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## **Coping when a child has a disability: exploring the impact of parent-to-parent support**

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### **Summary**

***Aim*** To explore the impact of parent-to-parent support when a child is born with a disability.

***Design*** The research approach was qualitative. Data were collected retrospectively and were derived from in-depth interviews with parents. The audio-taped interviews were transcribed and then analysed using constant comparative procedures.

***Setting*** Scotland.

***Participants*** The parents of 63 children born with a congenital upper limb deficiency.

***Findings*** The early weeks and months following the birth of their baby was a difficult and emotional time for most parents. Feelings of isolation were common and there was a lot of concern about what the future would hold. Although a certain amount of support was derived from contact with family, friends and health professionals, parents did not generally obtain the level of support that was required from these sources. Contact with other parents of limb-deficient children, however, clearly exerted a powerful stress-buffering influence, providing much needed emotional, social and practical support.

***Conclusions*** This study suggests that parents of children with special needs are uniquely qualified to help each other. The challenge is to ensure that health professionals are aware of the potential benefits of parent-to-parent support and provide parents with information about appropriate local organizations/contacts.

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## Introduction

When a child has a disability parents experience the typical stressors associated with parenthood plus a host of additional stressors unique to their child's condition (Ainbinder *et al.* 1998). Previous research has demonstrated the importance of social support for families of children with special needs (Telleen *et al.* 1989; Hartman *et al.* 1992; Ainbinder *et al.* 1998). Specifically, social support can be an effective buffer against the stress and isolation faced by this population. It has been suggested by some that the greatest benefit in terms of stress reduction is achieved when parents are able to share and compare their experiences with other parents who are in a similar situation (Phillips 1990; Matloff & Zimmerman 1996; Santelli *et al.* 1997). There is a strong theoretical argument in favour of this assertion (Thoits 1986; Gottlieb 1988; Taylor *et al.* 1990). However, there is a dearth of research-based evidence explicating the mechanisms involved.

This paper reports qualitative findings on the benefit of parent-to-parent support in families of children born with a congenital limb deficiency. Parent-to-parent support refers to the support derived from contact with 'similar others', that is the support derived from other parents of children with limb deficiencies. The findings presented form part of a wider study on the process of coping and adaptation.

## Methods

### The research approach

The research approach used to explore the families' experiences was hermeneutic phenomenology (Gadamer 1989; Thompson 1990). When using this approach the particular phenomenon of interest is accessed through establishing a dialogue with the study participants. This dialogue may occur through conversation (interview) and/or participant observation. The observations or narratives are then transformed into text which is interpreted. For the purposes of this study, data were collected retrospectively and were derived from in-depth interviews with parents.

### The sample

The sample was selected using maximum variation sampling, a form of purposive/nonprobability sampling. When using this method of sampling a broad range of participants is selected: the aim is to produce a sample that will encompass a diversity of lived experience (Lincoln & Guba 1985). In this study efforts were made to ensure that the sample included children with a variety of limb deficiencies, that both sexes were represented and that the ages of the children varied from a few months to 16 years. Additionally, the selection process was designed in such a way that families from a broad spectrum of socio-economic and geographical settings were included. Access to families was negotiated through six separate sources: the four limb fitting centres in Scotland, a major hand and plastic surgery unit in the west of Scotland and Reach, a national association for families of children with hand or arm deficiencies (Table 1). Ethical approval was granted by all 15 Health Boards in Scotland.

The aim was to recruit 50–60 families, and as the pilot work suggested the response rate would be approximately 60%, letters requesting participation in the study were forwarded to 90 families. Following recall, a total of 63 families agreed to participate (three letters were returned marked addressee unknown), the response rate was therefore 73% ( $63/87 \times 100$ ) (Table 1). The characteristics of the 63 children recruited into the study are summarized in Table 2. The Deprivation Index was derived from the participants' postcodes, using the Carstairs scoring system (McLoone 1997). The Carstairs scores are calculated using indicators of disadvantage and are a method of quantifying levels of relative deprivation or affluence in localities throughout Scotland. The scoring system ranges from DEPCAT 1 (the most affluent postcode sectors) to DEPCAT 7 (the most deprived).

**Table 1** Sources used to gather the sample

	No. of letters forwarded	Responses
Child: Care, Health and Development	Reach (throughout Scotland)	33
	Limb fitting centre (west)	10
	Limb fitting centre (north-east)	1
	Limb fitting centre (east)	10
VOLUME 26 NUMBER 4	Limb fitting centre (north)	6
	Plastic surgery unit (west)	3
2000	Total	63

**Table 2** Sample characteristics

	Frequency (n = 63)	%
Age		
6 months-4 years	12	19.0
5-9 years	27	42.8
10-14 years	20	31.7
15-16 years	4	6.3
Sex		
Male	32	50.8
Female	31	49.2
Type of limb deficiency		
Transverse*	49	77.8
Longitudinal†	13	20.6
Intercalary‡	1	1.6
Side affected		
Left	32	50.8
Right	19	30.2
Bilateral	12	19.0
Deprivation index (DEPCAT scores)		
1 (affluent)	4	6.3
2	12	19.0
3	17	27.0
4	18	28.6
5	7	11.1
6	4	6.3
7 (deprived)	1	1.6

\* Distal part of the limb is missing, limb has developed to a particular level beyond which no skeletal elements are present (e.g. arm terminates below the elbow).

† Reduction or absence of a particular element or elements within the long axis of the arm (e.g. radius and thumb may be absent).

‡ The distal and proximal parts of the limb have developed normally, the long bones are either shortened or absent (resembles Thalidomide).

### Data collection

The 63 participating families were interviewed during a 5-month period of fieldwork. Parents were interviewed as a couple in 34 instances and mothers were interviewed individually in 29 instances. Efforts were made to include both parents where feasible: two of the 29 mothers interviewed individually were single parents and 11 were either divorced or separated. The interviews were audio-taped and lasted between 40 min and 3 hours. The 63 transcribed interviews, complemented by hand written field-notes, provided the data for analysis.

### Data analysis

A thematic analysis was undertaken with the assistance of the qualitative software package QSR NUD.IST. The lengthy interpretive process comprised intensive reading and re-reading of the transcripts. First-level analysis involved categorization of the data in line with the broad areas listed in the topic guide (Table 3).

During subsequent readings, constant comparative procedures were used to identify themes within these categories, as patterns of similar response emerged (Lincoln & Guba 1985). Following this process, scrutiny of the initial coding scheme led to refinement of its structure, with several themes being merged and a small number of new themes being identified.

### Findings

#### The birth of a child with a limb deficiency

The response of parents to the birth of a child with a limb deficiency has been described in detail elsewhere (Kerr & McIntosh 1998). In summary, feelings of shock, numbness and disbelief at the time of the birth were common. Following disclosure, although some parents very quickly accepted the situation, the majority described the time spent in hospital as a period of emotional turmoil.

[03] I felt ashamed of the baby, I wanted to hide his hand.

[35] I felt guilty in case it was something I had inflicted upon him.

[27] I felt devastated and very isolated.

[37] 'The feelings that I had were terrible. I just didn't like the idea that everybody else's baby had two hands.

**Table 3** Interview guide:  
topics covered

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Pregnancy
Labour and delivery
Stay in maternity unit
Early weeks at home
First year
Pre-school years
Primary school years
Secondary school years
Self-help groups/contact with other parents
Summary

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*Support provided by the midwives*

Although the majority of midwives readily offered practical assistance with feeding, changing and bathing, many of the parents reported that they were poor at providing the necessary emotional support.

[22] They did all the practical things but they avoided talking about her hand, nobody mentioned it.

[08] . . . there was no support at all.

[06] A wee bit of tender loving care would have been nice.

*Support provided by the doctors*

In general, what parents said they wanted from the doctors during their stay in hospital was information. They wanted to know what their child's condition was and what had caused it, they wanted to know how the limb deficiency would affect their child's development, and they wanted to know what assistance health professionals would be able to offer in the future. Unfortunately, many parents felt that the information they received from the doctors was inadequate. This lack of information elevated concern, with the parents fearing what the future would hold. Some parents described feeling abandoned when they were discharged from hospital.

[09] The first thing we wanted to know was why it had happened, and the doctor couldn't answer that, it wasn't his field.

[30] We got very little information from the doctors. I mean none of them really knew anything.

[18] It was a case of here's your baby, away you go home and get on with it.

In summary, the findings reported in this section demonstrate that the birth of a baby with a limb deficiency was a traumatic experience for most parents. On the whole, the midwives and doctors did not appear to provide the necessary level of support and as a consequence parents reported that they were confronted with an uncertain future, lacking the information, reassurance and emotional support required at the time of discharge.

**The early months**

In most cases, these initial feelings of uncertainty and concern were not alleviated during the early weeks and months following discharge, and this continued to be a difficult and emotional period for parents.

### *Feelings of isolation*

Many parents, particularly mothers, felt that the situation they found themselves in was unique. They were familiar with conditions such as Down's Syndrome and Spina Bifida but most had never seen nor heard of children born with a limb deficiency (apart from those linked to Thalidomide). It was unusual for the family's General Practitioner or health visitor to have any experience of the condition and consequently parents tended to feel very isolated, believing that their child was 'the only child in the world that had ever been born with a limb deficiency'.

[39] The first 6 months were like a nightmare really. I had nobody to talk to. I felt very isolated, I didn't know there was anybody else out there at that point.

[38] To begin with I was very isolated.

### *Concern about the future*

A considerable amount of time in the early weeks was spent contemplating what the future would hold. Unfortunately, as most parents had very little information to base their judgements on, they tended to consider the future rather negatively.

[41] Initially I couldn't see past this one armed baby lying in the cot. I couldn't see the future, I couldn't see him in the future playing happily with [his sister]. I just couldn't see past this missing arm.

[34] We were worrying about things like how will she ride a bike, how will she swim, will she be able to play the piano, imagining that she wouldn't be able to do these things.

[45] Our biggest concern was how he would manage at school. You know what kids can be like.

[21] I was racing away ahead, I had her married by the time she was 3-day-old . . . it was like husband, married, everything.

### *Taking the baby out*

Finally, a number of mothers reported that situations they had looked forward to before the birth, such as 'showing the baby off' to family, friends and neighbours and taking the baby out in the pram or to the child health clinic were transformed into traumatic events that they often wished to avoid. Avoiding contact with other people of course compounded any feelings of isolation that the mothers may have already been experiencing.

[17] There was a few of us all pregnant at the same time and after we had our babies they wanted to have like coffee mornings at each others houses and that. And I just thought, I can't do it, I couldn't face it. I know it sounds daft but what if she needed her nappy changed or something and I would need to undress her, they would see her.

[55] And I remember being really upset when I went to the clinic to get him weighed. They took two babies in at a time and I just didn't want to go through that, I wasn't taking his clothes off in front of a stranger. . . . I just couldn't face it at the time.

In summary, what has been shown is that the parents were not able to derive the support that they needed from their familiar support networks. The majority of community based healthcare professionals had no experience of limb deficiencies and therefore had little to offer in terms of practical support and guidance. Although friends and family generally attempted to be supportive they were in many cases 'grieving' themselves and this often added stress and anxiety to the situation rather than alleviating it. Mothers tended to feel that their child was very different to other young babies and therefore the help and support that is often derived from informal contact with other 'new mums' was rarely sought.

So from what source were parents able to derive the support that they needed, and how did this support help them come to terms with their situation? Many found the necessary help and support from contact with other parents of children born with a limb deficiency.

### **How was contact with other parents achieved?**

Contact with other families was generally achieved in one of two ways, at a limb fitting centre or through the support group Reach. The opportunity to meet and talk to other parents varied at the four limb fitting centres, with one in particular very actively encouraging parents to meet. Support through the organization Reach was available in different forms and parents were encouraged to participate in whatever manner they wished. Families could be introduced to each other on an individual basis, or they could attend group meetings where a number of parents and children would be present. Some of the parents interviewed did not wish to meet other families, or were unable to attend meetings, and they received information and support from the Association's newsletter and fact sheets.

### **How did contact with other parents help?**

#### *The realization that you are not alone*

For many parents the realization that they were not alone marked a crucial turning point in their lives.

[08] I saw an article about Reach in a magazine and I just ran and got a paper and pen and wrote there and then. And a man phoned the next day, and he said I'm going to put you in touch with [another mother], she's. . . . I think it's only about seven miles up the road from you. And he said I've already telephoned her and she will be chuffed to bits to hear from you, and just, I can't describe how I felt, it was just like the light at the end of the tunnel.

[38] Just to know that there are other people out there who . . . who are in the same situation. I mean I felt very isolated initially. But as soon as I found out about Reach and I wrote to them, I felt a kind of a huge weight had been lifted, you know.

#### *Someone who understands*

Most parents felt that parents who were in a similar situation were the only people that could truly 'understand'. Whether meeting parents of an older child who had 'been in their shoes' or making contact with parents of a child of a similar age, an immediate and intense bond was often established.

[37] What helped was the fact that there were other people that had been through these problems. There were other people like me. It had happened to other people and it wasn't just, I wasn't an isolate you know, that was it. Being able to talk to other parents, having somebody listen to you and somebody that you think understands.

[41] Because we were all at the same kind of stage and we could talk to each other about how we were . . . you know, we were all going through the same kind of problems and difficulties at the same time.

#### *A glimpse into the future*

As discussed previously, there was initially a lot of concern about what the future would hold. Parents spent a lot of time in the early weeks and months considering how the limb deficiency would affect their child's life. Talking to parents and meeting other children who were a few months or years older

allowed parents to see into the future. This encouraged a positive outlook with parents realizing that their child would in fact cope very well.

[59] And em, for [another mother] to come in and talk naturally as any mother does about their child, about things that she's doing, and the things that she's up to, to me that was what was the most helpful thing. It suddenly brought home to me that she WILL be a normal child doing all the activities that other children do. . . . That was the biggest thing for me, because I couldn't see that to begin with.

[25] It was great. He brought his son to my house and he was playing away just like normal except he had a missing hand. And he was just great the things he could do . . .

#### *Coming full circle*

Many parents discussed the fact that after a number of months (sometimes years) of receiving support themselves they reached a point where they felt they could offer support to other parents. Again this appeared to be an important part of the process of adaptation and was obviously beneficial to both the parent/s receiving support and the supportive parent.

[15] I was asked to see a mother and father who had just had a new baby. It was the first time I'd ever done it and it was actually quite nerve-racking. I found out afterwards that they both got a lot of benefit from speaking to me, they seemed to find it really helpful. So I felt really good about that.

[32] I remember going to the first meeting when [my daughter] was 5 months old, I was absolutely petrified, you know. I was sitting there with this wee baby looking round at all these children roaming around just trying to take everything in. And when I was at a meeting a fortnight ago there was a woman there with a baby that was about 5 months old and she just reminded me of myself. . . . And I went right across to speak to her and I said I know how you are feeling. I felt I just had to tell her. I could see myself in her just sitting there. . . . So em that made me feel quite good cause I realized I'd come sort of full circle.

Child: Care, Health  
and Development

VOLUME 26  
NUMBER 4

2000

PAGES 309–322

#### *Lessening need*

Finally, most parents reached a stage where they felt a lessening need for support. Some reached this stage very quickly and colleagues felt the benefit of support well into the primary school years.

[04] I never thought that I would say this at the beginning but I eventually got to a stage when she was about 5 or 6 where I didn't need it as much, I'd reached a point where going to a Reach meetings wasn't my top priority.

Although most parents stopped attending formal meetings as their child got older they generally maintained contact, albeit by telephone, with other parents. Friendships had often been established and if problems arose, or there was a particular concern (for example a child commencing secondary school) there was generally a parent in the support network with an older child who could offer reassurance in addition to practical support and guidance.

## **Discussion**

It is clear from the parents' reflections on the birth of their baby and the time spent in hospital that support, both practical and emotional was needed. Sadly, it appears that the desired level of support was rarely evident. In particular, there were numerous complaints about lack of information, with parents reporting that they were discharged knowing little about their child's condition and the support (such as limb fitting) that could be offered. While it is acknowledged that the parents' perceptions of their experiences may not necessarily reflect what actually occurred, the findings in this study concur with previous research which has demonstrated that the situation is often handled poorly (Jupp 1992; Sloper & Turner 1993). This is of particular concern as the level of support provided during the very early days has been shown to be crucial and can affect both short and long-term coping and adaptation (Quine & Pahl 1986; Kerr & McIntosh 1998).

The early weeks and months following discharge continued to be a difficult and emotional time for most parents. Feelings of isolation were common and concern about the future remained. Although a certain amount of support was derived from contact with family, friends and health professionals, most parents said that they did not obtain the required level of support from these sources.

The transforming effect of contact with other parents was clearly evidence. This support operated on a number of levels. First of all, contact with other parents provided a sense of 'normality' in what had previously been considered an 'abnormal' situation. The discovery that there were 'other parents out there' who had shared the same experience very quickly banished any feelings of isolation that the parents may have been experiencing. Another benefit was that talking to other parents and meeting or hearing about other children

helped parents to visualise, in a very immediate way, a normal active and social life for their child. As a consequence, concern about a negative future, was replaced by a recognition that the future could, in fact, be very positive. Contact with other parents also provided emotional support, giving parents the opportunity to talk about and begin to resolve any feelings of confusion, guilt, anxiety, anger and depression that they were experiencing. Finally, other parents were able to provide practical advice and support, helping new parents resolve many day-to-day problems. It was very evident that the support provided by other parents was for many new parents central to the process of coping and adaptation. As discussed, after a period of months or years parents frequently entered a different role, that of 'supporting' parent. Again this appeared to be an important part of the process of adjustment and brought for many a feeling of closure— they had come full circle.

Most of the parents in the study who had not had contact with other parents believed that they would have benefited from meeting others in the same circumstance. Some had spent years attempting to come to terms with the situation. The number of parents who had no desire to meet other families was tiny. Some did not wish to join Reach because they felt that there was a stigma attached to being a member of a group of 'disabled' children. One family had coped very well from day one and had no need nor desire for support.

In conclusion, the findings presented in this paper appear to support the theory that parent-to-parent support can exert a powerful stress-buffering influence. Peer support provided the parents with the benefit of experiential learning, something that evidently could not be derived from other sources. This study also supports what others have stated, that parents of children with special health care needs are uniquely qualified to help each other (Ainbinder *et al.* 1998; Hartman *et al.* 1992). The challenge is to ensure that professionals are aware of the potential benefits of parent-to-parent support and provide parents with information about appropriate local organization/contacts, as early as possible following the birth of their child. Care must of course be taken not to introduce new parents to 'veteran' parents with unresolved problems or negative attitudes towards their child's disability as this could of course have a potentially damaging effect.

Child: Care, Health  
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VOLUME 26  
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2000

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