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# Pediatric Anesthesia

## Transition from pediatric to adult health services: the perioperative care perspective

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## Transition from pediatric to adult health services: the perioperative care perspective

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## Abstract

**Increasing** numbers of children with congenital and chronic diseases **are surviving** beyond adolescence. **Consequently** arrangements must be put in place to ensure that these groups of patients continue to receive high quality care into adulthood. Although some medical disciplines have reacted positively to this growing challenge, perioperative care has lagged behind. This review explores some of the difficulties in delivering optimal perioperative care in the transitional period. **Key issues**, including the paucity of experience in the management of pediatric diseases amongst adult trained clinicians and unfamiliarity with child/family focused care **are discussed**. **We provide** some suggestions for the development of transitional health care policies.

Keywords: transitional policies; adolescence; perioperative; anesthetic training

## Introduction

A generation ago, most children with severe chronic medical conditions and disabilities failed to survive into adulthood. In 1973 the average age of survival for a child with cystic fibrosis was 7 years; by the end of the 1990's this had increased considerably with an average life expectation of 31 years. Similarly a child born with spina bifida in the 1970's had a 30% chance of reaching 20 years of age whereas by 2005, greater than 80% reached adulthood (1). Overall it is estimated that 90% of children born in recent years with severe medical conditions will survive into adult life and that in the USA 500,000 per annum will cross the threshold into adulthood with health care needs that originated in childhood (2).

Undoubtedly this increase in survival has been prompted by improved healthcare most notably in the areas of management of the problems associated with premature birth, congenital heart disease and other life shortening conditions including cystic fibrosis. However some of the increased number of cases progressing into adulthood is due to an absolute rise in the number of cases e.g. acute lymphoblastic leukaemia and diabetes mellitus (3).

The consequences for healthcare services of this increased cohort of pediatric chronic disease surviving into adulthood have been recognized for some time by several medical disciplines (4, 5, 6). Most importantly it is apparent that arrangements need to be put in place to smooth the transition from pediatric to adult care. A US

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3 multidisciplinary group reported on this issue in 2002 and made recommendations for best practice in the  
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5 transitional phase (7) and these themes have been developed in the UK (8).

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8 What are the implications of this demographic change for anesthesia? Disappointingly there is very little in the  
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10 literature regarding how perioperative care should be organized and delivered for this group of patients. In this  
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12 article we shall consider some aspects of this important issue focusing on the differences in ethos between  
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14 pediatric and adult perioperative management, technical and training issues, familiarity with childhood diseases  
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16 by adult trained clinicians and developing transitional policies for perioperative care.  
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## 19 20 21 22 23 **Paediatric versus adult care**

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26 Many children with chronic medical conditions may have developed life-long attachments with the clinicians  
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28 and other care providers in their pediatric hospital. It therefore comes as a huge wrench when these young  
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30 people and their families are uprooted from such a familiar, safe and predictable environment. Many of the  
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32 fundamental principles of child and family centered care which are intuitive in a pediatric hospital environment  
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34 are no longer automatically available. Lack of the familiar child centered ethos from adult care healthcare  
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36 providers is often interpreted as callous and uncaring by parents. However it is more likely to reflect a lack of  
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38 training in the staff managing this vulnerable group of patients (9).  
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42 Some of the aspects of perioperative care likely to cause problems for young people during transfer to adult  
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44 services are as follows:

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47 a. Parents are actively encouraged to be present at all stages of perioperative care, including  
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49 **anesthetic induction** and in the postoperative care unit. **This** approach is not the norm in adult  
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51 practice. During the transitional phase young people, particularly those with intellectual  
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53 disabilities are likely to experience increased distress if their familiar perioperative routine  
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55 involving their parents/carers is denied. Transitional policies need to ensure that young people  
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57 and their parents **are appropriately included** in adult care facilities whenever feasible.
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59 b. Children become used to being guided through the perioperative period by a team that  
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includes trained age-specific care providers including pediatric nurses and play therapists (also

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3 known as child life specialists in the USA). Play therapists use structured play and cognitive  
4 behavioral approaches to address the anxieties associated with hospitalization including  
5 anesthetic induction (10). Access to play therapists for transitional patients is often limited or  
6 non-existent due to budgetary constraints. Consideration should be given to purchasing these  
7 services if large numbers of transitional patients with complex emotional and developmental  
8 needs are managed in an adult care facility.

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15 c. Many children, particularly those with challenging vascular access, presenting for repeated  
16 surgery will be accustomed to receiving inhalational induction of anesthesia and this will be  
17 their expectation on transfer to adult care. Even if the young person has 'good veins'  
18 inhalational induction is deeply ingrained as part of the young person's ritual for dealing with  
19 the stresses of the perioperative period. Adult trained anesthesiologists need to acknowledge  
20 these long established coping strategies and respect them as needle phobia for these patients is  
21 often a major issue. Topical local anaesthesia to facilitate intravenous induction is ubiquitous  
22 in paediatric practice and must be made available if requested on transfer to the adult facility.  
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31 d. Sedative premedication is commonly used in paediatric practice and as with the comments  
32 made about anesthetic induction, it may be part of the familiar path for young people who  
33 undergo repeated operative procedures. Although it would appear to be easy to subsume this  
34 practice on transition to adult care it may pose problems. Evidence suggests that anxiolytic  
35 premedication is under utilized in adolescents and young adults (11). For many young people  
36 with complex needs the agents and routes of administration of sedative premedication may be  
37 unfamiliar to adult health care personnel. For example the use of oral midazolam in flavoured  
38 syrups or the use of oral or intramuscular ketamine in some autistic patients.  
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47 e. Where should the young person be cared for in the perioperative period? It is a common  
48 policy that access to pediatric inpatient facilities ceases between the ages of 16 to 18 years in  
49 most health care systems. However this approach fails to recognize the complex needs of  
50 many of the young people who have reached the threshold of adult care. Many of this group  
51 may be chronologically adults but in other respects - anatomically, physiologically,  
52 developmentally and emotionally- are still children. Successfully managing this issue is one of  
53 the most difficult challenges in transitional care. However a detailed discussion of this  
54 important topic is beyond the scope of this short article.  
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3 Transfer to adult care is not all negative. The paternalistic approach of paediatric care relying on  
4 parental direction and consent may not be welcomed by many young people as they approach  
5 adulthood. Even young people with significant levels of intellectual handicap may appreciate the  
6 benefits of adult care which acknowledges and encourages autonomy in making decisions about  
7 treatment and life choices (12). Adult healthcare professionals are more likely to have the skills  
8 and experience to tackle issues such as work, emerging sexuality and pregnancy in the context of  
9 chronic ill health. Finally, adult health care facilities are more likely to offer single-sex  
10 accommodation and so afford the young person greater privacy.  
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## 23 **Technical & training issues**

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26 After many years of care in a child-centered hospital the family will have become accustomed to anesthesia  
27 being delivered by specialist pediatric anesthesiologists. One of the fundamental principles of a pediatric  
28 anesthetic management is that anesthetic procedures should be performed whenever possible under general  
29 anesthesia. It is a common expectation of young people and their parents that this approach should continue into  
30 adulthood. This highlights the problem with treating individuals based on chronological age rather than by fully  
31 evaluating their clinical, emotional and psychological needs. Many children with chronic diseases will have  
32 associated developmental delay or have learning difficulties that persist into adulthood resulting in poor  
33 compliance and co-operation with anesthetic interventions. For many young adults with inherited syndromes  
34 there may be technical difficulties due to short stature, dysmorphism and low body weight, requiring the use of  
35 equipment and techniques used in pediatric practice.  
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47 There are clear differences in how a pediatric and adult anesthesiologist would approach a particular clinical  
48 situation. For example, regional and neuraxial techniques in children are almost universally performed under  
49 general anesthesia whereas in adult practice central or peripheral blocks are usually inserted in the awake or  
50 lightly sedated patient to decrease the risk of neurological injury. The 'awake' approach is poorly tolerated in  
51 children, especially if electrical nerve stimulation is employed. The development of ultrasound guided nerve  
52 blocks has made this less of a problem. The development of ultrasound guided nerve  
53 blocks has made this less of a problem. Some centers perform blocks successfully in children under sedation  
54 (13) but this is still not a widespread practice.  
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3 Cerebral palsy is a particularly good example as patients often require repeated anesthesia for orthopedic  
4 procedures supplemented by local anesthetic techniques for postoperative analgesia. An adult-trained  
5 anaesthetist, unfamiliar with neuraxial or regional blockade **in small children**, may **lack the confidence to**  
6 **provide such** beneficial techniques (14). There are also safety concerns regarding the familiarity with managing  
7 pediatric opioid or epidural infusions regimens on adult wards. Perhaps more of a concern is the adult  
8 anaesthetist who uses their standard adult analgesic regimen on a very small patient with potentially disastrous  
9 results. Clearly the decision of where to safely manage, for example a 20 year- old, 30 kg patient with cerebral  
10 palsy, post-operatively is a difficult one. **I**nstitutions should develop policies on how to manage such vulnerable  
11 patients. **See case study 1.**

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13 Strategies for difficult airway management in adult practice include the use of an awake fiber-optic endoscopic  
14 technique. This is not generally considered appropriate in pediatric practice. **C**hildren with difficult airways will  
15 have become accustomed to this anesthetic problem being dealt with under general anesthesia and this may  
16 challenge the skills and experience of the adult-trained anaesthetist. The options for airway management include  
17 intubation via a laryngeal mask airway, use of the Bullard laryngoscope and asleep fiber-optic intubation (15). **I**t  
18 is essential that the resources of the adult facility include the range and sizes of airway equipment appropriate  
19 for patients of pediatric proportions.

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21 **A**ppropriate pain assessment is fundamental to the management of post-operative pain **in children**. Self reporting  
22 of pain is the gold standard and should be used whenever possible. Numeric rating scales and visual analogue  
23 scales are widely used in adult practice. Older children are also able to self report quite reliably from around the  
24 age of four using pain assessment tools such as Wong-Baker FACES pain scale. Younger children or those with  
25 cognitive impairment who are unable to report pain require behavioral pain assessment tools. The older child  
26 with cognitive impairment or other disabilities requires more specialized pain assessment tools such as the  
27 modified FLACC score which looks at facial expression, leg movement, activity, cry and consolability (16).  
28 These pain assessment tools may be less familiar to the adult anaesthetist and recovery staff. Consequently there  
29 is significant potential for this vulnerable group of young people following transition into to receive suboptimal  
30 analgesia.

## 31 32 33 34 35 36 37 38 39 40 41 42 43 44 45 46 47 48 49 50 51 52 53 54 55 56 57 58 59 60 **Familiarity with childhood disease**



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3 Compared to adults many of the conditions that affect children are congenital in origin. Diseases that were once  
4 limited to childhood are becoming increasingly prevalent within the adult population as survival rates improve  
5 due to advances in drug therapy and surgical techniques. Congenital heart disease is an important example of the  
6 problem. Currently 80-85% of patients born with congenital heart disease (CHD) survive into adulthood with an  
7 estimated 250,000 adults with CHD in the UK (17). As children these patients have generally been cared for in a  
8 specialized pediatric setting including surgeons, cardiologists and anesthesiologists who are familiar with their  
9 specific clinical, emotional and psychological needs.  
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18 As adolescents become adults, they undergo transition from the paediatric to the adult specialty. This often  
19 means that their centre of expertise moves away from the familiar pediatric setting to a hospital with more adult  
20 orientated perioperative care. Integrated services for the management of CHD in adulthood are lacking in many  
21 healthcare systems (18). Solutions to this difficult problem may require pediatric hospitals to be more flexible in  
22 providing adult surgical services or that paediatric clinicians, including anesthesiologists, support their adult  
23 colleagues in joint programs based in adult hospitals. **This may also entail pediatric anesthesiologists working  
24 alongside their adult colleagues in the operating room.**  
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33 Besides specialist cardiac surgery, anesthesia may well be required for a non-cardiac procedure and this is more  
34 likely to be performed by anesthesiologists who are less familiar and experienced with the specific cardiac  
35 condition. Indeed urgent surgery such as trauma management may well be required away from the patient's base  
36 hospital where appropriate anesthetic expertise may be even more difficult to find. Most generally trained  
37 anaesthetists (at least in the UK) who have not undergone specialist pediatric training will only have a basic  
38 appreciation of the issues surrounding the perioperative care of a patient with complex congenital heart disease  
39 (19). Clearly all specialties including anesthesia need to ensure that there are appropriate training programs in  
40 adolescent health issues that span the transfer from pediatric to adult care.  
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49 The disparity between the transition arrangements of a given parent specialty and perioperative care may cause  
50 difficulties for the patient, their family and the anaesthetist. As a family learns to live with caring for a child  
51 with a chronic condition they often become exceptionally well informed and knowledgeable. Readily accessible  
52 information on the internet and disease specific support networks has made it relatively easy for a family to  
53 become "expert" in their child's condition. The adult anesthesiologist may be relatively inexperienced in the  
54 practical anesthetic management of patients with conditions that are more familiar to pediatric anesthesiologists.  
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3 The young adult patient and their family may feel a degree of anxiety that the professionals caring for them have  
4 a different approach to what has been familiar and lack the confidence with which they are familiar. Similarly  
5 the anesthesiologist may feel uncomfortable dealing with a very well informed family who are used to a very  
6 different environment and style of perioperative care.  
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## 10 11 12 13 14 15 **Transitional policies for perioperative care** 16

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18 Although transitional policies for many specialties are increasingly being developed, perioperative care is  
19 lagging behind. An Australian study looking at a tertiary children's hospital found that surgical admissions of  
20 young adults over 18 years old had more than doubled over a 10 year period and that over 50% of the adolescent  
21 surgical inpatients had no transitional arrangements in place for adult care (20). Why is this a growing problem?  
22 The increasing numbers of transitional young adult patients has not been matched by a concomitant increase in  
23 experience in the adult arena to manage many of these 'pediatric' conditions, with congenital heart disease being  
24 a good example. There is also a belief amongst many parents and some clinicians that inadequate care would be  
25 provided within the adult sector (21). Many young people requiring ongoing surgical care have complex  
26 disorders affecting several body systems which require multidisciplinary care and this can be difficult, if not  
27 impossible, to coordinate in a single adult centre.  
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39 So what is the way forward for transitional care for the surgical/perioperative patient? The most important  
40 principle should be to start the transfer discussions with the young person and their families early if it is likely  
41 that a surgical condition is going to require ongoing care into adult life. The aim should be to have a transitional  
42 plan in place for every young person by age 14 years (8). Pediatric surgeons and anesthesiologists, particularly  
43 those working in a purely children's hospital, will need to forge links with appropriate adult services to provide  
44 continuity of care on transfer. It is vital that there is anesthetic input into transition planning if only to advise on  
45 the degree of anesthetic expertise that will be required to safely manage the patient in the future. **In some  
46 complex situations it may be beneficial for adult and pediatric clinicians to collaborate in the assessment and  
47 operative management of these patients.**  
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57 Transfer to adult care should be a process and not an event driven by chronological age with flexibility being the  
58 watchword. Clinicians should resist healthcare managerial attempts to dictate the pace of transfer if they are not  
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3 satisfied that safe, appropriate arrangements have been identified for ongoing care in the adult sphere. It is  
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5 encouraging that a recent UK government commissioned report on pediatric health services has recognized the  
6  
7 crucial importance of **developing** transitional arrangements. Policy in this area must be dictated by the  
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9 individual needs of young people rather than artificial chronological boundaries which are convenient for  
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11 bureaucrats. Sir Ian Kennedy's report has clearly stated that NHS funding must be identified for transitional  
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13 healthcare that is separate from funding dedicated to adults (23). Finally for many young people with chronic  
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15 health problems outside of the UK the transition to adult health care brings the added problem of lack of  
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17 affordable health care insurance coverage (22). **This may result in suboptimal care being delivered with**  
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19 **potentially disastrous results (see case study 2).**

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22 **Word count 2740**

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For Peer Review

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**Case study 1**

A 19 year-old young man (body weight 33 kg) with cerebral palsy associated with spastic paraparesis and global developmental delay required a femoral osteotomy. Initially it was agreed that he would be cared for on a pediatric ward but on the day of surgery the pediatric unit was full and so he was admitted to an adult orthopedic ward instead.

Surgery was performed by an adult orthopedic surgeon staffed by an adult trained anesthesiologist. No local anesthetic techniques were used to supplement anesthesia. Postoperatively he was managed in an adult recovery room. He had severe pain. Therefore the anesthesiologist prescribed bolus morphine followed by an adult intravenous PCA morphine regimen.

Six hours postoperatively the duty anesthesiologist was called urgently to the adult orthopedic ward as the young man was now unresponsive with a respiratory rate of six breaths per minute. The patient's mother had been activating the morphine PCA on her son's behalf in a single room. The young man responded to intravenous naloxone and was transferred to the paediatric HDU where he made an uneventful recovery.

**Comment**

Despite the initial appropriate plan to manage the patient via a paediatric ward, service constraints meant the young man was managed via an adult ward. Adult centered perioperative care from medical and nursing staff unwittingly resulted in a near disaster. Pediatric focused care **might** have prevented all of the issues highlighted in this case.

**Case study 2**

An 18 year-old US woman with Klippel-Feil syndrome underwent prolonged plastic surgery to correct a chest wall deformity. The main anesthetic concern of this condition is congenital synostosis of the cervical vertebrae. The combination of the characteristic short neck and reduced neck movement results in a predictable difficult airway, often necessitating fiber-optic intubation. This young lady had required multiple surgical procedures as a child and these were performed in a specialist children's hospital, where she was intubated with the aid of a fiber-optic scope.

Following her eighteenth birthday her insurers refused to pay for her care in a children's hospital. She had a general anesthetic for an extensive plastics procedure in an adult hospital with an adult trained anesthesiologist. The anesthesiologist elected to maintain her airway using a laryngeal mask airway. Unfortunately, towards the end of the case she aspirated gastric contents and had a cardiac arrest. Attempts at intubation in these dire circumstances were unsuccessful and tragically she died.

**Comment**

This young woman's transition from paediatric to adult health care was enforced by a healthcare system based on financial constraints. The venue for her surgery was determined by the insurer, on the basis of her chronological age rather than by her specific health care needs. The children's hospital was familiar with her condition and the challenges of her difficult airway, but was denied the opportunity to care for her. However, we accept that transition to adult based services at some point is inevitable and indeed appropriate for the majority of patients. This incident may have occurred much later in life. This reinforces our view that good communication and support between adult and pediatric trained colleagues is fundamental to a smooth transition.