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Original Article

The views of parents concerning the planning of services for rehabilitation of families of children with congenital cardiac disease

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:* Although much previous research has focused on the medical aspects of congenital cardiac disease, there is a growing body of research which suggests that families may need help and support with the wider issues associated with the medical condition. We have previously ascertained from young people with congenital cardiac disease their views on this subject. The purpose of this study was to obtain the views of their parents about the need for, and shape of, services for rehabilitation. *Methods:* This was a qualitative study using semi-structured interviews. We interviewed 17 parents in their own home. Interviews were tape-recorded and transcribed. *Results:* Parents would welcome more help and support from health professionals to enable them to manage more effectively the condition with their children. Particular areas of concern relate to the information they receive about the condition; communication between themselves and health professionals; establishing safe levels of activity; and managing the condition at school. *Conclusions:* This is a small study of the experiences and views of parents, which provides some important information on ways in which health professionals could address the current lack of services for rehabilitation.

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

OVER THE LAST DECADE, THERE HAS BEEN AN increasing interest in the psychosocial issues affecting children with congenital cardiac disease. Studies have been conducted of the emotional and intellectual functioning of patients^{1–5} and physical aspects of the children's quality of life. These findings have led to calls for the provision of exercise-based programmes of rehabilitation.^{6,7} Few studies have directly sought the views of young people with congenital cardiac disease or their parents. Studies with parents^{8,9} show that they experience raised levels of psychological distress, and less adequate strategies for coping, in comparison to normative reference groups. Similar findings were noted in

the recent Kennedy report.^{10a} Studies which have consulted young people directly^{11–13} have also suggested that they had needs for rehabilitation that were not met. A recent survey of all centres for paediatric cardiology in the United Kingdom indicated that, whilst the health professionals agreed that rehabilitation was required, only one centre reported having a formal programme serving this purpose.¹⁴ Two of the most commonly reported barriers to providing a service were scarce resources, and the distance that patients would have to travel for a hospital-based service. There has been no research on the form of rehabilitation service that patients and parents would find most useful. Our preliminary work¹⁴ suggests that a traditional hospital-based service may not be the most suitable means of delivering the help required. In adults with ischaemic heart disease following myocardial infarction, a solution to such problems has been developed in the form of home-based, self help, programmes facilitated by telephone from the hospital,

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

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community-based rehabilitation, or “case management”, where a named member of staff is responsible for organising the multidisciplinary input required by the patient. In the accompanying paper, we reported the views of young people with congenital cardiac disease as to the best methods for meeting their rehabilitation and psychosocial needs.¹³ In the parallel study, reported here, we examined the views of their parents on the same topic.

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 in the United Kingdom. The sample aimed to represent the age range from 5 to 18 years, a broad range of “severity” of the cardiac condition, to include both urban and rural dwellers, and a range of ethnicity, and social class. Families residing outside the catchment area, such as those from overseas, were excluded from the study, but these represented a minority of the whole sample. 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, along with separate parent and patient information sheets explaining the purpose of the research and the commitment required from the family. For families with children aged less than eight years, only parents were sent information and asked to take part, as we believed that younger children would find it difficult to talk about provision of services. Once families expressed an interest in taking part in the study, the researcher contacted them by telephone to answer any queries. Then, if they agreed, a convenient date for interview was arranged. Written consent to take part was obtained from both parents and the young people. The details of the recruitment, and of the young people involved, are reported in the accompanying paper.¹³ In brief, a total of 33 interviews were carried out, 17 with parents and 16 with young people. A list of the congenital conditions for the children of the parents interviewed is shown in Table 1. Of the 17 families that took part in the study, two each had two young people with a congenital cardiac condition. Thus, between them, the families had 19 children with congenital disease, and four of the children had associated neurological complications, of which three had learning difficulties. At the time of the interviews, eleven young people were at primary school, seven at secondary school, and one had a college place reserved pending

Table 1. Diagnoses of the children of the interviewees.

| Number of cases | Congenital cardiac condition |
|-----------------|---|
| 1 | Supramitral ring |
| 2 | Aortic stenosis |
| 1 | Congenitally corrected transposition |
| 3 | Atrial septal defect |
| 1 | Ebstein’s malformation |
| 1 | Common arterial trunk |
| 1 | Totally anomalous pulmonary venous connection |
| 2 | Tetralogy of Fallot |
| 1 | Double inlet left ventricle |
| 2 | Coarctation of aorta. Aortic stenosis |
| 1 | Transposition of the great arteries |
| 1 | Tetralogy of Fallot with pulmonary atresia |
| 1 | Atrial septal defect. Pacemaker insertion |
| 1 | Atrioventricular septal defect |

(Number of cases = 19 young people aged from 5 to 17 years)

surgery. Five young people had undergone cardiac surgery or other intervention within the previous two years, whilst two had never had surgery.

One researcher carried out all interviews, which were tape-recorded and later transcribed. Interviews were semi-structured using a topic guide. The topics covered in the interviews were: whether the cardiac condition affected their child’s life; their attitude to their child’s 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 clinical workers from the paediatric centre, in suitable community resources, for example a General Practice surgery or a sports centre.
- A key-worker, case management approach.

The appropriateness and acceptability of each scenario was elicited.

Interview analysis

The “framework method”¹⁵ was used to analyse this data. This is a staged process which involves:

- An initial familiarisation with data through reading the transcripts.
- Identifying the main themes to form a thematic framework.

Table 2. Hypothetical Rehabilitation Scenarios presented to parents 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?*

- The verbatim responses are then coded into categories and entered by category onto a series of charts. The charts are used to identify over-arching themes by tracing any associations and patterns in the data, so that reading across the chart provides information about a particular respondent, whilst reading down the chart enables comparison across all respondents.

To ensure rigour of analysis, a second researcher experienced in qualitative data analysis read the interview transcripts and identified the main themes. The final themes and coding framework were achieved through discussion and consensus between the two researchers.

Results

Five main themes emerged from the interviews. These were:

- Knowledge and information about their offspring's congenital cardiac condition.
- Parents' attitude to the condition.
- Experiences of hospital visits.
- Effects of the condition on everyday life.
- What helps?

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

It was clear from the accounts that, whilst most actively managed the condition with their offspring,

they would welcome more support. Help from others was needed to help them cope with the effects of the condition. Better communication and follow up from health professionals was cited most frequently as being needed.

Knowledge and information

Many of the concerns were related to communication issues between themselves and health professionals. The main issues that they raised were:

- When best to deliver information.
- Giving information to others, including school, friends and family, General Practitioners and local hospitals.
- The content of the information.
- How best to deliver information.

When to give information

All of the parents said that the time of diagnosis or surgery was not the best time for detailed information to be given. These times were too stressful for them to absorb much detail or to be able to discuss the situation and ask pertinent questions. Parents talked about feeling “shell-shocked” and suffering from “information overload” at such times. Parents would welcome the opportunity of a follow-up visit specifically to go through the information again, possibly in the out-patient clinic, when they had had time to adjust to their situation. Parents thought written

information for them to absorb in their own time before such a visit would help them understand their child's condition and help them formulate questions. However, eight parents said they felt unable to ask questions at routine outpatient clinic appointments, the reasons given included lack of time because the clinics were very busy, feeling under pressure during the consultation because the doctor is "very busy", too many people in the room and feeling intimidated by health professionals, particularly doctors. Three others felt it was difficult to ask questions regarding their child's long-term prognosis because the young person was present. Other opportune times for giving and updating information were cited as whenever there was a change in the young person's condition, listed by 11 parents, and on changing school, commented on 10 times. Six parents felt communication should be an ongoing process, irrespective of any changes, "as questions do come up", especially as children grow up.

Information for others

Parents had different views as to who should be given information, but all felt that they were responsible for giving details of the condition to their child and also to the school. It was the parents who gave information to school about their child's condition and any educational implications. They gave advice on what to do in emergencies and on which activities the child may or may not take part in. Most parents felt comfortable with this role whilst the child was at primary school, usually because they could speak directly to the teacher concerned, but felt it was much more difficult to ensure there was adequate communication at secondary school. Some parents reported a lack of communication within schools, often due to the child having several different teachers during the day. Four parents suggested that information for teachers should be available in the staff room. Some parents preferred to use a "need to know" approach, only giving school the details they felt necessary. They feared their child would be "treated differently" if they gave too much information. Others reported similar dilemmas when completing medical forms for school trips or other activities.

"Well alright, you've got to declare it (the medical condition) but it's not a problem for ... to go on a trip, but by the time you've written it all down, people think "oh heck" you know and it sounds like a problem ... It's putting it across to people so they are not frightened, but yet they know that if there is a problem they can deal with it."

Only two parents had asked health professionals to visit school to help them explain their child's condition. In each case it was because the school had not

accepted that the child had a problem and did not inform other staff. One parent explained the teacher's attitude and lack of understanding:

"Because they don't fit into little slots and they're not a normal child as such, I think he (teacher) didn't want to be aware. He just thought he was a normal, healthy child because he looks normal ... He wouldn't acknowledge that it could be quite dangerous".

Parents adopted a similar role as "gatekeepers" in giving information to others, for example family and friends. Most thought it was important for others "to be aware" of the child's condition, but not necessarily know all details. Two parents felt they had inadequate knowledge of the condition to answer questions from other family members, but did not feel able to ask for information from health professionals.

"... they did explain but I was like in a state of shock so it's something that I just didn't take in and then afterwards I just didn't feel comfortable asking."

"... and if you ask something once and you don't quite get it, you don't like to ask again."

Seven parents felt General Practitioners and local hospitals had inadequate information regarding their child's condition, causing the parents to lack confidence in them. The majority of parents, 14 in all, thought it was important that they kept their child informed about their condition, making individual decisions about when and how much detail to give. Most parents, specifically 13, felt that help and guidance from health professionals was necessary to enable them to do this effectively. However, 6 parents reported barriers to asking health professionals for help and advice. They felt staff were too busy, or that their questions were too trivial and they would be considered "a nuisance" or that they were not coping.

Parents were asked how they thought information should be delivered and what the content should be. All parents wanted simple, direct information that gave them full individual details without being "too medical"; some suggested someone other than the cardiologist could give this. Five thought there was a need for "honesty" and openness and that medical staff should not withhold information. Ten others wanted much more specific information regarding activity. There was a clear consensus that information should be specific, individual, and understandable, that it should be kept updated and should be in written form as well as given verbally.

Parental attitude to the condition

All parents talked about the importance of trying to achieve as "normal" a life as possible for their family and not treating their child "differently". Many

coped by trusting their child to know their own limitations regarding physical activity, especially when younger. This became more difficult as the child grew up and went to secondary school where there were greater demands physically. Parents talked about their fears and anxieties in allowing children to take part in activities, and the uncertainty of knowing whether they were doing the right thing or not. Some said they had to be “brave” and “strong willed” to cope. As two parents put it:

“Anyone less confident just wouldn’t have coped. Some families would fall into the trap of overprotecting early on.”

“You need to know what they can and cannot do and have confidence that what you are doing is right.”

Eleven parents voiced concern for the future over issues such as careers and employment, and how the young person would cope as they grew up and became more independent.

It was evident from the interviews that most of this group of parents had enabled their children to lead as “normal” a life as possible but that they experienced stress as a result and would have valued more help in determining what was “normal” and acceptable for their child.

Experiences of hospital visits

Parents reported feeling “safe” whilst their child was in the care of the specialist paediatric cardiac unit; they had confidence that their child was receiving “expert” care. However, nine parents talked about a lack of follow up, especially following discharge from hospital. Twelve parents described problems they had experienced following discharge from the cardiac centre. These were mainly related to feeling “isolated” at home, and anxiety about whether the child was being too active. There were perceived barriers to seeking help and reassurance from health professionals, even though parents had been told they could contact staff. Reasons for not contacting health professionals were, “feeling silly” or “stupid” at having to ask questions – parents knew they had been given information and did not feel they could ring up and ask again; not wanting to “bother” staff who were busy – they felt their questions might be considered “trivial” and they could only ring up for “bigger” problems; parents who had been told whilst in hospital that they had “coped very well” or that the child had a “simple” condition talked about that making it harder for them to seek help later – fearing staff would think they were not coping. Four parents reported their experiences of finding out key information about their child’s condition “by chance” and also spoke of having to “struggle” to get support or special services.

Effects of the cardiac condition on everyday life

All parents reported that it was most often the attitude and interactions of other people that affected their child’s lifestyle. They talked about a general lack of awareness and understanding in others being the root cause of any problems, for example, a tendency to “overprotect” and to unnecessarily restrict activities – teachers and grandparents being cited most often. Some felt that teachers sometimes “forgot” about their child’s condition because there was nothing “to see” or they “looked normal”. Overall, parents wanted to achieve as normal a lifestyle as possible for their child but felt they were sometimes hindered in this by the actions of others.

What would help

Parents were asked what would help them better deal with their child’s condition. All parents wanted better information regarding the condition and its impact on the child’s life, they thought this should be a permanent written record, supported by explanation by health professionals, which could be updated. They wanted to know how the condition would affect aspects of everyday living and did not want “too technical” or “too medical” an explanation. Many, 10 in all, thought specific follow up and guidance regarding activity levels was needed. The majority of parents, namely 15, thought that follow up by health professionals following a hospital admission would be helpful in resolving any queries or problems, this may be via telephone or if necessary, a home visit. Almost all, again 15, parents talked about the need for “family support”, that is all family members, not just the child with the cardiac condition, perhaps benefiting from contact with other families with a congenital cardiac condition. Many parents, 11 on this occasion, cited a need for better communication between the specialist cardiac centre and schools, local hospitals and General Practitioners.

The scenarios for provision of service

The concept of “rehabilitation” was discussed with parents, and three hypothetical scenarios were presented to help them focus their ideas. Table 2 shows the three scenarios used. A fourth scenario, using the Internet/website as a means of communication, was added from interview 8, as it had emerged as a suggestion in several interviews. The parent’s views are summarised below.

- Almost all parents, 16 in all, would like to have information to use at home, either in booklet form and or on videos, but thought this would need to be supported by health professionals. However,

six thought that children would not use “work-books” and that information would be more useful for the parents. Generally the idea of permanent records to refer back to was popular.

- Whilst 13 parents thought there would be benefits for themselves and their child to meet other families with congenital cardiac conditions, few thought it would be achievable. Reasons given included lack of time, other commitments and distance to travel.
- Almost all parents, again 16, thought it was a good idea to have a “contact person” to turn to for help and advice. Some likened this to a local liaison nurse service.
- Use of a website was considered useful by eight of the ten parents who were specifically asked about this. They thought it would appeal to children more as they could ask questions without having face-to-face contact. Others thought it would be a useful alternative to group contact as a means of “sharing” information. However five expressed reservations about this method, these were cost and problems of access to computers, the security of the website, possible problems with inaccurate or misleading information being given, or the information being “too medical or technical”.

Overall, 15 parents thought that a combination of all of the methods would be the better solution, no single scenario meeting all of their requirements. Key issues were identified as being important components, these were: having appropriate information given to each family, being supported by a health professional when necessary, ensuring that families are aware of exactly how the condition will affect their child and enabling them to deal with this. As some parents commented:

“Parents are the key, they need proper information and backup to be able to deal with the situation... it should be given in stages and checked now and again.”

“Parents need reassurance that what they are doing is OK, even with the more simple conditions.”

Strengths and limitations of the study

This study was undertaken within one regional paediatric cardiac centre, and families were recruited from local hospitals where they attended peripheral cardiology clinics, in addition to those families recruited from the main cardiac centre. It is reassuring that researchers from other centres have reported similar concerns and parental opinions.⁸⁻¹⁰ Where this study extends our knowledge is by including the users’ views of the range of services that could be provided. In keeping with qualitative research methods, interviews

in this study did reach “saturation”, that is no new themes were being generated by the end of the interview period. However, a key limitation to this study is the small sample size which means there is little opportunity to look at differences between different groups, such as age, gender, culture or condition. For example, the sample included only one family from a minority ethnic group and four families with children having neurological conditions and/or learning difficulties. The needs of parents from these groups may be different. Also, the great majority of the young people in the families interviewed had a good level of physical functioning. A larger study including a wider range of participants would be of value in establishing whether or not differences do exist. Despite these limitations, we feel that these data, combined with data from the young people,¹³ have significant messages for health professionals. These are discussed below.

Discussion

Parental role in giving information

It was clear that parents took the role of information-giver, both to the child and to others who interact with the child, notably schools. There were problems with this approach if parents were unwilling, or unable, to pass on information.

The interviews with this group of parents show that whilst some are very proactive and confident about contacting health professionals and seeking help and guidance, others are not at all confident in that role. It seems that those parents who are assertive, articulate and able to directly contact health professionals, receive higher levels of support. This has also been noted by other researchers.¹⁶

There are other problems with parents taking responsibility for giving information. This research indicates that parents themselves do not always know enough about their child’s condition, either because they cannot remember or did not understand everything they had been told. This is also a finding of the Kennedy report^{10b} and of other research with chronically ill children.¹⁶ Additionally, other research shows that parents cannot be reliably used as proxy-informants in relation to the child’s own experience of the condition, as adults and children experience situations in different ways, thus their needs and opinions also vary.¹⁷

Another problem experienced by some parents was ensuring schools had appropriate information that they acted upon. Some schools did not “understand” enough about their child’s condition and so did not always heed advice given by parents. Other parents did not feel comfortable liaising with school.

"... parents can get it wrong. I'd rather the hospital contacted the school. I'd rather know what was said too. That would be nice, if I was sort of involved in it but to be honest I don't know what to say to the school."

There is evidence from other research that communication difficulties exist between parents, school staff and health professionals.¹⁶ Those results show that whilst parents are the usual source of information for schools, the teachers have concerns about the accuracy of information and would prefer more contact from health professionals.

Differences between the attitudes of parents and young people to the condition

The interviews with parents highlighted important differences in attitude and coping with the condition to those of the young people themselves. As reported in the young people's interviews,¹³ there was a wide variation in whether or not they wanted information about their condition. Any information they did want was related to lifestyle issues. Young people wanted above all to have a "normal" life. The parental attitude to information and coping with the effects of the condition was quite different. Parents report needing much more information about the condition. Whilst it was also important to parents that their child had as normal a life as possible, this often caused them to suffer more stress and anxiety than their offspring, largely due to uncertainties about what they allowed their children to do. More information, support and follow-up regarding activity levels was cited as being one possible method of improving this.

Implications for health professionals

The findings of this research suggest that parents of young people with congenital cardiac disease need better directed help and support from a wide range of health professionals including cardiologists, liaison nurses, psychologists, physiotherapists, occupational therapists, dieticians and social workers. There may also be resource implications for health service managers. The main areas of concern are:

- The quantity, timing and content of information given.
- School liaison.
- Guidance on activity.

Information

Our research with young people¹³ and that of others,¹⁶ shows that health professionals cannot predict a patient's information needs which should be ascertained on an individual basis. Parents would like

individual information about their child's condition which is updated at regular intervals, such as when there is a significant change in condition and/or lifestyle, for example starting or changing school. They would like a written record and a specific consultation time offered to discuss the condition and ask questions. Health professionals need to be aware that parents reported that the acute healthcare situation was generally not the optimum time for in-depth discussions, and some parents reported finding it difficult to ask questions. Thus, a flexible approach will be needed to ensure parents needs are met. Some of these needs may be addressed by the liaison nurse service, however, whilst such services are well developed in some local areas, nationally the service is in its infancy.²¹ The time and expertise that families will require to receive information will have resource implications for health service managers in terms of both time and specialist manpower.

School liaison

This research shows that school, particularly secondary school, poses a problem for both parents and teachers in managing individual children with a congenital cardiac condition. Some parents wanted health professionals to be more proactive in giving information to schools. It is known from research with schools¹⁶ that teachers also want more specific advice on exactly what individual young people can and cannot do. Empowering the parents to better deal with their child's condition may help but the development of specialist resources such as liaison nurses, physiotherapy, psychology, to address the problems may also be required and could be linked with the activity issues below.

Guidance on activity

Activity issues in general were raised by parents as being a problem. Parents want more specific and individualised information regarding safe activity levels. Vague instructions such as "nothing too strenuous" are difficult to interpret. Health care professionals in the future will have to provide more specific information based on individual needs. Specific resources to guide families and also teachers about individual children's activity may help.

Summary of implications for health professionals

Currently there are no effective services fully to meet all the above requirements. The development of such specialist services, and/or the allocation of out-patient clinic time to provide them, will have resource implications for health service managers.

Health professionals need to be aware of the differences between the parental attitude to the condition, and strategies adopted for coping, and those of the young people themselves. They need to use an individual approach to providing services. Given the parental responsibilities as providers of information to others, and their role as caregiver, it is important that health professionals develop a three-way partnership, with parents and their children, empowering and informing where they are in doubt.

Conclusions

Parents wish to see health professionals adopt a more holistic approach to providing services. Although they take responsibility for managing their child's condition, they often feel less than adequately informed or supported in this task. They believe that there is a need for family based support on an ongoing basis. They would welcome a partnership between child, parent and health professional, using a wide range of approaches. Some, but not all, would welcome the use of the Internet as part of this process. Parents also realise that the ultimate goal is to give the young person the knowledge and confidence to do this him or herself as they grow into adolescence and adulthood.^{18,19} It seems clear that, from the parental viewpoint, services should include both physical and psychosocial rehabilitation, which should be based on a systematic and individual assessment of the needs of the whole family. As noted by other authors,²⁰ this is likely to require the input of a multidisciplinary team with particular expertise in congenital cardiac disease and rehabilitation. At present, these services do not exist in the United Kingdom.¹⁴ Additional resources, and further research, are required to develop and evaluate such a service.

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