Young adults in children's hospitals: why are they there?

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ABSTRACT

Objective: To measure the pattern of admissions of young adults to a children's hospital.

Design and setting: Ten-year audit (1992–2001) of admissions of young adults aged 18 years and over to the Royal Children's Hospital (RCH), Melbourne, with a detailed chart review of the 2001 cohort to assess disease complexity and transition planning.

Outcome measures: Number of admissions, disease complexity, transition planning.

Results: There was a significant increase in the number of young adults admitted over 10 years, from 308 in 1992–1993 to 659 in 2000–2001. The greatest increase was in admissions to surgical units. There was significant variation in admission practices between units over time. Many young adults required multidisciplinary care: 57% had more than three medical/surgical units involved in their care, and 34% had two or more allied health units involved. Fifty-one per cent of surgical inpatients and 28% of medical inpatients had no documented plan for transition to adult care. Only 30% of medical and 17% of surgical inpatients in 2001 had been transferred to adult services by 2002.

Conclusions: Both disease complexity and failure of transition planning appear to have contributed to the increased admission of young adults to the RCH. While greater support of transition planning is needed, there are also concerns about the lack of appropriate services within the adult sector for young adults with complex, multidisciplinary healthcare needs.

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The prevalence of chronic illness in childhood and adolescence has increased in recent decades due to several factors.[1] Firstly, children with previously fatal conditions of early childhood, such as extreme prematurity, congenital cardiac disease and cystic fibrosis, now frequently survive through adolescence because of improved clinical care.[2] Secondly, there has been a true increase in prevalence of certain chronic illnesses such as asthma, diabetes mellitus and acute lymphoblastic leukaemia.[3] Thirdly, young people are now more likely than previously to experience conditions such as obesity, mental disorders and HIV.[4]

Over the same period, there has been an upward age shift in paediatric practice in the Western world. Tertiary children's hospitals now commonly admit young people to at least 18 years of age.[5,6] A recent audit of adolescent admissions to the Royal Children's Hospital (RCH), Melbourne, showed that adolescents (aged 10 and older) now constitute nearly one in three admissions.[6]

Increasing admission of older adolescents to children's hospitals has important implications for paediatric and, in turn, adult health services in terms of the specialist services required, the way in which developmentally appropriate care is delivered, and the design of physical environments.

The concept of a planned transition from child- to adult-oriented health services is now recognised as an important component of quality healthcare for young people with chronic illness.[7-9] Nevertheless, multiple barriers to timely transfer[10-12] may mean that some young people continue to access paediatric services well into their twenties.[6,13]

A study by Goodman et al revealed that young adults aged 18 years and over constituted almost 5% of discharges from 10 US paediatric hospitals.[13] The complex healthcare needs of this population have important implications for healthcare planning and policy, yet there is a dearth of Australian data to inform service planning and policy in this area. We set out to measure the changing pattern of admission of young adults to an Australian tertiary paediatric hospital over a 10-year period. Our aim was to explore the extent to which disease complexity and failure of transition planning may contribute to young adults' healthcare continuing to be based at a children's hospital.

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METHODS

Two datasets were obtained from the RCH, the major tertiary paediatric hospital in Victoria. The first consisted of hospital admission data from 1 January 1992 to 31 December 2001, from which we identified admission trends of young adults over 10 years according to admitting unit. The second dataset consisted of a detailed, retrospective chart review of the cohort of young adults admitted in 2001. This provided a "snapshot" of a single year's admissions in terms of admitting unit, disease complexity, and transition planning. Within each dataset, "young adults" were defined as any patients aged 18 years or over. Day stay patients, transplant donors and postnatal mothers were excluded from the analysis.

At the time of our study, the hospital had no formal age policy for young people with chronic illness. However, there was a widespread expectation that a young person's care would be transferred to the adult sector some time after completion of secondary schooling. The Emergency Department had a policy of not admitting young people over 18 years who presented with acute (but not chronic) illness.

Ethics permission for the study was obtained from the RCH Research in Human Ethics Committee.

Hospital admission data, 1992–2001

Admission data for the 10-year period were reviewed and categorised according to admitting unit. We conducted a linear

1 Number of young adults (aged 18+ years) admitted to the Royal Children's Hospital, Melbourne, from 1992 to 2001, by hospital unit

Admitting unit	1992–1993	1994–1995	1996–1997	1998–1999	2000–2001	Slope of fitted trend (95% CI)
Medical units						
Adolescent Medicine	8	18	23	13	10	–0.7 (–1.2, 1.1)
CDR	3	4	22	18	17	1.1 (0.2, 1.9)
Endocrinology	12	22	21	18	14	0.1 (–1.2, 1.5)
Gastroenterology	2	18	30	74	48	3.7 (1.5, 5.9)
General Medicine	8	32	50	32	25	0.8 (–1.2, 2.8)
Nephrology	2	0	17	36	35	2.4 (0.2, 4.6)
Neurology	2	2	6	8	6	0.4 (–0.7, 0.8)
Oncology	36	44	37	47	47	0.9 (–0.4, 2.1)
Respiratory Medicine	84	93	50	106	50	–1.4 (–4.9, 2.2)
Total (medical units)	157	233	256	352	252	13.7 (–4.2, 31.6)
Surgical units						
Cardiac Services	26	31	37	46	62	2.2 (1.2, 3.3)
ENT Surgery	8	9	11	13	15	0.6 (–0.3, 1.5)
General Surgery	40	35	50	54	68	1.8 (–0.2, 3.8)
Neurosurgery	13	29	28	11	17	–0.2 (–1.7, 1.3)
Orthopaedic Surgery	17	40	66	70	87	4.0 (2.3, 5.8)
Plastic Surgery	47	104	149	106	158	6.0 (1.6, 10.3)
Total (surgical units)	151	248	341	300	407	19.0 (3.3, 34.6)
Total (all units)	*308*	*481*	*597*	*652*	*659*	*22.2 (13.5, 30.8)*

CDR = Child Development and Rehabilitation. ENT = Ear, Nose and Throat.

regression analysis and used the slope of the line to assess change over time.

Chart review, 2001

A retrospective chart review was conducted of all patients admitted between 1 January and 31 December 2001. We obtained data on demographic characteristics, disease complexity and transition planning.

Demographic data

Demographic data included age at admission, admitting unit, admitting ward and case-managing unit (primary unit of care). Case-managing units were categorised as medical or surgical units. The Cardiology and Cardiac Surgery units were incorporated as a single unit ("Cardiac Services") and classified as surgical.

Complexity measures

Disease complexity measures included length of stay, number of admissions in 2001, number of pre-existing or comorbid conditions in 2001, and number of medical units and allied health units involved over the previous 12 months.

Transition planning

Transition planning was categorised into five groups, after a review of all documentation to the end of 2002 to identify the outcomes of transfer plans made in 2001. The groups were as follows:

- *Transferred to adult healthcare provider.* This was identified by a referral letter and at least one letter of communication from an adult healthcare service.
- *Transition plan documented.* This was identified by *any* mention of transfer or referral to an adult hospital or provider.
- *No transition plan documented.* This was identified by the presence of ongoing plans for further management at the hospital without recording of transfer or referral plans.
- *Death/palliative care.* Progression to palliative care was identified by documentation in the medical record of palliative care provision, either within the hospital or by community services.
- *Lost to follow-up.* This included patients followed up privately, those who failed to attend booked appointments, and a small number of international patients.

RESULTS

Hospital admission data, 1992–2001

There was a significant increase in admission of young adults over the 10-year period ($P < 0.001$). However, trends in admission were highly variable across different admitting units (Box 1).

Three of the six surgical units showed a statistically significant increase in admission of young adults over the decade. This was most pronounced in Plastic Surgery and Orthopaedic Surgery.

Of the nine medical units, three (Gastroenterology, Nephrology and Child Development and Rehabilitation) had significantly increased admissions, while the Department of Respiratory Medicine had a non-signficant reduction in the number of young adults admitted.

Chart review, 2001

There were 341 admissions of 247 young adults in 2001, comprising 2% of total hospital admissions. Fifty-seven per cent of these young people were aged 18–20 years at admission, 35% were aged 20–25 years and 8% were over 25 years (ranging up to 47 years).

About two-thirds (68%) of these young adults were admitted to surgical departments, with the largest numbers admitted under the departments of Plastic Surgery and Orthopaedic Surgery (Box 2).

Half (52%) of the young adults were admitted to the hospital's adolescent ward, with the rest admitted to specialist wards throughout the hospital.

Complexity measures

Ninety-one per cent of the 247 young adults had at least one pre-existing diagnosis, while 64% had two or more pre-existing complications of either the principal diagnosis or comorbid conditions. Fifty-seven per cent had three or more medical and/or surgical units involved in their ongoing care, and 34% had two or more allied health services involved.

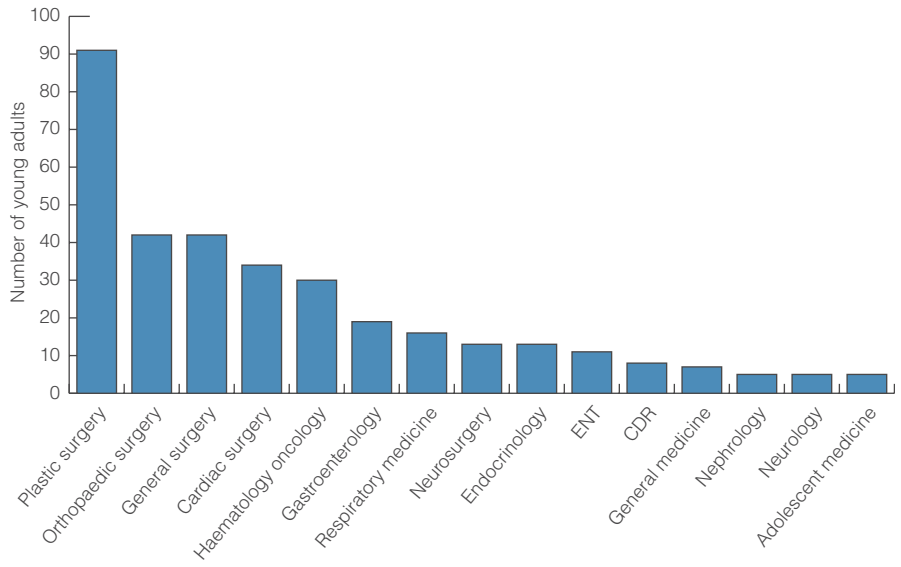
The mean length of stay was 4.5 days (SD, 7.1 days), with means 5.4 days and 4.1 days for medical and surgical units, respectively. (The mean length of stay for all hospital patients in 2001 was 4.3 days.)

Twenty-seven per cent of the 247 patients had more than one admission in 2001, and 17% were also admitted in 2002.

Transition planning

For 13% of young adults there was a documented transition plan, and 21% had been

2 Number of young adults admitted in 2001, by unit



CDR = Child Development and Rehabilitation. ENT = Ear, Nose and Throat.

transferred to the adult sector in 2002. Almost half (49%) of young adults admitted to medical units in 2001 had either been transferred to adult healthcare by 2002 or had a transition plan, compared with 28% of surgical patients (Box 3).

Of all units, Plastic Surgery had the smallest percentage (7%) of young adults who were transferred by 2002. There was no documented transition plan in any young adult admitted under the departments of General Surgery or Ear, Nose and Throat Surgery. About half of all young adults admitted under the Department of Gastroenterology had active plans for ongoing care at the hospital. In contrast, there was a documented transition plan for all young adults admitted under the Departments of Endocrinology and Neurology.

DISCUSSION

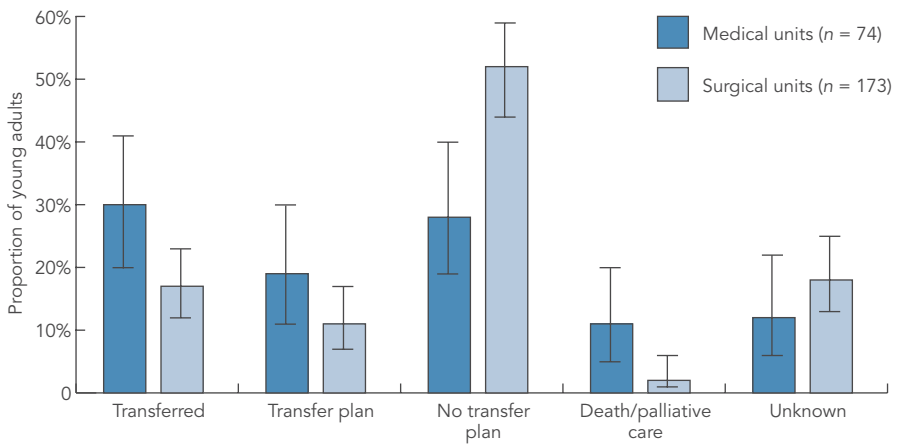
There has been a significant increase in the number of young adults admitted to the RCH over the past decade, the greatest increase being within surgical rather than medical units. What do these increased admissions reflect? It might be argued that as the number of young people with chronic illness increases, we should expect the proportion of older adolescents and young adults within paediatric hospitals to increase (this was recently confirmed at the RCH[6]). While some changes are likely to reflect changing technical capacity or variable access to health services between paediatric and adult systems, a doubling of annual admissions of young adults (in the absence of a major policy and funding change to cater for these young people within the paediatric system) raises concerns about inadequate transfer to adult healthcare.

It is well recognised that attitudinal barriers, such as beliefs of parents or paediatricians that inadequate care would be provided within the adult sector, delay transfer to adult services.[12,14] The lack of appropriate health services within the adult sector for young people requiring multidisciplinary care[14,15] is another likely reason for delayed transfer. That over half of the young adults who continued to be managed at the RCH had more than three units involved provides some evidence that clinical complexity is a barrier to timely transfer. As we did not determine the availability of services within the adult healthcare sector for individuals in this study, we are unable to determine the appropriateness of their healthcare continuing at the RCH.

However, it has been argued that young adult patients who have the most complex needs or who demonstrate the most concern about the lack of available services are the very group that requires careful planning to support successful transition.[15] In view of this, and notwithstanding clinical complexity, our audit shows a striking lack of evidence supporting transition to adult healthcare. This was especially the case for young people managed by surgical units, of which only one in 10 had a transition plan. We deliberately chose a broad definition of "transition planning". Thus, *any* relevant comment in the medical notes provided evidence of planning. This may mean that our results overestimated the level of transition planning, given that best practice constitutes application of many principles and not simply documentation.[7-9] On the other hand, it could also be argued that these figures may reflect poor clinical documentation, thus giving an *underestimate* of the true level of transition planning. As only 30% of medical and 17% of surgical patients were successfully transferred by the following year, poor documentation alone seems an unlikely explanation.

There was a trend towards falling admissions within the Department of Respiratory

3 Level of transition planning for young adults in 2001, by type of unit*



*Bars represent 95% CIs.

Medicine. This department has a well established transition program with adult cystic fibrosis services: young people are transferred to these services in the year after completing secondary schooling via a process that is carefully coordinated by a senior nurse.

Similarly, despite the increasing prevalence of diabetes, there was a stable pattern of admission of young adults within the Department of Endocrinology, which transfers about 150 young people with diabetes each year to adult services. One explanation is that, like the Department of Respiratory Medicine, the Department of Endocrinology has established effective links with adult providers with experience in managing diabetes. Another explanation is that, as in Respiratory Medicine, a designated person is responsible for coordinating the transfer to adult services.

There are well defined principles underpinning the concept of transition to adult healthcare.[7-9] These include understanding that the process of transition to adult healthcare occurs within a developmental context, recognising the importance of promoting the young person's increasing capacity for self care, supporting the ongoing involvement of the family, and the need for flexibility about the timing of transfer.[7] Our audit suggests that these principles are yet to be translated into systematic approaches that support transition to adult healthcare.

Our data come from a single tertiary children's hospital. Most data about transition to adult healthcare comes from single-disease programs (eg, cystic fibrosis, diabetes). We believe the particular value of our study is its focus on the hospital as a whole rather than a specific disease, enabling comparison of local clinical practices that act as barriers or facilitators to successful transition.

However, even in settings where transition to adult healthcare is established, greater focus on clinical and developmental outcomes is needed.[15] For example, there are concerns that unsupported transfer to adult healthcare or dissatisfaction with the adult system increases the drop-out rate from adult services, but there are few available data to support this.

Rather than developing a policy of limiting the admission of young adults to children's hospitals, we suggest there should be greater focus on the infrastructure supporting the transition of young people with chronic illness from paediatric to adult services. Developing management plans that include transition planning will increase successful transition in the short term, especially for patients without complex conditions. In the medium term, greater emphasis on clinical workforce development around transition appears indicated. In the longer term, specific healthcare planning and policy development will be needed to ensure that developmentally appropriate services, including appropriate physical environments, are provided for the growing numbers of young people with chronic illness requiring hospitalisation.

COMPETING INTERESTS

None identified.

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