Cardiology in the Young (2017), **27**, 1014–1017
doi:10.1017/S1047951116002973

Brief Report

Are patients bypassing paediatric cardiology outreach clinics?

Alexander Fletcher,[1] Ray Samson,[2] Karen McLeod[3]

[1]*Level 1, Neonatology;* [2]*Cardiac, Critical Care, Theatre and Neonatal Services;* [3]*Paediatric Cardiology, Ward 1E, Royal Hospital for Children Glasgow, Glasgow, Scotland*

Abstract Previous studies have identified that receiving specialist care close to home can positively influence patients' experience. Despite this, a review of cardiology outpatient appointments at the Royal Hospital for Children in Glasgow demonstrated that a large number of families are bypassing their local children's cardiology centre to attend cardiac clinics at the specialist children's surgical centre. We used patient questionnaire, audit of local facilities, and examined the relationship between diagnosis and bypass numbers to better understand factors influencing this trend. Our results suggest that patient preference, short travelling distance to specialist children's cardiac centre, a more severe cardiac diagnosis, and inconsistent local facilities, expertise, and support are likely to influence a family's decision to bypass their local children's cardiology centre.

Keywords: Scotland; outpatient; care close to home; network of care

Received: 14 December 2015; Accepted: 18 December 2016; First published online: 25 January 2017

Background

A move towards locally accessible specialist health care was one of the major themes in a recent report by the Department of Health, a view that was echoed in recently published national guidance on the organisation of congenital cardiac services in England.[1,2] Outreach clinics, where a paediatric cardiologist travels to a local children's cardiology centre to review patients alongside the resident paediatric team, allow patients to receive specialist care closer home. A systematic review and in-depth qualitative analysis both suggest that being reviewed and supported locally improves parent and patient experience as well as being more convenient.[3,4] The managed clinical network of paediatric cardiology clinics in Scotland consists of the following: one specialist children's surgical centre, Royal Hospital for Children in Glasgow (level 1); one specialist children's cardiology centre (level 2); and 10 local children's cardiology centres (level 3). Despite the proposed benefits, we found that a relatively large number of families are still being reviewed in the specialist children's surgical centre rather than local children's cardiology centres. Our aims were to determine how many patients are bypassing these local centres and to explore potential influencing factors.

Methods

The Royal Hospital for Children Glasgow cardiac database – HeartSuite – was searched to identify all paediatric cardiology outpatient appointments at the specialist children's surgical centre between January and December 2015. Patients' postcodes, National Congenital Heart Disease Audit diagnosis, and a brief clinical summary, including previous and planned procedures, were collected. Patients' postcodes were used to identify those who had a local children's cardiology centre where they could have been reviewed, and from this the number of bypassers was determined.

To ascertain why families bypassed their local children's cardiology centres, we offered a questionnaire to all patients attending the specialist children's surgical centre outpatient clinic between July 2014 and April 2015. Responders could select more than one reason if applicable.

The patient's cardiac diagnosis and summary were used to stratify the patient into "Risk Adjustment for Congenital Heart Surgery" (RACHS-1) categories.[5]

Correspondence to: K. McLeod, Paediatric Cardiology, Ward 1E, Royal Hospital for Children Glasgow, 1345 Govan Road, Glasgow G51 4TF, Scotland. Tel: 0141 201 1000; Fax: 0141 201 2215; E-mail: Karen.McLeod@ggc.scot.nhs.uk

In addition to diagnosis, we analysed how bypass numbers were influenced by travelling distance to specialist children's surgical centre and local children's cardiology outreach clinic frequency by performing linear regression. Finally, in July 2016, we formulated a questionnaire, distributed to all paediatric cardiologists responsible for each of nine local children's cardiology centres across Scotland to ascertain the local facilities and training background of staff. The questions were constructed around recently proposed national standards.[6]

Caldicott approval was granted for the audit, and the questionnaires were deemed to be part of a service evaluation project and were approved by the Regional Clinical Governance Group.

Results

In 2015, 1365/3413 (40%) paediatric cardiology outpatient appointments at the specialist cardiac surgical centre were attended by patients who had a local children's cardiology centre (see Table 1). Of the 1365 bypassers, 717 (53%) had a coded National Congenital Heart Disease Audit diagnosis and background summary data available for assessment. Of these, 147 could not be given RACHS-1 risk category as they had a non-categorical diagnosis, subsequently deemed "non-surgical". A further 23 patients had an unclear risk category and were removed from further analysis. Bypasser RACHS-1 status varied between local centres (see Table 1). Overall, a higher percentage of bypassers were RACHS-1 category $\geqslant 3$ (mean 45%, 95% confidence interval 29–62%) than RACHS-1 category <3 (mean 35%, 95% confidence interval 27–43%, t-test $p = 0.006$).

A total of 129 parents/patients responded to the questionnaire, of which 60 (47%) were bypassers. Of these, 23 (38%) did not feel well supported in outreach, 18 (30%) stated that the physician in charge of their care did not visit locally, 16 (27%) did not know they could be seen locally, nine (15%) felt that the specialist centre was easier or cheaper to access than their local hospital, five (8%) felt the local children's cardiology clinics were too infrequent, two (3%) used it as a social opportunity, four (6%) had other medical reasons to be seen at a specialist children's surgical centre, and eight (13%) stated other reasons for bypassing.

Linear regression demonstrated a trend towards increasing bypasser numbers from the more proximal local children's cardiology centres (correlation coefficient −0.48, $p = 0.18$). There was no recognisable trend between local children's cardiology outreach clinic frequency and bypass number (correlation coefficient 0.20, $p = 0.60$).

Questionnaire responses from paediatric cardiology consultants at all nine local children's cardiology centres were received. Responses regarding three (33%) of the local centres were clear that echocardiography was not up to a similar standard compared with that received at the specialist cardiac surgical centre, and further that the poorer-quality echocardiography would stop them reviewing some patients in local children's cardiology centres. Among all, five (56%) local centres had the support of a cardiac physiologist to perform echocardiograms, four (44%) provided exercise testing, two (22%) had access to a specialist liaison nurse, two (22%) had access to electronic integrated case notes, and eight (89%) had 24-hour tapes and cardiac event monitor evaluation. All nine local centres had a paediatrician with expertise in cardiology, of which three (33%) had formally recognised training that is facilitated by the Paediatricians with Expertise in Cardiology Specialist Interest Group. The level of training of the other six local paediatricians with expertise in cardiology was variable and difficult to quantify objectively; five (56%) reviewed cardiology outpatients outwith the outreach clinics, two (22%) of whom ran cardiology-specific clinics.

Table 1. Outreach centre bypass numbers, bypasser RACHS-1 category distribution and outreach centre distance from specialist centre.

Local children's cardiology centre number	Annual bypass number 2015	Distance from Royal Hospital for Children (miles)	Non-surgical category (number (%))	RACHS-1 category 1/2 (number (%))	RACHS-1 category 3/4 (number (%))	RACHS-1 category 5/6 (number (%))
1	179	38	26 (22)	44 (37)	40 (33)	10 (8)
2	13	86	5 (39)	4 (31)	4 (31)	0 (0)
3	52	80	4 (13)	12 (38)	14 (44)	2 (6)
4	52	61	5 (11)	18 (39)	21 (46)	2 (4)
5	145	24	16 (17)	36 (38)	40 (42)	4 (4)
6	42	148	5 (15)	10 (29)	17 (50)	2 (6)
7	116	169	14 (26)	16 (29)	23 (42)	2 (4)
8	564	20	69 (25)	111 (40)	89 (32)	12 (4)
9	53	80	3 (8)	15 (38)	19 (48)	3 (8)

RACHS-1 = Risk Adjustment for Congenital Heart Surgery

https://doi.org/10.1017/S1047951116002973 Published online by Cambridge University Press

Discussion

According to our study, 40% of paediatric cardiology outpatient clinic appointments at the Royal Hospital for Children in Glasgow could have been seen in a local outreach centre. The commonest reason for bypassing, as stated by parents/patients, was that they felt less well supported in outreach clinics, although small numbers did bypass for social reasons indicating an element of patient preference.

We demonstrate a trend towards a higher likelihood of bypassing at the local children's cardiology centres more proximal to the specialist children's surgical centre. Beyond the fixed element of geographical location influencing bypass, we recognise an association between higher risk (RACHS-1 category $\geqslant 3$) lesions/procedures and increased likelihood to bypass. These results are limited in that, although RACHS-1 has demonstrated a good correlation with clinical outcome,[7] it operates as "best-fit", with some procedures – for example, heart transplant – not stratified and non-surgical diagnosis not included. Further, only 53% of patients in our database had labelled diagnosis. Improving local facilities and staff expertise in line with national standards could allow more complex outpatients to be seen locally.

Consistent with previous studies,[8] we found significant variation in the facilities and experience of personnel available between local children's cardiology centres, which may have an important impact on families' perception of support. After comprehensive engagement with service users and stakeholders, national guidance in England has endorsed developing the role of the local paediatrician with expertise in cardiology.[1] As examples of how paediatricians with expertise in cardiology can make a significant impact on the delivery of care, those at local children's cardiology centres 1 and 2 manage to conduct cardiology-specific clinics outwith the cardiologist-led outreach clinics. Centre 1 has seen a significant fall in the number of bypassers since 2012 (unpublished data), and centre 2 has the lowest bypass numbers of all. The official Paediatricians with Expertise in Cardiology Specialist Interest Group training, which was only formally recognised by the Royal College of Paediatrics and Child Health in 2008, has standardised the level of knowledge and competencies expected of paediatricians with expertise in cardiology, and will allow future evolution of the children's cardiology network of care to become more homogeneous. For those paediatricians with expertise in cardiology who were well established before 2008, a clear pathway to formally obtain Paediatricians with Expertise in Cardiology Specialist Interest Group accreditation could add further consistency to the level of expertise delivered locally.

The paediatric cardiology outreach network in general falls behind national standards on nurse liaison support, which has a well-recognised impact on patient/parent perceived support,[9] and is thus recognised as one of the primary requirements to be made available for all children with confirmed cardiac diagnosis.[2] Better access to local cardiology nurse specialists could facilitate more complex patients to be seen in outreach clinics as well as improving parent/patient perceptions of support.

Conclusion

We have identified a large number of Scottish cardiac patients who are bypassing their local outreach clinic in favour of receiving outpatient care in the specialist surgical children's centre, with a significant percentage stating that they still feel less well supported in their local children's cardiology centre. Our results suggest that short travelling distance, severity of cardiac diagnosis, and inconsistent provisions of local facilities and staffing expertise may influence the patients towards bypassing local outreach centres. Investing in local children's cardiology centres to provide diagnostic facilities to the level of recently proposed standards by NHS England, as well as improving access to cardiac nurse liaison support and further standardising the expertise of the paediatrician with expertise in cardiology through Paediatricians with Expertise in Cardiology Specialist Interest Group, could help make patients feel more supported in outreach clinics. Continued engagement with patient stakeholders and re-evaluation of bypass numbers after future developments will be important to successfully shape the evolution of paediatric cardiac care in outreach clinics.

Acknowledgements

None.

Financial Support

This research received no specific grant from any funding agency or from commercial or not-for-profit sectors.

Conflicts of Interest

None.

Ethical Standards

The authors assert that all procedures contributing to this work comply with the ethical standards of the relevant national guidelines on human experimentation and with the Helsinki Declaration of 1975,

as revised in 2008, and has been approved by the institutional committees.

References

1. Safe and Sustainable Team. Safe and Sustainable Children's Congenital Heart Services in England. NHS England, London, 2011.
2. Wilson M, Humberstone N. Paediatric congenital heart disease specification. NHS England, London, 2016.
3. Powell J. Systematic review of outreach clinics in primary care in the UK. J Health Serv Res Policy 2002; 7: 177–183.
4. Heath G, Greenfield S, Redwood S. The meaning of "place" in families' lived experiences of paediatric outpatient care in different settings: a descriptive phenomenological study. Health Place 2015; 31: 46–53.
5. Jenkins KJ, Gauvreau K, Newburger JW, Spray TL, Moller JH, Iezzoni LI. Consensus-based method for risk adjustment for surgery for congenital heart disease. J Thorac Cardiovasc Surg 2002; 123: 110–118.
6. Wilson M, Humberstone N. Paediatric congenital heart disease standards. Level 3 – Local childrens cardiology centres. NHS England, London, 2016.
7. Boethig D, Jenkins KJ, Hecker H, Thies WR, Breymann T. The rachs-1 risk categories reflect mortality and length of hospital stay in a large german pediatric cardiac surgery population. Eur J Cardiothorac Surg 2004; 26: 12–17.
8. Andrews H, Singh Y. Review of paediatric cardiology services in district general hospitals in the United Kingdom. Cardiol Young 2016; 26: 528–531.
9. Pless I, Feeley N, Gottlieb L, Rowat K, Dougherty G, Willard B. A randomized trial of a nursing intervention to promote the adjustment of children with chronic physical disorders. Pediatrics 1994; 94: 70–75.