CLINICAL RESEARCH

Workload of ambulatory activities in a tertiary paediatric cardiac centre

Charge de travail de l’activité de consultation externe dans un centre tertiaire de cardiologie pédiatrique

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KEYWORDS
Paediatric cardiology; Outpatient referrals; Health education; Patient care; Child

Summary

Background. — Few data are available on the evolution in the number of referrals and the spectrum and frequency of issues addressed in paediatric cardiac outpatient clinics.

Aim. — To assess the volume and range of symptoms and diagnoses in patients, referred to a paediatric cardiac outpatient clinic in an academic hospital setting.

Methods. — Data were collected prospectively over 6 months.

Results. — Historical comparison showed that the number of outpatient visits increased from 819 during the first semester of 2004 to 865, 1045 and 1391 during the first semesters of 2005, 2006 and 2007, respectively. During the 6-month study period in 2007, 854/1391 visits concerned patients with known heart disease; the reason for the visit was follow-up of congenital heart disease (n = 616 children, 128 adults), arrhythmia (n = 91) or acquired heart disease (n = 19). During the visit, the decision to perform diagnostic or therapeutic cardiac catheterization or a surgical procedure was taken in 47 cases. Foetal echocardiography was performed in 60 foetuses and was abnormal in 21 cases. Among the other 477 visits, which concerned patients without known heart disease, the most frequent clinical concern was cardiac murmur (n = 193) and there were new diagnoses of congenital heart disease (n = 28), ventricular dysfunction (n = 2) and arrhythmia (n = 7).

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Introduction

Although a variety of cardiac conditions and symptoms occur in the paediatric population, few data [1–3] are available on the spectrum and frequency of issues addressed in paediatric cardiac outpatient clinics.

Education of medical students and residents in paediatric cardiology is challenging because structural heart diseases are uncommon and because conditions that potentially have a cardiac basis often have other causes [4,5]. It is therefore important to establish the appropriate emphasis for clinical instruction in paediatric residency training programmes.

Moreover, referrals to outpatient clinics for a cardiology opinion appear to be increasing alarmingly, with the majority of the children referred having normal hearts [2,3,6,7]. Such an increase in demand for specialist services has important implications not only for training but also for resources.

The aim of this study was to assess the volume and range of symptoms and diagnoses in patients referred to a paediatric cardiac outpatient clinic in an academic hospital setting.

Patients and methods

Queen Fabiola Children’s University Hospital (HUDERF, Free University of Brussels [ULB], Belgium) is the only Belgian university hospital devoted entirely to children’s medicine. As a medicosurgical hospital with 168 beds, it accommodates more than 11,000 children per annum who require hospitalization. The ambulatory sector is one of most important in Belgium and receives more than 100,000 patients per annum. The activities of the paediatric cardiac outpatient clinic of our institution were collected prospectively over a period of 6 months. A proforma was completed by the paediatric cardiologist, seeing the patient at the time of the visit between January 01 and June 30, 2007. Tabulated data included date of visit, age, indications for referral, whether the patient was new or was known to the cardiology service, electrocardiographic and echocardiographic assessments, and subsequent management if necessary. For each patient, visits were tabulated as separate encounters if they occurred on different days. The study protocol was approved by the Institutional Review Board (Ethical Committee).

Results

Over the 6-month period, there were 1391 outpatient visits to our tertiary paediatric cardiac centre. Historical comparison showed that the number of visits increased from 819 patients during the first semester of 2004 to 865 during the first semester of 2005, 1045 during the first semester of 2006 and finally, 1391 during the study period in 2007. At the time of the study, the staff included three full-time equivalent paediatric cardiologists.
There were 1203 patients less than 18 years of age (mean age \( \pm \) standard deviation [SD] 5.6 \( \pm \) 5.1 years), 60 pregnant women for foetal echocardiography (mean age \( \pm \) SD 29.5 \( \pm \) 5.4 years), and 128 patients with grown-up congenital heart disease (mean age \( \pm \) SD 25.5 \( \pm \) 7.2 years). The range in age of the patients in the general study population, in the population of patients with previously known heart disease and in the population of patients without previously known heart disease (foetuses excluded) is shown in Fig. 1.

In 854 cases, patients had a heart disease that was known previously to our service and the reason for visit was the follow-up of a child with congenital heart disease (\( n = 616 \)), an adult with grown-up congenital heart disease (\( n = 128 \)), an arrhythmia (\( n = 91 \)) or an acquired heart disease (\( n = 19 \)). Table 1 shows the diagnostic categorization of congenital heart disease (predominant lesion) for the different age groups. Logically, most infants and young children with simple lesions were unoperated, whereas the reason for the visit was postoperative assessment in older patients with simple lesions and in patients of any age with complex lesions.

During these visits, the decision was taken to perform a diagnostic cardiac catheterization in three cases, a therapeutic cardiac catheterization in 16 cases and a surgical procedure in 28 cases. Additionally, atrial fibrillation and exercise-induced ventricular tachycardia were diagnosed in two adults and one adult respectively, with grown-up congenital heart disease.

Foetal echocardiography was performed in 60 foetuses and was abnormal in 21 (35%). The following diagnoses were noted: complete atrioventricular septal defect (\( n = 3 \)), truncus arteriosus (\( n = 2 \)), D-transposition of the great arteries (\( n = 2 \)), perimembranous ventricular septal defect (\( n = 2 \)), incomplete atrioventricular septal defect (\( n = 2 \)), Taussig-Bing anomaly (\( n = 2 \)), hypoplastic left heart syndrome (\( n = 1 \)), hypertrophic cardiomyopathy (\( n = 1 \)), univentricular heart (\( n = 1 \)), severe pulmonary stenosis (\( n = 1 \)), atrial flutter (\( n = 1 \)) and supraventricular extrasystole (\( n = 3 \)). No parents opted for termination of pregnancy. Birth in our referral centre was organized for the cases of severe congenital heart disease (\( n = 10 \)) and atrial flutter (\( n = 1 \)).

There were 477 new referrals. By far, the most frequent reason for referral was previous auscultation of a cardiac murmur, accounting for 40.5% of referrals (\( n = 193 \)). Other clinical concerns included chest pain (8.2%, \( n = 39 \)), drenocytosis (7.3%, \( n = 35 \)), palpitations (6.9%, \( n = 33 \)), syncope (5.9%, \( n = 28 \)), cardiac function in oncological disease (3.1%, \( n = 15 \)), cisapride therapy (3.1%, \( n = 15 \)), recurrent respiratory infections (3.1%, \( n = 15 \)), exercise intolerance (2.5%, \( n = 12 \)), renal insufficiency (2.1%, \( n = 10 \)), Marfan’s syndrome (1.7%, \( n = 8 \)), Kawasaki’s disease (1.7%, \( n = 8 \)), systemic arterial hypertension (1%, \( n = 5 \)), cardiac family history (1%, \( n = 5 \)), cyanosis (0.8%, \( n = 4 \)), Rx abnormality (0.8%, \( n = 4 \)), unidentified syndrome (0.6%, \( n = 3 \)), absent femoral pulses (0.6%, \( n = 3 \)) and a variety of other reasons in isolated cases (8.8%, \( n = 42 \)).

Of the 477 patients referred, 440 (92.2%) were found to have structurally and functionally normal hearts, and no arrhythmias. Most letters of referral did not suggest a diagnosis, but simply stated the presence of a physical sign, for example, a murmur or a symptom such as thoracic pain or palpitations. In this population, without previous known cardiac disease, there were new diagnoses of congenital heart disease in 28 cases: murmur (\( n = 18 \)), Marfan’s syndrome (\( n = 5 \)), absent femoral pulses (\( n = 3 \)), unidentified syndrome (\( n = 1 \)) and tuberous sclerosis (\( n = 1 \)). The three patients with absent femoral pulses had severe aortic coarctation and required urgent surgery. The others had minor or moderate heart diseases (pulmonary or aortic stenosis, ventricular septal defect, mitral valve prolapse, cardiac tumour or aortic root dilation). Ventricular dysfunction was noted in one patient with treated leukaemia and another with drenocytosis. Finally, arrhythmias were diagnosed in six cases of palpitations (extrasyostoly, \( n = 3 \); junctional rhythm, \( n = 1 \); supraventricular tachycardia requiring medical treatment, \( n = 2 \)) and one patient with an ‘abnormal electrocardiogram’, performed before sports participation, had an asymptomatic Wolff-Parkinson-White syndrome.

**Discussion**

This study has illustrated the significant workload of ambulatory paediatric cardiology, which results from more new patients presenting and more ‘old’ patients requiring review.

Although the prevalence of congenital heart diseases is probably static, referrals to outpatient clinics for specialist cardiology opinion appear to be increasing. There is a growing need for paediatric cardiologists to see patients to exclude heart diseases, as non-specialists are increasingly reluctant to take responsibility for deciding if a patient is normal [8]. Previous studies have shown that 25—75% of all newly-referred patients have normal hearts [2,3,6]. New patients referred to the outpatient clinics are an increasing area of activity for those providing paediatric cardiology services at a tertiary level, amounting in our centre to more than one-third of the visits, with fewer than one-tenth of those seen having any cardiac pathology. As others have done [2], we performed an echocardiogram in nearly all newly-referred patients. While it is our view that clinical examination alone is adequate in many cases, increasingly it is our experience that parents are dissatisfied if an echocardiogram is not performed, because many have been told that they are being ‘sent for a scan’, rather than for the specialist opinion of the paediatric cardiologist.

Such an increase in referrals might be the consequence of increased possibilities for cardiac evaluation, but it is also...
Table 1  Diagnostic categorization according to age group.

<table>
<thead>
<tr>
<th>Diagnosis</th>
<th>&lt; 1 year</th>
<th>1—4 years</th>
<th>5—9 years</th>
<th>10—17 years</th>
<th>&gt; 17 years</th>
</tr>
</thead>
<tbody>
<tr>
<td>All diagnoses</td>
<td>159</td>
<td>201</td>
<td>134</td>
<td>122</td>
<td>128</td>
</tr>
<tr>
<td>Atrial septal defect</td>
<td>15</td>
<td>19</td>
<td>11</td>
<td>1</td>
<td>2</td>
</tr>
<tr>
<td>Repaired/occluded atrial septal defect</td>
<td>2</td>
<td>9</td>
<td>14</td>
<td>8</td>
<td>3</td>
</tr>
<tr>
<td>Ventricular septal defect</td>
<td>39</td>
<td>34</td>
<td>12</td>
<td>9</td>
<td>12</td>
</tr>
<tr>
<td>Repaired ventricular septal defect</td>
<td>5</td>
<td>19</td>
<td>4</td>
<td>8</td>
<td>6</td>
</tr>
<tr>
<td>Repaired atrioventricular septal defect</td>
<td>1</td>
<td>6</td>
<td>7</td>
<td>2</td>
<td>6</td>
</tr>
<tr>
<td>Repaired total anomalous pulmonary venous connection</td>
<td>2</td>
<td>6</td>
<td>1</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Tetralogy of Fallot</td>
<td>6</td>
<td>0</td>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Repaired tetralogy of Fallot</td>
<td>9</td>
<td>17</td>
<td>7</td>
<td>17</td>
<td>23</td>
</tr>
<tr>
<td>Pulmonary stenosis</td>
<td>7</td>
<td>10</td>
<td>4</td>
<td>3</td>
<td>3</td>
</tr>
<tr>
<td>Operated/dilated pulmonary stenosis</td>
<td>4</td>
<td>1</td>
<td>4</td>
<td>1</td>
<td>5</td>
</tr>
<tr>
<td>Repaired pulmonary atresia + ventricular septal defect</td>
<td>0</td>
<td>1</td>
<td>7</td>
<td>5</td>
<td>3</td>
</tr>
<tr>
<td>Patent arterial duct</td>
<td>10</td>
<td>3</td>
<td>0</td>
<td>1</td>
<td>0</td>
</tr>
<tr>
<td>Left ventricular outflow tract obstruction</td>
<td>7</td>
<td>5</td>
<td>5</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>Operated/dilated left ventricular outflow tract obstruction</td>
<td>4</td>
<td>14</td>
<td>7</td>
<td>12</td>
<td>6</td>
</tr>
<tr>
<td>Repaired aortic coarctation</td>
<td>11</td>
<td>14</td>
<td>13</td>
<td>15</td>
<td>6</td>
</tr>
<tr>
<td>Repaired D-transposition of the great arteries</td>
<td>6</td>
<td>10</td>
<td>3</td>
<td>4</td>
<td>8</td>
</tr>
<tr>
<td>Palliated single ventricle (Glenn, Fontan)</td>
<td>16</td>
<td>10</td>
<td>9</td>
<td>6</td>
<td>12</td>
</tr>
<tr>
<td>Rastelli for double outlet right ventricle + transposition of the great arteries</td>
<td>0</td>
<td>5</td>
<td>2</td>
<td>6</td>
<td>4</td>
</tr>
<tr>
<td>Other unoperated congenital heart diseases&lt;sup&gt;a&lt;/sup&gt;</td>
<td>9</td>
<td>12</td>
<td>11</td>
<td>11</td>
<td>16</td>
</tr>
<tr>
<td>Other operated congenital heart diseases&lt;sup&gt;a&lt;/sup&gt;</td>
<td>6</td>
<td>6</td>
<td>13</td>
<td>9</td>
<td>8</td>
</tr>
</tbody>
</table>

<sup>a</sup> with fewer than five cases in each age group.
likely to be due, to some extent, to lack of expertise among the referring practitioners, as emphasized in the study from Leeds [2]. It is remarkable that in some institutions nowadays, generalists receive no training in paediatric cardiology — the assumption being made that it is too specific. Furthermore, even in specialist training for paediatricians, the training received in paediatric cardiology is often meagre. These findings must have consequences for planning, training and manpower. Cardiac malformations are rare, but the reality is that many more patients are now referred simply for safety. Unequivocally, there is an increasing field of referral simply for cardiovascular evaluation. Our results, as with those of previous studies, ought to be noted by those responsible for provision of services for paediatric cardiology [9] and by those who establish the appropriate emphasis for clinical instruction in paediatric residency training programmes. Although a variety of conditions were assessed in the outpatient paediatric cardiology clinic, some diagnoses were encountered more frequently and should be given emphasis in future curriculum development for cardiac training for paediatric residents. Evaluation of murmur was the most frequent reason for outpatient visits. Developing stethoscope skills among residents for diagnosis of an innocent murmur and for detection of the conditions that occur most frequently would often fulfil clinical needs. It has been suggested that paediatricians with special expertise in paediatric cardiology should be trained to provide an efficient basic screening service in secondary centres [10]. However, other studies [6] noted that children are sent preferentially to tertiary referral centres. The fact that this service is provided by an experienced paediatric cardiologist who is able to examine the child, perform and interpret the echocardiogram, and discuss its findings with parents in a single consultation, in a centre where operative and other interventional procedures can be performed if necessary, may influence the decision for such a referral.

Recently, there have been many changes in technology and clinical practice in paediatric cardiology. A tertiary centre now provides a wide range of sophisticated diagnostic services and the full range of treatments, interventions and surgeries needed to produce high-quality outcomes in all paediatric patients with congenital and acquired heart diseases. These activities are very demanding in levels of skill, time and resources. This care improvement also induces a pronounced increase in the number of patients seen at the ambulatory clinic, which reflects primarily the fact that infant surgical mortality has fallen, leading to many more patients with complex heart disease, requiring long-term follow-up into childhood and then into adult life. Referrals for detailed foetal echocardiography are also increasing as routine anomaly scans in obstetric departments become more searching. Antenatal diagnosis of cardiac anomalies is now recognized as an opportunity to reduce morbidity by optimizing early neonatal management. However, fewer parents are opting for termination of pregnancy and a large reduction in the number of children born with major cardiac defects is unlikely.

The increased need for attendance at outpatient clinics has inevitable consequences for the clinical, teaching and research activities of specialists in tertiary centres. Staffing in tertiary paediatric cardiac centres must be adapted to the increasing workload in the subspecialty, and the development of local expertise (general paediatricians with an interest in cardiology) will also be required.

Conclusion

The workload of ambulatory paediatric cardiology in tertiary academic hospital settings is increasing at an alarming rate. The reasons are multifactorial and these data may be helpful in future planning of consultant manpower. They may also contribute to curriculum development in the cardiology training of medical students and paediatric residents.

References