Transition from paediatric surgery: how many patients do we need to plan for?

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ABSTRACT

INTRODUCTION Transitional care is an NHS priority with newly published NICE guidance. Many paediatric surgical patients need quality care to continue into adulthood. We undertook an evaluation of our departmental activity to assess the magnitude of this issue.

METHODS We identified all outpatients ≥ 15 years (potentially requiring imminent transition) seen over a 12 month period for all five general paediatric surgery consultants in our tertiary centre. Those patients requiring transition were highlighted and the appropriate adult team for referral recorded.

RESULTS There were 2989 general paediatric surgery clinic appointments within the year; 289 (9.7%) were for young people aged 15 years or older; 62 patients (28% of those ≥ 15 years) were deemed to require transition into adult care. Significantly more patients having colorectal surgery required follow-up ($P = 0.0009$ Chi-square test) compared with patients in other subspecialties.

CONCLUSIONS More patients than expected required transition. This may be the case in other units. Current best practice includes time intensive preclinic planning, careful preparation of patient and family, followed by joint clinics. A joint clinic appointment takes 30 minutes, allowing for comprehensive handover and forging new relationships. In our department, we need at least ten transition clinics across 2 years. Coalition with adult colleagues is vital. These data enable us to plan services to provide quality care for our adolescent patients and highlights colorectal surgery as a priority.

KEYWORDS

Transition – Transitional care – Adolescent medicine

Accepted 24 July 2016

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Introduction

Transitional care is 'a purposeful, planned process that addresses the medical, psychosocial and educational/vocational needs of adolescents and young adults with chronic physical and medical conditions as they move from child-centred to adult-oriented healthcare systems'. A growing number of children with congenital or chronic disease and life-limiting conditions survive into adulthood.¹ Adolescence is recognised as a vulnerable time and important for forming behaviours which will continue into adulthood. An important distinction is the planned process of *transition*, which may take considerable time (years) compared with *transfer*, a discrete point in time and space.

Poor transition has a significant effect on disease-specific morbidity. There is evidence, for example, that good transition, with associated improvement in treatment compliance, results in a reduced burden of surgical disease in later life in patients with kidney transplants and diabetes care.^{2,5} There have been many attempts at national level to encourage care

providers to instigate or improve transition planning and delivery. Both the Department of Health and the Care Quality Commission (CQC) have produced a number of reviews, with disappointing findings. New guidelines from the National Institute of Health and Care Excellence (NICE) bring together the existing evidence. To date, children's services have borne the burden of planning transition, but it is clear (and supported by the NICE guidance) that engagement of adult specialist teams is vital in providing transitional care.

One of the difficulties within paediatric surgery (particularly in standalone children's hospitals) is in identifying adult surgeons who have an interest in the surgical conditions of young adults, and who are willing to take on this sometimes challenging group. Their experience of surgical disease in adulthood, together with the normal encouragement of independence and self-advocacy for patients, make the adult surgical team an indispensable part of planning and delivering transitional care.

We set out to review our cohort requiring imminent transition and transfer from our tertiary unit. This followed

the urology transition service in our centre and the inception of a colorectal surgical transition clinic. We present our data as a baseline for planning a continuing service in an environment where there is currently little provision.

Methods

We interrogated outpatient records for 12 months between November 2013 and October 2014 for all five general paediatric surgery consultants. Patients under the care of the paediatric urologists were excluded as there is an established local transition pathway in place. All patients aged 15 years and older were deemed close to transition. The primary surgical problem was recorded, together with comorbidities and involvement with other specialty teams. Based on these parameters, the authors judged whether transfer to adult services (and to which subspecialty team) would be needed. Results were compiled, tabulated and reviewed using Microsoft Excel® 2013.

Results

Within the study period, there were 2989 clinic appointments; 218 patients aged 15 years or above were seen, in 289 (9.7%) appointments; some were seen more than once during the study period;

62 patients (28%) were deemed to require transition. These were distributed across specialties (Table 1). Those patients requiring urological care were those with simple urological conditions seen within general paediatric surgery clinics, such as undescended testes or varicocele. There were significantly more patients having colorectal surgery who required follow-up than those needing other surgeries ($P = 0.0009$, Chi-square test).

Seventy-five (34%) patients in the group 15 years and older were new referrals to the paediatric surgery service during the study period. Of these, 10 were older than 16 years when referred; 16 patients were deemed to require transition. Of the 62 young people requiring transition, 22 (35%) were also under the care of another specialty. There was great variety (Fig 1); 11 patients (18%) were under the

care of multiple teams and, for 8, this included a paediatrician, either in secondary care or in the community.

Discussion

A number of healthcare transition models are already established. One of the most commonly used, ‘Ready, Steady, Go’⁴ begins with a planning stage by the paediatric team. Between 16 and 18 years, transition clinics are attended, where the young person meets both paediatric and adult teams, culminating in a transfer of care. Beyond 18 years, there may still be support from specialist nurses or youth workers but care is delivered by the adult team.

A number of specialties have well established pathways.⁵ These include diabetes,⁶ cystic fibrosis,^{7,8} and cardiac care. These are predominantly examples of single specialties moving patients on to the equivalent adult specialty, where there are already clinicians who have an interest in, and knowledge of those conditions. A special case is congenital cardiac disease; where there is a need to recognise late effects that differ from de novo adult disease. This is an example of transition delivery in a different environment over time (the children’s hospital first, then adult clinics later) but by the same clinical team. This model requires no ‘transfer’ of care but is continuous.

One of the difficulties for transition from paediatric surgery is that individual clinicians care for large numbers of children with diverse and rare conditions. There is no single ‘general’ surgeon who can provide care after transfer. The building of professional relationships and joint clinics with several different teams poses logistical difficulties, notwithstanding challenges in commissioning and delivering the service. Further subspecialisation within paediatric surgery may make provision of transitional care more straightforward.

Our results show that the group with colorectal conditions should be our priority. These are patients with anorectal malformations, Hirschsprung’s disease, inflammatory bowel disease and severe chronic constipation requiring surgical intervention with antegrade continence enema (ACE) and enterostomy. To address the group with colorectal

Table 1 Numbers of patients seen by each consultant, reflecting their scope of practice										
Consultant	Total appointments	Patients ≥ 15 years	Needing transition	Subspecialty						
				Colorectal	General surgery	Home enteral feeding	Gastro-enterology	Urology	Thoracics	Upper GI
1	764	60	32	16	3	1	5	5	0	2
2	494	45	7	0	2	3	2	0	0	0
3	642	63	17	5	4	2	0	1	4	2
4	515	17	2	0	1	0	1	0	0	0
5	574	33	4	0	0	3	0	1	0	0
Total n (%)	2989	218	62	21 (33)	10 (16)	9 (14)	8 (13)	7 (11)	4 (7)	4 (6)

Figure 1 Patients also under the care of other specialties

conditions, we began planning for transition by establishing a quarterly joint clinic with a colorectal surgeon, supported by both paediatric and adult stoma nurses.

There are smaller numbers of patients in other subspecialties who will need transition and may need surgical intervention at any age. These groups remain a challenge. Many young people have multiple comorbidities with different specialty input. Quality and timely communication between teams is crucial. Our results demonstrate a significant challenge ahead for surgery across the age range. The numbers of young people requiring transition may appear small but they were more than we expected to find for a single point in time. It is highly likely that this is also the case in other units around the UK.

In real capacity planning terms, to provide one joint transition clinic appointment for each of our patients needs at least ten clinics over 2 years. A joint clinic appointment takes

about 30 minutes, to build new relationships and for comprehensive clinical review and planning. This also impacts on job planning.

Good transition is patient-centred and also caters for the social, emotional, educational and vocational needs of young people. Involvement of specialist nurses, school nurses, social workers, and community teams and youth workers is vital and is beyond the remit of most surgeons. We must engage with, and actively involve the multidisciplinary team as we plan our transitional care. Funding transition is important and, at present, is not commissioned. NICE guidance will raise the profile of transition to this end.

Conclusions

A significant number of paediatric surgical patients require quality transition planning and transfer. Our data show the magnitude of the need and points to where focus might be required. Provision of this service, together with seamless coordination between paediatric and adult surgeons is challenging, but vital to the health and wellbeing of the young people for whom we care.

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