

Adult patients in paediatric intensive care units

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Introduction

With advancement in technology and medical care, approximately 1 in 10 paediatric patients with chronic diseases and life-threatening conditions can now survive into adulthood.¹ Paediatricians caring for critically ill adults in the paediatric intensive care unit (PICU) should be aware of the potential challenges that are unique to this group of patients. We recently admitted to our PICU a patient in his 30s with chronic renal disease and respiratory failure. The patient had a complex history of end-stage renal failure due to crescentic glomerulonephritis, and previous peritoneal dialysis and cadaveric renal transplant had been unsuccessful. He had received subsequent haemodialysis under the care of the paediatric nephrology unit. He had severe skeletal deformities and multicentric carpotarsal osteolysis syndrome likely due to a heterozygous mutation in the MAFB gene.² The patient developed respiratory failure and necessitated admission to the PICU for stabilisation.

In Hong Kong, many patients with chronic childhood illnesses receive excellent multidisciplinary care from territory-wide paediatric services. When these patients reach adulthood, the transition to adult services involves multiple stakeholders, including paediatricians, adult physicians, allied healthcare professionals, and the patient's family, all having to work together in the patient's best interest. This transition can involve several challenges. Firstly, paediatricians and paediatric allied health providers may be unfamiliar with adult diseases and must continue the child's care until they are transitioned to adult services. Likewise, adult physicians are often unfamiliar with paediatric conditions with degenerative sequelae and may be reluctant to take on the risks in managing these patients. Secondly, there is a lack of comprehensive healthcare policy on this subject matter, and this can affect healthcare resource allocation and budgeting. Thirdly, there is currently no standard paediatric transitional programme or educational framework to prepare patients and their families for transition into the

adult healthcare services.³ Lastly, patients and their families, who have become familiar with the paediatric approach, might have difficulty adapting to adult services or even lose confidence in their medical professionals during the transition period.

Transitional care is widely defined as '*the purposeful, planned movement of adolescents and young adults with chronic physical and medical conditions from child-centred to adult-oriented healthcare systems*'.⁴ An effective transition process can provide appropriate high-quality uninterrupted medical care services for the patient, and a communication platform for the main participants in the patient's treatment to enhance the patient's health, life outcomes, self-management, and autonomy.⁴⁻⁹ In contrast, a premature transition to adult-oriented therapy may lead to insufficient preparation, resulting in transition failure, non-adherence to treatment and poor engagement with healthcare services subsequently, excess morbidity, and even mortality.¹⁰⁻¹² Therefore, a better management strategy for chronically ill adolescents is necessary to address the additional needs of patients in adult life.¹¹ Data on the overall number of patients involved are scarce; however, registries of subspecialty populations provide strong evidence to support the general consensus that transitional care is a growing challenge.^{13,14}

Transitional care of paediatric patients to adult care in Hong Kong should be easy to carry out, as the majority of these patients with chronic conditions are managed under the public healthcare system. However, paediatric transitional care services in Hong Kong are rather underdeveloped and fragmented and, in comparison with other countries, lack an agreed framework³ (Table¹⁵⁻²²). In Hong Kong, only limited success in transition care has been established, primarily in patients with cerebral palsy, Down syndrome, and diabetes mellitus. Notorious challenges are present for those with oncologic diseases, congenital heart diseases, chronic renal diseases on renal replacement, and inborn errors of metabolism. Transitional care for

TABLE. Comparison of international transitional care of adolescents to adult care services

	Hong Kong ¹⁵	United Kingdom ¹⁶	United States ¹⁷⁻²⁰	Australia ^{21,22}
Transition care policy	No consensus. Fragmented service for type I diabetes mellitus and developmental disabilities	National guidelines from the National Institute for Health and Care Excellence	Consensus statement from the American Academy of Paediatrics, the American Academy of Family Physicians and the American College of Physicians	Policy published by The Royal Australasian College of Physicians
Age to initiate transition care	No consensus	13-14 Years old	12-21 Years old	Early puberty through to adolescence
Key principles	No consensus	<ul style="list-style-type: none"> - Involve young people and their carers in service design, delivery and evaluation - Ensure transition support is developmentally appropriate - Person-centred approach 	The Six Core Elements of Health Care Transition™ <ul style="list-style-type: none"> - Transition and care policy - Tracking and monitoring - Transition readiness - Transition planning - Transfer of care - Transition completion 	<ul style="list-style-type: none"> - A systemic and formal transition process - Early preparation - Identification of a transition coordinator - Good communication - Individual transition plan - Empower, encourage and enable young people to self-manage - Follow up and evaluation
Major issues to be addressed	No consensus	<ul style="list-style-type: none"> - Education and employment - Community inclusion - Health and well-being - Independent living and housing options - Develop agreeing goals and transitional plan 	<ul style="list-style-type: none"> - Development of a transition policy - Identification of adult clinicians - Pre-visit outreach and appointment reminders - Self-care skill assessment and education - Assistance in establishing referrals for medical specialists / behavioural health / reproductive care / community supports 	<ul style="list-style-type: none"> - Physical and pubertal health - Medication - Developmental and academic progress - Sexual health and education - Nutrition, exercise and other health promotion activities - Mental health - Relevant entitlements, eg, disability allowances and benefits, insurance - Substitute decision-making and guardianship law - Ethical decisions, eg, respiratory support, end-of-life decisions
Funding of programme	No programme	National Health Service	Federally funded national resource centre on healthcare transition	National Health Service
Adults in PICU (age ≥19)	0.3% (data from one PICU)	No data	2.7% (data from 70 PICUs)	No data

Abbreviation: PICU = paediatric intensive care unit

most of these other chronic conditions remains fragmented, and for solid organ transplant recipients it is even less developed.^{8,9} In 2010, a Hong Kong study reported that it was commonplace for paediatricians to continue seeing chronically ill adolescents well into adulthood¹¹; sadly, this remains the case at the time of writing. In the 2010 study, the majority of adolescents (85.3%) and parents (82.5%) were willing to be transferred to adult care; however, fewer than 10% had received any transitional information.¹¹ It is evident that the main obstacle to a successful transition is the lack of a structured transitional care programme and healthcare system, not resistance of patients and families.²³

The outcomes of adult PICU patients are often overlooked in paediatric clinical studies, and there have been no local data or reports on adults admitted to a PICU. In a large report of such patients in the United States, patients aged 21 to 29

years had two-fold greater odds of PICU mortality compared with adolescent patients, after adjusting for Paediatric Index of Mortality score, sex, trauma, and having a complex chronic condition. Being aged ≥30 years was associated with a 3.5-fold greater odds of mortality.¹⁷ It is difficult to draw a general conclusion on whether a PICU or an adult intensive care unit can provide the best critical care for this group of patients. Paediatricians are more familiar with some childhood-onset chronic conditions than adult physicians; however, paediatricians may not have the expertise to optimise the care of adult-acquired conditions. Therefore, some investigators have suggested that PICUs should have plans and protocols specifically focused on this group of adult patients.¹⁷

Transitional care programmes should be tailored to the specific medical condition to ensure optimal care and outcomes. Adult congenital heart

disease or cystic fibrosis, for example, are obvious candidates for the establishment of centralised, disease-specific services that would bring together specific paediatric and adult expertise for small and complex patient cohorts.^{24,25} Other more common conditions such as cerebral palsy, asthma or type 1 diabetes will benefit from a broader framework that can guide clinicians and patients through a successful transition from paediatric to adult care in a variety of healthcare settings. A successful transitional programme should include the following factors: (1) a structured and written policy; (2) patient and family involvement in preparation and planning; (3) adequate training for staff and sensitisation to the needs of adolescent patients; (4) continuity of care to adult service (eg, paediatricians and adult physicians should develop and implement joint recommendations on diagnosis and treatment); and (5) financial support for special healthcare service needs.¹ In addition to transitional care for chronic medical conditions, psychiatric disorders, including attention deficit hyperactivity disorder or autism, should also be addressed. Developing transitional care programmes for adolescents is an important healthcare policy, as it can improve adherence to healthcare services, long-term outcomes for the patient, and better utilisation of healthcare resources.¹²

As survival rates improve for chronic childhood conditions, it is inevitable that some adults with rare childhood conditions, especially those with congenital heart disease, might be admitted to a PICU. The PICUs should have protocols, infrastructures, and transition pathways specifically focusing on this unique group of adults, who are 'too old' to be a paediatric patient, but might not be best treated in an adult intensive care unit.¹⁷ From initiating collaboration with adult physicians to developing a structured transitional care programme covering both in-patient and out-patient services, paediatricians are ultimately responsible for the clinical care and long-term outcomes of this group of adult patients, so that they are not overlooked by our healthcare system. This process should be an integral practice of humanism, humanistic medicine, and humanitarianism. The modern PICU may take on an additional role as a 'Progressive Integrative Care Unit'.

Author contributions

All authors contributed to the concept or design of the study, acquisition of the data, analysis or interpretation of the data, drafting of the manuscript, and critical revision of the manuscript for important intellectual content.

All authors had full access to the data, contributed to the study, approved the final version for publication, and take responsibility for its accuracy and integrity.

Conflicts of interest

As an editor of the journal, KL Hon was not involved in the peer review process. Other authors have disclosed no conflicts of interest. Other authors have no conflicts of interest to disclose.

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References

- Mazur A, Dembinski L, Schrier L, Hadjipanayis A, Michaud PA. European Academy of Paediatric consensus statement on successful transition from paediatric to adult care for adolescents with chronic conditions. *Acta Paediatr* 2017;106:1354-7.
- Zankl A, Duncan EL, Leo PJ, et al. Multicentric carpotarsal osteolysis is caused by mutations clustering in the amino-terminal transcriptional activation domain of MAFB. *Am J Hum Genet* 2012;90:494-501.
- Lau KK. Transition care in Hong Kong. *Hong Kong Med J* 2016;22:408-9.
- Blum RW, Garell D, Hodgman CH, et al. Transition from child-centered to adult health-care systems for adolescents with chronic conditions. A position paper of the Society for Adolescent Medicine. *J Adolesc Health* 1993;14:570-6.
- van Staa AL, Jedeloo S, van Meeteren J, Latour JM. Crossing the transition chasm: experiences and recommendations for improving transitional care of young adults, parents and providers. *Child Care Health Dev* 2011;37:821-32.
- Fair C, Cuttance J, Sharma N, et al. International and interdisciplinary identification of health care transition outcomes. *JAMA Pediatr* 2016;170:205-11.
- Rosen DS, Blum RW, Britto M, Sawyer SM, Siegel DM, Society for Adolescent Medicine. Transition to adult health care for adolescents and young adults with chronic conditions: position paper of the Society for Adolescent Medicine. *J Adolesc Health* 2003;33:309-11.
- McDonagh JE, Kelly DA. Transitioning care of the pediatric recipient to adult caregivers. *Pediatr Clin North Am* 2003;50:1561-83.
- Jin YT, Chen CM, Chien WC. Factors influencing transitional care from adolescents to young adults with cancer in Taiwan: a population-based study. *BMC Pediatr* 2016;16:122.
- Reiss J, Gibson R. Health care transition: destinations unknown. *Pediatrics* 2002;110:1307-14.
- Wong LH, Chan FW, Wong FY, et al. Transition care for adolescents and families with chronic illnesses. *J Adolesc Health* 2010;47:540-6.
- Gabriel P, McManus M, Rogers K, White P. Outcome evidence for structured pediatric to adult health care transition interventions: a systematic review. *J Pediatr* 2017;188:263-9.e15.
- Bell SC, Mall MA, Gutierrez H, et al. The future of cystic fibrosis care: a global perspective. *Lancet Respir Med* 2020;8:65-124.
- Iyengar AJ, Winlaw DS, Galati JC, et al. The Australia and New Zealand Fontan Registry: description and initial results from the first population-based Fontan registry. *Intern Med J* 2014;44:148-55.
- Pin TW, Chan WL, Chan CL, et al. Clinical transition for

adolescents with developmental disabilities in Hong Kong: a pilot study. *Hong Kong Med J* 2016;22:445-53.

16. National Institute for Health and Care Excellence, UK Government. Transition from children's to adults' services for young people using health or social care services. NICE guideline [NG43]. 2016. Available from: <https://www.nice.org.uk/guidance/ng43>. Accessed 27 Aug 2020.
17. Edwards JD, Houtrow AJ, Vasilevskis EE, Dudley RA, Okumura MJ. Multi-institutional profile of adults admitted to pediatric intensive care units. *JAMA Pediatr* 2013;167:436-43.
18. McManus M, White P, Schmidt A, et al. Health care gap affects 20% of United States population: transition from pediatric to adult health care. *Health Policy OPEN* 2020;1:100007.
19. White PH, Cooley WC, Transitions Clinical Report Authoring Group, American Academy of Pediatrics, American Academy of Family Physicians, American College of Physicians. Supporting the health care transition from adolescence to adulthood in the medical home. *Pediatrics* 2018;142:e20182587.
20. gottransition.org. Overview: transitioning youth to an adult health care clinician. 2020. Available from: <https://www.gottransition.org/6ce/?leaving-full-package>. Accessed 27 Aug 2020.
21. The Royal Australasian College of Physicians. Transition of young people with complex and chronic disability needs from paediatric to adult health services. 2014. Available from: <https://www.racp.edu.au/docs/default-source/advocacy-library/transition-of-young-people-with-complex-and-chronic-disability-needs.pdf>. Accessed 27 Aug 2020.
22. Agency for Clinical Innovation, Australia Government. Key principles for transition of young people from paediatric to adult health care. 2014. Available from: https://www.aci.health.nsw.gov.au/_data/assets/pdf_file/0011/251696/Key_Principles_for_Transition.pdf. Accessed 27 Aug 2020.
23. Scal P, Evans T, Blozis S, Okinow N, Blum R. Trends in transition from pediatric to adult health care services for young adults with chronic conditions. *J Adolesc Health* 1999;24:259-64.
24. Bassareo PP, McMahon CJ, Prendiville T, et al. Planning transition of care for adolescents affected by congenital heart disease: the Irish national pathway. *Pediatr Cardiol* 2022 Jun 23. Epub ahead of print.
25. Office D, Heeres I. Transition from paediatric to adult care in cystic fibrosis. *Breathe (Sheff)* 2022;18:210157.

Answers to CME Programme

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I. Perinatal mortality rate in multiple pregnancies: a 20-year retrospective study from a tertiary obstetric unit in Hong Kong

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|---|----------|---------|---------|---------|----------|
| A | 1. True | 2. True | 3. True | 4. True | 5. True |
| B | 1. False | 2. True | 3. True | 4. True | 5. False |

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II. Frailty and sarcopenia—from theory to practice

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|---|----------|----------|---------|---------|----------|
| A | 1. False | 2. False | 3. True | 4. True | 5. False |
| B | 1. True | 2. False | 3. True | 4. True | 5. False |