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Original Article

Living with congenital or acquired cardiac disease in childhood: maternal perceptions of the impact on the child and family

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Abstract *Aims:* Firstly to assess maternal perceptions of the impact of congenital or acquired cardiac disease on the child, parents, and siblings, and secondly to determine whether there were differences between different diagnostic groups, or between those with and without other health problems, with a view to informing the development of a cardiac liaison nursing service for children. *Methods:* A postal survey of 447 families of children with congenital or acquired cardiac disease. *Results:* Completed questionnaires were received from 209 (46.8 percent) families. The cardiac lesion was perceived to have a negative impact on many areas of family life for about one fifth of the sample, particularly in those families where the child was perceived to be more ill. Family relationships, however, were affected in a very different way, with 43 percent reporting that family members had become closer, and only 8 percent that they had been "pulled apart" by the condition of their child. There were a number of differences in the perceived impact of the cardiac malformation on school and family life between children with different diagnoses, with this being particularly evident for families of the patients who had undergone transplantation. When the sample was divided according to the presence or absence of other problems with health, however, many of these differences between the diagnostic groups disappeared. *Conclusions:* Irrespective of the severity of the disease, the presence of a cardiac malformation has an impact on everyday life for a significant number of children and families, particularly if associated with other problems with health. Implications for targeting resources to reduce morbidity in these children and families are discussed.

Keywords: Psycho-social factors; siblings; perceptions

Improvements in the medical and surgical treatment of congenital cardiac disease have resulted in the majority of congenital cardiac malformations being amenable to some form of surgical intervention, with an ever-increasing duration of survival. As a result, there is now a significant population of children and adolescents living with congenital cardiac disease, and having to cope with the impact that it has on their own lives, and those of their families.

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Caring for a child with a chronic illness has been identified as one of the most stressful experiences for any family,[1] and it has been suggested that families of children with congenital cardiac malformations experience more difficulties and stress than those with other congenital problems.[2] Parents of children with cardiac lesions have reported higher levels of stress than parents of children with other chronic illnesses, or parents of healthy infants,[3,4] with mothers reporting more stress than fathers.[5] Furthermore, the number of additional or unusual demands for the giving of care is highly correlated with the amount of stress.[6] Maternal adjustment has been found to be associated with high levels of daily stress, and the use of palliative strategies for coping.[7] Studies of congenital heart disease, and other chronic illnesses,

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have consistently found that psychological adjustment is associated with adaptational processes rather than the severity of the disease.[7–10] Studies which have addressed illness-related concerns of parents of children with heart disease have identified a number of themes which are constant across different levels of medical severity, and across a wide range of ages.[11,12]

It has been suggested that overall improvements in the state of patients with congenital heart disease may lead medical professionals to underestimate the level of concern and stress experienced by their families.[12] Parents may find it difficult to communicate anxieties, or ask questions, during busy outpatient visits, and recall and comprehension of new information at stressful times may be less than optimal. Within the last few years, the spotlight has fallen publicly on the services provided for paediatric cardiology in the United Kingdom, and the subsequent publication of the Inquiry into the Bristol Royal Infirmary[13] highlighted a number of shortcomings and difficulties with existing services, including poor involvement of patients, and disjointed delivery of services. The development of cardiac liaison services for children with heart disease was recognised as one of the strategies that should be adopted to improve the existing services. Prior to the publication of these reports, understanding the impact of a cardiac malformation on children and families, and recognising the needs arising from such a diagnosis, had already been identified within our Trust as crucial to establishing an evidence-based cardiac liaison nursing service. A research programme was therefore implemented in 1998 to obtain such information. This paper presents data from the first phase, which was a descriptive, population-based, study that focused on the perceptions of the mothers regarding the impact of the cardiac lesion on the child and family. Results from this first phase were then used to design a specific cardiac liaison nursing intervention, targeting those areas that had been identified by mothers as being of concern.

Methodology and patients

Ethical approval was obtained for the study.

All families whose children had been inpatients on the paediatric cardiology ward at Harefield Hospital between January 1995 and December 1999, and whose children were under the age of 19 years of age, were sent a questionnaire by post, together with a covering letter explaining the study, a consent form to be completed if they agreed to participate, and a stamped addressed envelope for return of the completed questionnaire. We found 478 patients who met the criterions for inclusion, and all families of these patients were sent the questionnaire. In 31 cases, envelopes were returned to us as not known at the postal address, leaving a sample size of 447, 209 of whom (46.8 percent) returned the completed questionnaire. The responders and non-responders did not differ in terms of patient age, gender, diagnosis, or the presence of a syndrome (Table 1).

Table 1. Demographic details of responders and non-responders.

Item	Non-responders (n = 238)	Responders (n = 209)	p
Gender			
Male	117 (49%)	114 (55%)	0.297
Female	121 (51%)	95 (45%)	0.297
Mean decimal age in years, with standard deviation, at survey	8.1 (5.0)	8.4 (5.2)	0.450
Classification of heart disease			0.378
Acyanotic	139 (58%)	132 (63%)	
Cyanotic	52 (22%)	42 (20%)	
Post-transplant	30 (13%)	24 (11%)	
Miscellaneous	17 (7%)	11 (5%)	
Presence of syndrome (% yes)	24 (10%)	25 (12%)	0.547

There were 95 females and 114 males, with a mean age of 8.4 years, the standard deviation being 5.2 years, the median 6.9 years, and the range from 1.3 to 18.9 years. The majority of children had acyanotic or cyanotic lesions, 24 had undergone transplantation, and 11 had miscellaneous cardiac disorders such as rheumatic valvar disease, cardiomyopathy, arrhythmias or Kawasaki disease.

The questionnaire was developed as a result of reviewing the existing literature on the psychological impact of, and needs associated with, chronic illness in general, and congenital heart disease in particular, for children and families. The questions covered a broad spectrum of topics, and were a mixture of 5-point rating scales, questions requiring an answer of either yes or no, and open-ended questions. Areas covered included medical and surgical aspects of the diagnosis and treatment, basic demographic information, information about perceived social support, the impact of the cardiac malformation on activities, family relationships, care issues and education. In addition, the 14-item version of the Functional Status II (R) measure,[14] to assess the state of health of children with chronic physical disorders, was also incorporated in the questionnaire. This measure specifically looks at dysfunction related to illness, rather than dysfunction itself, and instructions to parents asked them to assess whether any problems were fully, partly, or not at all related to the cardiac condition. If parents responded "not at all", the behavioural item was recoded to indicate that there were no problems on that item.

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Table 2. Impact of illness (%s shown in parentheses).

	Acyanotic	Cyanotic	Post-transplant	Miscellaneous	Total
Impact of illness					
Severe impact					
(1)	4 (3)	1 (2)	5 (21)	1 (9)	11 (6)
(2)	5 (4)	1 (2)	1 (4)	0 (0)	7 (4)
(3)	13 (10)	8 (20)	6 (25)	1 (9)	28 (14)
(4)	30 (24)	10 (25)	7 (29)	2 (18)	49 (24)
No impact					
(5)	72 (58)	21 (51)	5 (21)	7 (63)	105 (52)
Different to healthy friends					
Yes	46 (35)	18 (43)	17 (71)	5 (45)	86 (41)
No	85 (65)	24 (57)	7 (29)	6 (55)	122 (59)
Things unable to do					
Yes	21 (16)	13 (31)	11 (48)	3 (27)	48 (23)
No	109 (84)	29 (69)	12 (52)	8 (73)	158 (77)

A copy of the questionnaire is available from the authors on request.

Statistical analysis

Quantitative data were analysed with non-parametric statistics. Differences between groups were analysed by chi-squared tests, Mann–Whitney tests or Kruskall–Wallis analysis of variance. Thematic analysis of qualitative data was undertaken independently by the two researchers and a constant comparative method was used to facilitate the identification of patterns, categories and constructs in the data. Discussion between the researchers facilitated the clarification and description of the coding patterns.

Results

The questionnaire had acceptable reliability, with a Cronbach alpha of .75 for the 17 questions concerning the impact of the cardiac condition.

Parents were asked to describe how ill or well they perceived their child to be on a scale of 1, representing ill, to 5 if the child was well. Almost three-quarters of the sample (71 percent) rated their child as well, with only 5 children (2.4 percent) rated as ill. Of these five children, four had previously undergone heart transplantation. The difference between the diagnostic groups was significant (χ^2 equal to 16.69; p less than .005).

The ratings made by the parents of the impact of the cardiac malformation on the ability of their children to carry out everyday activities are shown in Table 2, together with responses to whether parents thought that their child was different compared with healthy friends, and whether there were things which their child was unable to do as a result of the cardiac problem. There were significant differences between the different diagnostic groups in all three of these areas (impact: χ^2 equal to 16.69; p less than .005); different to healthy peers: χ^2 equal to 10.76; p less than .05; things unable to do: χ^2 equal to 13.50; p less than .005), with parents of transplanted patients perceiving their children to be more affected by the cardiac condition compared with perceptions of parents in the other diagnostic groups. We elicited four main themes from the thematic analysis about the ways in which parents perceived their children to be different to healthy peers (Box 1). These related to appearance, behaviour and emotional development, cognitive development and education, and medical aspects. In terms of activities that parents felt their children were unable to do, qualitative analysis indicated themes that focused

Box 1. Differences with healthy peers.

- Appearance
  - Cyanosis
  - Small stature
  - Scars
  - Frailness/weakness
  - Thinness
- Behaviour and emotional development
  - Misery/easily upset
  - Lack of confidence
  - Low self esteem
  - Less independent
  - Less mature
  - More affectionate
- Cognitive development/education
  - Behind peer group developmentally/academically
  - Unable to participate in activities
  - Lack of energy
- Medical
  - Need to take medicines
  - Oxygen requirement
  - Prone to infection
  - Bed wetting (due to diuretics)

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mainly on physical limitations and lack of stamina or tiredness, and the impact of this on participation in physical and sporting activities. There were also some issues regarding the side effects of surgery, such as scarring and the effect of this on self esteem and body image. Parents also revealed anxieties projecting into the adult life of their child concerning the likelihood of obtaining insurance, pensions, and full-time jobs.

Data for the measure of functional state were available for 191 of the children (Table 3). The mean total score for the whole group was 89.75, with a standard deviation of 14.57, and with 11 children (6 percent) obtaining scores of more than two standard deviations below the mean. Comparison of the score of our total sample with that obtained from a sample of children with chronic illness, having a mean of 86.8, and a standard deviation of 15.7, revealed no significant differences.[15] Within our sample, there was a significant difference in mean total scores between the diagnostic groups (χ^2 equal to 25.3; p less than .001).

Impact of cardiac condition on activities

Parents were asked a series of questions about whether the cardiac malformation of their child affected various activities (Table 4). In 125 (60 percent) families, there was no perceived impact of the condition on any activities. There were significant differences between the diagnostic groups in the impact on social activities (χ^2 equal to 12.1; p less than .05), going on holiday (χ^2 equal to 23.4; p less than .001), going shopping (χ^2 equal to 9.3; p less than .05), leaving the child with a babysitter (χ^2 equal to 9.8; p less than .05), and hobbies (χ^2 equal to 11.3; p less than .05). Greater perceived severity of ill health was also significantly associated with the impact of the malformation on all activities.

Family relationships

Parents were asked about the effect of the malformation on family relationships. In 98 families (49 percent), there was no change, but in 88 families (43 percent) parents felt that family members had become

Table 3. Results using the Functional Status II(R) survey (%s in parentheses).

	Acyanotic (n = 124)	Cyanotic (n = 37)	Post-transplant (n = 21)	Miscellaneous (n = 9)	Total (n = 191)
Mean	93.12	87.64	76.36	83.33	89.75
SD	11.54	15.96	16.88	21.42	14.57
Range	36–100	39–100	46–100	54–100	36–100
Number scoring >2 SDs below the mean	2 (2)	3 (8)	4 (19)	2 (22)	11 (6)

Table 4. Impact on activities (%s in parentheses).

	Acyanotic	Cyanotic	Post-transplant	Miscellaneous	Total
Family					
Yes	22 (17)	7 (18)	9 (38)	3 (30)	41 (20)
No	109 (83)	33 (82)	15 (62)	7 (70)	164 (80)
Social					
Yes	22 (17)	13 (33)	11 (46)	2 (20)	48 (23)
No	109 (83)	27 (67)	13 (54)	8 (80)	157 (77)
Holiday					
Yes	24 (18)	7 (18)	15 (62)	2 (20)	48 (23)
No	107 (82)	33 (82)	9 (38)	8 (80)	157 (77)
Hobbies					
Yes	10 (8)	10 (26)	6 (27)	2 (20)	28 (14)
No	115 (92)	29 (74)	16 (73)	8 (80)	168 (86)
Public transport					
Yes	14 (11)	5 (13)	6 (25)	1 (10)	26 (13)
No	117 (89)	35 (87)	18 (75)	9 (90)	179 (87)
Shopping					
Yes	13 (10)	6 (15)	8 (33)	2 (22)	29 (14)
No	118 (90)	34 (85)	16 (67)	7 (78)	175 (86)
Babysitter					
Yes	21 (16)	7 (18)	10 (42)	1 (13)	39 (19)
No	109 (84)	32 (82)	14 (58)	7 (87)	162 (81)

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closer, whilst in 16 (8 percent) they had been "pulled apart". There were no differences between the diagnostic groups. In terms of relationships between partners, 66 (37 percent) rated the relationship as more positive, 18 (10 percent) as less positive, and in 95 (53 percent) cases there was no change in the relationship. Of the 180 families who had other children, siblings in 54 (30 percent) of the families were perceived to be affected by the cardiac malformation. There were significant differences between the diagnostic groups (χ^2 equal to 11.6; p less than .01), with siblings of children with acyanotic lesions being affected in 16 percent of families, compared with 60 percent of siblings in families of transplanted patients, and 43 percent of siblings in families whose child had a cyanotic lesion. Whilst the majority of parents (74 percent) gave the same amount of time and attention to their healthy children as to the ill child, in 44 families (25 percent) parents gave more time to the ill child. There were differences between the diagnostic groups (χ^2 equal to 10.9; p less than .05), with this being reported more frequently in the families of the patients undergoing transplantation. Thematic analysis of the impact on healthy siblings revealed eleven main themes (Box 2).

Box 2. Impact on healthy siblings.

- Extra attention to sick child
- Prevented from doing things as a family
- Fear of getting too close to sick sibling
- Feeling that sick child doesn't have same rules to adhere to
- Feeling left out
- Anxiety/depression
- Anger
- Intolerance
- Jealousy
- Resentment
- Insecurity

Education

Table 5 shows the type of education that the children were receiving. Of those not receiving any education, 35 were too young, 13 had left school, and 6 were of school age but not attending. For 50 children (29 percent), assessments had been made by their Local Education Authority, and 40 children (25 percent) were restricted in activities at school because of their cardiac condition (Table 3). There were significant differences between the diagnostic categories in terms of restriction at school (χ^2 equal to 10.1; p less than .05), with the differences between the categories on assessment by the Local Education Authority almost reaching significance (χ^2 equal to 7.6; p equal to .055). Restrictions focused primarily on physical education and sporting activities, school trips, and play-time. Restrictions in the class room related to learning difficulties and an inability to participate in the school curriculum.

Presence of other problems with health

Almost half of the sample had other problems. Thematic analysis elucidated five categories, which were disease or malfunction of other organs, developmental delay, sensory problems, allergies, and a miscellaneous group, the latter of which included recurrent coughs and colds, migraines, and orthopaedic problems. For some children, multiple problems were reported, whilst others had a single problem other than their cardiac defect.

Children with other problems of health were rated as more ill (χ^2 equal to 16.9; p less than .005), more different to healthy peers (χ^2 equal to 12.3; p less than .001), less able to do things (χ^2 equal to 31.5; p less than .001), and experiencing a greater impact on their ability to carry out daily activities (χ^2 equal to 14.9; p less than .005) than children without other problems with health. Participation in all family and social activities was affected to a greater (p less than .005 in all cases) extent in families of children with

Table 5. Education (%s in parentheses).

	Acyanotic	Cyanotic	Post-transplant	Miscellaneous	Total
Special school/unit	8 (6)	1 (2)	3 (13)	0 (0)	12 (6)
Main stream	61 (47)	22 (54)	14 (58)	5 (56)	102 (50)
Nursery/playgoup	23 (18)	9 (22)	1 (4)	2 (22)	35 (17)
No education	37 (29)	9 (22)	6 (25)	2 (22)	54 (27)
Assessed by Local Education Authority					
Yes	27 (25)	11 (32)	11 (48)	1 (11)	50 (29)
No	82 (75)	23 (68)	12 (52)	8 (89)	125 (71)
Restricted					
Yes	17 (17)	12 (36)	8 (38)	3 (30)	40 (25)
No	81 (83)	21 (64)	13 (62)	7 (70)	122 (75)

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other problems. There were, however, no significant differences in terms of family or partner relationships between those with or without other problems of health, but other siblings were more affected (χ^2 equal to 15.6; p less than .001) and received less attention than the sick child (χ^2 equal to 8.9; p less than .05) in families where the child had additional problems. More children with other problems had been assessed by their local education authority (χ^2 equal to 24.0; p less than .001), but there was no difference in terms of restriction within school between those with and without the other problems.

Analysis of those children with and without other problems of health as separate groups indicated that within these two groups there were few significant differences between the different diagnostic categories. For those children with additional problems, the only significant differences were on the variables looking at the impact of the problem on the ability to carry out daily activities (χ^2 equal to 11.9; p less than .05), the rating of how well the child was (χ^2 equal to 11.5; p less than .05) and the score on the scale for functional state (χ^2 equal to 14.9; p less than .05). For those children without other problems, there were no significant differences on any of the variables between the different diagnostic categories.

Discussion

This descriptive, population-based study was the initial phase in a research strategy designed to elucidate firstly the perceived impact of cardiac disease on children and families, and secondly their unmet needs, in order to inform the development of an evidence-based cardiac liaison nursing service for children. In contrast to previous research, parents of a large cohort of patients encompassing the complete diagnostic spectrum were asked specific questions on a broad range of topics pertinent to living with cardiac disease, and its effects on their everyday lives.

There are some limitations that should be considered when interpreting the results of this study. Firstly, although the response rate was comparable to that of other postal surveys, and there were no differences in terms of demographic characteristics between the responders and non-responders, just over half of the population initially canvassed did not return their questionnaires. Secondly, mothers completed the questionnaires, so the impact on fathers and siblings is not known from their own perspective. This is a problem pervasive in much paediatric research, and needs to be addressed in the future. Similarly, the patients themselves were not evaluated directly, and although this group has been studied previously in terms of areas such as development and cognitive abilities,[16–19] behaviour,[20,21] and self perception,[22,23] it is increasingly being recognised that there is frequently a lack of agreement between mothers and their children on the reporting of symptoms or in areas such as evaluation of the quality of life,[24–26] highlighting the need for multiple informants. Within the current research paradigm, however, evaluation of the children themselves by questionnaire was not undertaken because of the validity of mailing children in terms of who completes the measure, the potential for a decreased rate of response if children also had to fill in the questionnaires, and the fact that maternal perceptions were the focus of this phase of the research. Thirdly, within some of the diagnostic groups the numbers of returned questionnaires were small. Although this reflects the proportion of such patients within the population, it precludes meaningful conclusions being drawn about the impact on patients with these diagnoses and their families. Finally, although parents were asked whether or not their child had other problems with health, and if so what they were, there was no indication given of the severity of these problems.

Although relatively few parents rated their child as ill, a significant proportion reported that the cardiac condition suffered by their child affected different aspects of their everyday life. In two-fifths of cases, parents perceived their children as being different from healthy peers, which is not surprising in view of the effects on appearance, physical limitations, and need for medications associated with some congenital cardiac lesions. This is confirmed by the qualitative data, which identified four main areas of difference between children with heart disease and their healthy peers.

Whilst the cardiac lesion was clearly perceived to have a negative impact on many areas of family life for about one fifth of the sample, particularly in those families where the child was perceived to be more ill, family relationships were affected in a very different way, with two-fifths reporting that family members had become closer, and less than one-tenth that they had been "pulled apart". Previous findings suggest high levels of stress in families of children with congenital cardiac disease,[3,4] although these studies evaluated stress in parents of young children with cardiac lesions, and for many the diagnosis was recent. In contrast, the children in our sample were older, and for the majority it is probable that their health condition was relatively stable, even though many had undergone high-risk open heart surgery previously. Partner relationships reflected this stability, with the majority showing no change, and only one-tenth being rated as less positive. In 32 cases, nonetheless, the children were in a single parent household, and no account was taken of relationships which had broken down since the birth of the child, and what

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contribution the cardiac condition may have made to this. Siblings in almost one third of families were affected by the cardiac condition, with the impact greater for siblings of patients who had undergone transplantation, or children with cyanotic lesions. Siblings of children with chronic illness are at greater risk of difficulties in adjustment,[27] and siblings of children with a cardiac condition have an increased prevalence of antisocial behaviours.[28,29] In one quarter of families, less time was given to the healthy sibling, which rose to half of siblings of those transplanted. These data support previous findings of a relationship between the intensity of treatment and care of the ill sibling with behavioural problems, and reduced provision of care for the healthy siblings.[30,31]

Overall, there were a number of differences in the perceived impact of the cardiac condition on school and family life between children with different diagnoses, with this being particularly evident for families of the children who had undergone transplantation. Although children had to take immunosuppressive medication daily after transplantation, and attend hospital for checkups, none were hospitalised at the time of the study, and most were at mainstream school or nursery. Furthermore, in contrast to those children with cyanotic or acyanotic lesions, the transplanted patients all had a structurally normal heart. Transplantation, nonetheless, is offered as palliative treatment, rather than a cure, and even when the patients are healthy and able to lead a normal life, uncertainty remains about the future. Although transplanted patients are subjected to few restrictions, parental anxiety and overprotectiveness can result in a restricted lifestyle for these children, and this can be exacerbated by the fears and reluctance of others, such as teachers.[32]

Almost half of the sample had other problems with health and, not surprisingly, there were many differences between those with and without these other problems in terms of the impact on activities, education, and healthy siblings. When these two groups were looked at separately, most of the differences between the different diagnostic groups disappeared. The implication of this finding is that the addition of further problems with health, irrespective of the underlying cardiac diagnosis, has a significant impact on the perceived ability to carry out normal activities. This highlights the importance of assessing all aspects of health, rather than focusing exclusively on the cardiac condition. There was a wide range of other problems, from other major organ dysfunction to relatively minor skin or upper respiratory tract problems, although in the absence of any quantification of perceived severity it is not possible to analyse the impact of severity of these additional problems on family and school life.

Much has been written in the literature about the importance of maternal perceptions in determining psychological adjustment,[7,8] and our findings confirm the importance of assessing perceptions of the severity of the illness in clarifying the impact on the capacity to function. The majority of children with acyanotic lesions tend to be less incapacitated, and are more able to participate in normal activities than are children with cyanotic lesions. We found few differences between these two diagnostic groups, however, again supporting the evidence for the real severity of the disease being less important than its perceived severity in determining the impact of the condition. Within our healthcare service, there are still some healthcare professionals who continue to subscribe to the view that more severe disease equates to poorer adjustment. Findings for children with innocent murmurs suggest that this is not true,[33,34] but there is a real need to ensure that professionals working with children with cardiac disease and their families become aware of the growing evidence on this topic. Together with assessing maternal perceptions of the severity of the illness, associated conditions also need to be identified and recognised as potential risk factors for greater impact on everyday life, so that resources can be targeted to reduce psychosocial morbidity. For the patients who have been transplanted, in particular, there is a clear need to identify the perceived impact of the condition on the ability of both the child and the family to carry out everyday activities, and to identify any misconceptions held by the family or others in the community in order to facilitate as normal a life as possible for all family members. Siblings of children with congenital cardiac disease have not been studied extensively, but our results suggest that a significant minority of healthy siblings are affected, and could benefit from interventions targeted specifically for them.

Our results suggest that, irrespective of the real severity of the disease, the presence of the cardiac condition has an impact on everyday life for a significant minority of children and families, particularly if associated with other problems with health. Our data also indicate some very positive outcomes, such as the fact that, in three-fifths of families, there was no perceived impact of the cardiac condition on family activities, that family relationships had remained stable or improved in nine-tenths of families, and for siblings in seven-tenths of families there was no perceived detrimental impact. Identifying families in which there are perceived difficulties is vital, but we also need to recognise those factors that promote resiliency and positive adaptation. The role of the cardiac liaison nurse will be paramount in identifying those children and families most affected by their heart condition and facilitating, through liaising with

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the child, family, community professionals and health professionals, a reduction in the impact the cardiac malformation has on everyday life. The roles of maternal perceptions, and the presence of other problems with health, have important implications for the management of the caseload, particularly at a time when the cardiac liaison nurse continues to be a scarce resource.

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