

Original Article

Specialist cardiac services: what do young people want?

Jo Wray, Linda Maynard

Royal Brompton & Harefield NHS Trust, Harefield Hospital, Harefield, Middlesex, United Kingdom

Abstract *Purpose:* With improvements in the surgical and medical management of children with congenital heart disease, the majority are now expected to transition into adult services. Whilst the importance of successful transition is increasingly acknowledged, previous research has identified a number of areas of concern. We therefore wished to elicit the views of young people themselves concerning their requirements from a specialist cardiac service. *Methods:* Using an exploratory approach our aims were to increase awareness of the service needs and expectations of young people, identify good practice and areas where communication processes and facilities could be improved, and enhance understanding of transition between paediatric and adult services. Postal questionnaires were sent to 63 young people with congenital cardiac disease aged 17 to 20 years. Open ended questions asked for views and experiences about facilities in the paediatric and adult areas, perceptions of transition between services and suggestions for improvements. Qualitative data were transferred verbatim into electronic format to facilitate coding and theming. *Results:* Thirty-eight (60.3 percent) completed questionnaires were received. A number of themes, including communication, care processes/caring interactions and environment, emerged regarding areas of satisfaction and dissatisfaction within the paediatric and adult services, together with areas for improvement and important aspects of transition. *Conclusions:* Young people's views need to be taken into account at all stages of the patient journey. They want an individualised approach to their care which recognises that they have specific emotional and practical needs. Such findings need to be incorporated into an ongoing model of care.

Keywords: Congenital heart disease; adolescents; transition

MORE THAN 85% OF CHILDREN BORN TODAY with a chronic medical condition are expected to live into adulthood.¹ In the United Kingdom approximately 90 babies are born every week with some form of cardiac disease² and currently there are around 135,000 young people and adults with congenital cardiac disease living in England.^{2,3} Although scientific and technological advances have improved the prognoses for these young people,⁴ cardiac surgery cannot be regarded as corrective for the majority of patients, but rather definitive palliation.³ Some young people with complex congenital cardiac disease will have continuing care needs

as adults which will necessitate life-long management and review. Current international guidelines recommend that just over half of adult patients with congenital cardiac disease should be seen every 12 to 24 months by a cardiologist with specific expertise in congenital heart disease^{5–9} yet the process of transition from paediatric to adult cardiac services has only recently started to be systematically evaluated.

The time of transition to adult services has been identified as one of increased vulnerability in other disease groups^{10,11} and within the cardiac population a recent study of patients with congenital cardiac disease found an increase in hospitalisations surrounding the transition to adult programmes.¹² In a comprehensive evaluation of young adult patients with complex congenital cardiac disease initially treated at a specialist paediatric cardiac centre in Canada, less than half of the patients were

Correspondence to: Dr Jo Wray, Children's Clinic, Royal Brompton & Harefield NHS Trust, Harefield Hospital, Harefield, Middlesex, UB9 6JH. Tel: 01895 828761; Fax: 01895 828554; E-mail: jo.wray@btopenworld.com

Accepted for publication 2 September 2008

found to have transferred successfully to adult care.¹³ Whilst there are a number of generic issues facing young people with congenital cardiac disease who are transitioning to adult services, other issues, such as concerns about body image, delayed physical development and impaired cognitive function, may be specific to subgroups of patients. Involving young people themselves in specialist service development is therefore of paramount importance as they have specific health needs, many of which continue to be unmet.^{14,15} Furthermore, if they are to engage with professionals in the adult service it is imperative that their views are sought concerning the process of transition and their requirements from the service.

This study reports the views of young people with cardiac disease about their experiences with paediatric and adult services provided by one London National Health Service Trust in the United Kingdom. Using an exploratory approach our aims were to increase awareness of the service needs and expectations of young people, identify good practice and areas where communication processes and facilities could be improved, and enhance understanding of transition between paediatric and adult services.

Methods

Local Research Ethics Committee approval was obtained for the study. The eligible study population was sixty-three young people aged 17 to 20 years with complex cardiac disease³ and continuing health care needs (annual or more frequent follow up) who had received inpatient treatment during adolescence (aged 13 to 16 years). A postal survey was chosen as the most cost-effective method to generate a preliminary theoretical framework with which to inform a more focused study. One reminder and an additional copy of the survey were sent to the whole sample as responses were anonymous. Open-ended questions asked for views and experiences about facilities in the paediatric and adult areas, perceptions of transition between

services and suggestions for improvements. Qualitative data were transferred verbatim into electronic format to facilitate coding and theming. Independent thematic analysis was undertaken by the authors with consequent discussion confirming categories of data and generating higher levels of abstraction themes.^{16,17} Anonymised direct quotations have been used to illustrate these themes. Descriptive statistics were used to report information from Likert scales comparing information about communication and decision-making processes in paediatric and adult areas.

Results

Quantitative data

Thirty-eight (60.3 percent) respondents returned completed questionnaires, 33 (86.8 percent) of which were self reports with the remainder being completed by a carer (in 3 cases) or the patient and carer together (in 2 cases). Preparation for transition generally started between 16 and 18 years of age, with the majority transitioning at 18. However, one third of the sample reported that they would have liked to transfer to adult care at 16 years of age.

The frequency of views concerning explanations of treatment, involvement in decision making and communication processes are detailed in Table 1.

In terms of care in the paediatric area, having their own television and video and friendly staff were the two areas most endorsed, whilst the least favourable aspects were the lack of facilities for teenagers, the bathroom facilities and having to share a ward area with younger children. Within the adult areas, friendly staff and their own bathroom facilities and television were the aspects which were most highly valued whilst being with older, sick patients and lack of anything to do were the areas of greatest concern to young people.

Qualitative data

Aspects of the paediatric services. Analysis of qualitative data revealed aspects of paediatric services

Table 1. Frequency of views concerning explanations of treatment, involvement in decision making and communication processes.

	Care in children's area			Care in adult areas		
	Never (%)	Often (%)	Always (%)	Never (%)	Often (%)	Always (%)
Did the doctors explain your treatment to you in a way you could understand?	1 (3)	15 (44)	18 (53)	0	9 (27)	24 (73)
Were you involved in making decisions about your treatment?	11 (26)	17 (40)	14 (33)	4 (15)	9 (35)	13 (50)
Did the doctors listen to your views about your care?	13 (42)	8 (25)	11 (34)	0	14 (47)	16 (53)
Were you given opportunities to discuss your care with the doctors by yourself?	3 (11)	10 (37)	14 (52)	Not asked	Not asked	Not asked

Table 2. Views of young people concerning paediatric services.

Aspects valued	Aspects causing dissatisfaction
Feeling at home <i>"My mum was allowed to stay with me when I was ill and the staff were always very friendly which made my stay easier and I felt at home"</i>	Communication – mainly with parents – being patronized <i>"It would have been better if they had listened to me more – rather than patronising me".</i>
Respect for beliefs <i>"Being a Jehovah's Witness was never an issue, all staff respected my views and beliefs and never tried to change my mind".</i>	Lack of knowledge – made hospital experience more frightening <i>"Was in hospital a lot when I was younger because I was born with heart problems. The experience could have been better by doctors explaining the treatment to me more clearer. I didn't really know what was happening to me and consequently the hospital experience was scary".</i>
	Lack of privacy <i>"The only thing that can be difficult is when your consultant has around 5–6 student doctors who want to examine you and have a poke, especially as a teenager when you are at your most self-conscious. I know it has to be done but perhaps it could be done more discreetly than the middle of the room".</i>

which were highly valued and those with which patients were most dissatisfied (Table 2). A number of patients also took the opportunity to praise the care and services which they had received in the paediatric areas: *"I thought the care was really good so I don't know how the facilities could be improved – sorry!"*

Aspects of adult services. Three main themes were elicited from the data concerning young people's views on adult services (Table 3), namely communication, care processes/caring interactions and environment.

Important issues during transition. During their transition period respondents perceived it to be important to have their family and support network around and the continuing involvement of their carers (Table 4). Several young people reported that they were still dependent on their parents/carers for activities of daily living and to help them with care and treatments, whilst carer respondents voiced their feelings and concerns about their child's transition process: *"Now that my daughter has moved from paed to adult care, I feel as if I am now supposed to*

Table 3. Views of young people concerning adult services.

Aspects valued	Aspects causing dissatisfaction
Communication ● Being kept informed ● Doctors easy to talk to ● Doctors listen more ● Staff explain everything to me not my parents	Care processes/caring interactions ● Long waits at appointment times ● Long waits for drugs ● Transfer ○ No preparation/not being fully prepared ○ Rushed ○ No choice in timing
Care processes/caring interactions ● Have a 'voice'/have choice ● Treated as an adult ● Seen more quickly ● Formal meeting with adult consultant ● Presence of nurse advisor ● Smoothness of transfer	● Loss ○ Missing paediatricians ○ Sudden cessation of contact
Environment ● Facilities – own en-suite room ● Less noise (no small children)	Environment ● Being with older people, feeling out of place ● No television ● Poor meals

be redundant – that I am expected to sit back and not be involved in her care anymore. But I can't do that because I am her carer and she needs extra help with day-to-day living. I sit in with her in clinic appointments (at her request), but I feel as if I'm in the way. I know she has to be responsible for her illness, but her needs are such that she needs the help that I give her. In our case, I feel that (and my daughter does too) her care should be 3 way between her, myself and the team."

They felt that being informed and prepared for the changes in the processes of delivery of care between paediatric and adult areas was also essential: *"The most important thing to me when transferring to the adult clinic was that all the decisions were made with me involved and I was able to talk about what was going to happen when I saw the doctors, which I never had a chance to do in the children's clinic".* In particular, young people talked about "having a voice" and 'more of a say' about being involved in making decisions about their care and treatment, receiving the same standard of care as they had in paediatrics, with reassurance that their care was handed over safely, and the importance of adult doctors also having specialist expertise so that they would quickly gain confidence in them. It was important for them not to 'feel lost' in adult services: *"To be heard and for my treatment to stay the same".*

"The most important feeling was that I could fit in and that I would still receive the same care".

Suggested areas for improvement

Four major areas of need (Table 5) were revealed when we analysed the data regarding suggestions for improvements in services for young people with complex cardiac conditions.

Facilities – structural. There was a need for separate facilities designated for adolescents and young people, which was identified from the perspective of both paediatric and adult services: “When I was 13, I was in a side ward with 5 babies, all were very ill and cried all night. It was a very upsetting experience for myself and any visitors. It would have been much better if there was a young adult unit. (The experience was also upsetting for the parents of the babies as they did not have privacy)”.

“It is a bit of a shock when you see all the old men, and you are young. I think we need more wards for young people”.

“To have a separate ward for teenagers and young adults with facilities for a parent to stay and look after me as I am severely disabled”.

Table 4. Issues in transition important to adolescents and young people.

Involvement of carers

- Have family/support network around

Communication

- Being informed, being prepared

Care processes/caring interactions

- Being involved in decision making – to have ‘a voice’ or ‘more of a say’
- Have the same standard of care – reassurance of specialist expertise
- Gain confidence in new doctors – get to know new team quickly
- To ‘fit in’ with new team
- Not feel lost in adult care
- Records kept safe

Facilities – environment. Respondents wished for appropriate activities tailored to young people’s needs and preferences. For example, being able to use personal computers and have internet access, other facilities such as computer games, magazines and books as well as the need to address concerns regarding quantity and quality of hospital meals. “Bigger meals. More privacy, own television, more varied facilities because the adult age range is from 16 to over 100, and people have very different interests, no matter how old they are”.

Caring processes. The need to streamline the outpatient appointment system to reduce waiting times was identified. Young people wanted enhanced family visiting in adult care areas, and recognition of privacy and dignity issues, with care provided away from small children. The importance of female doctors being available for female patients was also mentioned.

Caring interactions. Fourthly, adolescents and young people moving to adult care wanted the reassurance that they would receive the same high standard of care that they had enjoyed within the children’s areas (although they did reveal some aspects of care were not satisfactory in paediatrics – for example the lack of involvement in decision making and not being involved in their care and not understanding their care and treatment). “Haven’t seen liaison nurse in clinic since transition visit. Feel vulnerable because there doesn’t seem to be the same effort made by the staff to get to know you as there was in paediatrics”.

Discussion

Listening and responding to the needs of young people is an important guiding principal in the

Table 5. Improvements in services for adolescents and young people.

Facilities – structural	Facilities – environmental	Caring processes	Caring interactions
Need for separate facilities for adolescents and young people	Need for appropriate activities tailored to young people’s needs and preferences, such as computers and internet access, playstation, appropriate magazines	Streamlined outpatient appointment system to reduce waiting times	Competent staff with specialist expertise
	Need to address concerns regarding quantity and quality of hospital meals	Enhanced family visiting in adult care areas	Better communication – “voice and choice”. For example, involvement in decision making about care and timing of transfer
		Recognition of privacy and dignity issues – for example: Care away from small noisy children	Explanations Listen more
		Consultation/examination out of ear shot of other patients/visitors	“For staff to be aware that although I’m now an “adult” I’m also a teenager and still need some of the support a “child” would need”.
		Female doctors for female patients	

National Service Framework for Children.¹⁸ Some young people with cardiac disease have unmet needs and have clear views about what would improve both the paediatric and adult services, as well as the process of transition between the services. As has been identified previously,¹⁹ some patients viewed the paediatric service more positively than the adult service, which may be related to different models of care. Within paediatric services a family-centred approach to care is more usually adopted, which is a collaborative model that holds the family as central within a child's life. A number of young people clearly valued this approach and some found the contrasting patient-centred approach of adult services impersonal and rushed. The family-centred approach, however, also had some drawbacks when young people felt disempowered by their own lack of involvement in their care and decision-making, and when communication focused on their parents, rather than on them. Within the paediatric setting almost half of our patients reported that their views about their care were never listened to, and one quarter never felt involved in making decisions about their treatment.

Although young people valued aspects of both the paediatric and adult service, a number of suggestions for improvement were offered. Four main themes were elicited from the responses, three of which could be addressed without the need for significant resources. Issues regarding the environment, caring processes and caring interactions could be tackled relatively easily, whilst the need for separate facilities is a structural issue and would require significant resources to address. When new services are planned, however, these issues should be considered, so that inpatient services are sensitive to the needs of young people.²⁰

Research of this nature highlights the importance of asking young people themselves about what they need from a service, particularly as there can be a discrepancy between what we think we offer them and what they perceive is offered to them. These findings also emphasise the need to support young people moving into adult services, and to recognise the fact that some patients with congenital cardiac disease, although of adult age, do not feel like adults. Chronological age is not necessarily an accurate predictor of emotional maturity and developmental level²¹ and input needs to be tailored to the adolescent's current level of development.²² Likewise, it is important to support parents and carers through the transition process and to facilitate their appropriate involvement within the adult setting. The differences between adult and paediatric services can be difficult for some patients to cope with, and indicate the need for better

preparation of young people and their families. Patients' beliefs about transition and what has been recommended for their adult follow-up have been found to be significantly correlated with successful transfer to adult services,¹³ supporting the need to engage with the young person themselves regarding their beliefs and perceptions about their ongoing care as they move into the adult service.

Although this is a small study, the response rate was acceptable and the extent of rich qualitative data revealed that young people valued the opportunity to record their views. Further research needs to focus on a number of areas, including the development of alternative methods of engaging adolescents and young people in research which are more suited to young people's lifestyle, such as text message or internet based surveys. Understanding concepts such as patient anxiety around transition, the sense of loss/sadness at leaving the paediatric team and the feelings of uncertainty regarding an unknown and less predictable future in terms of health care services are important steps in facilitating a smooth transition to adult services.

One solution to addressing some of these issues lies in the appropriate training of health professionals involved in the care of young people with cardiac disease and it has been suggested that physicians themselves can be barriers to successful transition.²³ A reluctance to "let go", a perception of transition as being unimportant, and poor communication between paediatric and adult professionals can all impede the process of transition. A number of our findings suggest a need for professionals working with young people to change their own perspective regarding the transition to adult services.

The recurrent theme throughout all of our findings is the importance and need for good communication, and for young people's views to be taken into account at all stages of the patient's journey. Young people want an individualised approach to their care which recognises that they have specific needs related to the fact they are in a process of transition from childhood to adult life.^{24,25} They also want their emotional needs to be understood and validated, such as their sense of loss, anxiety, and need for reassurance and recognition that they may not yet be fully independent adults. As the population of adults with congenital cardiac disease continues to increase, it is evident that services in both paediatric and adult areas need to ensure that a holistic approach to meeting the needs of young people is delivered in order to empower them to make appropriate choices and decisions in adulthood.

References

1. Seal 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: 259–264.
2. Department of Health. Report of the Paediatric and Congenital Cardiac Services Review. London: Department of Health, 2003.
3. Report of the British Cardiac Society Working Party: Grown-up congenital heart (GUCH) disease: current needs and provision of service for adolescents and adults with congenital heart disease in the UK. *Heart* 2002; 8(suppl 1): i1–i14.
4. British Heart Foundation Statistics Database. Congenital heart disease statistics. Oxford: BHF Health Promotion Research Group, University of Oxford, 2003, www.heartstats.org
5. Warnes CA, Liberthson R, Danielson GK, et al. Task force 1: the changing profile of congenital heart disease in adult life. *J Am Coll Cardiol* 2001; 37: 1170–1175.
6. Landzberg MJ, Murphy DJ, Davidson WR, et al. Task force 4: Organization of delivery systems for adults with congenital heart disease. *J Am Coll Cardiol* 2001; 37: 1187–1193.
7. Therrien J, Dore A, Gersony W, et al. CCS Consensus Conference 2001 update: recommendations for the management of adults with congenital heart disease. Part I. *Can J Cardiol* 2001; 17: 940–959.
8. Therrien J, Gatzoulis M, Graham T, et al. Canadian Cardiovascular Society Consensus Conference 2001 update: Recommendations for the Management of Adults with Congenital Heart Disease – Part II. *Can J Cardiol* 2001; 17: 1029–1050.
9. Therrien J, Warnes C, D'Alto L, et al. Canadian Cardiovascular Society Consensus Conference 2001 update: recommendations for the management of adults with congenital heart disease – Part III. *Can J Cardiol* 2001; 17: 1135–1158.
10. The Association for children's palliative care. The transition care pathway. Bristol 2007.
11. Watson AR. Non-compliance and transfer from paediatric to adult transplant unit. *Pediatr Nephrol* 2000; 14: 469–472.
12. Gurvitz MZ, Inkelas M, Lee M, Stout K, Escarce J, Chang RK. Changes in hospitalization patterns among patients with congenital heart disease during the transition from adolescence to adulthood. *J Am Coll Cardiol* 2007; 49: 875–882.
13. Reid GJ, Irvine J, McCrindle BW, et al. Prevalence and correlates of successful transfer from pediatric to adult health care among a cohort of young adults with complex congenital heart defects. *Pediatrics* 2004; 113: 197–205.
14. British Heart Foundation. We'll tell you what we want: A DVD for teenagers with congenital heart disease. London 2005.
15. Royal College of Paediatrics and Child Health. Bridging the Gaps: Health care for Adolescents. London: Royal College of Paediatrics and Child Health, 2003.
16. Miles M, Huberman M. *Qualitative Data Analysis: an expanded source book*. Sage, London, 1994.
17. Strauss A, Corbin J. *Basics of Qualitative Research: Techniques and Procedures for Developing Grounded Theory* 1998. Thousand Oakes, Sage Publications, CA, USA, 1998.
18. Department of Health. Getting the right start: National Service Framework (NSF) for Children, Young People and Maternity Services – Standard for Hospital Services. London, 2003.
19. McCurdy C, DiCenso A, Boblin S, Ludwin D, Bryant-Lukosius D, Bosompra K. There to here: young adult patients' perceptions of the process of transition from pediatric to adult transplant care. *Prog Transplant* 2006; 16: 309–316.
20. Hudsmith LE, Thorne SA. Transition of care from paediatric to adult services in cardiology. *Arch Dis Child* 2007; 92: 927–930.
21. Tong E, Sparacino PS. Special management issues for adolescents and young adults with congenital heart disease. *Crit Care Nurs Clin North Am* 1994; 6: 199–214.
22. Tong EM, Kools S. Health care transition for adolescents with congenital heart disease: patient and family perspectives. *Nurs Clin N Am* 2004; 39: 727–740.
23. Fox A. Physicians as barriers to successful transitional care. *Int J Adolesc Med Health* 2002; 14: 3–7.
24. Dore A, de Guise P, Mercier LA. Transition of care to adult congenital heart centres: what do patients know about their condition? *Can J Cardiol* 2002; 18: 141–146.
25. Higgins SS, Tong E. Transitioning adolescents with congenital heart disease into adult health care. *Prog Cardiovasc Nurs* 2003; 18: 93–98.