

This is a repository copy of *The views of young people with congenital cardiac disease on designing the services for their treatment*.

White Rose Research Online URL for this paper:

<https://eprints.whiterose.ac.uk/1744/>

Article:

Kendall, L., Sloper, P., Lewin, R. et al. (1 more author) (2003) The views of young people with congenital cardiac disease on designing the services for their treatment. *Cardiology in the Young*. pp. 11-19. ISSN 1047-9511

<https://doi.org/10.1017/S1047951103000040>

Reuse

Items deposited in White Rose Research Online are protected by copyright, with all rights reserved unless indicated otherwise. They may be downloaded and/or printed for private study, or other acts as permitted by national copyright laws. The publisher or other rights holders may allow further reproduction and re-use of the full text version. This is indicated by the licence information on the White Rose Research Online record for the item.

Takedown

If you consider content in White Rose Research Online to be in breach of UK law, please notify us by emailing eprints@whiterose.ac.uk including the URL of the record and the reason for the withdrawal request.

Original Article

The views of young people with congenital cardiac disease on designing the services for their treatment

Lynne Kendall,^{1,2} Patricia Sloper,³ Robert J. P. Lewin,² Jonathan M. Parsons¹

¹Paediatric Cardiac Department, Yorkshire Heart Centre, Leeds General Infirmary, Leeds; ²Department of Health Sciences, Research Section, Seebom Rowntree Building; ³Social Policy Research Unit, University of York, Heslington, York, UK

Abstract *Background and purpose:* There is little documented evidence of young people with congenital cardiac disease being consulted as to what help, if any, they really need in relation to their condition. Most research concentrates on the medical aspects of the condition. There are studies of psychological and social functioning, but few have directly sought the opinions of the young people. More recent research has indicated a need for health professionals to develop services to meet both psychosocial and physical needs of young people with congenital cardiac disease. The findings of the recent Kennedy Report support this need. The purpose of this study was to explore the views of young people with a range of congenital cardiac conditions, on what would help them better deal with their condition, and when and how help might be provided. *Methods:* This was a qualitative study using semi-structured interviews. We interviewed 16 young people in their own home. Interviews were tape-recorded and transcribed. Analysis was conducted using the “Framework” method. *Results:* Whilst most of the young people interviewed actively manage their condition, they think more support from others would be beneficial. Issues of activity and communication were cited most often as areas requiring more understanding from people they interact with, for example teachers and peers. The discussion focuses on how health professionals might change or develop their practice to help young people better cope with their condition. *Conclusions:* Most of the young people interviewed in this study had developed their own strategies for coping with their condition. Although this is a small study, the young people provided important suggestions as to how health professionals could better develop current services.

Keywords: Congenital heart disease; adolescents; young adults; rehabilitation; physical activity

PREVIOUS RESEARCH INTO CONGENITAL CARDIAC disease has largely concentrated on the haemodynamic effects of medication, surgery, or other invasive procedures. Studies have mainly used physiological measurements, such as treadmill testing or bicycle ergometry, along with various psychological tests and rating scales. For example, a study by Bowyer and colleagues¹ looked at 20 children aged between 6 and 14 years, who had previously undergone surgery

for transposed great arteries. Each child performed a graded treadmill test, and parents completed a questionnaire about the ability of their child to exercise. One of the findings was that the parents were pleased with the result of the surgery, even when that fell short of “normality”. The parents did not, unless specifically asked, draw attention to any moderate limitation in exercise. Other studies^{2,3} have used similar methods to assess health related quality of life and exercise capacity in patients with congenital cardiac conditions. There have also been a number of studies of psychological and social functioning, which have produced mixed results. Some suggested an increased risk of poor psychosocial outcome.^{4–6} Problems identified include low self-esteem, high levels of anxiety and depression, and poor social and behavioural

Correspondence to: Mrs L. Kendall, Research Physiotherapist, Ward 10 Yorkshire Heart Centre, Jubilee Wing, Leeds General Infirmary, Leeds, LS1 3EX, UK. Tel: 0113 392 7310; Fax: 0113 392 8474; E-mail: lynne.kendall@leedsth.nhs.uk

The project was funded by the NHS Executive Northern & Yorkshire Regional Research Capacity Committee.

Accepted for publication 23 September 2002

adjustment. Other studies⁷⁻⁹ reported more positive psychosocial outcomes. In addition, several studies have reported the positive effects of programmes of cardiac rehabilitation for these children.¹⁰⁻¹³ The studies were mainly small scale, uncontrolled trials measuring the effects of supervised exercise programmes on exercise capacity. More recent reviews concluded that a number showed worthwhile change in work capacity, self-esteem and psychological status, but recruitment and retention of patients is a major problem.^{14,15} Much of the research into congenital cardiac disease is very medical in its approach, and also relies heavily on the parental perspective of the child's condition. A study by Lightfoot et al.¹⁶ investigated the views of pupils, parents, and teachers regarding the service support needs of pupils with a chronic physical condition in mainstream schools, including some children with congenital cardiac disease. One recommendation was that "all health professionals need to take a holistic approach to caring for children, including consulting them about their own needs, since their views are not necessarily the same as adult proxies".¹⁶ Few studies, with some exceptions,^{17,18} have directly sought the views of young people with congenital cardiac disease. The findings of studies that have consulted young people suggest that they had needs for rehabilitation that were not met. A recent survey of all centres for paediatric cardiology in the United Kingdom confirmed that healthcare staff agree that rehabilitation is required, but all but one centre reported a lack of such provision.¹⁹ Two of the most commonly reported barriers to providing a service were resources, and the distance that patients would have to travel for a hospital-based service. A solution to these problems is the use of home-based, self-help, rehabilitation programmes facilitated by phone from the hospital, developed for adults following myocardial infarction. The purpose of this study, therefore, was to explore the views of young people with congenital cardiac disease as to the best methods for meeting their rehabilitative and psychosocial needs. A parallel study investigating the views of the parents is reported separately.²⁰

Materials and methods

Ethical approval for the study was obtained from the Local Research Ethics Committee.

Sample

A purposive sample was drawn from a regional paediatric cardiac centre database taking into account age, from 8 to 18 years, a broad range of congenital cardiac conditions, urban and rural dwellers, ethnicity, and social class. Purposive sampling was chosen

rather than random sampling in order to represent as wide a range of variables as possible within the limitations of the planned small sample size. Families residing outside the catchment area, such as those from overseas, were excluded from the study, as were those young people with a severe neurological condition or learning difficulties that would prevent them from taking part in an interview. The parents of such children, however, could take part in the parallel study of parental views, which also included parents of younger children from the age of five years.²⁰

Recruitment packs were sent by post to families inviting them to participate in the study. The packs contained an introductory letter signed by the researcher and the patient's cardiologist, separate parent and patient information sheets explaining the purpose of the research and the commitment required from the family, a participation sheet, and a stamped addressed envelope. Once families expressed an interest in taking part in the study, the researcher contacted them by telephone to answer any queries and then, if they agreed, arranged a convenient date for interview. A total of 44 packs were sent out over a period of three-months, and 29 families responded, of which 25 agreed to take part in the study and four declined. There was no response from 15 families. Of the 25 families who agreed to take part, eight were not interviewed, one young person changed his mind on the day of the interview, one had been discharged to the adult cardiology service, a convenient interview date could not be found for two, and four could not be contacted again by telephone or letter within the timescale of the interviews. Thus, 17 families took part in the study and a total of 33 interviews were completed, 16 with young people aged from 8 to 17 years, and 17 with parents of young people aged from 5 to 17 years.

Interviews with young people

Previous experience, and that of other researchers,²¹ suggests that interviews are appropriate for young people of eight years and over. Semi-structured interviews were carried out with 16 young people, nine being male, with a broad range of congenital cardiac conditions. The same researcher carried out all interviews. Table 1 shows demographic and clinical details of the interviewees.

The interviewee was given the choice as to when and where the interviews would take place, and whether the interview was tape-recorded or not. All interviews were tape-recorded and transcribed. The interviewee was also given the choice whether or not they wished anyone else to be present during the interview, for example, a parent. If they did want someone present, they decided whether that person

Table 1. Details of participants.

Sex	Age at interview	Congenital cardiac condition	Age at (most recent) surgery
F	8	Supramitral ring	5 years
M	9	Aortic stenosis	No surgery
F	9	Congenitally corrected transposition	No surgery
F	9	Atrial septal defect	4 years
F	10	Ebstein's malformation	8 years
M	10	Atrial septal defect	10 years
M	11	Totally anomalous pulmonary venous connection	3 years
M	11	Tetralogy of Fallot	1 year*
M	13	Aortic stenosis	13 years
M	13	Coarctation of aorta. Aortic stenosis	2 days
M	14	Tetralogy of Fallot	1 year
M	15	Transposition of the great arteries	1.5 years
F	15	Tetralogy with pulmonary atresia	5 years
F	15	Atrial septal defect. Pacemaker insertion	15 years
M	17	Coarctation of aorta. Aortic stenosis	16 years*
F	17	Atrioventricular septal defect	2 years

* On waiting list for further surgery

- 17 families took part in the full study, 2 of the families each had 2 young people with a congenital cardiac condition (19 young people aged 5–17 years).
- Young people aged 8–17 years were interviewed (n = 16).
- At the time of the interview, 8 young people were at primary school, 7 at secondary school, and 1 had suspended a college place pending surgery.

could speak during the interview, one 10-year-old chose to have his mother present. All interviews were conducted in the young person's home. The topics covered in the interviews were whether their cardiac condition affected their life; their attitude to physical activities in relation to the cardiac condition; "what, when and how" any help or support from others could be given. In addition, three potential scenarios for meeting rehabilitation and psychosocial needs were presented, illustrated by practical examples (Table 2). These were:

- Home based, time limited, telephone facilitated, self help interventions for the parents of younger children and a self directed programme for adolescents.
- Outreach rehabilitation provided locally by a clinical workers from the paediatric centre, in suitable community resources, for example a general practitioner's surgery or a sports centre.
- A key-worker, case management approach.

The appropriateness and acceptability of each scenario was elicited.

The topic guide was used to provide a loose framework for the interview, but allowed the interviewee to introduce new ideas not thought of by the researcher. Open-ended questions were used to explore perceived needs, and prompts and probes were used when necessary to fully explore issues raised. The participants were given the opportunity to draw or write during the interview if they wished. Booklets and pictures were used to help illustrate and explain the rehabilitation scenarios. This method has been shown to be a useful tool in helping children focus their discussion, by giving context to an abstract idea.^{22,23} Participants were fully informed as to the purpose of the research, confidentiality and what happened to their data. Consent to take part was rechecked before the interview and permission to use the data checked again at the end.

Analysis

Transcripts were analysed using the "framework method".²⁴ Initially, familiarisation with data is gained through reading transcripts. A thematic framework is then identified. Data are then coded into categories and entered by category onto a series of charts, so that reading across the chart provides information about a particular respondent, whilst reading down the chart enables comparison across all respondents. The charts are used to identify over-arching themes by tracing any associations and patterns in the data. To ensure rigour of analysis, the interview transcripts were examined for relevant themes by a second independent researcher experienced in qualitative data analysis. The two researchers then compared and discussed their results and total consensus on the final themes and coding framework was achieved.

Results

At the time of the interviews, eight children attended primary school, seven secondary school, and one had given up his place at college due to his cardiac condition whilst awaiting surgery. Of the young people interviewed in this study, seven had no memory of surgery or other intervention for their cardiac condition, two had never had surgery, three had some recollection, and four had surgery within the previous two years. Only one patient said they had activities restricted by their cardiologist. As a group, these young people mostly had a good level of physical and social functioning, as reported by themselves.

Four key themes relevant to this research were identified from the interviews, these were:

1. What helps young people now.

Table 2. Hypothetical Rehabilitation Scenarios presented to young people for discussion.

Cardiac rehabilitation has been shown to help adults with heart problems. It has three main parts:

- *Information* – learning more about your problem and how to deal with it. Learn how to look after your heart and about medical treatments and pills.
- *Exercise* – an exercise plan to get you stronger so that you have less symptoms when you are running or playing. This can help people to live a more normal life. It may protect them from other problems.
- *Other help* – to deal with any stress or worries like bullying or problems with friendships. To help the person feel OK about themselves.

DO YOU THINK THAT IT WOULD BE GOOD TO HAVE SOMETHING LIKE THIS YOURSELF?

WE HAVE THOUGHT OF 3 WAYS TO DO IT

- A. *At home*: by working through a plan using workbooks, probably with tapes and videos. Younger children would do it with their parents help. There would be a section to complete each week. Older children would work through it themselves. For both there would be phone support from a worker at the cardiac centre. She would ring you up for a chat now and again for a couple of months to see how you were getting on. The book would have information, a simple exercise plan and advice on common problems.
- B. *Locally*: a team from the nearest cardiac centre would visit a local hospital or sport centre one day a week. You would come once a week for 2–3 months. You would be there for a couple of hours each time with a group of other people your age and have a talk. Then there would be some exercise and then maybe talk about ways of coping with common problems. Some centres would charge for using their services.
- C. *Through a key worker*: Each family would have a “key worker” who would try to find out what help you need. They would arrange help locally. For example, they might find out about local exercise facilities you could go to. If you were having problems at school they could try and find a local worker who could help, or they might speak to the school for you if you wanted them too.

✓ *What do you think of each of these ideas?*

✓ *Can you think of a better way?*

✓ *What would you not like to use?*

2. Ideas on what would help.
3. Information for the young person/self.
4. Information for others such as school/family/friends.

Their views on the rehabilitation scenarios were recorded on a separate chart.

What helps now

Young people were asked what helped them deal with their condition. In some cases, they talked about how they coped when younger, as they were symptom free and clinically well at the time of the interview.

The support and “understanding” of friends and teachers was cited most often as being helpful to young people in dealing with their cardiac condition. They appreciated teachers making concessions to them taking part in activities, for example, trusting them to know their limitations as to which activities they could do, and allowing them to stop and rest when tired. Similarly, support from friends was valued, for example, on missing taking part in school sports days, one 11-year-old said he didn’t feel too bad, because “my friend always used to come back and we’d have a little chat and watch games”.

Not being treated differently and “being left alone” was also important to some young people. One boy complained about the attitude of his cub pack leaders,

“They’re like overprotective at cubs, they say ‘Just stop if you need to’, like all the other stuff I’ve heard and they kept coming over to me – ‘Are you alright?’ It just got on my nerves”.

Male aged 11

The boy was much happier when he moved to the scout group, as there he was not treated any differently to the other children. Three others appreciated that their mum had not stopped them from doing things or treated them differently to siblings or peers.

Information: a 17-year-old girl reported that a visit from the liaison nurse was very helpful because she appreciated the chance to “chat about lifestyle issues” and compared it to the visit to the cardiologist, which seemed “all medical and serious and things”. A 17-year-old male reported that a group visit to the hospital before his operation had helped him cope better post-operatively.

The overarching theme identified in “what helps now”, is the importance of other people “understanding” the condition, and being aware of the impact it has on the young person’s life.

What would help

When asking the young people “what could be done to help?” in relation to their condition, the researcher used the technique of asking “If you knew someone

Table 3. Young people's suggestions for improved communications with health professionals.

Suggestions	Number of comments
Health professionals need to talk to young people and explain more specifically what they can or cannot do, either when they are in hospital or at an out-patient visit	8
Give written plus verbal information before discharge from hospital	4
Teachers should be given more information about a young person's condition and what they are capable of doing	4
Use computers to disseminate information by e-mail, websites and/or CD-Rom	4
It might help others to see/meet someone who had "done well"	4
Follow up post-operatively by a home visit from a health professional	2
More people to man telephone information/help lines would be useful	1
Put information leaflets and posters on display in general practitioner surgeries and out-patient clinics	1
Health professionals should build confidence and identify goals with young people to help them achieve more function	1
Employment and career issues needed to be addressed more	1

of your age with these problems, what do you think might help?" to help them formulate their ideas. Their ideas of how help could be provided were based on two main areas, communication issues and activity issues.

Communication

Young people thought that improved communication between health professionals and patients and also giving others information about the condition "so they understand" was very important. Their suggestions as to how this may be done are listed in Table 3.

As one 15-year-old boy explained:

"Let your friends know more about the condition and let them understand it, so they can support you in different ways".

A 15-year-old girl described her problems when applying for work experience in an office and their reluctance to take her:

"... they called the week before, they were quite worried about me, and about hospital, and if I collapsed what they should do. Mum said just treat her as normal. I said if they don't treat me normally, then I'm going to say something, because I'm a normal person and there's nothing wrong with me".

She thought that the problems arose due to a lack of understanding on the part of employers. Her suggestions of what could help included:

"When each business sets up a new workplace, they should be given a variety of leaflets of different medical issues ... so they are more aware ... I think it's not just people that are directly involved with people with heart defects, I think more information needs to be available to the wider public".

Activity issues

Of the respondents, nine thought it was important that young people with a congenital cardiac condition were encouraged to participate in activities, for example socially and at school.

"I suppose it's not a nice thing to have your child not as healthy as everyone else, but if you know that they can get on with it, then I think they (parents) should let them, like let them lead a normal life, because they are not going to have much of a good childhood if they get kept indoors all the time".

Male aged 14

"Make sure they want to do it, if they don't then they don't. Build confidence so they know a bit more about what they are doing and they can realise that 'I can participate in this'."

Male aged 15

Of the others, three thought children needed to be encouraged to play and be active "from a young age", teaching them what they are allowed to do and when to stop. Five also said giving more detailed information about activity levels would be helpful; two suggested this could be done in the young person's home, as "they would feel more secure". One 9-year-old girl pointed out that, if a child did not take part in any activities when young, they were unlikely to do anything when older. Three thought meeting or talking to other young people with congenital cardiac disease might be useful.

Information for the young person/self

"Information" was frequently cited during the interviews as being important. The views of the young people varied as to their own need for information about their condition. Three said they knew enough about their condition at the time of interview, three others wanted more in depth information and four thought they would want more details when they were older. Only three older respondents aged 14, 15 and 17 years, reported ever asking any questions of the cardiologist at their clinic visits, the rest left communication to the parents. A 17-year-old girl, who had undergone surgery as a baby, had never wanted any details about her condition, "I'll bear it if someone wants me to but

I'm not that bothered". The same girl had childhood memories of her mother talking to others about her condition,

"I can also remember being a bit ratty whenever my mum mentioned it – not to me because she never mentioned it to me – but talking about it to people, because I was like 'it's not a big deal, stop it' – I hated that, I hated her talking"

How information could be given

Only one 15-year-old girl regularly asked her cardiologist questions during her outpatient appointment. All the other young people relied on their parents, usually mum, to give them any information. Of the respondents, seven stated that the cardiologist, or "the person who knows about the condition", would be the best from whom to get information. A 15-year-old thought any written information should be accompanied by verbal explanations:

"It could be a doctor, or a liaison nurse type of person, or a nurse or a kind of translator. Someone who understands all the technical, medical terms but can put it into things that are easier to understand".

Two older boys thought information should be "staged", starting at a young age and continuing as the young person grew up. They suggested starting, changing and leaving school and choosing careers as important milestones, at which information should be given.

There are marked differences in *what* this group of young people wanted to know, and *when*. Each individual had his or her own style of coping. This included seeking information at one extreme, to not wanting information at the other, with a range of attitudes in between. Overall, the young people were mainly interested in information about what they could or could not do and the impact of the condition on their lifestyle, rather than medical or technical details.

Information for others

School

All said they thought their teachers knew about their condition, usually because parents had informed the school. Some thought this was necessary and were confident to speak to teachers about their condition, usually when asking if they could adapt the activities the teacher was supervising. Others were ambivalent as to whether the teachers knew or not. Two gave examples of their unpleasant experiences when having to go to school wearing a portable cardiac monitor.

One 14-year-old remembers:

"I had to have a 24 hour tape on, it was Year Three so I would be about seven or eight years old, and my teacher

watched over me the whole day just to make sure I was okay, so I felt a bit like there was something wrong with me then".

A 9-year-old girl was embarrassed during a physical education lesson when a teacher either "forgot" or "maybe doesn't know about me". She explained:

"Once I had a heart monitor and I went to school and we were doing physical education and this teacher said to me 'Take your bag off, you can't do PE wearing your bag'."

Two 9 year olds however, said it caused them problems when teachers "forgot" about their condition, and pushed them to do too much physically, in neither case did the child feel able to remind the teacher.

Friends/peer group

Similarly, young people's views differed as to whether friends and peers should know about their condition. Some wanted friends to know so that they "understood more". One girl said she "got told off by all the team" because she needed to rest during football games.

"I've got something very special that's wrong with my heart and they don't understand that sometimes I'm out of breath and I need a rest, and they don't get it and they think I'm lying, so they say 'Well hurry up...'"

Female aged 9

Two reported that because they "look okay" peers sometimes cannot accept that there is anything wrong, or they "forget".

"They (friends) don't forget as soon as the teachers, but they do forget. They do know, but I wish they would remember all the time, instead of me having to tell them."

Male aged 9

All the young people said their close friends knew about their condition, but mostly on a "need to know" basis. Two older boys strongly felt it was a private matter and not a concern for anyone else. Two younger girls did not want "it all around the school" for fear of being bullied, something which they had experienced at previous schools, due to their condition.

The recurring theme was that it was up to the individual to decide *who* to inform about their condition and in how much detail. Young people wanted other key people to "understand" their condition but did not necessarily want peers to know all about it.

Rehabilitation scenarios

The researchers wanted to explore the views of the young people about the services available for rehabilitation. Since this was a difficult concept for young people to understand, three hypothetical scenarios were used. The interviewer used booklets, pictures, and verbal explanation to describe each scenario. Table 2

shows the three scenarios used. A fourth scenario, using the Internet/website as a means of communication, was added from interview 8, when it emerged as a suggestion from the previous interviews. The young people's views are summarised below.

Home based option: Eleven respondents liked the idea of having "information" to use at home. A variety of formats appealed, including audiotapes, booklets and videos ideally featuring young people with a cardiac condition explaining their experiences, as well as more "medical" information. The format depended upon age and the preferences of the individual. Although only three thought they would use written information on its own, most preferred diagrams or pictures combined with videos, tapes or verbal explanation. Two thought a home visit post-operatively, by a health professional, would help the young person regain "normal" activity levels. One would not want any information for herself, but thought it may be useful for parents; another would not want anything which made him feel different, or that "there was something wrong", with people "watching him all the time".

Group option: Eight thought there might be benefits from meeting other young people with a cardiac condition, for example to increase confidence to do sports as "others might need to rest as well"; and to meet other families and talk to people with the same condition. Four would not want to meet as a group, three because they did not like the idea of meeting "strangers", and one because it would make her feel different. One ten year old suggested that she could talk to others, awaiting surgery for example, as she felt she could offer reassurance, having undergone two operations herself.

The "key worker": Only three of the older respondents would use the option of a "key worker" or contact person, two of them would prefer to know the person offering them help. One other ten year old, suggested that someone could talk to them on the telephone, but not visit them at home.

Website option: Six young people thought using a special website was a good idea. Suggestions included: using the website to find out more about their condition; include information from young people's experiences of congenital cardiac disease as well as the "medical" information; have separate sites for parents; siblings and friends could use the site to help them understand more. A 15 year old summarised her view:

"You do need to ask questions to find things out. Because doctors understand it, they might think automatically that you do as well, so people do need to ask questions so they do understand it, and I think the website would be a very good idea, because then, if there was a lot of information readily available, then they could just check up on it any time they

wanted, and they could do it without maybe feeling intimidated by all the doctors and professional people around".

One 14-year-old pointed out a possible disadvantage in using personal experiences posted on a website, he thought some young people may think their condition was more severe, if they were unable to do the same things that others described. He also noted, that it would be important to ensure others did not use a "chat room", for example "to have a laugh at us".

Strengths and limitations of the study

In a qualitative study, using semi-structured interviews, it is important to avoid bias in either the sampling or analysis. The sample in this study included young people from different socio-economic backgrounds, with different levels of educational ability. Young people were recruited from different hospitals across the region. There was a spread of ages, and a broad range of conditions and severity of condition.

As a strategy to ensure rigour in the analysis, a second experienced qualitative researcher examined the transcripts, to ensure the themes identified were a true reflection of the data.²⁵ Credibility to the findings of the study was enhanced by comparison with similar results from research into other groups of young people with a chronic illness or disability.²⁶⁻²⁸

A key limitation to this project was the small sample size. Although "saturation" was achieved in the interviews, with no new themes were being generated by the end of the period of interviews, it does mean there is little opportunity to look at different variables such as age, gender, culture or condition. Only one young person was recruited from a minority ethnic group. He also used English as his first language, but his parents did not. The study did not, therefore, explore the needs of young people from the minority ethnic groups, or those who do not use English as their first language. Another limitation was that the majority of the young people interviewed had good physical functioning, so the study did not tap the views of those young people more severely affected. It may be that the needs of these groups are different to those reported here. Further research using a wider range of participants from different groups would establish whether or not differences do exist.

Despite the limitations we feel that these data, combined with the parallel study of parent's data²⁰ carry important messages for health professionals.

Discussion

Support for young people

What helped young people to cope with their condition was how well others, such as parents, friends and

teachers, “supported” them. This meant that others “understood” how the condition affected their life and made allowances. This was important to the young people because it helped them integrate with their peers. Such support is often “informal” from friends and family, but may also be needed from teachers and health professionals. Other researchers have also found this in their work with chronically ill or disabled young people.^{17,26,29}

It is important therefore that health professionals give detailed information on what young people *can* do, so that teachers for example may adapt activities to include, rather than exclude, the young person.²⁶

What information young people need

This research showed a wide variation in how much young people wanted to know, and when they wanted to know. Health professionals cannot assume that having a cardiac condition necessarily means the young person wants to know everything about the condition and its management; as research with other chronic childhood illness has shown.^{29,30} What most young people did want to know about, was exactly how the condition would impact on their daily life, that is, the lifestyle issues that they face as a consequence of having congenital cardiac disease.

The research shows that young people mainly rely on their parents for information regarding their condition, especially the younger children. The findings of the recent Kennedy Report²⁸ indicate that parents themselves do not always feel fully informed about their child’s condition, something found in our interviews with parents.²⁰ One of the key recommendations of the Kennedy report was that patients should be involved, where possible, in decisions about their treatment and care. Other researchers agree that this approach to identifying patients’ needs is necessary.^{29,31}

The implications for health professionals

The research suggests that health professionals need to consider a more holistic view of the young person’s life. When giving “information”, it is important that health professionals discuss with the young person and their parents what their individual needs and requirements are, taking account of the wider issues, in addition to the “medical” details.

Conclusions

Although it was not possible to identify a single method of providing rehabilitation services the young people did identify key issues:

- *Information.* This should be available in a variety of age-appropriate formats, it needs to address

the lifestyle issues including specific information regarding physical activity, as well as the medical aspects of the condition. Health professionals should ensure that information is updated and offered at regular intervals to young people and their parents, taking a more proactive approach.

- *Support.* This could be from health professionals to provide individual explanations and give specific advice, and also from other young people with a congenital cardiac condition and their families. Such help need not always require face-to-face contact, other methods for example telephone, e-mail, websites, may be appropriate and indeed preferable to some young people.

Health professionals need to take account of a wide range of issues when considering rehabilitation for young people with congenital cardiac disease. An individual, non-prescriptive approach should be used, to identify needs and, in consultation with the young person and their parents, plan appropriate methods of intervention. Consideration of psychosocial issues should be given equally with medical issues.

Acknowledgements

Our especial thanks go to the young people, and their parents, who took part in this study. We also thank Suzanne Mukherjee, research student in the Department of Health Sciences at the University of York, for reading the interview transcripts and agreeing the themes. The study was funded by the NHS Executive Northern & Yorkshire Regional Research Capacity Committee. This part of the project was undertaken as part of a Masters by Research at Leeds Metropolitan University, for which, a grant was received from the Chartered Society of Physiotherapy, Charitable Trust Fund.

References

1. Bowyer JJ, Busst CM, Till JA, Lincoln C, Shinebourne EA. Exercise ability after Mustard’s operation. *Arch Dis Child* 1990; 65: 865–870.
2. Meijboom F, Szatmari A, Deckers JW, et al. Cardiac status and health related quality of life in the long term after surgical repair of tetralogy of fallot in infancy and childhood. *J Thorac Cardiovasc Surg* 1995; 110: 883–891.
3. Fredriksen P, Chen A, Veldtman G, Hechter S, Therrien J, Webb G. Exercise capacity in adult patients with congenitally corrected transposition of the great arteries. *Heart* 2001; 85: 191–195.
4. Kramer HH, Awiszus D, Sterzel U, van Halteren A, Classen R. Development of personality and intelligence in children with congenital heart disease. *J Child Psychol Psychiatry* 1989; 30: 299–308.
5. Utens EMJW, Verhulst FC, Meijboom FJ, et al. Behavioural and emotional problems in children and adolescents with congenital heart disease. *Psychol Med* 1993; 23: 415–424.
6. Casey FA, Sykes DH, Craig BG, Power R. Behavioural adjustment of children with surgically palliated complex congenital heart disease. *J Pediatr Psychol* 1996; 21: 335–352.

7. Linde LM, Rasof B, Dunn OJ. Attitudinal factors in congenital heart disease. *Pediatrics* 1966; 38: 92–101.
8. Wright M, Jarvis S, Wannamaker E. Congenital heart disease: Functional abilities in young adults. *Archives Phys Med Rehabil* 1985; 66: 289–293.
9. Utens EM, Bieman HJ, Verhulst FC, Meijboom FJ, Erdman RA, Hess J. Psychopathology in young adults with congenital heart disease. Follow-up results. *Eur Heart J* 1998; 19: 647–651.
10. Goldberg B, Fripp RR, Lister G, Loke J, Nicholas JA, Tainer NS. Effect of physical training on exercise performance of children following surgical repair of congenital heart disease. *Pediatrics* 1981; 68: 691–699.
11. Longmuir PE, Turner JA, Rowe RD, Olley PM. Post-operative exercise rehabilitation benefits children with congenital heart disease. *Clin Invest Med* 1985; 8: 232–238.
12. Galioto FM, Tomassoni TL. Exercise rehabilitation in congenital heart disease. *Progress in Pediatr Cardiol* 1993; 2: 50–54.
13. Calzolari A, Pastore E, Biondi G. Cardiac rehabilitation in children. Interdisciplinary approach. *Minerva Pediatr* 1997; 49: 559–565.
14. Tomassoni TL. Role of exercise in the management of cardiovascular disease in children and youth. *Med Sci Sports Exerc* 1996; 28: 406–413.
15. Fredriksen P, Kahrs N, Blaasvaer S, et al. Effect of physical training in children and adolescents with congenital heart disease. *Cardiol Young* 2000; 10: 107–114.
16. Lightfoot J, Wright S, Sloper P. Service support for children with a chronic illness or physical disability attending mainstream schools. Social Policy Research Unit, University of York, 1998.
17. Tong EM, Sparacino PSA, Messias DKH, Foote D, Chesla CA, Gillis CL. Growing up with congenital heart disease: the dilemmas of adolescents and young adults. *Cardiol Young* 1998; 8: 303–309.
18. Kendall L, Lewin RJP, Parsons JM, Veldtman GR, Quirk J, Hardman GF. Factors associated with self-perceived state of health in adolescents with congenital cardiac disease attending paediatric cardiologic clinics. *Cardiol Young* 2001; 11: 431–438.
19. Lewin RJP, Kendall L, Sloper P. Provision of services for rehabilitation of children and adolescents with congenital cardiac disease: a survey of centres for paediatric cardiology in the United Kingdom. *Cardiol Young* 2002; 12: 412–414.
20. Kendall L, Sloper P, Lewin RJP, Parsons JM. The views of parents concerning the planning of services for rehabilitation of families of children with congenital cardiac disease. *Cardiol Young* 2003; 13: 20–27.
21. Hill M, Laybourn A, Borland M. Engaging with primary aged children about their emotions and well-being. Methodological considerations. *Children and Society* 1996; 10: 129–144.
22. Finch J. The vignette technique in survey research. *Sociology* 1987; 21: 105–114.
23. Hazel N. Elicitation techniques with young people. *Social Research Update* 1996; Issue 12, University of Surrey.
24. Ritchie J, Spencer L. Qualitative data analysis for applied policy research. In: Bryman A, Burgess RG (eds). *Analysing Qualitative Data*. Routledge, London, 1994, pp 173–194.
25. Mays N, Pope C. Rigour and qualitative research. *BMJ* 1995; 311: 109–112.
26. Lightfoot J, Wright S, Sloper P. Supporting pupils in mainstream school with an illness or disability: young people's views. *Child Care Health Devel* 1999; 25: 267–283.
27. Beresford B, Sloper T. Information needs of disabled young people. Social Policy Research Unit, University of York, 2000.
28. Kennedy I. The Report of the Public Inquiry into children's heart surgery at the Bristol Royal Infirmary 1984–1995. 2001.
29. Beresford B, Sloper T. The information needs of chronically ill or physically disabled children and adolescents. Social Policy Research Unit, University of York, 1999.
30. Phipps S, Srivastava DK. Repressive adaptation in children with cancer: it may be better not to know. *J Pediatr* 1997; 130: 257–265.
31. Frederickson LG. Exploring information-exchange in consultation: the patients' view of performance and outcomes. *Patient Education and Counselling* 1995; 25: 237–246.