

Transition During Adolescence, Is There Room To Improve?

Sinead Glackin, Sinead Molloy, Orla Neylon

Sligo Regional Hospital

Introduction

Transition is a difficult period for young people with type 1 diabetes. During adolescence, young people develop autonomy of their diabetes. However a number of factors make this very difficult including; increasing insulin resistance associated with puberty; challenging family and social circumstances; the development of the adolescent brain, as shown by functional MRI studies, which can contribute to adolescents placing a higher value on peer acceptance over the necessity for correctly taking insulin; the risk of psychopathology including anxiety, depression and eating disorders; and the transition from paediatric to adolescent services(1). During this period of turmoil, adolescents are vulnerable to poor mental and physical health and ensuing deterioration in metabolic control(2). In this country we do not have an established adolescent service with dedicated specialists in adolescent medicine. Young people with chronic disease leap from the supposed warm and nurturing paediatric services to the distant and intimidating adult services. However, some vulnerable young people fall through the gap(3). This puts these young people at risk of short and long term co-morbidities.

Definition of Transition

Planned, purposeful movement of the adolescent or young adult with a chronic disease from a child (and family) centred to an adult orientated health care system(4).

Aims and Objectives

The primary aim of this study was to assess the levels of satisfaction with the current transition process among adolescents with type 1 diabetes in our hospital. Our objectives were to investigate how this process could be improved and to find out the reasons for disengagement of adolescents with services post transition.

Methods

We developed a questionnaire for adolescents and their parents/ legal guardians who had transitioned to adult services within the last 5 years. Transition has traditionally depended on different factors including age, maturity, timing of education and state exams.

Participants were approached at their adult outpatient appointments and the study was discussed with them. They were given the questionnaire to fill out in the waiting room after signing an informed consent sheet. Those who missed their adult appointments, or who had been transferred to adult services at a different hospital were contacted by phone and the study was explained to them. They were then posted out a consent form, information sheet and questionnaire for both the young person and their parents/ legal guardians with a stamped addressed envelope to return.

Questionnaires

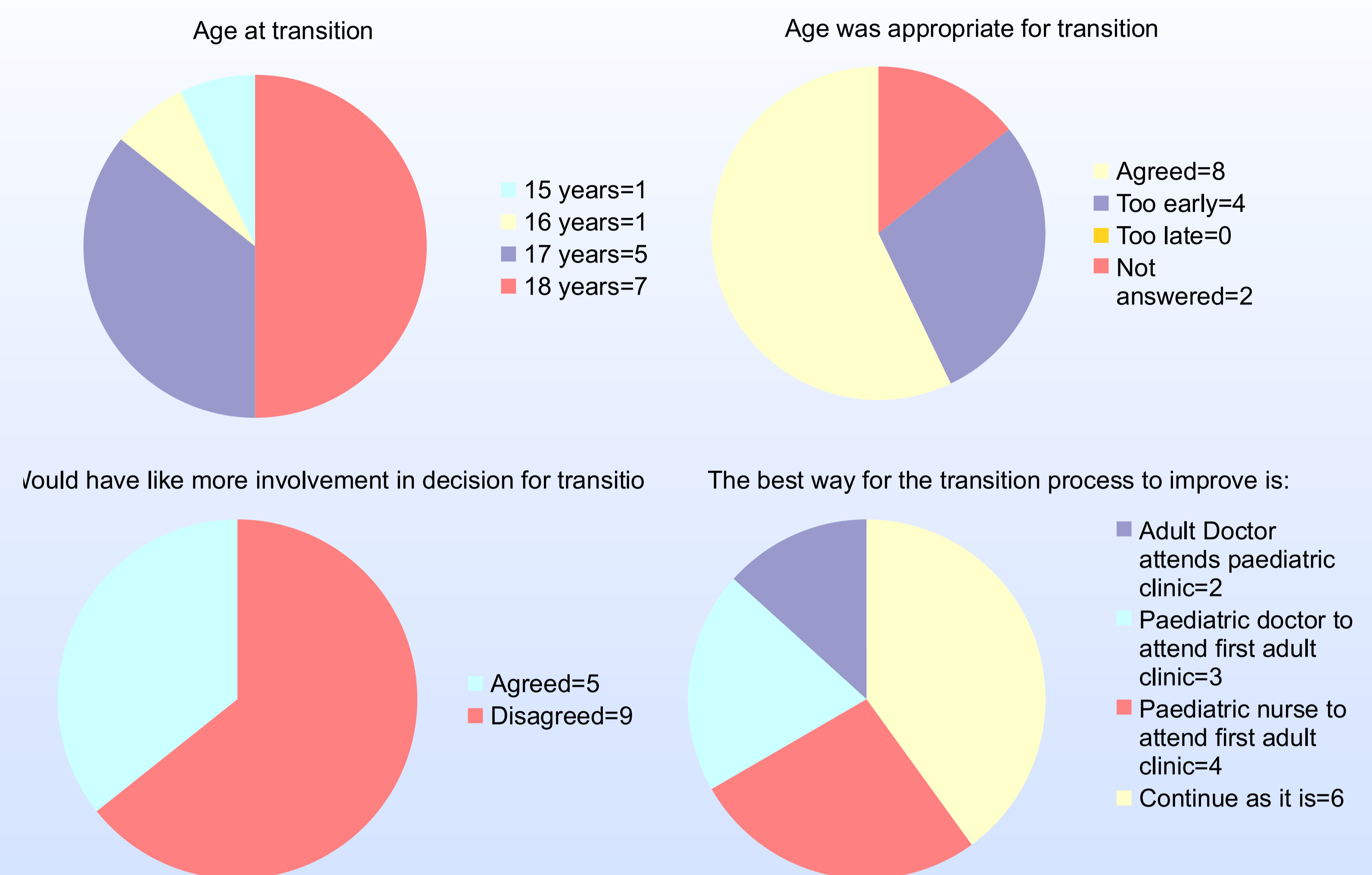
Parents

	Strongly Agree	Agree	Don't Know	Disagree	Strongly Disagree
My son/daughter is capable to go on their own to clinic visits					
My son/daughter is knowledgeable about their diabetes and its management					
My son/daughter is responsible for their own medication at home					
My son/daughter knows how to contact the hospital themselves if they have a problem					
My son/ daughter can organise their own repeat prescriptions					
My son/ daughter know where to access reliable sexual health information for young people					
I understand the changes (physical and emotional) which occur during adolescence and how the effects this has on their diabetes					
I understand the differences between paediatric and adult medical care					
I understand the importance of an appropriate healthy diet for young people					
I understand the importance of regular exercise for young people					
I understand the effect of smoking, drugs & alcohol on my son/daughter's diabetes and general health					
I think the best way for the transition process to improve is (please select one option):					
The adult doctor to join the paediatric clinic for the final Paediatric clinic appointment:	Yes/No				
The paediatric doctor to join the adult clinic for the first young adult clinic appointment:	Yes/No				
The paediatric nurse specialist to attend the first few young adult clinic appointments:	Yes/No				
To continue the current service of a direct transition from Paediatric to Adult services:	Yes/No				
Other					

Patients

	Strongly Agree	Agree	Don't Know	Disagree	Strongly Disagree
I felt stressed by the transition process					
I was well prepared for my transition from paediatric to adult care					
I had started attending paediatric clinics on my own before I transitioned to adult care					
I felt supported throughout the whole transition process					
I felt upset by the exclusion of family members from my diabetes care					
I would have liked to have been more involved in the decision for transition					
If I have any problems or worries, I know how to contact the diabetes team for advice					
I feel supported by my family/ friends					
The young adult care team are stricter on my glycaemic control than the paediatric team					
I feel comfortable to attend clinics on my own					
The doctor treats me as an adult					
I have a good relationship with my new team					
The doctor explains blood/ urine results/ risks of complications					
I leave clinic confused with the health information discussed with me					
I understand the importance of an appropriate healthy diet					
I can manage my own diabetes for any sports/ exercise					
I can manage my own diabetes when I go out with friends					
I can manage my Diabetes on my own when I am sick					
I understand my eligibility for benefits					
I know how to deal with unwelcome comments/ bullying					
I know someone I can talk to when I feel sad/ fed-up					
I know how to cope with emotions such as anger or anxiety					

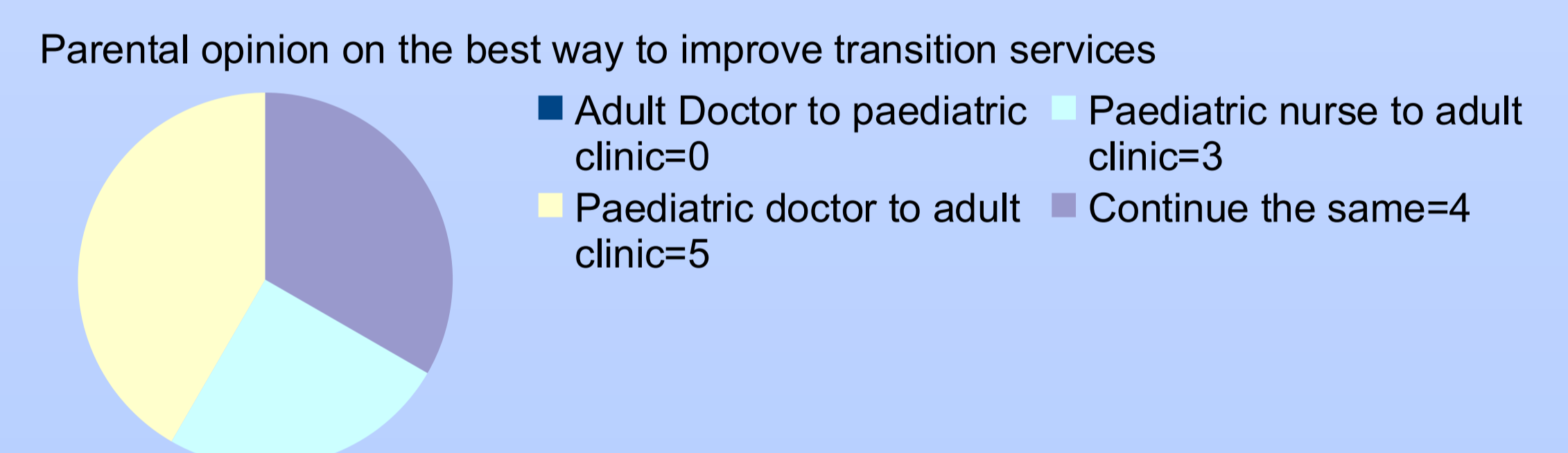
Results- Patients



Results- Patients

A total of 22 patients were eligible for inclusion. Of these, 14 (63%) responded. 10 patients felt that they were well prepared for transition. 4 patients were attending clinics on their own before transition. 3 patients disagreed with the statement that they were managing on their own before transition. 11 felt supported through the transition process. 6 patients admitted to having missed adult clinic appointments because "couldn't make it". 3 patients admitted missing appointments because "they didnt want to go".

Results- Parents



Conclusion

The results of this study highlighted areas for improvement in the transition process for adolescents with chronic disease. This includes a need for improved communication and organisation between paediatric and adult teams, jointly staffing young adult clinics, appropriate scheduling of young adult clinics during college breaks and encouraging participation and independence of adolescents during clinic visits.

Discussion

ISPAD guidelines recommend: A joint adolescent or young adult clinic with both members of both professional teams working together; Good communication, including a written protocol to facilitate understanding between all services providing care for the young person and ideally a liaison person between teams; A data-base and a named professional, to identify and locate all young people who fail to attend follow-up consultations(5).

In peripheral hospitals where both paediatric diabetes and adult endocrinology services are on co-habitated, there is additional benefit of the consistency of computer systems for lab results, patient history, ongoing problems including psychological difficulties, co-morbidities such as retinal disease or microalbuminuria and co-existing patient charts.

References:

- Hamilton J. & Daneman, D. (2002) Deteriorating diabetes control during adolescence: physiological or psychosocial? *J Pediatric Endocrinol Metab*, 15 (2): 115-126.
- Grey, M., Boland, E. A., Yu, C., Sullivan-Bolyai, S. & Tamborlane, W. V. (1998) Personal and family factors associated with quality of life in adolescents with diabetes. *Diabetes care*, 21 (6): 909-914.
- Anderson B., Ho, J., Brackett, J., Finkelstein, D. & Laffel, L. (1997) Parental involvement in diabetes management tasks: relationships to blood glucose monitoring adherence and metabolic control in young adolescents with insulin-dependent diabetes mellitus. *The Journal of pediatrics*, 130 (2): 257-265.
- Kipps S, BAHU T, ONG K et al. Current methods of transfer of young people with type 1 diabetes to adult services. *Diabet Med* 2002; 19: 649-654
- Werther GA, COURT JM. Diabetes and the Adolescent. 1998, Miranova Publishers, Melbourne
- ISPAD guidelines 2009 http://ispad.org/sites/default/files/resources/files/ispad_guidelines_2009_-_adolescence