

Diabetes “on the side-lines with normal life”: A qualitative study of adolescents’ experiences of living with and managing type 1 diabetes

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Dear Editor,

While biomedical measures (HbA1c levels) have traditionally guided diabetes research, there is increasing awareness for the need for person-centred or family-centred diabetes research and care¹, particularly during adolescence and young adulthood as these periods pose unique challenges for type 1 diabetes (T1D) management². We write to share the findings of our research, conducted in University Hospital Limerick, which aimed to enhance understanding of adolescent experiences and management of T1D. Our findings benefit UHL’s paediatric diabetes clinic and are transferable to similar clinics seeking to provide person-centred diabetes care aligned with adolescents’ lifestyles.

We conducted online qualitative interviews with ten adolescents aged 14 to 18 years old. The in-depth interviews explored various aspects of T1D, with scope for adolescents to discuss what they felt was important. The data was analysed using reflective thematic analysis³.

Three overarching themes were generated, some with additional subthemes (Figure 1).

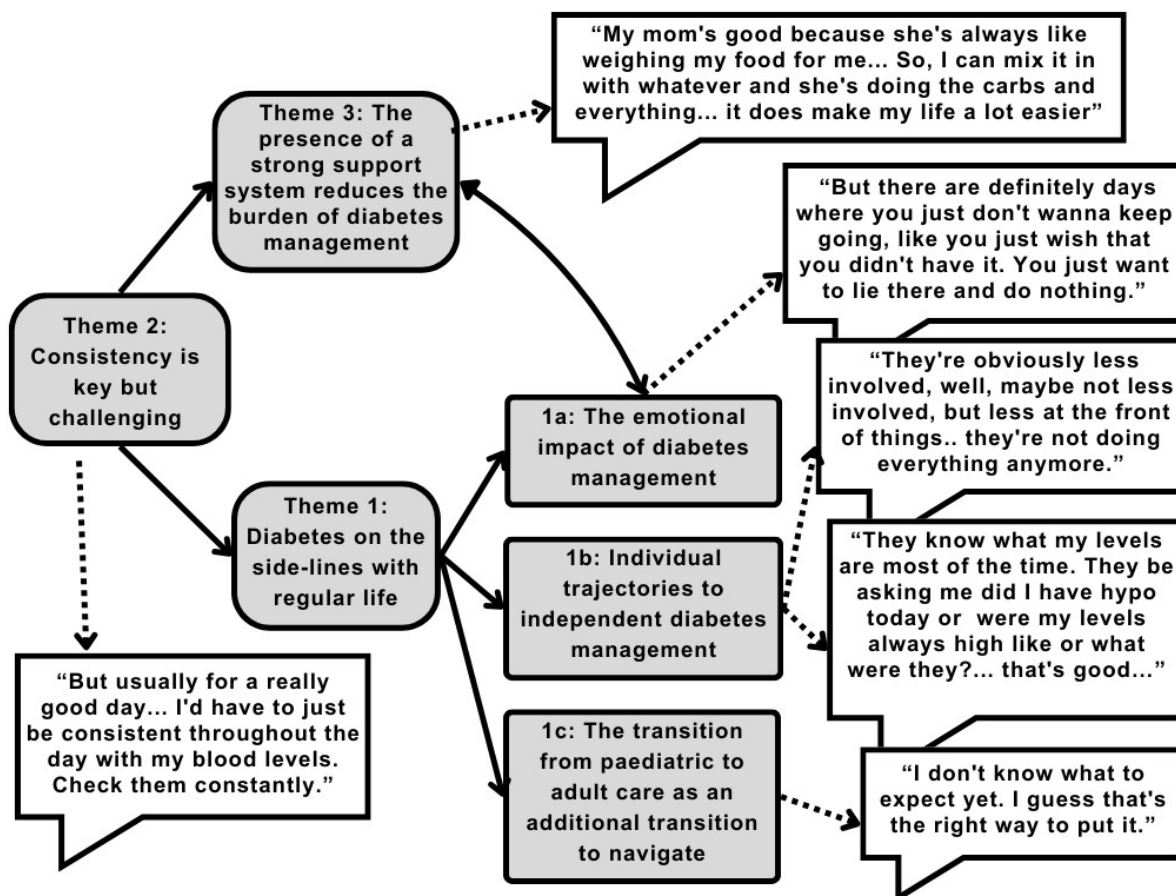


Figure 1: Visual overview of the themes and subthemes from thematic analysis, including participant quotations.

Firstly, living with and managing diabetes was described as an ever-present aspect of adolescents' lives. While the adolescents were generally positive about living with T1D, the emotional impact was evident, ranging from annoyance and frustration to deeper levels of emotional distress. Adolescents discussed their evolving trajectories towards independent diabetes management, highlighting the importance of individualised approaches. The transition from paediatric to adult diabetes care emerged as an additional stressor, with adolescents expressing anxiety about the unknowns associated with this change. They suggested a need for more in-depth discussions with the paediatric team and designated support during this transition.

Secondly, adolescents acknowledged the importance of consistency in T1D management but faced challenges in incorporating it into their busy routines. Disruptions to routines due to hectic lifestyles and the draining responsibilities of management were reported. Interestingly, the COVID-19 pandemic provided a temporary respite from adolescents' busy lifestyles, leading to improved consistency in management and reported improvements in glycaemic control.

Finally, the adolescents emphasised the crucial role of a supportive system. Parents played a central role, offering practical and emotional assistance, alleviating the burden of T1D. The diabetes care team was a vital resource, with participants comfortable seeking help when needed. Additionally,

friends provided emotional support and, despite limited diabetes knowledge, understood basic actions in case of emergencies. Friends also provided a safe space for some participants to begin to navigate typical adolescent behaviours.

Our findings reveal that managing T1D alongside busy adolescent lifestyles poses challenges, potentially explaining previous findings of suboptimal management during adolescence⁴. The emotional impact of T1D on adolescents, including experiences of diabetes distress, underscores the need for enhanced emotional supports. While social support from parents and the care team is positive, evolving support to meet adolescents' changing needs is crucial.

In conclusion, we recommend the development of individualised diabetes management strategies for each adolescent, increased psychoeducation on managing emotional distress, and early discussions about the transition from paediatric to adult diabetes care. Clearer education and support during this transition could alleviate emotional distress and improve self-management and psychosocial outcomes.

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