

Original Article

Transition from pediatric to adult diabetes care: smooth or slippery?

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Objectives: The purpose of this study is to evaluate the practices of diabetes health care providers concerning the transition from pediatric to adult diabetes care. The information presented here may help increase awareness of the organization of transitional care for young people with diabetes and prevent the loss of follow-up during this vulnerable period in their lives.

Methods: A questionnaire with an explanatory letter was sent to all members ($n = 578$) of the International Society for Pediatric and Adolescent Diabetes (ISPAD). A follow-up mailing was sent 4 months later.

Results: In total, 92 questionnaires (16%) from members representing 36 countries were included in the analysis. In 76% of the centers, youth are seen until the age of 18 yr; 36% of the pediatric centers see adults > 25 yr; 30% report children under the age of 16 receive follow up from adult diabetologists or internists. About half of the programs already have a structured transition process usually targeting youth 16–25 yr of age. The majority of responders propose that preparation for transition starts at least 1 yr prior to leaving the pediatric center.

Conclusion: Youth with type 1 diabetes often struggle to keep diabetes management a priority and find it challenging to maintain optimal metabolic control. When they graduate from pediatric care, some of these young people opt out of care altogether, only to resurface in the medical system when they develop complications which may have been prevented. Our survey of diabetes health care professionals in 36 countries worldwide shows that the actual transition practices in many places are far from optimal and require improvement. Transitional care should start early and strategies should promote uninterrupted, comprehensive, and accessible adult care.

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Optimal metabolic control and quality of life are the major goals in the care of children and adolescents with diabetes mellitus (1). Successful management requires an intensive treatment regimen from diagnosis onward. Diabetes affects many aspects of life: this is true for people with diabetes in general and for adolescents in particular (2). Social factors and peer pressure feature prominently in adolescence and influence the teen's choices around lifestyle and decisions about self-management. During this relatively healthy time in their lives teens feel invulnerable. Diabetes management may not be a priority for the teen, and whereas parents

consider it important, parental influence is waning. Late adolescence is a time characterized by change: change in schooling, employment, living situations, and relationships. This transitional period can be a lonely and vulnerable period in the life of the youth with diabetes. Ideally, young people with special health care needs should have access to uninterrupted, comprehensive, and accessible care during this high-risk time. Over the last decade or two, more and more attention has been given to the need to improve the transition experience of young people with chronic disabilities (3, 4). Adapted care and structure have

been suggested in order to promote a smooth passage from the pediatric setting to the adult clinic and to prevent large numbers of drop-outs (5, 6).

The purpose of our study was to collect data about the practices of pediatric diabetes health care professionals in different parts of the world concerning the transition from pediatric to adult diabetes care. The results of this study will provide baseline information for future evaluation and also help to inform the development of strategies to improve the transition process.

Methods

In order to audit transition practices in different parts of the world, a questionnaire was developed by the authors and submitted by e-mail to all members of ISPAD. At the time of mailing, this international society had 578 members interested in childhood diabetes with approximately two thirds of the membership being physicians and the rest, other health care professionals such as nurses, psychologists, and dieticians. The survey was resent to the membership 4 months later in an attempt to increase the response rate.

The 21-item questionnaire was designed to collect information about the health discipline of those completing the questionnaire, the setting in which they work, the age range of the patients followed up in their center, and the type of physician specialist who is most often responsible for caring for adolescents in their practice. Several of the survey questions address the transition process, for example, where and at what age are youth transferred to adult care, who initiates the referral, how formalized is the process and how many teens make a successful transition. The survey also invited participants to provide an opinion on the ideal age for transition as well as suggestions for improving the transition process.

Results

Ninety two members representing 16% of the ISPAD membership from 36 countries responded to the questionnaire. Eighty-eight of the 92 respondents were physicians and the rest were nurses. Most (63.7%) were from university hospitals, but 27.4% work in regional hospitals, 4.4% in national centers/district hospitals and 4.4% were in private practice. Table 1 shows the differences observed with respect to the age range of youth followed in the centers. Although 52 centers do not see any young adults beyond age 25 yr, almost 10% of the centers still see more than 40 patients over 25 yr of age. As expected most children under the age of 12 (87%) are followed by a pediatric diabetologist; in some cases (30%), care is shared with

Table 1. Age distribution of the children seen by the different centers

Age (yrs)	Number of patients			
	n < 10	n = 10–20	n = 20–40	n > 40
0–4	32	22	13	15
5–9	3	21	24	34
10–14	2	5	33	42
15–18	4	8	26	44
19–25	24	6	7	17
> 25	20	1	3	9

a pediatrician. A small number of responders (10%) report that internists or adult diabetologists care for children < 12 yr of age in the adult environment. In the 12–15-yr age-group, 30% receive diabetes care from internists, adult diabetologist and general practitioners (GPs) and while this number rises to just over half (58%) of those who are 16–18.0 yr of age cared for by adult specialist, pediatric diabetologists remain involved in 76% of these. Respondents indicate that young adults (> 18–25 yrs) remain in pediatric diabetes clinics in 37% of centers; the majority see adult diabetologists as well. In 53% of the centers, teens over the age of 18 can no longer be followed up as outpatients. An even larger number of centers (77%) will not admit patients over the age of 18 yr.

Half of the centers surveyed report a structured transition program; 44% of centers suggest transition between the ages of 14 and 25 yr. In 41 centers, transition age is between 18 and 25 yr of age. Only one center reports no age limit. An evaluation of successful transfer to adult care is done in 35% of the centers. Evaluation is reported to be rare or not at all by 60% of those surveyed. In some clinics (25%) the transfer is always to the same adult clinic. In general the transition is initiated by the pediatric unit. Different approaches to transition were described, including phone contact, letter, joint clinics either at the pediatric or adult site, cross-over meetings with pediatric and adult team, and group transfer. The larger centers generally reported using more than one method to promote successful transition. Ninety percent of those who responded to the survey recommended that transition planning begin at least 1 yr prior to transfer.

Discussion

Despite an increased awareness of the need to improve transitional care for young people with chronic illness (7, 8), most pediatric diabetes centers lack a structured program to promote a smooth and systematic transition to adult diabetes care. Where such programs do exist, they mainly occur at the local level and are limited to informal, personal contact between centers.

When youth drop out of care at this vulnerable age they miss the opportunity for expert self-management education and coaching as well as complication surveillance and the early detection and treatment of problems. There is a risk that they will resurface in the medical system only when serious problems which otherwise may have been averted occur: hence the importance of a structured transition program (9–11).

Because of the limited sample and sample size the information in this paper must be interpreted with caution. It is not an exhaustive study of transition practices for diabetes care neither worldwide, or among ISPAD members. Furthermore, most of the responders were physicians and those who did respond may be those for whom transition is a particular passion or problem. All the same, the results clearly suggest a lack of organized transition and follow-up as well as a lack of evaluation of the efficacy of the transition approaches.

This study also shows that in a large number of countries, children with type 1 diabetes are still seen in adult clinics where they may not benefit from a pediatric approach to treatment where developmental issues are considered and addressed. Indeed the high prevalence of type 2 diabetes in adults compared with the relatively low frequency of diabetes in children and young adults may result in these young people getting lost in the crowd at the adult clinic (12, 13). Clearly adolescents and young adults require an approach that is sensitive to their stage of development and readiness to fit diabetes management more successfully into their lives. Pediatric teams are wise to collaborate with and refer to adult diabetes specialists/teams who enjoy and understand this population and who follow up a number of youth in their clinic.

Finally, responders to our survey suggested a number of strategies to improve the transition to adult care. These include early joint clinics, a multidisciplinary team approach to transition, an early and gradual promotion of personal responsibility for self-management always including parents and other care takers where appropriate, and finally the increased inclusion of adolescents in the planning of their future health care. Transition should be a long, planned process, and referral should be accompanied by a written summary of the pediatric experience and medical situation. Structured transition and the monitoring of its effects are necessary if drop-out rates are to be reduced and complications prevented (14–16). Likewise it is critical that increased efforts to optimize control in children and adolescents are not followed by rapid deterioration in young adulthood because of the lack of thoughtful transitional care (17,18).

Transition guidelines, as proposed by Weissberg-Benchell et al. (2), might be useful, but an evaluation

of efficacy, as a standard rating of such assessments, is necessary.

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