A SURVEY OF EXERCISE ADVICE AND RECOMMENDATIONS IN UK PAEDIATRIC CARDIAC CLINICS

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Abstract

Background: Physical activity and exercise have important health benefits for children and adolescents with congenital heart disease (CHD). The objective of this study was to survey the provision of advice and recommendations in UK paediatric CHD clinics.

Methods: A three page questionnaire was sent out to paediatric cardiac consultants in the UK, paediatric consultants with expertise in cardiology and nursing staff (PECSIG), as well as all members of the British Congenital Cardiovascular Association (BCCA). The aim of this questionnaire was to determine the extent and scope of current information provision and to assess the importance that clinicians place on this advice.

Results: There were 68 responses in total, and the data showed that, of these, 24 (36%) clinicians had never provided paediatric CHD patients with written advice about exercise. Only 27 (39%) clinicians provided physical activity advice at every appointment. Lack of time during consultation (n=39, 56.9%), lack of training (n=38, 55.2%) and uncertainty about appropriate recommendations (n=38, 55.2%) were identified as the main factors preventing clinicians from providing patients with advice about physical activity.

Conclusion: Although healthcare providers consider physical activity to be very important, the provision of clear, specific advice and recommendations are underutilised. Therefore, more education and the provision of resources to support the promotion of exercise need to be provided to clinicians and their support teams.

Key words

Exercise promotion and prescription; clinical education; physical activity; exercise; healthcare; congenital heart disease; adolescents

Introduction

Many children with CHD can safely participate in all sports and recreational activities without the need for restrictions (Takken, et al., 2012). However, exercise training has been shown to be an underused resource in paediatric healthcare (Pieles, et al., 2013). In addition, several studies have found a significant and worrying mismatch between the medical opinion of the cardiologist and the perception of the patient and their parents (Falk, et al., 2006, Kendall, et al., 2007 , Moola, et al., 2009). One study conducted in the UK found that 30% of parents and their children overestimated the level of exercise they could safely participate in, with 6.7% of the overestimated exercise cases considered as potentially dangerous participation (Kendall, et al., 2007). As a result of no clear and specific advice many cardiac patients (44%) incorrectly assumed that all exercise is safe, (Swan & Hills, 2000). Whilst patients who overestimate their capabilities is to be cautioned against, for fear of the exercise doing more harm than good, just as important are the many patients who overestimate the extent of their exercise restrictions, with 12% needlessly avoiding participation (Kendall et al., 2007). However, it is also likely that uncertainty about which physical activities are appropriate will also cause anxiety, both in patients and their parents/carers. Such anxiety may represent a significant barrier to leading a physically active lifestyle (Longmuir & McCrindle, 2009).

It is worth noting that the terms physical activity, exercise and sport are often used synonymously in the literature. Here, we are categorising ‘physical activity’ (PA) to include any activity that is a part of daily life that results in an increase in heart-rate and energy expenditure above resting values. ‘Exercise’ is a form of physical activity that is structured and performed with the aim of improving strength, flexibility or aerobic endurance. We focussed our attention on the provision of ‘exercise’ advice in this study, due to most school-based activities being classified as such an activity.

The American Heart Association has published a scientific statement on the promotion of physical activity for those with congenital heart defects, highlighting the need for the proactive promotion of an active lifestyle by health professionals (Longmuir, et al., 2013). In addition, the "Recommendations for physical activity, recreational sport and exercise training in paediatric patients with congenital heart disease" (Takken, et al., 2012), emphasised that clinicians should provide patients, parents and primary care providers with recommendations in writing. Indeed, written instructions have been found to be more effective than verbal communication alone (Swinburn, et al., 1997). Other authors have highlighted the importance of providing adolescents with individualised written advice, enabling them to participate in the management of their own health (Swan & Hills, 2000) (Caplan & Allen, 2011). A randomised control trial (RCT) showed written advice to be more successful at motivating people to exercise than verbal advice alone (Swinburn, et al., 1998).

To the best of the authors' knowledge, no other recent studies have examined the provision of paediatric exercise advice given by cardiac healthcare professionals in the UK. The long term goal was to obtain information that could then be used to identify areas for improvement, as well as new activity programmes, including written advice and guidelines for use by clinicians and their support teams. Therefore, the aim of this study was to clarify the current level of advice and provision related to physical activity, which is provided nationwide to CHD patients and their families at the time of consultation.

Methods

Paediatric cardiac consultants in the UK were identified from the National Institute for Cardiovascular Outcomes Research (NICOR) website and were invited to complete an online questionnaire. Email requests were also sent to all members of the British Congenital

Cardiovascular Association (BCCA). A total of 85 paediatric cardiac consultants were contacted through the BCCA.

Paediatric consultants with expertise in cardiology and nursing staff (Clinical Nurse Specialists, Advanced Nurse Practitioners and Cardiac Liaison Nurses) working within paediatric cardiac centres were also invited to complete the online questionnaire. These were identified by the Paediatricians with Expertise in Cardiology Special Interest Group (PECSIG) and the Congenital Cardiac Nurses Association respectively. A total of 104 paediatric consultants and nursing staff were invited to complete the online questionnaire.

Respondents were asked to identify their professional role and confirm whether or not the centre had a rehabilitation programme; defined as a 'structured programme to help patients recover and improve physical, mental and social functioning'; this rehabilitation programme is for all patients, irrespective of whether or not they have undergone surgery. The three-page questionnaire requested details on the frequency with which PA is discussed with patients, the scope and format of the advice provided and what information is considered when making recommendations. Respondents were also asked whether or not the centre routinely assessed patient's understanding of which PAs are appropriate for them and to identify the main factors limiting the provision of advice to patients and their families. Clinicians were also asked to determine the importance that they assign to the provision of PA advice. This was quantified using a Likert scale ranging from 1 (not important) to 5 (very important).

Local Research Ethics Committee approval was sought but as the study was a survey on healthcare provision and did not require individual patient information to be revealed, the NHS Research Ethics Committee deemed an ethical review was not required. However, the project followed the guidelines as outlined by the Helsinki Agreement. Respondents' rights to anonymity and confidentiality of their responses were adhered to throughout the procedures.

Results

Each of the CHD specialist centres found in the UK had at least one respondent. Cardiac centres contacted are shown in Figure 1. Of the total number of questionnaires sent out to individuals, there was a response rate of 33%. Questionnaires were returned by 27 (32%) of Paediatric Cardiac Consultants contacted, representing at least one completed questionnaire from each of the CHD 'specialist centres' at the level of consultant. A total of 41 questionnaires were returned from the other healthcare professionals specialising in CHD, these included: Paediatric Cardiology Registrars, Paediatric Consultants with Expertise in Cardiology, Clinical Nurse Specialists, Advanced Nurse Practitioners and Cardiac Liaison Nurses (Table 1).

The findings show that there is no clear consensus about what constitutes a 'rehabilitation programme' for paediatric CHD. A total of 8.8% of all respondents answered 'Yes' when asked if their centre has a rehabilitation programme for children and adolescents with CHD, 80.9% answered 'No', and the remaining 10.3% were unsure. Although the questionnaire included a definition of a rehabilitation programme; "a structured programme to help patients recover and improve physical, mental and social functioning", in four centres, respondents (different clinicians) provided contradictory information about whether or not their centre had a rehabilitation programme.

According to 39% of respondents, physical activity advice is provided at every appointment. However, only 25% of healthcare professionals considered that there were specified times, such as transition to secondary school, when advice was provided. The results (Figure 2A) suggest that exercise is discussed in the majority of consultations, with 60% of clinicians considering that exercise is usually discussed and 21% stating that it is always discussed.

Furthermore, almost all healthcare professionals consider exercise and PA to be 'very important' for their patients' quality of life; with a mean rating of 4.62 on a Likert scale ranging from 'not important' (1) to 'very important (5).

Although exercise is often discussed during consultations, it is uncommon for patients to be provided with written information. In our survey 36% of clinicians stated that written advice about exercise is never provided to patients (Figure 2B).

When contemplating what exercise advice to provide to patients, the majority (87%) of clinicians consider the patient's interests, and although general physical activity guidelines are taken into account by 81% of all clinicians, specific AHA/ESC guidelines are taken into account by less than half (40%) of all clinicians surveyed (Figure 2C).

This figure increases to 70% when only the responses of cardiologists are considered. When cardiologists are excluded from the results it was shown that only 19% of other health care professionals consider published guidelines when providing exercise advice.

Additionally, the majority of healthcare professionals (60.6%) do not assess their patients' knowledge about the level of exercise that is appropriate for them. Nurses were more likely to assess this knowledge than other clinicians (Table 2).

In response to the question "Which factors do you feel prevent you from providing patients with more detailed, individualised advice and recommendations about exercise?" two respondents replied that there were no limiting factors. However, three of the options given were identified by more than 50% of respondents. Firstly, the lack of time during consultation (57%), followed by the lack of training in this specific area (55%) and finally, uncertainty about appropriate recommendations (55%) were cited. The latter response remains high (39%) when only responses from consultants are considered. The main factor identified by cardiologists was lack of time during consultation (70%). In contrast, the main factors

identified by nurses were lack of training (77%) and uncertainty about appropriate recommendations (62%). This uncertainty remained high (38%) when only responses from consultants are considered (Figure 3).

Discussion

The main findings of this study show that whilst exercise is discussed in the majority of consultations, the provision of written information is rare. Reasons why the advice given to patients is insufficient varied depending on the role of the clinician, and less than half of all clinicians surveyed consider the published guidelines for exercise and CHD when discussing exercise with patients. The findings of this survey also highlight that there is no clear consensus as to what constitutes a 'rehabilitation programme', emphasised by the fact that on occasion contradictory answers were given from the same centre.

This failure to consider the published guidelines is a concern because it is known that inactivity even from an early age has implications for basic motor development and quality of life (Tong, et al., 1998). In addition, regular physical activity is known to reduce the risk of developing chronic health conditions in later life (Cavill, et al., 2001). Since 80-85% of patients born with CHD now survive to adulthood (Moons, et al., 2010), early interventions are becoming more important than ever, as the cost of the disease is going to increase in line with birth rate.

Only a quarter of respondents considered that there were specified times, such as the transition from primary to secondary school when PA is provided and just 39% of respondents reported discussing PA at every appointment**.** This indicates that the timing of information provision is arbitrary and there is often no systematic procedure for determining when PA advice is to be given.

Perceptions of CHD and physical activity advice differed amongst clinicians, particularly when asked what they considered to be the main barriers to the provision of exercise advice (Figure 2). A small proportion of paediatricians and nurses cited the risks associated with PA as a barrier but this was not identified by any consultants. Conversely, consultants identified a lack of time during consultations to be the main obstacle to their provision of more individualised exercise advice. Lack of training in this specific area was highlighted by over half of all respondents. On consideration of all responses, it is clear that the majority of clinicians do not have the time, resources or specific knowledge to confidently provide exercise advice for youngsters with CHD. The variation in responses suggests that different forms of action need to be taken depending on the role of the clinician in order to truly address the issue. This would present excellent CPD opportunities where consultants promote the value of PA to their patients, whilst passing on the responsibility of prescribing PA to cardiac nurses and physiotherapists, providing they have the necessary skills and education. This provision seems an ideal opportunity for the medical profession to engage with other health professionals, namely registered exercise professionals.

Exercise advice should not be overlooked during the transition stages; this advice should also reflect the changing nature of sporting activities between the mid-teens and early-teens. During this period, activities become more competitive, and the players may be put under increased pressure to do well, either from themselves, peers or coaches. This may cause over-exertion, which is potentially dangerous for a child with a heart defect. It is important to implement this extra advice from the very beginning of the transition period, starting when the patient is 12 years old, until full transfer to adult services. The need for better and more thorough information during transition was identified in a 2009 study by Moons and colleagues, where a number of patients noted that they were largely unaware of what the

outpatient visit would entail until they actually arrived there, which increased their feelings of anxiety (Moons, et al., 2009). The American Heart Association (AHA) and the European Society of Cardiology (ESC) recommend physical activity for the majority of CHD patients (Longmuir, et al., 2013), (Pelliccia, et al., 2005), however the individual nature of CHD makes it difficult to apply these generic guidelines from consensus statements to the myriad of CHD patients. Similarly, Budts has produced a protocol for defining appropriate exercise prescription in congenital heart disease but this is limited to adolescents and young adults (Budts, et al., 2013). This could explain the large reported percentage of uncertainty amongst clinicians about the appropriate recommendations (Figure 2).

As with all studies several limitations are acknowledged. It is noted that, as with the majority of surveys, those who responded are more likely to be interested in this topic (non-response bias), and therefore there will be a degree of bias in the responses (Suchman & McCandless, 1940 ; Jackson, 1946 ; Larson & Catton, 1959). However, these findings are not uncommon in other chronic disease groups e.g., cystic fibrosis (Stevens et al., 2010) where the value of exercise is recognised by clinicians and their support teams but is underutilised. The only method that could be used to truly decipher the extent of the problem would be to perform an audit.

Conclusion

In summary, this survey showed that in the UK PA and exercise is discussed in the majority of consultations, but written advice is not a common practice. Secondly, the provision of rehabilitation programmes in UK paediatric CHD patients is very limited. These practices were attributed to several reasons, such as lack of time during consultations, uncertainty about appropriate recommendations and lack of training. Importantly, none of the

cardiologists who took part in the survey felt concerned that the potential risk associated with exercise prevented them from providing more detailed advice. Therefore, better education to increase the promotion and prescription of exercise is required and should form part of the clinicians and their support teams continuing professional development. This demonstrates a need for individualised, written advice for patients, through a method which is not time-consuming for clinicians and their support teams to perform. Further training and consultant awareness on published exercise guidelines would also be advantageous. Potentially, there is a role that registered exercise professionals, with specialist paediatric training, could take to ease the burden of delivery of these types of programmes. The role of physical activity and exercise should therefore play an important role in reducing costs for the increasing financial commitment of the long term care of CHD patients.

List of Abbreviations

CHD: Congenital heart disease

PA: Physical activity

Competing Interests

Nothing to declare: This project was instigated and funded by the charity Heart Research UK, as part of their 'Helping Little Hearts' campaign.

Author's Contributions

Author's Information

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Table 1

Clinician's survey respondents filtered by job role.

Respondents	Number of Responses:	
Cardiac consultant	27	(39.7%)
Paediatric consultant (with expertise in cardiology)	15	(22.1%)
Clinical nurse specialist / Advanced nurse practitioner	11	(16.2%)
Cardiac liaison nurse	6	(8.8%)
Other (please specify)	9	(13.2%)
Total	**68**	**(100%)**

Table 2

Is patient's knowledge of the appropriate level of exercise routinely assessed?

	All responses:	Filtered for cardiologists:	Filtered for paediatricians (PECSIG):	Filtered for CNS, CLN and ANP:
Yes	26 (39.4%)	12 (48%)	2 (14.3%)	9 (52.9%)
No	40 (60.6%)	13 (52%)	12 (85.7%)	8 (47.1%)
Number of responses	**66**	**25**	**14**	**17**

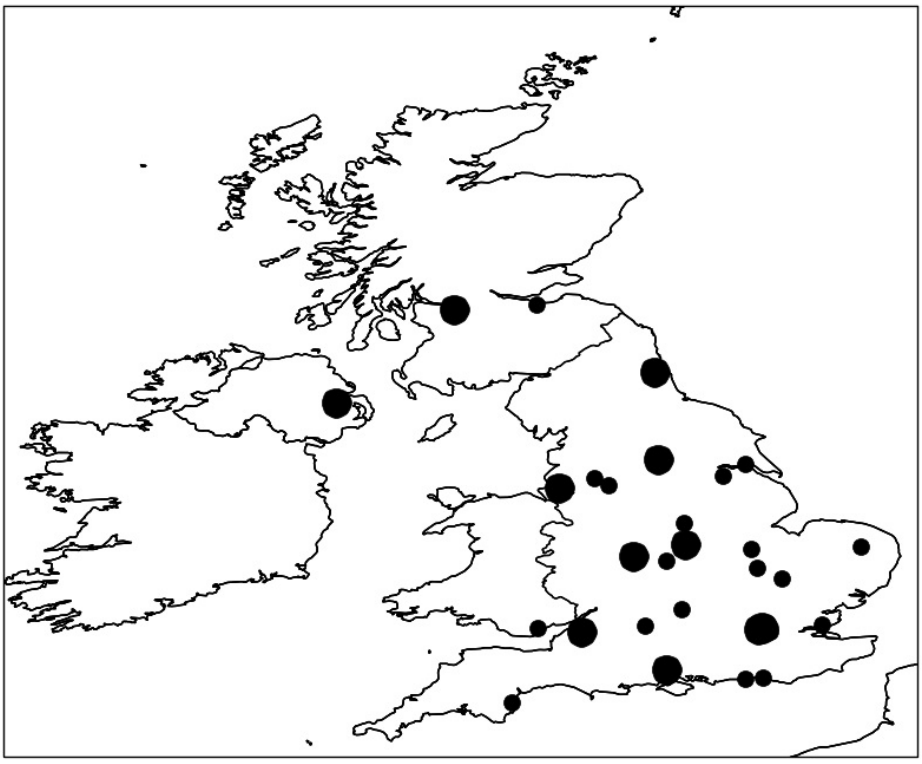

Figure 1: UK Map showing the cardiac centres contacted for the survey. Large dots indicate surgical congenital heart centres, and smaller dots indicate non-surgical congenital heart centres.

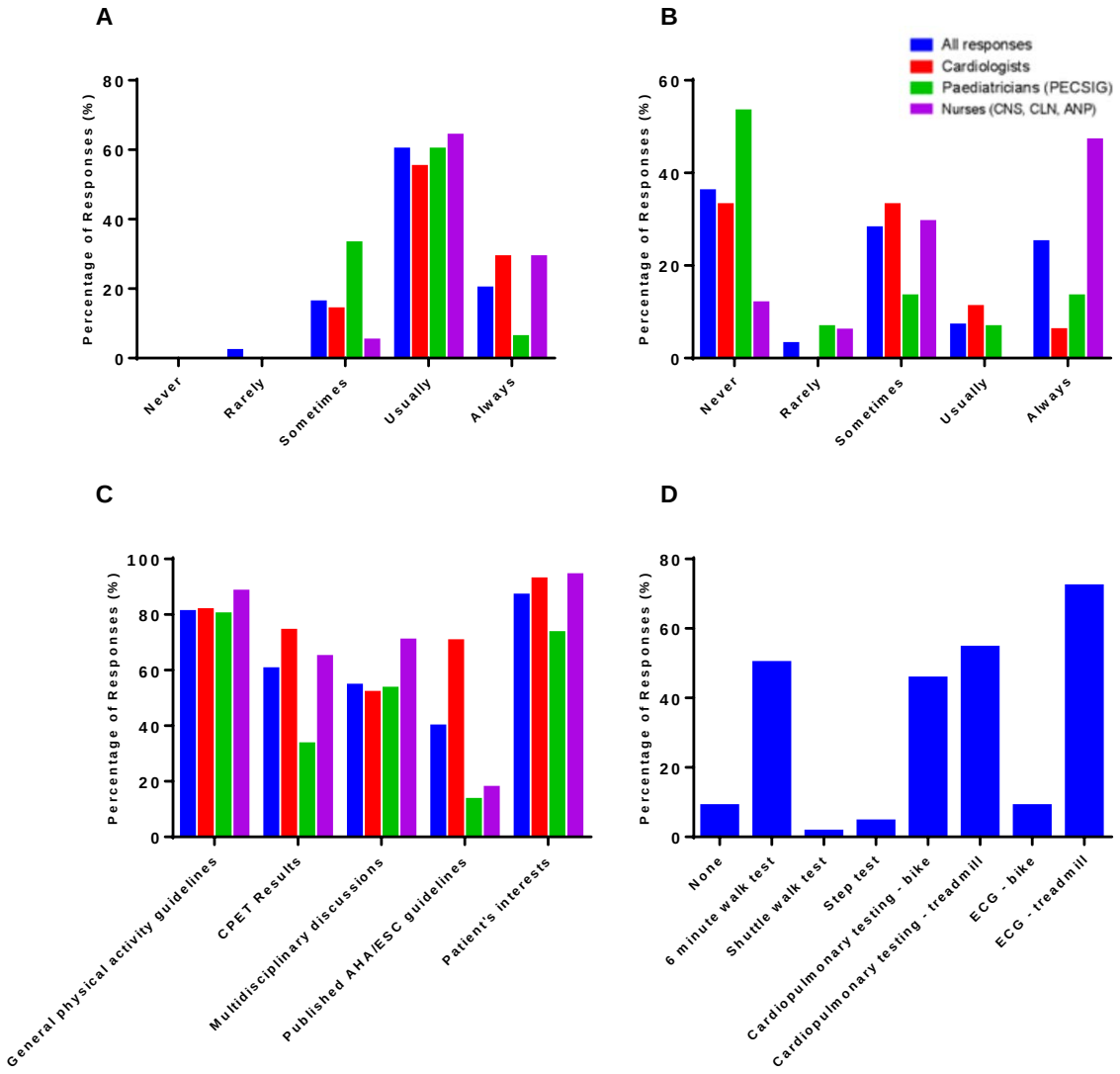

Figure 2: Survey responses to: (A) How often is exercise discussed during consultations? n = 68 (B) How often is written exercise advice provided in consultations? n = 67 (C) What information do you consider when providing exercise advice? n = 68 (D) Which exercise tests are currently employed? n = 68. Questions A – C are filtered by role for cardiologists, members of PECSIG (Paediatricians with Expertise in Cardiology Special Interest Group) and nurses

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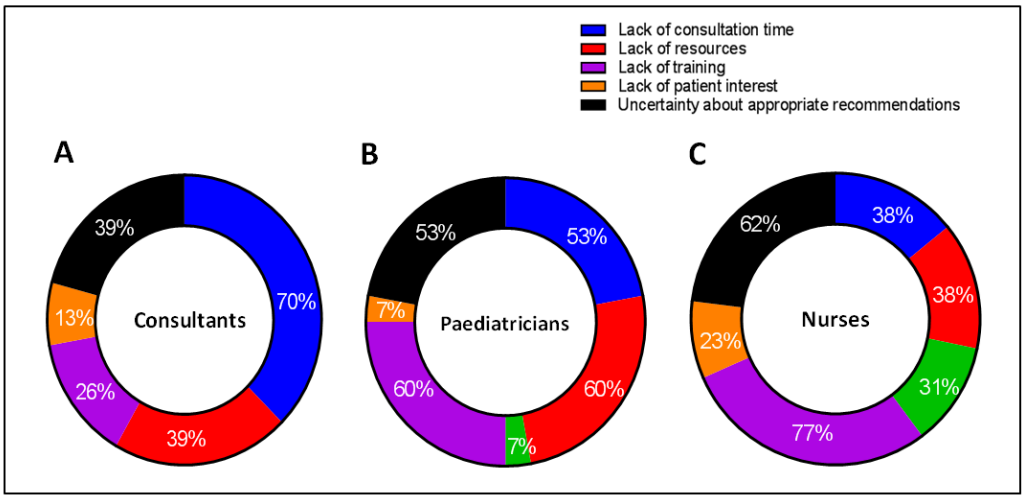

Figure 3: Survey responses to the question: "Which factors do you feel prevent you from providing patients with more detailed, individualised advice and recommendations about exercise? filtered for (A) Consultants (n=23), (B) Paediatricians (n = 15) and (C) nurses (n=13). Respondents could give multiple answers to the question.

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