Leg Pains in Congenital Heart Disease – A Distressing Symptom of a Wider Problem

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Abstract

Purpose: Anecdotal reports suggest that children and young adults with congenital heart disease frequently experience pain in their legs. The purpose of this pilot study, performed by Little Hearts Matter patient organization, was to assess the burden of leg pains in this group and begin to investigate associated factors and consequences for daily living.

Methods: An internet-based survey was distributed by Little Hearts Matter patient organization. Following anonymization and collation, responses were analyzed and compared to their healthy siblings.

Results Of the 220 patients that responded, 94% reported leg pains compared to 30% of siblings (n=107; $p<0.001$). In respondents, pain was typically reported to occur in the lower legs or around the knees or ankles, often associated with crying and screaming (49.0%) and most commonly occurring at night-time (82.0%). Individuals taking aspirin and those who were more active were more likely to report leg pains. Older age was associated with leg pain that occurred with stress ($p=0.02$) and at night ($p=0.05$). Analgesia (64.1%) or massage (53.9%) was the preferred option for alleviation. There was no gender bias, association with diagnosis, surgical history and or relationship with diagnosed orthopaedic issues.

Conclusion Leg pains are more frequent in those with congenital heart disease than their healthy siblings. Aetiology is uncertain but pains share many common characteristics with benign “growing pains”.

Keywords

Congenital heart disease, Leg pains, Patient reported outcomes

Introduction

Mortality in childhood from congenital heart disease has fallen dramatically over recent decades due to advances in surgical and intensive care management. As a result, morbidity metrics are increasingly important in evaluating the outcome of congenital heart disease treatment.

Concurrently, increasing access to the internet and communication via social media has impacted how those affected by congenital heart disease seek information and manage their own healthcare. Online discussion amongst patients has begun to reveal common but under-reported issues that impact on daily living and may also indirectly influence healthcare outcomes [1,2].

Evidence from those living with cystic fibrosis suggests online support enables young people and parents to share experiences of living with long-term conditions and thus develop expertise to empower them in interactions with health-care professionals [3]. The understandable caution with which clinicians have approached social media, has more recently been rivalled by the recognition of the opportunity to better understand the patient experience and thus focus efforts to improve outcomes [4,5].

In this study, we responded to anecdotal, but common complaints of leg pains in children and young adults with congenital heart disease by carrying out a questionnaire investigating the key characteristics and circumstances of the pain as well as methods used for alleviation.

Materials and Methods

Study population

Little Hearts Matter is a United Kingdom registered charity dedicated to supporting and enabling families of children and adults with a diagnosis of a single ventricle heart conditions (www.lhm.org.uk). Through a shared Facebook site the charity identified concerns amongst patients and their carers regarding the issue of leg pains. A questionnaire was devised by one of the authors (SH) in order to gain insight into the prevalence of their concerns. Participation was offered

to all members (3,200) of the Little Hearts Matter support group through their social media sites and disseminated to other congenital cardiac charities. The study was also publicised in paediatric outpatient settings, allowing others with congenital heart disease, who were not members of Little Hearts Matter, to participate.

Survey design

The survey contained questions on general demographic information, diagnosis, medications, co-morbidities, diet and activity. Specific questions addressed the nature of leg pains and exacerbating and relieving factors. Questions were also asked regarding siblings, including whether they experienced leg pains. The survey questions are available in the **Supplementary Table**. The survey was performed using the SurveyMonkey web tool (<https://www.surveymonkey.net>) and results were collated by SH before being passed in fully anonymised form to the remaining authors for analysis.

Ethical Approval

As the survey was initiated, developed and administered by the Little Hearts Matter patient group (SH) and analysis was limited to data provided without patient identifiable information ethical approval was not required. This study was reviewed and the non-requirement for approval by a National Health Service Research Ethics Committee was confirmed by the chair of North East – Tyne & Wear South Research Ethics committee.

Statistics

Data is presented numerically and also as a percentage of the stated denominator. Associations were tested using χ^2 or Fisher's exact tests. When assessing association between precipitating factors and methods of alleviating pain p values were corrected using the sequential Bonferroni method and phi (ϕ) reported to reflect the degree of association. Data was analyzed in SPSSv.24 with $p < 0.05$ considered statistically significant.

Results

A total of 220 respondents [57.4% male, 8.3 years (0.2-29.8)] completed the survey. Whilst parents and carers often completed the survey on behalf of the patient, the subject of the survey is described as the respondent in the resulting analysis. Demographic and diagnostic details are shown in **Table 1**.

The response rate was greater than 90% for 14/16 questions and all questions had a response rate greater than 80%. The survey was available for one year, however the majority of responses occurred within the first three months.

Description and Impact of Leg Pains

206/220 (93.6%) survey respondents reported leg pain. The frequency of leg pains and precipitating factors are shown in **Figures 1 and 2a**). Each respondent identified a median of three out of nine precipitatory factors (inter-quartile range zero-four)." The majority of affected respondents experienced leg pains nocturnally (169/206, 82.0%), a feature consistent with 'growing pains' of childhood [6]. Other features consistent with growing pains were an association with day time activity and an intermittent course. The location of the pain was typically bilateral and involved the lower legs including knees, shins and muscles, but not thighs, hips or toes. A range of phrases were used by respondents to describe the pains including '*cramps*', '*tightening*' or '*aches*'. Importantly, however, respondents mainly used the word '*pain*' itself to describe their symptoms with just under half (101/206, 49.0%) reporting associated crying or screaming.

The methods used to alleviate pains are depicted in **Figure 2b**: analgesia (132/206, 64.1%), massage (111/206, 53.9%) and rest (107/206, 51.2%) were the most frequently employed options. "Improvement with resting was significantly associated with pain occurring after walking ($\phi=0.277$), brought on by stress ($\phi=0.260$) and with pain occurring whilst unwell ($\phi=0.279$). Relief with elevation ($\phi=0.248$) was also associated with pain brought on by stress whilst relief with warming was associated with pain occurring in response to cold ($\phi=0.294$). Interesting the strongest significant association was seen between nocturnal pain and relief with

painkillers ($\phi=0.335$). Nocturnal pain also was also associated with relief with massage ($\phi=0.276$)."

Respondents also described their attempts to seek validation of these symptoms and the lack of available information to them. The nature and impact of leg pains is reflected in free text comments made by individual respondents (**Table 2**). A small number of respondents (8/206, 38.8%) described organic features of pain including limping, knee swelling and unilateral symptoms. 170 respondents reported having siblings although only 107 (62.9%) provided information as to the presence or absence of leg pains. Leg pains were more frequently reported in respondents than their generally healthy siblings (32/107, 29.9%, $p<0.001$).

Associations of Leg Pains with Other Factors

There was no gender bias in the reporting of leg pains (94.6% females versus 92.9% males, $p=0.60$) or the frequency at which they occurred ($p=0.57$). Whilst there was no relationship between reported leg pain and age, older respondents were more likely to associate leg pains with times when they felt stressed ($p=0.02$) and at night ($p=0.05$). Frequency of pains did not differ significantly between groups ($p=0.28$). Individuals taking aspirin were more likely to report leg pains (98.2% vs 89.0%, ($p=0.01$)). 48% (105/220) of respondents described themselves as active either outdoors or indoors whilst 51.8% (114/220) reported reduced levels of activity with five wheelchair-bound. Those who were more active were more likely to have frequent leg pains [$> once a week$] (50.0% vs 37.1%, $p=0.04$).

69/220 (31.4%) described hypermobility, postural or orthopaedic defects (including flat feet, high arches, talipes, hypochondroplasia or scoliosis). All respondents with hypermobility ($n=12$) reported leg pains. Individuals with hypermobility reported pain predominantly after exercise as is typical in this condition ($n=9$, $p=0.011$), and in hot weather ($p=0.019$). Leg pains were not more prevalent in those with orthopaedic or postural issues.

Discussion

This is the first study to report leg pains in children and young people with congenital heart disease. Using an online survey, 93.6% respondents reported having leg pains, which was significantly higher than reported in their generally healthy siblings (29.9%). The majority experienced pains nocturnally or when tired and most alleviated symptoms with painkillers or massage.

Although, reported pains are likely to reflect a mixture of aetiologies, the dominant features, such as nocturnal occurrence, intermittent nature and focus in knees and calves, share clear similarities with benign childhood “growing pains” [6]. “Growing pains” are a clinical diagnosis made when other potentially serious causes are excluded. Persistence of symptoms, presence of joint involvement, systemic features, limping or abnormalities on examination or investigation should alert the clinician to other diagnoses [7]. Whilst the condition is self-limiting and the acknowledged prognosis benign, symptoms can be highly distressing. The precise cause remains poorly understood. Various mechanisms are proposed and associations with obesity, orthopaedic factors such as flat feet, reduced bone strength, lowered pain thresholds and psychosocial factors are documented [8–13]. Positive family history and suggested overlap with restless legs syndrome also indicate a possible genetic component [10,14]. Treatment with Vitamin D supplementation (small Italian cohort study of healthy 5-11 year olds) and efficacy of a twice daily muscle stretching programme (small Canadian unblinded randomised controlled trial in 5-14 year old healthy children) have suggested benefit in relieving symptoms [15,16].

In our selected cohort with congenital heart disease, leg pains occurred more often than in their generally healthy siblings. Skeletal muscle and bone deficits, as well as Vitamin D deficiency have been observed in patients post Fontan completion, a dominant component group amongst respondents, and may therefore be implicated in the aetiology of their leg pains [17,18]. Patients with Fontan completion, understandably report reduced quality of life, however, little work has been done to elucidate the effects of this on pain thresholds and reporting of symptoms [19]. Progress in congenital heart disease has been measured by stepwise improvements in survival. Now most children born with these conditions are expected to survive into adulthood, focus has shifted

to functional capacity, morbidity and quality of life. While questionnaires such as PEDSQL, PCQLI, SF 36 and ConQol are validated and may provide useful information these mainly explore areas defined by clinicians, though PCQLI does include some patient defined measures [20–22]. Patients use social media and join online health communities to complement rather than bypass healthcare professionals; fulfilling unmet needs including informational and network support as well as emotional expression or social comparison [3,23]. The relationship with the healthcare professional is generally viewed by patients as a clinical one, where the professional provides expertise and treatment based on medical knowledge, but not first-hand experience [23,24]. Although patient groups can offer practical and emotional support between patients with similar experience, which is more difficult to provide in the traditional medical setting, support may be limited if problems and potential solutions are not recognized and addressed by clinicians.

In this study, the poorly documented yet clearly distressing symptom of leg pain was identified by Little Hearts Matter from their patient base and a larger survey undertaken. Whilst, limitations (see below) exist for this type of data, the results can direct researchers to investigate new areas of unmet need which may be of growing importance to patients as issues of mortality and morbidity are addressed. Focused efforts are however required to validate patient reported outcome tools relevant to this population to facilitate this. Better education of congenital heart disease healthcare professionals in the patient experience could also help alleviate perceived contradictions with scientific knowledge that in other domains has been a recognized source of distress to patients resulting in detrimental consequences [25].

This study suffers from reporting bias as it is likely that individuals with leg pains were more likely to respond to a questionnaire on this subject than those without. Parents and carers responding on behalf of their children may also influence reporting rate. Although we cannot provide exact numbers, it is apparent that around 90% of respondents were parents or carers responding on behalf of their child. Discrepancies in patient and parent reporting of quality of life issues are recognized and may reflect differences in illness perception [26]. It is interesting, that in

a few cases parents reported leg pains in young babies, where it may be difficult to conceive how this symptom could be expressed. This may reflect unaddressed needs in the carers as well as the physical symptoms of the child. Nevertheless, the difference seen between subjects and their healthy siblings, whose rate of leg pains was consistent with that reported in normal children, suggests that this condition is more common in those with congenital heart disease, although admittedly the age of the siblings is unknown and sibling data was incomplete [7]. Overall response rate as a proportion of Little Hearts Matter members may be interpreted to be low, but it is likely that not all Little Hearts Matter members engage with the social media sites through which it was publicized. Further, because of the methodology used it is not possible to be completely certain how many potential respondents there were. It would be important to repeat the survey, or a modified version, in another congenital heart disease population to validate the results.” However, nearly everyone had leg pains so there was low statistical power to analyze associations. Additionally, we tested multiple associations in this study and therefore there is an increased risk of type I errors. It is evident, for example, that participants report several precipitatory factors each for their leg pains; elucidating the contribution of each is likely to require both more detailed questioning and larger sample populations than available in the present study.

It is also the case, that not all leg pains should necessarily be attributed to “growing pains” as this was not a validated questionnaire, rather a survey designed by a patient group to address their members’ needs. Other limitations to the results reported are that co-morbidities in this population are likely to be under-reported as, whilst this group are typically well-educated about their condition, lay understanding or description of medical terms may be restricted. Equally, a degree of subjective interpretation has had to be applied by the investigators to permit the responses to be analyzed using statistical methods. Also, more refined open questions could have enhanced the richness of the qualitative dataset obtained with respect to the nature of the leg pains.

Leg pains are an under-recognized, distressing symptom for patients with congenital heart disease and are reported more frequently than in their generally healthy siblings. It would be

interesting to know how leg pains impact on quality of life, participation in sport and school and to understand if and how medical and surgical intervention may influence their manifestation. This requires further investigation and offers an important example of how patient experiential knowledge can identify new areas for research and thus address perceived inconsistencies with existing medical knowledge.

Acknowledgements

Little Hearts Matter would like to thank charity members and friends of the organization for raising concerns about leg pains and for taking part in the survey. The charity would also like to thank the CardioVascular Research team at Newcastle University for their support of the project and their dedicated analysis of the survey's data.

Financial Support

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

Conflicts of Interest

Dr David Crossland is a Medical Advisor to Little Hearts Matter.

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	All n=220	Single ventricle circulation n=153	Biventricular circulation n=51	Other n=16
Male	126(57.2%)	91(59.5%)	30(57.7%)	5(31.3%)
Age (years)	8.3(0.2-29.8)	8.7(0.2-29.8)	6.6(1.2-25.3)	7.6(1.0-13.4)
Hypoplastic left heart		72	0	0
Hypoplastic right heart*		51	0	0
Double inlet left ventricle		12	0	0
Mitral atresia or Shone's complex		5	1	0
Complete atrioventricular septal defect		4	3	0
Transposition of Great Arteries†		4	9	0
Truncus Arteriosus		0	2	0
Tetralogy of Fallot or variant		0	13	0
Aortic valve disease/Coarctation		0	10	0
Other		0	13	2
Unspecified		5	0	14
Fontan circulation	126(57.2%)	126(82.4%)	0 (0.0%)	0 (0.0%)
Biventricular Repair	45(20.5%)	0 (0.0%)	45 (88.2%)	unknown
Chromosomal Abnormality		2	2	0
Pacemakers		7	2	0
Kidney or bowel co-morbidity		14	6	0
Neurological co-morbidity		10	0	0
Hypermobility	12 (5.5%)	8	4	0
Postural/orthopaedic condition	57 (25.9%)	36	18	3
Developmental or behavioural condition	10 (4.5%)	9	1	0
Aspirin	100			
Warfarin	60			
Beta blockers	6			
ACE Inhibitor/ARB	85			
Inhalers	11			
Diuretics	14			

Table 1. Demographic details, diagnosis, co-morbidities and medications [* including tricuspid atresia and pulmonary atresia, †including simple and complex forms and congenitally corrected, hypoplastic left heart syndrome with heart transplant whilst and Ebstein with Glenn shunt]

Respondent Comments	
Nature of pains	<ul style="list-style-type: none"> described as 'cramps', 'tightening' or 'aches'.
Intermittent course	<ul style="list-style-type: none"> <i>'It happens in waves. They hurt for a while about 6 months ago and it was an everyday pain. Then it stopped for a few months, and about 2 months ago she said they were hurting again. At the current time, they aren't bothering her.'</i>
Relationship with activity	<ul style="list-style-type: none"> <i>'If X has a very active day e.g sports day or a day with not much rest, then leg pain will occur that night, sometimes in the day but that is rarely.'</i>
Distressing nature	<ul style="list-style-type: none"> <i>'X doesn't really cry if he hurts himself and is quite tough but this leg pain will always bring him to tears and he will be holding the leg around the knee and is very restless. He finds it difficult then to get comfortable.'</i> <i>'She is inconsolable at night time. It's like she's panicking, she can't keep still and settle to sleep.'</i>
Attempts to seek validation	<ul style="list-style-type: none"> <i>'My 17-year old son has been complaining of leg pain for years. Just last month, we spoke to his cardiologist who couldn't identify with it from a heart perspective.'</i> <i>'She wakes up crying (has never managed a full night if sleep!) and quite frequently she tells us that she has pains in her legs. We have mentioned this to her consultant.'</i>
An unmet need?	<ul style="list-style-type: none"> <i>'I would certainly have liked some more information about it as at the time we thought it was just him.'</i>

Table 2. Respondent comments reflecting nature of leg pains and their impact on the patient and family

Figure Legends

Figure 1. Frequency of Leg Pain in Respondents

Figure 2a) Factors precipitating leg pains (above) and **b)** methods employed to alleviate leg pains (below)

Figure 1. Frequency of Leg Pain in Respondents

Figure 2a) Factors precipitating leg pains (above) and **b)** methods employed to alleviate leg pains (below)

Data statement

The anonymized dataset is available on request to the corresponding author.

No	Question	Choice of answer if given
1	<i>Your heart child's date of birth*</i>	
2	<i>Are they male or female?</i>	
3	<i>What is the name of their heart condition?</i>	
4	<i>What operations have they had to date?</i>	
5	<i>Do they have any other medical conditions? Please name them.</i>	
6.	<i>What medication are they taking?</i>	
7.	<i>Does your child suffer with leg pains?</i>	Yes No
8.	<i>How often do they occur?</i>	More than once a week. Once a week. Once a month. Other.
9.	<i>When do the leg pains occur? You can tick more than one box.</i>	After exercise. After walking. At night. When your child is tired. When your child is dehydrated. When your child is stressed. When they are unwell. In hot weather In cold weather
10.	<i>Describe how you know your child has leg pain.</i>	
11.	<i>What do you do to relieve leg pain?</i>	Encourage your child to rest Elevate the legs Give painkillers Warm the legs up Cool the legs down Other please describe.
12	<i>What is your child's usual level of activity?</i>	Active/plenty of outdoor exercise. Active/usually indoors. Reduced activity levels/gets outside. Reduced activity levels/usually indoors. Sometimes needs a pushchair or wheelchair otherwise mobile. Wheelchair bound/limited mobility. Other please describe.
13	<i>What is your child's diet like?</i>	Eats everything - x 5 fruit and veg, drinks milk. Eats everything but is picky or does not eat a great deal. Vegetarian. Vegan. Other please describe.
14	<i>Does your child have any of the following foot conditions?</i>	Flat feet. High arches. A history of talipes Other please describe.
15	<i>Does your child require specialist shoes?</i>	Yes No
16	<i>Does your heart child have any siblings?</i>	Yes No
17	<i>Please describe any leg pain problems experienced by your heart healthy children. Using the questions completed above as a guide.</i>	Do they have any other medical conditions? Do they have any regular medications? How often do they experience leg pains? When do their leg pains occur? Please describe their leg pain? How do you relieve their leg pain? What is their normal activity level? What is their diet like? Do they have any foot conditions? Do they have specialist shoes?

Supplementary Table Survey questions answered by respondents [*this response was converted to age prior to analysis]