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Exploring health-related experiences of children and young people with congenital heart disease

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Abstract

Objective To determine the health-related experiences of children with congenital heart disease.

Design Qualitative, semi-structured interviews.

Participants A purposive sample ($N = 35$) of children and young people, aged between 8 and 19 years, with a variety of congenital heart conditions recruited from one treatment care centre in the north of England.

Results The main themes identified included: physical limitations of their condition; restrictions; attitudes of others; choices about information; coping with life and privacy.

Conclusions This study suggests that while many of this sample of children said that they coped well with their condition some children did experience significant impact on their quality of life in several domains. Children and young people identified a need for improved strategies to help them communicate about their condition with peers, schoolteachers and health-care professionals to allow a better understanding of what they are able to achieve.

Introduction

In the last 20 years there have been huge improvements in the survival of children with congenital cardiac disease, especially those with more complex conditions. While initial medical interest focused on mortality and progressed to functional capacity, there is now increasing interest in and awareness of the need to address the psychosocial issues that may affect these children as they develop.

Previous work in this area has provided equivocal results. Many studies have predominately measured physiological parameters, such as symptom report or treadmill performance and have, not surprisingly, shown a wide variation between the functional ability of those with very minor anatomical anomalies and those with complex problems.[1] Some studies have concentrated on health-related quality of life deficits in these children and have reported few problems.[1–3] Other studies have reported an increased risk of negative psychosocial outcomes, including low self-esteem, increased anxiety and depression, as well as poor social and behavioural adjustment in comparison to reference groups of children without chronic conditions.[4–6]

Much of the work undertaken in this area concentrates on young adult populations who have survived complex surgery.[7,8] Cyanosed patients with complex disease indicate worse quality of life than those with non-cyanotic less complex cardiac conditions, particularly in older children, but the age groups examined vary from study to study.[6] Very few studies have directly accessed the views of children with congenital heart disease, and those that have concentrate on adolescents.[9–11]

Research indicates that children who have other chronic conditions are at increased risk for psychosocial adjustment problems when compared with their peers.[12] Much of this research has been framed within theories of stress and coping, which emphasize the importance of understanding individuals' own appraisals of potentially stressful situations, such as a chronic condition, the resources and support available to them and the coping strategies they use to deal with a situation.[12,13] The study reported here explored the experiences of children with a variety of congenital heart conditions, in particular focusing on their views on the effects of their condition on their everyday lives and any strategies they used to deal with having a cardiac condition.

The range of conditions and their effects, subsumed under the umbrella term of congenital heart disease is large and varied, but the children are often considered as one population with similar needs and limitations, especially by the wider public with little knowledge of the range of conditions. While children with particularly complex heart conditions may take medicines and have apparent symptoms, in common with most other children with a chronic condition, the majority may only experience symptoms or even think of their condition infrequently.

Previous work has, to some extent, provided information about topics that may be raised by the children. Research with children with a variety of chronic illnesses or disabilities has highlighted the importance of effects on school life and relationships with peers.[14,15] Research also shows that although parents and other family members are mentioned more often and help in more tangible ways, friends are identified as a particularly important source of emotional support and companionship.[15] School and peers are often overlooked when considering the experiences of young people with cardiac conditions and previous work has suggested that, for many children, these factors may be more important than the severity of the symptom load in determining overall wellbeing.[16]

The aim of the study was to describe the health-related experiences of children with congenital heart disease in a group of children between the ages of 8 and 18 years. While a small number of studies have looked at younger adults we are unaware of a similar study in younger children. The perspective of younger people may well differ from young adults and provide insights for clinicians to achieve a better understanding of these children's day-to-day lives and improve their communication with the children and the support they offer.

Methods and sample

Participants

All children attending both peripheral and outpatient clinics of the Yorkshire Heart Centre were invited to take part in interviews subject to the following exclusions, those: with a normal heart or innocent murmur; younger than 8 years of age; neurological problems which made communication difficult; within 2 months post-surgery; or unable to speak English.

Sampling was subject to continuous monitoring to ensure a group of children with a variety of different conditions from excellent to poor prognostic outcomes were interviewed. After the first 20 interviews further children were sampled by identifying individuals with specific conditions (from case notes). These families were then approached via a letter from the hospital. This ensured adequate representation in each of the treatment categories recommended by the expert steering committee (see Table 1). The use of treatment categories was adopted as the variety of congenital heart conditions is extremely broad and children often have complex pathogies that are difficult to describe. The use of the

Table 1 Range of participants over treatment sampling categories

Category	Number of children interviewed
No treatment but followed up	12
Treated, no future intervention anticipated	6
Treated, future treatment anticipated	12
Palliated	5

categories provided a useful tool to ensure that a range of children and young people with different prognostic outcomes were sampled. Sampling was purposive and subject to continuous monitoring. The first children recruited from outpatients, on the whole, had less complex conditions. The case notes approach was used to ensure the representation of children with more complex lesions. Recruitment continued until a group of children covering the required age range and treatment categories was obtained and until data saturation was achieved. The sampling was guided by the direction of an expert clinical steering committee with patient-proxy representation.

Forty-four responses were received from children in outpatients giving a response rate of 19%. The response from families mailed from the hospital was 31%. Thirty-seven children were interviewed; one interview was not transcribed as the child's learning disability and speech made it difficult to determine what was being described, one interview was lost due to equipment failure. Therefore, 35 interviews were available for analysis.

Table 1 shows the numbers of children who fell into the four treatment categories. Patients were categorized by a consultant cardiologist from case note review. The treatment groups included children with several co-existing conditions, such as 22Q11 deletion, Noonan's syndrome, epilepsy and mild to moderate learning disability. The ages of participants ranged between 9 and 19 years with a mean age of 12.

While formal data on socio-economic background and family size and structure were not collected from the children and young people, they came from a range of backgrounds. Both rural and urban areas were represented and social circumstances varied from affluent areas to areas of high deprivation. Different family structures and sizes were also represented and three of the children were from ethnic minority families.

Procedures

Ethical approval for the study was obtained from Northern and Yorkshire Multi-centre Research Ethics Committee and the Leeds Hospital Local Research Ethics Committee.

Invitations to take part and information packs, which included information sheets for parents and children and response forms to be returned to the research team if children were interested in taking part, were given out in clinics or mailed to families via the hospital. All packs had an accompanying letter signed by all the consultants, which stated that they were aware of the study and supportive of its aims, and a letter from the research team inviting children to take part. Recruitment literature was divided into age bands for 8–11 year olds, 12–16 year olds and 16 and over as well as parents. Families needed to speak and read English to participate in this study as funding was not available for translation of recruitment materials or interpreters.

For children under 16 years response forms were signed by both child and parent. All children who returned the response form were contacted by the interviewer and, if they agreed to take part, to arrange an interview time in their own home. The interviewer went through the project information again and obtained written consent at the visit. For children under 16 years, parental consent was also obtained.

A qualitative interview approach was adopted as it was felt that this would be the most appropriate way to explore children's experiences, allowing them time to build a relationship of trust with the interviewer and avoided the need for writing, which some children and young people may experience difficulty with. This approach also allowed the interviewer to probe children's responses and follow-up additional topics raised by children as they arose.

One member of the research team conducted the interviews, which took place in the children's homes. The interviewer had received training in conducting research with children and was an experienced paediatric nurse and researcher. Interviews were conducted in a similar way to those in adult populations but adapted to the age of the child with attention to the phrasing of questions, comfort of the child and allowing the child to control recording equipment if they wished. Interviews also included a significant amount of pre-interview time to allow the child to ask questions and develop a relationship with the interviewer. If possible the children were interviewed in a room where the child and the interviewer were alone. This was to allow them freedom to express views they may not feel able to in the presence of their parent or carer. In two cases children asked to have someone to accompany them. In a third case, the child's mother was unhappy about the child being interviewed alone and wished to stay.

The interviews were structured around a topic guide. The sequencing of topics within the interview was adapted to allow the child to dictate the structure of the interview. Open-ended questions covered the following topics.

- Knowledge of condition.
- Relationships with their family.
- School.
- Relationships with peers.
- Health.
- Limitations imposed by their condition.
- Body image issues.
- The future
- Below are examples of the questions from some of the topics.
- Can you tell me what you know about your heart condition?
- How do you get on with your Mum and Dad?
- How do you find school?
- What do you like to do with your friends?
- What sort of things do you do to keep healthy?
- Does your heart condition stop you doing anything you want to do?
- Do you think your heart condition makes you look different from other people?
- Do you think about how your heart condition will affect you in the future?

The list of topics was generated from a variety of sources, initial topics were generated from previous research in the area of congenital heart disease and from previous studies of children with chronic conditions. This was presented to the expert panel and further topics were added to supplement any areas they felt were lacking. Any further topics raised by the children themselves were added to the topic list for subsequent interviews. Interview length was dependent on the child but ranged between 20 and 90 min. All interviews were audio-recorded and transcribed.

Data analysis

The data were analysed using the framework approach.[17] The stages of this process include: familiarization with the data; identifying the thematic framework from both *a priori* areas of the topic guide as well as emergent issues from the transcripts; indexing the framework against transcripts and charting the data systematically. The final stage is to interpret the data by tracing patterns and associations to identify the overarching themes. The charting of the data allows the researcher to see data relating to each interviewee within themes at both the individual level as well as within the context of the sampled population. Two members of the research team read all interview transcripts and devised the thematic framework. The data were then coded by one researcher, with a sample checked by the second researcher. Data collection continued until data saturation was achieved. A report of the analysis was written for the participants and they were invited to comment on anything they felt was important, as were the steering committee.

Results

The main themes from the interviews covered are: children's experiences of the physical effects of their condition; the impact of these effects in restricting their activities, and on body image; the importance of other people's attitudes; feeling different; privacy; their own and others' understanding of the condition and ways of coping with the impact of the condition.

Physical effects

Participants described a range of physical effects of their condition and these effects had considerable impact on children's lives. Physical sequelae included breathlessness, tiredness, chest and leg pain, dizziness and fainting and changes in colour and scarring. Breathlessness and tiredness on exertion were the most frequently mentioned physical symptoms and were a particular problem for the children who had received palliative procedures or were waiting for surgery.

Most reported that these symptoms were associated with running; a few reported them as a result of walking short distances and using stairs. The children who had palliated conditions reported being breathless for as long as they could remember.

> 'Ever since I can remember I've been getting tired easily. Even if its just a little thing like walking upstairs, walking to my next class, even just tidying my bedroom can tire me out (ID30)'.

Tiredness and breathlessness were consistently linked together in these interviews and respondents would use the same terms interchangeably within a sentence. Many of the respondents mentioned lack of stamina in relation to physical activity.

> 'I used to do it (cross-country running) but I used to be alright at it but I got too tired and I really struggled with my breathing so I stopped it (ID22)'.

Reports of pain were common in the interviews, with leg and chest pain being most frequently reported. Headaches were usually described in the context of side-effects from medication. Children who described chest pain felt that this pain was associated with their heart but found it difficult to describe this mechanism in detail.

> 'It was definitely my heart but what was wrong with it I don't know … it was a sort of pain and I don't, it, it, was real, and I got hot and sweaty…. Recently I've had pains straight across my chest … I was thinking, don't happen again (ID3)'.

A quarter of the respondents had experienced dizziness or fainting attacks. One child described the fear associated with the unpredictability and uncontrollability associated with these fainting attacks. Most associated this symptom with specific activities or conditions. The majority of children who reported dizziness had disorders of rhythm or a pacemaker or were waiting for insertion of one.

There were also effects on children's appearance. At least half of the sample had a scar of some kind, but many of the children seemed to view it very much as part of themselves that other people could either accept or not. Only three respondents talked about 'going blue' (cyanosis) despite the fact that several had severe, complex heart conditions. One respondent noted that her cyanosis very rarely occurred since her recent surgery. Others described exacerbation of cyanosis in cold weather.

Impact on activities

Several subthemes comprised this area namely those of school Physical Education (PE), not being able to keep up with peers and do the same things as peers, limitations imposed by others, general school activity and careers.

The area of PE at school was problematic for the majority of the children. Every child attending secondary school mentioned distance running as a problem and swimming was also often problematic due to becoming cold. Several older respondents reported having taken part in stamina activities but had stopped them due to excessive tiredness later in the day.

Exclusion from running was usually talked about as a positive thing, but some children joined in and just ran as far as they could rather than be excluded completely. Where a sport was not mentioned specifically, the general term of contact sports was used to describe activities from which they were excluded. A few respondents mentioned being completely excluded from PE lessons. The majority of these were very cyanosed, but one child reported not being permitted to join in due to teacher anxiety. Some children described being at a point in their condition where they were near to a surgical procedure and were anxious to avoid much physical exertion in case it exacerbated symptoms. The majority of children did take part in PE but reported having to sit out when they got tired or taking things at their own pace. One child felt that joining her school sports teams would hold the team back so did not feel there was any place for her.

> 'I might not be able to keep up, there's no point going if I'm going to make the team lose (ID2)'.

For the younger children, being able to keep up with peers was very much related to play. Most reported having to ask friends to wait for them or slow down, although others reported being able to do as much as, and occasionally more than, their peers. Many had developed strategies with their friends to maximize their inclusion.

> 'All the other children can run around the playground but I could only run half way. If we're playing football I'm usually the goalkeeper because I can't run up and down (ID27)'.

For older children their condition restricted mixing with peers in other ways, such as not being able to keep up when friends went to town, in club activities, such as Cub Scouts which involved competitive play, and in school discos.

> 'I used to go to cubs but I stopped … sometimes the activities had loads of running and I hated it when that happened because you're like "my team will win" and they say "why didn't you keep up why did you stop" you know (ID8)'?

Other activities, in which they would like to join their peers, included judo, karate and basketball. In one case a child never went out to play either at home or at school, but had a friend to stay inside with her at break times. However, this was the exception and all other children appeared to find ways to interact with their peers either by picking activities that they could manage or by friends adapting their activity to include them.

Some of the older children talked about other issues that meant that they could not do some of the things that their peers did. All respondents who were 16 years and over drank alcohol with peers when they were able to but talked about drinking in moderation. One young person who was taking Warfarin (which interacts with alcohol) discussed the implications for her clotting but felt able to balance this with alcohol intake. Many of the sample, unlike friends, had not spent time sleeping over at friends' houses, although most reported being able to play at their friends' houses.

> 'I was quite annoyed 'cause I was usually having fun with them … the first time it was because I was really dizzy and the other two times I just felt really sick (ID17)'.

Two children reported always having a family member to accompany them wherever they went. They felt that this seriously affected their peer relationships and their ability to go on trips with school.

Fair ground rides were a topic that was mentioned by over half of the respondents as being something they had to avoid. The children mentioned fast rides and roller coasters in particular; however, it was not always clear whether avoiding such rides was a medical contraindication or a limitation imposed by parents. One child, however, conceptualized the risk in a different way and did not feel the limitations were applied to their type of heart disease.

> 'I'm 12 and I'm at (theme park) and it says, "people with heart conditions" but I suppose I'm thinking of people that are prone to go into shock and have a heart attack, I don't really think of it in terms of me (ID19)'.

The second quite specific restriction was that of piercing and tattoos. Many children said they would like to have piercings or a tattoo but that they could not. One child believed that piercing carried a 50% risk of dying.

Several respondents mentioned limitations imposed by other people. This usually involved teachers, but occasionally parents were mentioned. Most of these limitations were related to physical activity and sport. Commonly, the children were told not to push themselves too hard and two of the children talked about teachers who stopped them in physical tasks before they were ready to stop, or prevented them from participating at all.

> 'Teachers just won't let me do it (ID7)'.

Missing school as a result of their condition was also a problem for a significant number. Tiredness was experienced at school and some had to come home from school early every day to minimize their fatigue.

Respondents mentioned surgery coinciding with major academic assessments, missing course work for General Certificate in Secondary Education (GCSEs) and having to catch up on missed work generally.

> 'I have been missing quite a bit but Mum's been in to say "could you not give me all the work that I have to catch up on cause we do loads of work. And I fall behind quite easy anyway at school (ID34)'.

About a quarter of the respondents mentioned that they needed time off from school for attending outpatient appointments. This was particularly problematic if they had to attend the often distant tertiary centre rather than a local peripheral clinic.

All interviewees were asked about careers. Several children talked about career paths that they knew would not be open to them because of their heart condition. The police and the fire service were mentioned, as was professional rugby. Many had not thought about a career but when asked the majority of children did not think their heart condition would interfere with future career choices all though some children did feel that their future career choice would be limited.

> 'Normal healthy people who are my age … they've got a wide range of jobs they could be able to do. I've only got a limited … there's something with computers, something I can do that's not too energetic (ID34)'.

Impact on body image

While almost half the sample had scars from surgery, these were rarely viewed as a problem. The fact that other people noticed the scar and remarked on it was the most commonly reported problem. Most of the girls said that it did not stop them wearing the same clothes as their peers, with the exception of one of the older respondents who talked about some tops 'framing' her scar, which she thought looked odd. Two of the older boys said they did not like to take their shirts off on hot days but said that this was not because of scarring, and they did go swimming. Make up for scars were mentioned by two of the girls. One had been unable to match her skin colour as she was cyanosed and the other was anxious about forthcoming surgery and the scar it would leave.

Attitudes of others

This theme was composed of several subthemes, which were all important to the children in this sample. The subthemes were: importance of supportive friends; bullying, teasing and name-calling; and the problem of too much attention.

Almost all of the respondents stressed the importance of having friends who understood their condition. They talked about numerous ways in which their friends adapted to meet their needs or had supported them, especially taking time to stop and stay with them when they became breathless or tired on exertion, this applied for both genders and across the age groups. Friendships tended to be same sex friendships and very few of the respondents talked about having boyfriends or girlfriends. A couple of the older girls mentioned that they did not want boys to know about their condition as boys 'didn't understand that kind of thing' and it would put them off. Supportive friends were viewed as trustworthy but many of the children did not want people outside close friendships to know about their condition. Two children specifically mentioned finding it difficult to interact with peers and obviously felt they were missing out on friendships. One attributed this to using a wheelchair but did mention that she attended a youth club specifically for disabled children where she felt she had better friends, while another felt that having so much time off school and so much attention made potential friends jealous.

Bullying, teasing and name-calling were mentioned by seven of the sample. This ranged from minor teasing to very hurtful comments and one child mentioned having been subjected to violence, and all attributed this to their appearance as a result of their condition.

> 'I get picked on yeah, I get picked on at school, not by many people just a few people in my class … I don't really want to repeat the words, the things they say (ID30)'.

Many of the younger children were concerned about starting secondary school where they thought bullying would be more prevalent. Several of the children talked about being picked on because other children knew they would not be able to fight back either due to an implantable device or physical weakness. The children who did mention being bullied felt that teachers did little to stop teasing and name-calling.

Several children talked about being given too much attention and how irritating they found this. Fuss was a word that was mentioned frequently. Concerns about getting too much attention ranged from simply feeling that a parent made too much of minor ailments, always interpreting them as symptoms, to overmonitoring by teachers and friends. People making a fuss drew attention to differences, something which three quarters of the sample talked about.

> 'It's a bit annoying cause like it means that you're like, all these friends around you and like caring for you … all the attention's on you and sometimes you don't want it on you (ID34)'.

Feeling different

A few of the sample said that they felt there were no differences between themselves and other children. Most of the children felt they were not treated differently from their siblings but did regard themselves as different from peers. There was a range of responses from fairly positive to very negative, particularly with respect to feeling different from peers. In terms of siblings, most children identified differences, such as bedtimes or being allowed to stay out late, but felt that these differences were not related to their heart. Two respondents had younger siblings with heart problems that were more complex than their own and felt that this made them more fortunate than their sibling. One of the sample described feeling very resentful towards a younger sibling who had no problems, as well as feeling like an outcast in terms of peer relationships. This child had a condition that imposed the most physical limitations.

> 'I mean why can a sister be running in and out with all this energy and then, and then me, having to sit down all the time 'cause I'm getting too tired…. It just makes me feel like everything is unfair. …I don't feel like anyone else. Feel really different. Like I'm an outcast (ID30)'.

Interactions with peers also revealed a wide variety of experiences. Some reported that people were generally interested in their condition and once they had some information treated them no differently. Others had different experiences, describing themselves as 'disabled' and identifying with peers with disabilities. One used the disability of another as a benchmark for making himself feel less different, saying he was not as different as a child in his class who used a wheelchair. A lot of feelings about being different centred on not being able to keep up in physical activities.

> 'cause like they're all really healthy and things and I feel like they can do like running and they're all really fit and, but I can't do as much running in PE, like I was like left out just sat on the side watching. And you really want to join in with something, you can't (ID9)'.

Even those who said they were coping well with their condition and limitations would often acknowledge feeling different and pick out examples of how they felt different and the ways in which others either helped them or exaggerated differences.

> 'Just, today I was cold and I went to this lad who I knew, but he didn't know, he didn't know what was wrong with me, and he said, "how come your lips have gone all blue"? So I told him, and he was like, he didn't know what to say (ID13)'.

Privacy

A small number of the children raised the issue of privacy. One girl wanted to know why all the doctors were men and the second, who was slightly younger, said that she was unhappy about having to take her top off to have her echocardiogram. Another area was personal privacy at home where some of the children who had been very ill or were currently ill felt overprotected and wanted some more time to be with friends alone.

> 'Things like not having any freedom or always being followed and not having any privacy (ID30)'.

Information and understanding of their condition

Clear and accurate information about their condition is a resource that can help children and other people in their lives to understand what they are and are not able to do. Issues raised by participants covered: wanting or not wanting information; difficulties in communication with doctors; who to tell; and the importance of teachers having information and knowledge of symptoms.

The children were asked about what information they had about their condition. Many of them were unsure about what exactly was wrong but many talked instead about waiting for surgery or procedures and concrete examples of things that they were not allowed to do, such as body piercing and tattoos. Other children mentioned advice they had been given about losing weight and increasing their exercise. In several cases, the children stated that they did not want any more information about their condition, this could be for two reasons: either they felt they had enough information or they did not want to hear what information was available.

> 'Sometimes I get scared in case like it's scary answer or something like that. Other times I don't really know how to deal with the situation or something like that. So, my Mum just does it all (ID19)'.

Other children were keen to increase their knowledge. Two older female respondents were interested in genetic counselling.

While a few respondents felt comfortable asking questions about their condition, most did not, particularly in the outpatient setting, and communication with doctors was an area most of the sample found difficult. Most reported that they did not understand much of what was said by their doctor but felt they would appear stupid if they asked for clarification. Their primary point of information was usually a parent. Many of the children talked about doctors using 'posh' or 'long' words. In addition, many of the children felt that the doctors were speaking to their parents and not always including them.

> 'cause he kept speaking to my Mum and Dad, when he were like telling them all the details of what might happen … and I don't think he was speaking to me (ID2)'.

One of the young people interviewed was 19 years of age, which made her considerably older than the rest of the sample who were 16 years or below. Some of her comments on a recent consultation demonstrate the differences between her and the rest of the sample in the relationship between cardiologist and young person. She had recently been seen in outpatients and had gone alone, she described how she felt her relationship with the cardiologist had changed with emphasis on communication with her.

> 'I actually went and I decided that I wanted to ask questions. 'Cause I'm getting to the age now when I'm thinking more about not how it affects me, … more about passing it onto my children, and risks of pregnancy and all that sort of thing. And I went there wanting to ask him those sorts of questions …. But as I sat down he actually started talking about it himself … But if Mum and Dad were there I'd have felt silly asking about children … also I think he was, it's probably easier for him I would think, to say all that to me without my parents being sat there, 'cause I am still their baby (ID10)'.

A subtheme around information concerned whom to tell about their condition. Several children mentioned that they preferred people to know and felt that it should make no difference to their relationships. Of these children many of them had surgery as an infant and most had had no problems since then. This, however, was not the view of all of the children and in a third of the sample respondents talked about not wanting people to know and the difficulty of how to tell people. The issue of trust was very important, as some respondents only felt comfortable telling certain people. It would seem that fear of rejection was a big motivator in whom to tell and when. Some of the adolescent girls were anxious that boys should not know about their heart because they would laugh at them or not want to go out with them. The boys did not seem to have the same anxieties, although few of the boys talked about relationships with girls.

About a third of the children had experienced problems at school because teachers did not have correct information about their condition or did not understand what specific needs some children had. One cyanosed child was told to take off her lipstick by a teacher and another who was on diuretics was told to stop asking to go to the toilet between breaks.

> 'you've always suppose to go to toilet when you come in, at start of school, playtime, and then go after playtime, then go at dinner, and you can't go through lessons and I, I've got to go sometimes through lessons … I just ask my help, helper if I can go but teacher said that, from now on we're not having anyone getting out of a chair to go to the toilet and we're not having, er, ask asking for toilet in middle of lessons (ID27)'.

The majority of complaints about teachers were about PE teachers who either pushed children to do physical tasks they felt unable to do or accused them of putting on symptoms.

> 'Well they've got like this athletics pitch and this teacher he were, he were nasty as well. He said, "if you don't run round there you'll do an hour's detention". So I didn't go round, 'cause I couldn't have run round I'd have fainted. So, that's when he said to me, "oh come back at dinnertime" I didn't go back at dinnertime and I come home and told me Mum (ID33)'.

Some children described how teachers could make life easier for them if they understood what difficulties they might have. Generally speaking children found teachers at primary school more accommodating than at secondary school where they felt that some teachers made little effort to find out about their condition. One child was being educated at home because he and his parents were so unhappy with the way the school system dealt with him.

Coping

Children talked about a number of ways they dealt with having a cardiac condition. 'I don't think about it' was probably the most frequent response when the sample was asked about their heart. To some extent this was dependent on their current condition. Children who were waiting for an intervention and those who were extremely unwell tended to be more aware of their heart. In the case of children with co-existing conditions, the other condition was usually their primary concern. Some children seemed to be genuinely surprised about being asked about their experiences, some clearly made a conscious effort not to think about their condition.

Many children displayed a very positive or pragmatic attitude. This included statements that described 'getting through life OK' and acceptance of realities such as medication. A few children described using humour to down play feelings of difference or described themselves as 'special' or 'not boring and normal'.

> 'it's never really bothered me 'cause, it's kind of being like a bit different. Like it's boring being normal so just like little edge you've got of being different (ID7)'.

A small number of children talked about knowing their limitations and being able to judge what was far enough for them. A sense of biding time until the condition was corrected and being able to have a 'normal' life was also described.

> 'I know my time will come when I can have like fun and things (ID7)'.

Using knowledge of their symptoms was another way of coping described by approximately a quarter of the interviewees. They would use their previous experience of their symptoms remitting as a way of coping, reassuring themselves that the new symptom would pass.

> 'you kind of, sit down you know that you've got to like take deep breaths and just settle down a bit and just calm down, then it'll go away and it'll make you happier and things 'cause you get angry with yourself for like, 'cause you know that, you've kind of done it in a way because you've done the exercise and you've done the things, so you just kind of, think, "well I've done it so I'll have to make it go away". So you just kind of calm down (ID22)'.

Other observations

While many of the children had experiences in common, some of the children described quite individual experiences: some quite specific to certain conditions and some to the degree of limitation they experienced. Waiting for a diagnosis was described as 'scary', and the same child felt life would be finished if the diagnosis they feared was ultimately confirmed. Two children expressed anxiety about dying, one in the context of surgery and another as a result of their condition.

Another area that some of the children seemed to have problems with was that of cognitive function. Two of the children talked about feeling 'slowed down' both mentally and physically and some of the sample found it difficult to concentrate at school. One child mentioned that she found it difficult to remember things, both at home and at school.

One child who had a reveal device which is an internal device which monitors heart rhythm over a period of several months to a year was currently experiencing great distress over her potential diagnosis and showed none of the adaptation or coping which took place to some extent or another in all other participants. It would seem important to investigate this further as this is a growing group of children who may be in need of help to adapt to and cope with the uncertainty of their future.

> 'it can get scary.... It gets you down ... if it's bad, like I have got it or something then yeah, that's it, you know finished (ID34)'.

Discussion

Children and young people were able to describe several areas of their life which they felt could be improved upon. Despite this the majority appear to have developed successful strategies for coping with any problems that their cardiac condition caused, particularly where the condition had been corrected early in life. However, one or two children mentioned significant psychological problems including poor self-image, isolation and a fear of the future.

The main impacts of their cardiac condition were in restricting their activities, so that they could not do things that peers could do. As a result, some children felt different from their peers and were treated differently by teachers and peers. These main areas of concern were similar to those found in research with older samples of young people with cardiac conditions,[10,11] and research with children with other chronic conditions has shown that conditions that involve physical restrictions and pain are often associated with restricted social activities.[18] These findings are in line with the social model of disability which changes the focus away from people's impairments and towards removing the barriers that disabled people face in every day life. The fact that so many of the children developed strategies for dealing with barriers demonstrates their own expertise in their lives. This expertise is often undermined not only by clinicians, but also by their parents, peers and teachers.

In dealing with these impacts, peers and teachers could act as important sources of support or, on the other hand, their actions and attitudes could be sources of stress. Restrictions on activity do not necessarily lead to decreased social interaction with peers[18] and in this study children highlighted the supportive role of friends. However, some children appeared to have a limited knowledge of their cardiac condition and of what they could or could not do, replicating previous findings in an older group.[19] As in other studies of children with chronic conditions (e.g. Ref.[20]), children found communication with doctors difficult, felt talked over rather than involved in medical consultations and relied on their parents to digest and convey information. This important finding stresses the need for clearer and more effective provision of information from clinicians. We are not able to determine from this study if their parents had a better knowledge of their child's cardiac condition, but other research indicates that parents also have concerns about not knowing what the child can and cannot do.[21] Lack of knowledge may have made it difficult for children to explain their cardiac condition to others, yet key people, such as teachers and close friends, understanding the condition was clearly important. As research with children with other health conditions has found,[15] a lack of understanding by teachers impacts on children's wellbeing at school and could also lead to some children feeling that they were not believed about the impact of their cardiac condition. Children spoke about the dilemmas of whom to tell about the condition and concerns about negative reactions and lack of understanding. These have also been identified in research with adolescents and young adults with cardiac conditions.[10]

Building a better liaison between school and the clinical setting may be helpful for these children. In addition, it is important that there are systems within schools for ensuring that accurate information about children's health needs and the impact of these on school life is passed to all those who teach a child.[22]

Children also talked about the impact of missing school because of treatment, outpatient appointments, or being unable to attend full-time because of fatigue. Research with children with other chronic conditions has also shown that where children have prolonged periods of absence from school they have concerns about keeping up with work and maintaining relationships with peers.[23] Work with children with cancer has suggested that school reintegration and social skills programmes may lead to improvements in children's understanding and in psychosocial outcomes.[24,25]

Medical events, such as acute episodes in hospital, medicines and visits to outpatients were little discussed by the respondents. An exception was the small number who had reveal devices or pacemakers who did express some negative feelings about devices. This group of children may have specific difficulties and would warrant further research. Medication was dismissed as a fact of life by those children who took it and it was only if it had an impact on school life that it became a problem.

There are clearly areas which were not raised by the children which both parents, clinicians and other professionals will feel are important, such as the effects of their cardiac condition on employment, sexuality, relationships, contraception and pregnancy. While these issues should be a crucial part of the care and education of these young people, it would seem that they are issues, which are not raised independently by children until they are older. If these areas are to be discussed earlier then clinicians will need to address this in a more proactive way.

Limitations of the study

While children from ethnic minority families were included in this study, the lack of information sheets in other languages is a clear limitation of this study and means that the research may have excluded some children who were able speak English but had parents who prefer to receive information in other languages.

Children below the age of 8 years were excluded from this study as the funding constraints meant that interviews had to be completed within a short space of time. The authors acknowledge that the views of this group of children are often missed because of the increased time and resources required to elicit their views. It is also important to stress that the views of the children of 8 years and over may well differ significantly from younger children and will require further investigation.

Conclusions

The main issues identified in this study centre around the impact of the physical effects of cardiac conditions on everyday life in school and with peers and the strategies the participants employed to deal with these. Children state that they are often unnecessarily restricted or pushed by people who do not recognize the child's own expertise in coping with the every day impact of their condition. The current emphasis in adult care on patients as experts would seem to eminently translate to children as well and is an important finding in relation to practice in health care and education settings.

Children would also be more equipped to act as experts if communication between themselves and health professionals were improved to allow them to access accurate information about their condition and support in explaining this to peers and teachers.

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