains to be one of the best sources for understanding T1D adult care, however, focuses only on adults 18-30 years old, using surveys and self-reported tools for data collection [31]. The remaining existing adult T1D qualitative studies focus on special interest areas such as physical activity, complications, or compliance with treatments [32–35]. There is a clear need for more evidence that details the lived experiences of people living with T1D and perspectives of healthcare providers on complex T1D psychosocial issues. The adult T1D clinical perspective can provide valuable insights into care especially since 80% of adults living with T1D also have T1D related comorbidities [36].

Objectives & Research Questions

Research Questions: (1) what are the challenges facing people living with T1D who are seeking clinical care in Alberta? and (2) How can the lived experiences of people living with T1D in Alberta provide solutions to support person-first diabetes care?

Overarching Goal: To understand and describe the opportunities and challenges in providing T1D clinical care, identify factors associated with reduced or enhanced quality of care, and provide recommendations for T1D healthcare providers and administrators, led by study partners.

Objective 1: To understand the Albertan T1D lived experiences in accessing healthcare using co-created themes of appointments, barriers, influential supporters, adaptability and resilience, therapies and accessibility, and sex and gender.

Objective 2: Collaboratively develop integrated knowledge translation (iKT) strategies with study partners, using evidence generated from objective 1 to make recommendations to improve T1D care in Alberta.