Transition to Adult Care for Adolescents with Diabetes - A National Survey

Abstract:
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Currently, there are no national guidelines on transition from paediatric to adult services for children with Type 1 Diabetes Mellitus (T1DM) in Republic of Ireland. There are 19 hospitals in Republic of Ireland looking after children with T1DM. Seventeen have a designated clinic for children with T1DM. Ten have a transition clinic for adolescents with T1DM. Most centres transition after patients finish secondary education. Six centres hold transition information sessions and 6 have access to a psychologist. Fifteen centres describe a gradual transition process. There is little national consistency in transition and there is a need for a collaborative national framework on T1DM transition.

Methods
This study was a cross-sectional, mixed-methods data collection study. A questionnaire was developed, trialled and revised locally, to gather information on the local principles of transition. Questionnaire data were supplemented by telephone consultation with a member of each of the 19 paediatric T1DM multidisciplinary teams (MDT) nationally. Follow-up interviews were conducted for additional data collection, as required. Summary statistics were applied to the data.

Results
All 19 units (100%) that provide care to children with T1DM in RoI responded to both the questionnaire and telephone interview. The number of children attending each service varied (range 31-520) with a combined total of 2,768 children attending all 19 units. The largest numbers of children were reported attending units in Dublin (range 300-520). Self-reported staffing levels (for doctors, diabetes nurses, dieticians, psychologists and social workers) for all units were lower than national guidelines. The main issues relating to transition are summarised in Table 1. Screening practices prior to transition were very similar among all units. Transition age varied between 16 and 18 years, but most units transition children after completing secondary education. Self-reported barriers to optimising transition practices included lack of adequate MDT staffing levels and lack of transition guidelines.

Discussion
The transition period is increasingly recognised as an important part of paediatrics and adult medicine, but one which requires resource investment. When transition is poorly organised, the results include poor attendance at adult clinics and increased risks of short-term and long-term complications. The short-term complications of T1DM, such as diabetic ketoacidosis, are the leading cause of hospitalizations and death among children with T1DM. The respondents in our study cited lack of resources and lack of national guidelines as barriers to optimising transition in their own units. Many units could not provide data on adolescents following transition. There appears to be disconnect between paediatrics and adult T1DM MDT services, which could be improved with more resources and with a national database. In this study, it was not possible to reliably evaluate the short term complications experienced by adolescents with T1DM following transition. The majority of respondents from units with transition clinics were not aware of the transition practices in other units. Some units were trying to establish a transition clinic at the time of the survey. Of importance, 5/16 units with some post-transition data collection described that post-transition, some patients do not attend adult clinics. It is impossible to estimate based on currently available data, how many patients disengage from adult services following transition, but this is an important area for further research and quality improvement. Our study has limitations. The information provided by participants is subject to recall bias and double-counting of patients attending more than one centre is likely. One strength of our study is that all 19 units nationally freely contributed information; this belies the importance of this topic to the T1DM MDTs nationally. In summary, transition for children with T1DM in RoI demonstrates an opportunity for a national quality improvement initiative, aiming for equity of access and care nationally. A national framework for transition would facilitate T1DM care teams who are in the process of setting up or revising their own transition clinic.

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