



Original Article

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Corresponding author: C. A. Williams;
Email: c.a.williams@exeter.ac.uk

Curtis A. Wadey¹ , Fiona J. Leggat² , Julia Potter³, Nurul H. Amir⁴ ,
Lynsey Forsythe⁵, A. Graham Stuart⁵ , Alan R. Barker¹ and Craig A. Williams¹

¹Faculty of Health and Life Sciences, Children's Health & Exercise Research Centre (CHERC), Public Health and Sports Sciences, University of Exeter, Exeter, UK; ²Population Health Research Institute, St George's, University of London, London, UK; ³Department of Physical Education, University of Chichester, Chichester, UK; ⁴Department of Translational Health Sciences and Population Health Sciences, Bristol Medical School, University of Bristol, Bristol, UK and ⁵Bristol Royal Hospital for Children, Bristol, UK

Abstract

Background: Children and young people with CHD benefit from regular physical activity. Parents are reported as facilitators and barriers to their children's physical activity. The aim of this study was to explore parental factors, child factors, and their clinical experience on physical activity participation in young people with CHD. **Methods:** An online questionnaire was co-developed with parents (n = 3) who have children with CHD. The survey was then distributed in the United Kingdom by social media and CHD networks, between October 2021 and February 2022. Data were analysed using mixed methods. **Results:** Eighty-three parents/guardians responded (94% mothers). Young people with CHD were 7.3 ± 5.0 years old (range 0–20 years; 53% female) and 84% performed activity. Parental participation in activity ($X^2_{(1)} = 6.9$, $P < 0.05$) and perceiving activity as important for their child were positively associated with activity (Fisher's Exact, $P < 0.05$). Some parents (~15%) were unsure of the safety of activity, and most (~70%) were unsure where to access further information about activity. Fifty-two parents (72%) had never received activity advice in clinic, and of the 20 who received advice, 10 said it was inconsistent. Qualitative analysis produced the theme “Knowledge is power and comfort.” Parents described not knowing what activity was appropriate or the impact of it on their child. **Conclusion:** Parental participation and attitudes towards activity potentially influence their child's activity. A large proportion of young people performed activity despite a lack and inconsistency of activity advice offered by CHD clinics. Young people with CHD would benefit from activity advice with their families in clinics.

Introduction

Physical activity (referred to onwards as “activity”) is a modifiable behaviour and refers to any bodily movement that results in energy expenditure.¹ Activity is important in the development of cardiorespiratory fitness, which has been associated with perceived general health, health-related quality of life, and prognosis in people with CHD.^{2–5}

In the United Kingdom, Dua et al.⁶ measured the volume of activity accumulated by 61 adults who have CHD using accelerometry and reported ~85% failed to reach the national activity guidelines. These findings have been replicated in Germany, where 83% (165/199) of adults with CHD failed to meet the activity guidelines and accumulated significantly less moderate to vigorous activity compared to controls (~35 mins per day).⁷ It has been reported that the majority of children and young people who have CHD perform similar volumes of activity compared to healthy controls.⁸ However, increasing age, weight status, CHD complexity, and total cavopulmonary circulation have been associated with children and young people not meeting the activity guidelines.⁸

Despite the positive effects activity has on physical and mental well-being, there are concerns from parents, carers, and significant others (i.e., teachers, coaches), that exercise, a subset of activity, has the potential to cause harm to young people with CHD.^{9,10} There is a lack of data on what parent's attitudes are towards their children (who have CHD) participating in activity and whether these attitudes influence their children's activity. From the available evidence, parents have been reported to avoid opportunities where their child could be more active and fear for the future health of their child.¹¹ This may increase the likelihood of young people with CHD being excluded from developmental opportunities, such as physical education and sports, which are important opportunities to engage in activity.^{9,10} Exclusion from activity can have deleterious effects on the psychosocial health of young people. A recent systematic review of 44 qualitative studies (n=995) described the experience of living with CHD, the authors reported a theme of an “inability to participate in sport,” which for some individuals was “highly distressing and identity altering.”¹²

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Parental over-protection has also been associated to heart-focused anxiety in people with CHD, independent of age, sex, education, CHD complexity, and trait anxiety.¹³ Moreover, people with CHD and heart-focused anxiety may be less likely to perform activity due to concerns about symptoms and deterioration of their condition. Recent data provided by Willinger et al.¹⁴ states that adults with CHD ($n = 984$) had significantly higher heart-focused anxiety compared to the general population, and increased heart-focused anxiety was significantly correlated with lower cardiorespiratory fitness ($r = -0.28$, $P < 0.001$), independent of CHD diagnosis, CHD severity, and surgical status.

These cross-sectional findings by Willinger et al.¹⁴ indicate a need for individualised activity advice to families who have children with CHD, as this may empower parents and significant others to promote activity. The evidence from paediatric and adult CHD cohort studies^{15–17} and meta-analyses of physical activity interventions and exercise testing^{4,18} show the risk of cardiac events (i.e., arrhythmia and sudden cardiac death) during activity/exercise is unlikely and the benefits of activity outweigh the risks. Therefore, current guidelines by the American Heart Association and European Society of Cardiology state that activity should be discussed during routine follow-up appointments, and advice should be individualised in people with CHD, often with the aid of clinical exercise testing.^{19–23}

Unfortunately, there is a dearth of data to show that activity is being discussed in clinics with people who have CHD. One of the first studies to investigate clinical discussions of activity was in 2000, when a questionnaire was distributed to determine if appropriate advice was being disseminated by clinicians to their adult patients with CHD.²⁴ The authors reported that ~70% (70/99) of patients had never received activity advice and those who did often received inappropriate advice.²⁴ More recently in 2017, Williams et al.²⁵ distributed a multicentre survey in the United Kingdom to specialist health care professionals (i.e., cardiologists, paediatricians, and nurses) to assess barriers to providing activity advice. Sixty-eight responses (33% response rate) revealed a similar proportion of clinicians (~60%) did not discuss activity with their patients at every appointment. It is currently unknown whether the lack of activity advice from clinicians influences children and young people's activity behaviours, or whether activity advice is discussed more frequently since 2017.

Therefore, the aims of this study were to assess: (1) if parental demographics, behaviours, and attitudes are related to their child's activity habits; (2) identify barriers to activity in children with CHD; and (3) report on the activity advice families receive from health services and if this is related to children and young people's activity habits.

Materials and methods

Study design

To address the aims of the research, a mixed methods study design was selected. A questionnaire was distributed to parents and legal guardians who care for children and young people with CHD. Ethical approval was granted by the University of Exeter's Sport and Health Science ethics committee (Ref No: 210616-A-06).

Questionnaire development and structure

An initial list of questions was developed based upon the aims of the research, existing literature,^{6,24,25} and expert opinion from a clinician, academic, and cardiac physiologist (GS, CAW, LF).

Parents were approached through Facebook (Congenital Heart Defects – UK) to participate in patient and public involvement. Parents ($n = 3$) were sent the list of questions prior to the meeting and one-to-one conversations were held with the first author via Microsoft Teams (Microsoft teams, Version 1.5, USA). Conversations began with a presentation of the aims of the research and invited parents to share their experience of caring for young people with CHD (from pre-natal checks to current day), parents were also asked to provide feedback on the aims of the research and the initial list of questions.

Based on the feedback received from parents, the questionnaire was further revised, and four separate sections emerged (see Supplementary File 1): "Section 1. Parental demographics and activity behaviours" ($n = 12$ questions); "Section 2. Child demographics and activity behaviours" (reported by the parents; $n = 12$ questions); "Section 3 Parental attitudes towards PA" ($n = 9$ questions); and "Section 4 Clinical experience and questions about activity with CHD" ($n = 9$ questions). In Sections 1 and 2, participants were asked if they or their child participated in moderate and vigorous activity using the same wording that is present in the Global activity Questionnaire developed by World Health Organization (Supplementary, Questionnaire Section 1: Q9, Q11; Section 2: Q8, Q10).²⁶

Participants & data collection

Parents or guardians who look after young people with CHD were invited to complete the questionnaire. The questionnaire was distributed via an anonymous online survey software (Qualtrics, USA), and data collection took place between October 2021 and February 2022. The questionnaire was shared through social media platforms: Twitter, Facebook groups 'Heart Hero's' and 'Congenital Heart Defects – UK', and through the National Health Service's CHD Network. The inclusion criteria were as follows: (1) Parent/guardian of a child/young person with CHD (<21 years at time of survey), (2) both parent/guardian and child were based in the UK, and (3) a minimum completion of sections 1 and 2 of the survey.

Data analysis

Numerical data were imported from Qualtrics to SPSS (IBM, Version 28, USA). Submission rates (i.e., n valid submissions vs. n started) and question-level response rates (n responses) are reported. Data are reported as count (n) and proportion (%), median and interquartile range (IQR), and mean \pm standard deviation where appropriate. The associations between parental demographics, activity, and attitudes to young peoples participation in activity were assessed in those aged 4 years and above. Child/young people's participation in activity was defined as the parent reporting "yes" to questions 8 and 10 section 2 of the questionnaire (e.g., "Q8. Does your child do any vigorous-intensity sports, fitness or recreational (leisure) activities that cause large increases in breathing or heart rate ...?") and CHD complexity was categorised using contemporary guidelines (21). Responses were analysed using frequency analysis and non-parametric tests of association (i.e., Chi-squared (χ^2), Fishers Exact, and Fishers-Freeman-Halton). The χ^2 test was used preferentially, the Fishers Exact or Fishers Freeman-Halton tests were used if the assumption of expected count was violated. Phi and Cramer's V effect sizes were used to quantify the magnitude of an association, a value of 0.1 was considered small, 0.3 moderate, and 0.5 large.²⁷ The alpha level was set a priori at $p < 0.05$. Figures were produced using GraphPad (Version 9; GraphPad Software, Inc., San Diego, CA),

and the diverging stacked bar chart was produced in RStudio (RStudio, PBC, Boston, MA).²⁸

Qualitative analysis

All available data (i.e., includes data from young people aged 0–20 years) from five open-ended questions (Section 3: Q6_b, Q7; Section 4: Q4, Q7, Q9; see Supplementary file) were analysed using a reflexive thematic analysis.²⁹ In the analysis, themes can be considered patterns within the data that centre around a core meaning. Rather than analysing the data question by question, the data were analysed collectively following recommendations for “users of qualitative surveys to resist any temptation to summarise responses to each question, as this typically results in an impoverished and underdeveloped qualitative analysis.”³⁰ The process of the reflexive thematic analysis drew upon six fluid steps, which acted as analysis scaffolding.^{31,32} Framed by ontological relativism and epistemological constructionism, one of the authors (FL) started the analytical process by reading and re-reading the data from the questionnaires. During this process, the author reflected on her own positionality; the author entered the analysis with no prior personal knowledge of CHD, nor of the academic literature, and considered herself an “outsider.” The second step involved coding the data inductively and deductively, based upon the words of the participants, and the question the response was crafted for. Themes were developed from codes and refined over time, conversations were held with the lead author to evaluate the interpretations, and quotations from the data were used to enhance the credibility of the interpretations.³³ Whilst writing up, themes were further refined and defined until the author (FL) was comfortable with the theme construction. Finally, reflections on the interpretation were sought from three parents who have children with CHD to gain richer detail, and minor changes were made to reflect their insights.

Results

Parental and child demographics

In total, 130 participants started the survey, 101 consented, and 83 met the inclusion criteria. The median time to complete the survey was 7.5 mins (interquartile range 6.5). The full details of parental demographics are reported in Supplementary Table S1. In brief, most responders were aged between 31 and 50 years (72%), belonged to a white ethnic group (98%), and identified as mothers (94%). Parents/guardians' (n = 83) children were aged 7.3 ± 5.0 years (range 0–20 years), 53% female, most were diagnosed in the first year of life (93%), had moderate to severe CHD (86%), and had some form of cardiac intervention (Table 1). The majority were healthy on a day-to-day basis (77%), but ~40% had other health conditions (i.e., growth delays, syndromic pathologies, and learning disabilities) (Table 1).

There was a positive association between parental age and children and young people's participation in moderate activity (Fishers-Freeman Halton P = 0.01; Supplementary Tables S3, S4). There were no other significant associations between parental demographics such as employment status, education level, or smoking status in relation to their children's participation in moderate or vigorous activity (see Supplementary, Tables S3, S4).

There were no significant associations between a young person's age and presence of co-existing disease to their participation in activity. However, increased severity of the CHD lesion (e.g., mild, moderate, and severe) was negatively associated to moderate

Table 1. Demographics of the children and young people with CHD.

Demographics	n	%
Age (years)		
<3	26	31
4–6	16	19
7–9	19	23
10–12	8	10
13–15	9	11
16–18	1	1
19–21	4	5
Sex		
Male	39	47
Female	44	53
Age at diagnosis		
0–1	77	93
2–4	3	4
5–12	3	4
Undergone heart surgery		
Yes	77	93
Not yet but will need surgery	3	4
No	3	4
Day-to-day basis health		
Healthy	64	77
Minor illness	19	23
Other health conditions		
Yes	35	43
No	44	54
I'd rather not say/don't know	3	3
Total	82	100
Severity of CHD		
Mild	7	8
Moderate	46	55
Severe	26	31
Other	4	5

(Fishers exact, P < 0.05) and vigorous activity participation ($X^2_{(1)} = 5.7$, P < 0.05). There was a non-significant and small association indicating young people that were healthy on a day-to-day basis (compared to minor-illness) were more likely to participate in vigorous activity ($X^2_{(1)} = 3.5$, P = 0.06; Phi = -0.25).

Parental and child activity behaviours

Only 61% of parents/guardians reported that they participated in activity, whereas their children were reported as more active with 84% performing at least moderate intensity physical activities (Fig. 1, Supplementary Table S2). Parental participation in vigorous activity was positively associated with their children performing vigorous activity ($X^2_{(1)} = 6.9$, P < 0.05). There was a non-significant but small association towards

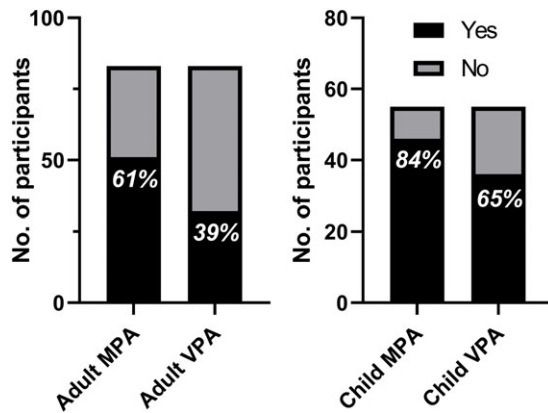


Figure 1. Parental and child physical activity behaviours. MPA = moderate physical activity; VPA = vigorous physical activity; children <4 yrs. old were excluded.

parental participation in moderate activity and vigorous activity of young people ($X^2_{(1)} = 3.3$, $P = 0.07$; $\Phi = 0.25$).

Parental attitudes towards activity

Approximately 40% of parents did not consider activity as important for themselves and tended to value the importance of activity more for their children (Fig. 2). Furthermore, children were reported to enjoy activity more than their parents. Parents/guardians mostly felt that exercise was safe for their child (85%, 63/74). However, 14% (10/74) were unsure if exercise was safe, and 1% (1/74) felt that exercise was unsafe. 67% (49/74) of respondents did not know or were unsure where they could receive additional information on activity/exercise advice. The top five reported barriers reported by parents as barriers to their child's activity were tiredness, school/homework pressure, their child being unwell, concerns about activity with CHD, and concerns about symptoms (heart palpitations, chest pain, etc.) (Table 2).

There was a significant positive association between child enjoyment of activity (parent-reported) and participation in moderate and vigorous activity (Fishers-Freeman-Halton, $p < 0.01$). Moreover, there was a significant positive association between parents viewing activity as important for their child and subsequent child moderate and vigorous activity (Fishers-Freeman-Halton $p < 0.05$). There was a non-significant but small association towards whether a parent enjoyed activity (Moderate activity, Cramer's $V = 0.27$; Vigorous activity, Cramer's $V = 0.27$), or how important they thought activity was to their own health (Moderate activity, Cramer's $V = 0.36$; Vigorous activity, Cramer's $V = 0.15$) to their subsequent child's activity behaviours.

Clinical experience and questions about activity with CHD

A large proportion of parents (78%, 39/50) reported their child had never had an outpatient exercise test, with the remaining 22% (11/50) saying exercise tests happened at some appointments. Of the 11 people who received an exercise test, 10 reported that they thought the test was useful and safe, and one person thought the test was safe but limited in terms of capturing all the information on their child's exercise tolerance. Exercise tests were conducted on a treadmill ($n = 9$) or cycle ($n = 2$) ergometer.

Activity advice was infrequently provided during outpatient appointments; 52 (71%) had never received advice, 15 (21%) had received advice but only during some appointments, and only 5 (7%) parents/guardians received exercise advice at every

appointment. Activity advice was given from a range of clinical staff with doctors providing the majority (Supplementary Figure S1). Of those who received activity advice, half the respondents said the advice was inconsistent. Furthermore, 10 (~15%) parents said they had unanswered questions about activity. However, no significant relationship was found between the clinical experience (i.e., exercise testing and activity advice) and participation in moderate or vigorous activity.

Qualitative findings

From the open-ended responses, one overarching theme was constructed "*Knowledge is power and comfort.*" The theme centred upon the great value placed in activity knowledge and information by parents of children with CHD. Parents perceived health care professionals in clinic to be the appropriate source for activity guidance. Yet, a lack of this desired information appeared to prompt some parental fear and influence perceptions of what constituted inclusive, safe activity for their child. Many parents described not knowing what activity was appropriate for their child, nor what the impact of activity on their child might be either for their short, or long-term health development. The discussion about activity was often absent during routine health care appointments, yet when parents initiated such discussions with clinicians themselves, responses to address concerns, or answer questions regarding activity were often deemed inadequate. In instances where information was provided in CHD clinics, parents noted feeling confused about what activity was appropriate for their child. Advice regarding appropriate activity could differ between setting and healthcare specialism (e.g., consultant, specialist nurse). The advice communicated could be difficult to understand or considered inappropriate by some parents:

I do not feel well informed about the risks posed to my baby as a result of physical activity/exertion. I know that CHD can impact every child differently, however, upon receiving the diagnosis, I did not have, and still do not have much information about how this could impact my baby's future. Instead, following his heart surgery, a joke was made that my baby could be in the Olympics.

Due to the lack of a one size fits all approach to activity, and the maturational changes in children with CHD, some parents were sympathetic to health care professionals providing inconsistent information. However, without information or advice to avoid looking for information, parents described feelings of fear and anxiousness. In comparison to parents who had received some guidance, and felt some reassurance, others who had received less, or perceived the information to be less helpful appeared focused on the detrimental impact of activity on their child. Concerns centred upon exacerbating their child's physical symptoms and overall condition (e.g., shortness of breath, tiredness, falling over and impacting pacemaker, sustained high heart rate, sickness, and heart palpitations). While some parents recognised these could all be short-term impacts of activity, parents were also fearful of the severity of the impact, such as the long-term physiological influence on their child:

I worry that he will wear himself out, or that really vigorous exercise will trigger something like a heart attack especially as he will not tolerate an echo at the moment, so we have not had a clear picture of how his vessels are growing.

With fears of physiological consequences for their child, parents possessed differing attitudes towards their child's participation in certain activities. Many parents shared the desire for their child to

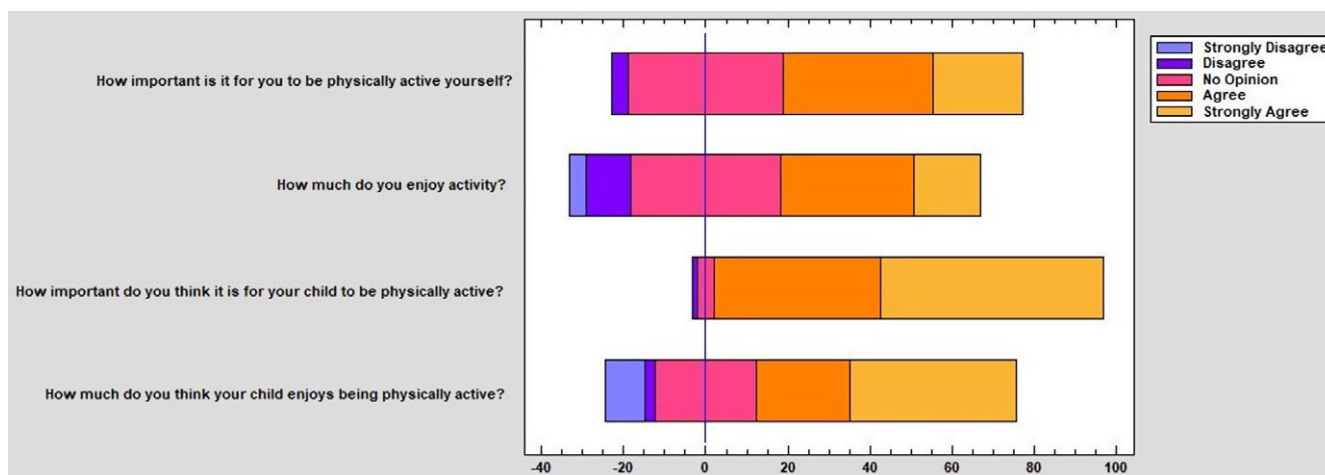


Figure 2. Diverging stacked bar chart displaying Likert survey responses.

Table 2. Barriers to physical activity reported by parents in descending order.

Barriers to physical activity	n	%
Tiredness	40	23
School/homework pressure	17	10
Unwell	15	9
Concerns about physical activity with congenital heart disease	15	9
Concerns about symptoms (heart palpitations, chest pain, etc.)	14	8
Would rather do something else with spare time	14	8
Lack of time	13	7
Lack of provision and cost activity (coaching, equipment, etc.)	12	7
Unclear what type / intensity of physical activity to do	9	5
Lack of enjoyment of activity	9	5
Concerns about weight loss / nutrition	5	3
Excluded from sessions groups due to their condition(s)	4	2
Too young to participate or physically unable	4	2
Body image/body confidence	3	2

participate in safe and/or inclusive activity opportunities, although perceptions of what constituted safe and inclusive across schools and local community provision varied. Some parents who had obtained some information described being open to letting their child “run freely.” However, other commented that local activity provision was poor and not inclusive for children with CHD. Inclusivity was mentioned in several different capacities. First, geographical and financial barriers were mentioned by parents including time for activity, activity availability, and cost. However, parents also suggested that some activities (e.g., team-based sports, contact activity) were not inclusive as they posed a physiological threat to their child. These inclusivity perceptions appeared to stem from parental instincts to protect their child, as opposed to activities being medically unsafe; parents who had received healthcare professional guidance considered some “unsafe” activities to be fine for their child. This observation highlights

that an absence of knowledge may lead to avoidance of activity participation, due to parental fear. Instead, disabled, or CHD-specific sports clubs, in the community were suggested to foster safer participation. Upskilling sports coaches and teachers, providing regular activity breaks, and low exertion, non-contact activity was also considered preferable by parents. Many also showed preferences for individual, non-contact activities (e.g., dance/yoga/swimming):

It would help if my child was about to participate in something at school that is not necessarily physically exerting. They should offer alternative sports, i.e., Pilates or yoga, rather than just sitting on the side line during sports lessons.

Parental fear extended beyond the possible physiological consequences of activity on their child’s health, to their child’s psychological and social development. Parents reported that children with CHD were often unable to participate in sports lessons due to their high exertional, team nature, instead having to sit out and unable to join their peers. This in part was attributed to schools, teachers, and local clubs lacking information on CHD, and likely also fearful of exacerbating the child’s physiological condition through participation. However, for those children with CHD who were permitted to participate and reap social benefits of activity, parents reported how such participation could still be psychologically challenging. For example, in competition:

My daughter is happy to take part in activities but seems quite behind in comparison to her “healthy” peers, and this can be very demotivating. Things like sports day when she never wins is often tough.

With risk to a child’s psychosocial development, coupled with the risk to physiological health and a lack of expert guidance, versus the benefits of activity, this highlights a delicate balancing act for parents of children with CHD. Parents expressed desires to both protect their child and encourage them to participate in safe inclusive activity opportunities, yet it was apparent that most felt unable to succeed in achieving both. Personalised support from health care professionals was desired by parents to provide comfort and reassurance and likely reduce the internal conflict they possessed surrounding their child’s activity.

Beyond health care professionals sharing guidance to parents and schools, parents also acknowledged the power of sharing knowledge directly to children with CHD. Parents indicated that their knowledge on activity is one thing, but their child’s awareness

of risk and adherence to instruction and activity participation is another. Therefore, even a well-informed parent could still feel apprehension at the thought of their child exercising:

Our son loves exercise and he plays football and goes to the gym. I worry about the impact exercise could have on his heart condition. His cardiologist said he can play football and do some weights, but in moderation. We worry that he does not understand moderation.

From parents' responses, guidance for themselves, local community services, and children with CHD may be necessary for increasing activity participation. Tailored guidance from health care professionals in outpatient appointments, who have established knowledge of the child and their condition, may be most preferable and instil the most safety, comfort, and trust in the guidance shared. Specifically, guidance explaining what signs to look out for and when to intervene was most desired by parents to provide a greater sense of control over and comfort in participation. The use of exercise tests was also mentioned as a tool to help explain risks and participation to their child if they were deemed old enough to understand. Parents noted that leaflets, apps, and knowledge they could share with schools and clubs may all support their child in activity participation. It was acknowledged that as children with CHD age, their physical ability and CHD can change, likely meaning any guidance and knowledge from healthcare professionals may need to adapt with time. However, from the survey, a clear message prevailed: more information on activity for children with CHD is needed. This is required to educate parents, those working in sport and exercise, and children with the condition, around what activity is safe and inclusive for those growing up and learning to live better with CHD. Clinics may provide an opportunity for such knowledge dissemination to children and parents.

Discussion

This study reports that parental participation in activity and their positive attitudes towards activity are significantly and positively associated to children and young peoples participation in activity. Specific barriers to activity for young people who have CHD were regarding the safety of the activity and the associated symptoms that activity may induce. There was a lack of activity advice provided by health care professionals and when it was provided it was insufficient. Furthermore, qualitative analysis produced a theme of "*Knowledge is power and comfort*," where parents did not feel well informed, received mixed messages, and were concerned about the potential negative influences of activity.

Parental factors

Previously, parents have been identified as key facilitators of childhood activity,^{10,11,34,35} and most parents surveyed believed activity was important for their child. However, there was evidence of parental concern around their child's ability to perform activity. Specifically, the child's ability to moderate their own exercise intensity and being unable to differentiate between physiological and pathological responses to exercise. Concerns around children and young people moderating the intensity of activity has been reported in a cohort of families (n = 7 parents) who have children (age 5–16 y.) with a Fontan circulation.¹¹ Parents either encouraged activity and allowed the child to self-regulate (despite concerns on the impact it may have), intervened when they perceived their child was overreaching, or avoided activity

entirely.¹¹ Bennett et al.³⁶ also report that parents of children and young people with CHD would hide their concerns regarding their child's ability to moderate their intensity.

In the current study, there were significant positive associations between parents who participated in activity or viewed it as important for their child and their child's subsequent activity behaviour. Moreover, parents who enjoyed activity or viewed it as important for their own health were more likely to have active children. Thus, parent's attitudes, behaviours, and confidence in their child's ability to perform activity is vitally important for their child's activity behaviours. These findings support the previous literature and highlight the need for appropriate activity education for families with CHD from a multidisciplinary clinical team. Specifically, education could focus on suitable activity types and intensities for the whole family.

Child & external factors

Children with an increased severity of CHD were less likely to participate in activity. These findings agree with Brudy and colleagues⁸ who directly assessed activity using accelerometers and reported that children with more severe disease (e.g., total cavopulmonary circulation), were less likely to meet the World Health Organization activity recommendations.

Other factors that appear to influence activity (via qualitative analysis) are concerns on the acute effects of exercise such as, discriminating between physiology and pathology (breathlessness, high heart rates, tiredness, etc.), potential damage to pacemakers through contact sports, and exclusion from physical education situations (i.e., a lack of inclusivity). Parents reported instances where their children had been completely excluded from activities (due to a lack of provision and inclusion) from teachers and coaches. These findings are supported by previous research in children and adolescents with CHD^{11,34} and cardiomyopathy,³⁷ where individuals were excluded from activity by teachers and even singled out and labelled "disabled" due to their cardiac condition.¹¹

There are numerous guidelines for teachers and coaches to facilitate inclusion in their professional practice, especially the SEND code of practice.³⁸ However, when it comes to health both professions (i.e., teachers and coaches) are inclined towards seeking advice from the participants and their caregivers with regards to what is appropriate. In fact not knowing pupils and their needs well was identified as a key factor leading to poor provision in schools.³⁹ If a child or young person is poorly motivated to take part in Physical Education and other school-based physical activities, then CHD will be an easy facilitator of their withdrawal. Alternatively, if parents assume a protectionist approach, perhaps as a derivation of a lack of information and confidence and suggest that low levels of activity are appropriate then it is unlikely teacher or coaches will step beyond the boundaries already established by the caregivers.

These scenarios will consequently lead to detriments in development of skills and fitness required to be successful in these settings, leading to a sense of exclusion and a progressive decline in access to activity through these settings. Therefore, an empowerment of parents regarding their knowledge of appropriate and up-to-date guidance for engagement in a range of activities is essential for both short- and- long-term health outcomes, as well a potentially simple mechanisms for this information to be fed forward to invested parties (i.e., schools). The findings detailed by the House of Commons Education Select Committee in 2019⁴⁰ on

the quality of the SEND system in schools pointed to a lack of coordination between education and health services that resulted in delays in assessing and meeting young people's needs. If families feel ill-informed with regards to what is appropriate activity, then this will feed into schools and will make it difficult for schools to set high expectations for pupils without external medical advice. Thus, parents, teachers and coaches would benefit from being provided with appropriate up-to-date written activity advice from clinical teams. This information can then be held by schools and form the basis of an individual's learning plan.

Clinical experience

Despite evidence on the unlikely risk of serious adverse events during activity in children with CHD (15,18,23) and guidelines on the prescription of activity in CHD,^{20,21} the current study reports that most young people with CHD have never received any form of activity advice or exercise testing. Exercise testing is important as it has been recommended as a cornerstone for an appropriate and individualised activity prescription.^{20,41} The low prevalence of activity advice reported in the current study is similar to the multicentre survey by Williams and colleagues,²⁵ which reported that the majority of clinicians (~60%) did not speak about activity with their patients at each appointment. These findings are important as a recent study exploring behavioural change interventions in CHD recommended an increased educational component to future activity interventions, to tackle concerns and misconceptions surrounding activity in CHD.⁴²

In the current study, parents reported that when activity advice was provided, it was inconsistent between appointments and staff, which led to further confusion (e.g., different advice between doctors and between doctors and specialist nurses). This is concerning as guidelines from the American Heart Association and European Society of Cardiology have been developed for clinicians to counsel and prescribe individualised and appropriate levels of activity to people with CHD.^{19,20,41} The European Society of Cardiology recommendations adopt a five-step approach in providing personalised activity advice including (1) history and physical examination, (2) assessment of five cardiovascular parameters at rest (i.e., ventricles, pulmonary artery pressure, aortic size, arrhythmia, and oxygen saturation), (3) exercise testing, (4) recommendation of activity, and (5) follow-up.²⁰

The recommendation of activity needs to be individualised, patient-centred, routinely reviewed, and allow the patient to identify facilitators and barriers. This facilitates young people to have ownership and focus on what they can participate in rather than their restrictions. These discussions can be facilitated by free resources provided by charities such as Heart Research UK, which provide information for young people with CHD, their parents, and teachers.⁴³ Heart Research UK also produces a useful and free physical activity recommendations form for clinicians to complete, this provides practical information to individuals, schools, and sports clubs (see Supplementary file). This is important because parents of young people with CHD find advice from medical sources (i.e., specialist cardiologists) significantly more trustworthy and helpful compared to informal sources (i.e., social media groups).⁴⁴ Therefore, to maintain trust in the clinician-patient relationship, appropriate and consistent activity advice is crucial for families to help promote participation in activity.

Limitations

A strength of this questionnaire was that it was co-developed with parents for parents. The co-development involved a small number of parents, which could be increased in future studies. The use of the online sampling strategy meant response rates were unable to be calculated, and it may have resulted in selection bias, as those who use social media and are interested in activity may have been more prepared to complete the survey. Another limitation is the lack of participation from fathers. Whilst this finding is not unique to the current study,⁴⁴ it limits the generalisability of the findings and it remains unknown if paternal activity behaviours and attitudes differ, and how any differences may influence their children. One further limitation is the wide age range (0–20 y, n = 83) and relatively small sample of adolescents (13–18 y, n = 10) included within the study, which resulted in a relatively younger sample (7.3 ± 5.0 years).

Conclusion

Historically parents who have children with CHD have been identified as barriers to their child's activity. These new data show that parents mostly believe activity is beneficial for their children. However, there is still uncertainty as to what type and intensity of activity is safe for their child. Part of the uncertainty can be explained by the lack of/inconsistent activity advice provided by CHD clinics. Recommendations for current practice include improving activity advice to families, using contemporary guidelines^{20,21} and resources⁴³ to improve the consistency and validity of the advice.

Recommendations

- Written physical activity advice should be provided after a clinical assessment and during every routine clinical follow-up appointment.
- The advice should be individualised and patient-centred.
- For children with CHD, physical activity advice would preferentially include activities the whole family can undertake, as active parents are associated with active children.
- Schools and sport-clubs responsible for the care of young people with CHD should be provided with the appropriate resources and knowledge to facilitate the safe inclusion of young people with CHD into physical activities.

Supplementary material. The supplementary material for this article can be found at <https://doi.org/10.1017/S104795112300327X>.

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Ethical standard. 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 (University of Exeter Sport and Health Science ethics committee (Ref No: 210616-A-06).

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