

*Miscellanea*

## Transition from paediatric to adult care: An emerging challenge

Shamali Abeyagunawardena<sup>1</sup>, \*Asiri Abeyagunawardena<sup>2</sup>, Shaman Rajindrajith<sup>3</sup>

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### Introduction

The adolescent age is the most vulnerable period of life when the adolescents have to deal with their physical changes of puberty and to bear more responsibilities in their dealings. When they suffer from a chronic disorder that makes it more difficult to cope with these vagaries and changing of their most loved health care personnel during this period could make matters worse. Currently in Sri Lanka, the decision to transfer an adolescent patient from a paediatric care unit to an adult medical care facility often happens abruptly as there are no clear strategies or guidelines laid down by the professional governing bodies. Although the paediatric age was increased from 12 to 14 years recently, it does not address the issues related to the transfer of the care of patients. For example, many diseases that were once considered to be confined to paediatrics, such as thalassaemia major and childhood renal disorders, *de facto* continue into adult life. In addition, paediatric medical care and adult medical treatments differ significantly considering the approaches in handling issues pertaining to growth and development. Many children with chronic illnesses are unlikely to have completed their growth or attained puberty as early as 14 or 16 years. The adult physician, who values patient autonomy, is likely to pay more attention to issues related to employment and reproduction than growth and development<sup>1</sup>. One of the greatest challenges that will be faced by the paediatricians and indeed the health services in the coming decades will be to arrange efficient and caring transfer of adolescents from paediatric services to adult care<sup>1,2</sup>.

<sup>1</sup>Senior Lecturer, Faculty of Medicine, University of Peradeniya, <sup>2</sup>Professor of Paediatrics, Faculty of Medicine, University of Peradeniya, <sup>3</sup>Professor of Paediatrics, Faculty of Medicine, University of Colombo

\*Correspondence: [asiriabey26@gmail.com](mailto:asiriabey26@gmail.com)

 <https://orcid.org/0000-0001-9540-5032>

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The older young adults who attend paediatric clinics may get transferred to adult medical clinics, or retained in the paediatric clinic for an extended period, or get discharged from medical care either voluntarily or because of parental neglect. The most appropriate definition of transition is described by the American Society for Adolescent Medicine as “the purposeful, planned movement of adolescents and young adults with chronic physical and medical conditions from child-centred to adult-oriented healthcare systems.”<sup>3</sup>

In Sri Lanka, even though some paediatric centres have established good links with adult centres, generally, there is a low-level awareness amongst paediatricians of the need for transition planning due to lack of national guidelines on a transition protocol. The professional bodies and colleges of Sri Lanka related to paediatric and adult healthcare will have to take the initiative to develop guidelines or policies on transition from paediatric to adult healthcare systems.

It must be noted that the transfer from paediatric to adult medical care systems can be difficult and challenging for those patients and their families with long-standing illnesses. As a result, there is a danger of these patients being left out from medical surveillance. Moreover, the burden of childhood illnesses during adolescence is increasing in all developed countries as children with chronic disorders tend to survive into their 2nd and 3rd decades in ever larger numbers<sup>4,5,6</sup>. Interestingly, there are reports describing the unacceptable outcomes resulting from the treatment offered by adult care services to grown-up paediatric patients with congenital heart diseases<sup>7</sup>. On the contrary, there is also accumulating evidence to show that well organized transition programmes will improve the quality of life of the patients and control of their diseases<sup>8,9,10,11</sup>.

In most of the paediatric centres, without a structured transition programme, the transfer of patients takes place often in an abrupt and haphazard fashion. The patient reluctance to attend paediatric clinics, the refusal of admission to a paediatric ward during an acute illness and subsequently ending up in an adult ward, and suicide attempts or teenage pregnancies<sup>2</sup> are common precipitants for an abrupt

transfer. It is not uncommon that when oppositional behaviour or non-adherence is encountered by paediatric professionals, it can result in a transfer to adult services out of disgust or desperation. When such abrupt transfers occur, especially when precipitated by crises or when the paediatric team is unable to deal with non-adherence issues, young adolescents may well interpret this act as a punishment meted out to them or as a rejection by the previous health care professionals.

The reluctance of paediatric professionals to trust the skills of adult physicians and to value the independence of the adolescents are also known to interfere with the process of transferring, thereby leading to a problematic transition. This often occurs when members of the paediatric team have had no contact with the receiving transition adult services. This lack of understanding among the paediatric care professionals may also provide these young adolescents some subtle indications that they will be moving to a different arena, casting some doubt in their minds about the competence or holistic approach of adult care physicians, which perhaps occur unconsciously or unintentionally to delay or undermine the process of a successful transition<sup>12</sup>. The emotional effects of the paediatric care professionals of losing a lifelong relationship with a young patient is also known to affect the transition, especially when the paediatric team have little confidence in the flexibility and the capability of the receiving adult physician<sup>1</sup>. The reduction in patient numbers with a negative impact on research opportunities may also undermine the commitment of the paediatric caregivers to arrange a timely transition<sup>1</sup>. Either one or combined reasons mentioned above may result in paediatric healthcare professionals retaining young adolescents well into their early adult life, especially the ones with genetic, metabolic or autoimmune disorders where the paediatricians may assume that they are the best to provide ideal care, irrespective of the age of the patient. Moreover, the negative financial impact as a result of losing patients to private healthcare delivery systems may also contribute for paediatricians retaining young adolescent patients without arranging a transition<sup>3</sup>.

A successful transition may also be influenced by the adolescent patients themselves or by their parents. The young patients who are in their tender years may perceive this process as a major life event by which they are forced to trust and believe in a group of unknown carers, while losing their most respected, loved and trusted carers. The difference between adult medical care and paediatric care is felt not only by the young adolescents but also by the parents as the adult medical scenarios are more individual-oriented than family-oriented<sup>3</sup>. It is needless to emphasize that the family support is an

integral part of a young patient with chronic illness requiring long-term care and it may have detrimental effects on transition if the parents feel that they are excluded from the decision making processes<sup>3</sup>.

The atmosphere and the procedures at adult services, by themselves, may pose challenges for a smooth and successful transition. The adult clinics which have busy schedules and are housed with feeble and sick patients can be an uncomfortable and alien atmosphere for young patients. When these patients are presented as new patients to the adult physicians, they will be naturally tempted to re-investigate extensively and re-structure the management strategies at the first visit to suit their style. This can be quite distressing to the young patients and to their parents and may deter them from regular attendance which may have serious consequences<sup>12</sup>.

Moreover, the lack of organized transition may lead to contradictory medical advice and miscommunications and may potentially trigger conflicts about the physician who is fully responsible for patient care and the young patients may seize the opportunity to escape from both systems. Therefore, the development of an effective, acceptable and practically implementable transition programme can easily overcome many of the intricacies inherent in moving between two operationally different systems.

#### **Timing of transfer**

This will be one of the most difficult decisions to make in the Sri Lankan context as the cut-off age between paediatric and adult care currently stands at 14 years. Timing of the transition should be based upon developmental status of the young patient, disease status as well as the facilities and skills of the adult health services handling the disease. Hence, it is clear that different specialties will have to develop their own policies on transition.

As there are several factors that influence the process, one cannot define a "right" time for transition and therefore a flexible approach is more appropriate<sup>3</sup>. However, it is useful to have a target transfer age for both paediatric health care providers as well as for the young patient to prepare for the anticipated transition. The developed countries usually have a transition target at around 18 years, as at an earlier age of 15 or 16 years, many patients who suffer from chronic illness may not have completed their growth or puberty. However, as the cut-off age between paediatric and adult care is 14 years in Sri Lanka, implementing a shared care model between paediatricians and adult physicians would be the most feasible option.

### Selection of the adult centre

The success of transition programme will highly depend upon the interest and the commitment of the adult health care team. Invariably, if the adult setting is inferior in quality of the services provided, compared to the quality and intensity of the paediatric setting, this option will be unacceptable resulting in a reluctance on the part of patients to attend on a regular basis<sup>13,14</sup>.

When selecting the adult centre, it is important to consider the potential impact on long-term research projects as well as the patient burden of the adult centre. If the two centres can develop close clinical and academic links between the two departments, this will not be counterproductive to both services and will enable long-term follow up of patients for research.

### Planning

At least one year before the anticipated transition, the family and the young adolescent should be briefed about the planned transfer, outlining the timelines and the facilities of the adult centre. Ideally, a personal introduction to the adult physician should be done by the paediatric team and at least a return visit to the paediatric base arranged to discuss any issues before the transfer takes place. Another successful way to hand over clinical issues to adult physicians is by conducting joint paediatric–adult clinics which, however, should not replace a coordinated transition programme<sup>13,14</sup>. The process will demand dedicated coordinators which the paediatric unit should select from available resources.

### Implementation of a transition programme

The implementation of transition programmes will largely depend on the resources available. Different models have been described for the process of transition, namely programmes based on diseases or generic programmes to suit any disease<sup>2</sup>. Therefore, the disease specific models could be adopted for high-end tertiary care centres while other hospitals could use a more generic model.

The transitional care in developed countries is well established. Most existing programmes are disease specific, which address the needs of the specialty patients<sup>13</sup>. The time-tested experience with transition of care comes from renal disease which is a disease specific programme built around a strong adult service that was already in existence<sup>15,16</sup>.

Generic transition programmes have been developed by establishing adolescent medicine services offering transition services to all specialties, with adolescent medicine healthcare personnel coordinating the transfer to the adult

environment<sup>1</sup>. The work done at Great Ormond Street Children's Hospital has demonstrated that the input of an adolescent medicine service is useful to develop a good transition to specialty clinics<sup>1</sup>. However, such transition services can be economically unsustainable in Sri Lanka.

In conclusion, transfer to adult care can be considered as a major life event for young adolescents with long standing illness, and timely transition is an essential component of best paediatric practice. It is important to emphasize that even if paediatric and adult clinics are located in the same hospital, coordinated transition programmes are still necessary, as geographical proximity does not necessarily indicate a cordial professional relationship. While there are many obstacles and challenges in organizing a smooth transfer in the development of a clear transition programme that suits the Sri Lankan health care system, cultural norms acceptable to both paediatric and adult healthcare professionals is the need of the hour. The authors believe that this article will act as a catalyst for the professional colleges to work in cohesion to enable smooth transition of care for the sake of this most vulnerable groups of patients.

### References

1. Rosen D. Between two worlds: bridging the cultures of child health and adult medicine. *Journal of Adolescent Health* 1995; **17**(1): 10-6.  
[https://doi.org/10.1016/1054139X\(95\)00077-6](https://doi.org/10.1016/1054139X(95)00077-6)
2. Sawyer S, Blair S, Bowes G. Chronic illness in adolescents: transfer or transition to adult services? *Journal of Paediatrics and Child Health* 1997; **33**(2): 88-90.  
<https://doi.org/10.1111/j.14401754.1997.tb01005.x>  
PMid: 9145346
3. Blum R, Garell D, Hodgman C, Jorissen TW, Okinow N, Orr DP, *et al*. Transition from child-centred to adult health-care systems for adolescents with chronic conditions. A position paper of the Society for Adolescent Medicine. *Journal of Adolescent Health* 1993; **14**(7): 570-6.  
[https://doi.org/10.1016/1054139X\(93\)90143-D](https://doi.org/10.1016/1054139X(93)90143-D)
4. Siegel D. Adolescents and chronic illness. *Journal of the American Medical Association* 1987; **257**(24): 3396-9.  
<https://doi.org/10.1001/jama.1987.03390240102032>  
PMid: 3586271

5. Newacheck P, Taylor W. Childhood chronic illness: prevalence, severity and impact. *American Journal of Public Health*. 1992; **82**(3): 364–71.  
<https://doi.org/10.2105/AJPH.82.3.364>  
PMid: 1536351 PMCID: PMC1694379
6. Gortmaker S, Sappenfield W. Chronic childhood disorders: prevalence and impact. *Pediatric Clinics of North America* 1984; **31**(1): 3-18  
[https://doi.org/10.1016/S00313955\(16\)34532-1](https://doi.org/10.1016/S00313955(16)34532-1)
7. Sommerville J. Near misses and disasters in the treatment of grown-up congenital heart patients. *Journal of the Royal Society of Medicine* 1997; **90**(3):124–7.  
<https://doi.org/10.1177/014107689709000303>  
PMid: 9135607 PMCID: PMC1296174
8. Cappelli M, McGrath P, Heick C, MacDonald N, Feldman W, Rowe P. Chronic disease and its impact. *Journal of Adolescent Health Care* 1989; **10**(4): 283–8.  
[https://doi.org/10.1016/01970070\(89\)90058-2](https://doi.org/10.1016/01970070(89)90058-2)
9. Salmi J, Huuponen T, Oksa H, Oksala H, Koivula T, Raita P. Metabolic control in adolescent insulin-dependent diabetics referred from paediatric to adult clinic. *Annals of Clinical Research* 1986; **18**(2): 84-7.
10. Werther G, Court J, Sawyer SM. Transition to adult health care. In: Werther G, Court J, editors. *Diabetes and the adolescent*. Melbourne: Miranova Publications; 1998. p. 255–68.
11. Rettig P, Athreya B. Adolescents with chronic disease: transition to adult health care. *Arthritis Care and Research* 1991; **4**(4): 174-80.  
<https://doi.org/10.1002/art.1790040407>  
PMid: 11188605
12. Barbero G. Leaving the paediatrician for the internist. *Annals of Internal Medicine* 1982; **96**: 673–4.  
<https://doi.org/10.7326/0003-4819-96-5-673>
13. Court J. Issues of transition to adult care. *Journal of Paediatrics and Child Health* 1993; **29** (Suppl. 1) 53–5.  
<https://doi.org/10.1111/j.14401754.1993.tb02263.x>  
PMid: 8268025
14. Rosen D. Transition to adult health care for adolescents and young adults with cancer. *Cancer* 1993; **71**(Suppl. 10): 3411-4.  
[https://doi.org/10.1002/1097-0142\(19930515\)71:10+<3411::AID-CNCR2820711746>3.0.CO;2-E](https://doi.org/10.1002/1097-0142(19930515)71:10+<3411::AID-CNCR2820711746>3.0.CO;2-E)
15. Cameron J. The continued care of paediatric patients with renal disease into adult life. *American Journal of Kidney Disease* 1985; **6**(2): 91-5.  
[https://doi.org/10.1016/S02726386\(85\)80147-5](https://doi.org/10.1016/S02726386(85)80147-5)
16. Watson AR, Shooter M. Transitioning adolescents from paediatric to adult dialysis units. *Advances in Peritoneal Dialysis* 1996; **12**: 176-8.