International Journal of Orthopaedic and Trauma Nursing (2011) 15, 176—184

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International Journal of Orthopaedic a Trauma Nursi

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Parenting a child with clubfoot: A qualitative study

Marta Pietrucin-Materek BSc(Hons), MSc (PhD student) [a,*], Edwin R. van Teijlingen MA(Hons), MEd, PhD (Professor of Reproductive Health Research) [b,1], Simon Barker BSc(Hons), MD FRCSEd (Tr&Orth) (Consultant Orthopaedic Surgeon) [c,2], Karen Forrest Keenan MA (Hons), MLitt, PhD (Research fellow) [d,3], Zosia Miedzybrodzka PhD, FRCP Edin, MRCOG (Reader in Medical Genetics and Director of Genetics Service) [d,3]

[a] *Centre of Academic Primary Care, University of Aberdeen, Foresterhill Health Centre, Westburn Road, Aberdeen, AB25 2AY Scotland, United Kingdom*
[b] *School of Health and Social Care, Royal London House, Christchurch Road, Bournemouth University, Bournemouth, BH1 3LT England, United Kingdom*
[c] *Department of Paediatric Orthopaedic Surgery, Royal Aberdeen Children's Hospital, Foresterhill, Aberdeeen AB25 2ZN, United Kingdom*
[d] *Clinical Genetics Service, Ashgrove House, Foresterhill, Aberdeen AB25 2ZA, United Kingdom*

KEYWORDS
Clubfoot;
Talipes;
Treatment;
Parenting;
Qualitative study;
United Kingdom

Abstract Congenital Talipes Equinovarus (clubfoot) is a condition affecting about one per thousand live births in Europe. Diagnosis of CTEV usually occurs through scanning in pregnancy and treatment of the child begins early after birth. The medical condition and treatment regime have an impact on the child's social environment and on family life. The aim of this qualitative study was to provide a better understanding of the psycho-social demands of parenting a child with CTEV. In-depth interviews were conducted with 15 families (four joint and 11 single interviews) in the UK. We identified three key themes from participants' accounts: (a) emotions and perceptions associated with the diagnosis of CTEV; (b) parenting a child with CTEV and (c) parents' concerns about the child's future. We report that participants experienced a range of negative emotions similar to those experienced by parents of children with what are considered to be more disabling conditions. We propose that more attention should be paid by healthcare professionals to the

* Corresponding author. Tel./fax: +44 1224 550683.
E-mail addresses: m.pietrucinmaterek@abdn.ac.uk (M. Pietrucin-Materek), vanteijlingen@bournemouth.ac.uk (E.R. van Teijlingen), s.barker@nhs.net (S. Barker), k.keenan@abdn.ac.uk (K. Forrest Keenan), zosia@abdn.ac.uk (Z. Miedzybrodzka).
[1] Tel.: +44 1202 962794; fax: +44 1202 962736.
[2] Tel.: +44 1224 554016; fax: +44 1224 840704.
[3] Tel.: +44 1224 552120; fax: +44 1224 559390.

1878-1241/$ - see front matter
doi:10.1016/j.ijotn.2011.02.004

emotional impact on parents of their child's CTEV diagnosis and treatment. More encouragement, information and support from health professionals could increase parental interest in the treatment as well as their satisfaction and will result in decreased non-compliance with treatment due to a lack of knowledge.

Editor's Comments
Club foot (CTEV) remains a relatively common childhood orthopaedic condition. This important paper which considers the parenting perspective adds significantly to our knowledge and understanding of the impact of the condition and its treatment on the lives of parents as well as children themselves. JS

Introduction

Congenital Talipes Equinovarus (CTEV often known as clubfoot) is a developmental disorder affecting between 0.57 and 6.8 children per 1000 live births worldwide (Ching et al., 1969; Engesæter, 2006) and 2.57 per 1000 births in the United States (Barker et al., 2003). The aetiology of clubfoot remains unclear but current evidence suggests that more than one mechanism may operate. Both genetic and environmental factors play a role in altering the outcome of the normal developmental mechanisms of intrauterine foot rotation. Evidence from animal models suggests that at least some cases may be caused by genetically programmed abnormality of the neuromuscular development (Duce et al., 2010).

In most cases CTEV results in the front half of the foot being turned down and pointing inwards (equinovarus). It can occur in one or both feet and is more common in boys than girls (Chesney et al., 2004). In the UK CTEV is often now first suspected at the detailed prenatal scan, which allows treatment of the child to begin soon after birth (Wallander, 2010). Both the medical condition and treatment regime have an impact on the child's social environment and on family life, with parents shouldering the main burden of care (Docker et al., 2007 Zionts and Dietz, 2010).

Treatment in the UK

In the UK Ponseti treatment is applied soon after birth and involves the assessment and gentle manipulation of the foot/feet followed by application of plaster casts once a week for approximately 6 weeks (Ballantyne and Macnicol, 2002; Grice et al., 1951; Ponseti, 1992). This is usually followed by tenotomy of the Achilles tendon at around six weeks of age. The corrected posture is maintained thereafter by bracing with ''boots and a bar'', for 23 h per day for the first three months. Subsequently the brace is worn for 12 h during each 24-h period, ideally until the child is five years old (Ponseti, 2008). In almost all cases this non-surgical treatment is successful although a minority of children require more invasive surgical management. Non-compliance with postcorrective bracing is seen as the most consistent factor associated with relapse (Zionts and Dietz, 2010). Despite the availability of Ponseti treatment and rehabilitation, affected individuals may experience persistent stiffness and discomfort through childhood and beyond, as well as a prolonged immobilisation regime. Even when fully corrected, a CTEV foot is smaller and a significant reduction of the calf muscles and a mild shortening of the leg may occur (Chesney et al., 2007; Ponseti, 2008; Porter, 1997).

Impact on parents

Research and clinical observations suggest that the diagnosis of such a congenital disease in children will also have a considerable impact on parenting and family life, with parents likely to experience a wide-range of emotions related to the diagnosis and early treatment of their child. Empirical studies into parents' responses to the diagnosis of disability in children indicate that many experience negative emotions such as depression, anger, shock, denial, fear, self-blame, guilt, sorrow, grief, confusion, despair, hostility and even emotional breakdown (Heiman, 2002; Goldbeck, 2006; Lawoko and Soares, 2004). Thus, when children are treated for clubfoot their parents (or care givers) have to cope with the emotional aspects of the diagnosis, and comply with the treatment regime in order to correct, and maintain correction of, their child's foot/feet.

Whilst it is clear that active parental/caregiver involvement in a child's treatment is important for achieving good patient outcomes (Shack and Eastwood, 2006) several barriers have been observed which may prevent adherence to this regime. In developing countries these may include: high transport costs' long travelling distances, poor social/family support and poor communication between parents and the clinician (Kazibwe and Struthers, 2009). However, in the UK little research has been undertaken into the experiences of parents/caregivers of children with CTEV and what factors are important to parents in aiding treatment compliance.

This qualitative study explores the experiences of parents caring for a child affected with clubfoot and aims to use the findings to inform the development of more effective services for these families.

Methods

Recruitment and sampling

Parents of children affected by CTEV and treated in a UK teaching hospital during the years 1994—2008 were identified by a consultant at the Talipes Clinic. Potential participants whose children had been treated both conservatively or/and surgically were invited to participate by the consultant through face-to-face contact or a telephone conversation ($n = 17$). We used purposive sampling to include participants with as wide a range of demographic characteristics as possible (Mason, 2002). After this initial agreement the researcher contacted participants by phone to give them more details about the study and to arrange a convenient time for the interview. A personal letter of confirmation of the date and the time of the interview was then sent out, together with a participant information sheet. Out of 17 potential families two declined because they were afraid of becoming distressed whilst talking face-to-face about their experience with CTEV. Only parents of children affected by CTEV who were treated at the Talipes Clinic were invited to participate in the study and the children were between six months and 14 years old. We excluded children with syndromic CTEV (e.g. cerebral palsy, spina bifida, or arthrogryposis) to exclude confounding of the data by the concomitant condition.

Data collection and analysis

A qualitative inductive research strategy was chosen because very little empirical research has been conducted in this area (Halloway, 2005; Schwandt, 1997). Semi-structured interviews were undertaken in order to allow the researcher to focus upon issues which were salient to interviewees, but also to clarify and probe when necessary (Mason, 2002). Parents were interviewed in early 2008 in a hospital interview room or at their home. Consent was obtained from participants prior to the interview.

The interviews were conducted by the first author using an interview schedule to start an open conversation. Interviewees were asked to explore several aspects of their experience of parenting a child with clubfoot such as the initial diagnosis, treatment and support, impact of clubfoot on their day-to-day living and wellbeing and demographic details. The interviews lasted about thirty minutes and were tape recorded with permission (van Teijlingen and Forrest, 2004). The tapes were anonymised but otherwise transcribed verbatim.

Data analysis was an ongoing iterative process (Forrest Keenan et al., 2005). It comprised three stages: coding (reducing the data into meaningful segments and assigning names for the segments), combining the codes into broader categories/themes, and displaying and making comparisons between the themes (Creswell, 2007). These processes were done manually by reading the transcripts and writing on them in order to group different segments into categories. Selected quotations are used to present the range of themes which emerged. Quotes are labelled M for 'mother' or F for 'father'. The project was of a self-funded MSc degree (MP) and approved by the regional NHS Research Ethics Committee.

Results

The participants

Fifteen families of children aged between 5 months and 14 years were interviewed; 10 mothers and 1 father were interviewed individually and we conducted four joint interviews with couples. All fathers/guardians were in full-time employment. Ten mothers were homemakers, and five mothers were in paid employment.

Overall, we identified three key themes from participant's accounts of parenting a child with clubfoot. These were: (a) emotions and perceptions associated with the diagnosis of CTEV; (b) parenting a child with CTEV; and (c) parents' concerns about the child's future.

Emotions and perceptions associated with the diagnosis of CTEV

Many (n = 10) parents found out about their child's condition from the 20-week pregnancy scan and some feared their baby had another more serious birth defect such as Edward's or Down's Syndrome. Five parents first knew of CTEV at birth. Emotions varied between parents, and ranged from relief and acceptance to anger and shock, being upset or depressed and self-blame. If the child had been diagnosed from the 20 week scan and perception of the initial diagnosis had been 'worse', for example where Down Syndrome had been predicted, relief was aired:

I didn't really know much about it tho'. I thought there was a lot more going wrong as well.... When I found out it was just...these feet. M1
I thought it could have been worse than it was. But it's just something that you need to get over and do it for your child. M9

Feelings of anger may also be experienced when a child was initially diagnosed, for example:

Initially I kind of... It was hard, and I was quite angry ... when drug addicts had perfectly healthy babies, and my one ...when I'd done nothing wrong. M9

Several interviewees were anxious about their child being labelled as different and for some this was combined with the child being diagnosed at birth, for example:

Upsetting, everybody wants their baby to be a perfect baby ... And when we've found out that she was gonna have casts on, and all these things, nobody wants their baby to go through that... M4

One mother reflected upon what might have caused the clubfoot in her child, suggesting that it could be due to her working in a laboratory or that she hadn't eaten the right food during her pregnancy. She expressed feelings of guilt and self-blame that her actions may have contributed towards her child's impairment. Yet, she also considered other possible causes which she acknowledged were out of her control:

... when she was still in the uterus I'd gone through the ...maybe I've done something wrong in the lab, or that it was something I didn't ...I hadn't eaten...Cos you go through a self-blaming process .... It probably more reflects on women than men, and I didn't really express that. And subsequently I think I was quite depressed after the birth. .... I'd love to have an opportunity to speak to the women that's not your fault. And what you're going through mentally ....that it's your fault and ... no it's not. It's a genetic thing ... it's spontaneous. You can't control that. M15

Interestingly, this participant questioned whether the process of self-blame occured more often in women than in men and also admitted that self-blame had contributed to her feeling depressed after childbirth, something she had not expressed before.

Parenting a child with CTEV

The treatment of CTEV can be emotionally and physically demanding for parents, especially when started so soon after birth, with participants raising a catalogue of difficult issues such as problems in handling the brace regime, broken nights, children crying, the burden of regular hospital visits and the reactions of other people to them and/or their child. For example:

The challenge, I mean I am up here [=hospital] every week .... We had to get up early to take off his casts, I don't know why ... it took ages [laugh]. But he didn't have a bath to lose those casts for the first 10 months. Well he had about two baths because I had to take his casts off and it took ages! And he was crying, and I would never do this again [laughter]. M9
When she was in those two casts at the time... I think she was a bit stressed, cause she was not able to move her legs and ... then cause you've got other people that stared. And that's probably the most upsetting thing ... they always looked at you that you have done something to your child. M4

Another mother also insinuated that people suspected poor parenting as her baby appeared to have two broken legs:

My friend, she had him [my son] in Asda when those ladies were staring at him. She went mad [and said:] ''He was born with clubfoot and he has not had broken legs!'' A lot of people do think he had two broken legs. M9

Parents also encountered a range of challenging practical issues which needed to be addressed such as breastfeeding, getting clothes and how to transport a baby in leg casts:

That's gonna be a challenge, cause I don't know how I'm gonna transport her. ...And clothing and things you can just adapt them ... breastfeeding is difficult because you can't put her feet round. ... she can't lay on her side. I've got to prop up the pillows ... I mean you can get round of it, but it just makes things awkward. M4

At a later age children with clubfoot faced problems with shoes, especially as seven out of 15 children had significant differences in the size of their feet ranging from 0.5 to 2.5.

There's two and a half sizes difference [between his feet]. So it's quite distinctive. ... they changed the children's style of shoes [laugh]. So one would be one style and the other would be the other style. It's very difficult to get a pair across the boot sizes ... I found the ... frustration, I always went to the shoe shop and then I had to go to the other one. M15

Having a child with clubfoot also impacted on parents' use of childcare provision such as babysitters or nursery care with many feeling uncomfortable about using such agents, especially if they felt their child looked different from the other children. Interestingly the majority of mothers did not report that their child's condition had impacted upon their career plans, but this is probably because most were not in employment at the time of interview. One participant did reflect that she would like to go back to work and this decision seemed related to an improvement in her child's condition. Thus she described how:

I didn't feel it would have been right to put him to a nursery. Mainly because I didn't want him to be the only child sitting down when everyone's been up and playing, and things like that. I don't feel it's quite fair with him to be put....and to be made to look different. But just now, when he can have them [= brace] off through the day ...it's something I would like to think about...to go back to work. M10

Several parents mentioned receiving support from their family. One mother who lived some 30 miles from the main hospital and who did not drive herself mentioned that getting to the weekly session at the clinic was hard:

[My husband] had to take time off, or my mum, or my mother-in-law. M2

It was also clear that some participants would have valued more support and information and that this occurred at different times in their child's treatment process. One father had enquired about whether there was a local support group for clubfoot and was unhappy with the response he received from the healthcare professional:

When she was seven to eight months we did feel it would be nice if there was somebody else to talk to ... other parents.... And I did say to the staff when we were in the hospital: is there a support group..... of Talipes? Because I'd seen there was on a website in England and in other countries, was there any in ...? And the answer I got back was''No, but if you want to start one you should consider it''. And I just thought ''right we've got enough around to play with''. We were looking for people to help us [laugh], not to help others. So I thought...it's rather a poor answer. D14

Some parents did not see much impact on their child's overall development. The child had accepted it and, usually before the age of four, did not see themselves as being different. One mother used to test this through her sisters (the child's aunts), she recalled:

Her feet don't look any different. I used to test it by my other two sisters.... they don't see her [daughter] that often ... I do the test of putting the socks and shoes off and saying 'What's the foot...?' And they look and say: 'Uhh, I don't know.' So you can't tell what foot it was ... M3

However, some children complained about pain and discomfort while walking, some also had difficulty riding a bike or running properly and some may have had other complications such as the difference in the appearance of their calf when unilaterally affected or may have developed a limp due to the difference in the length of their legs.

Parents' concerns about their child's future

Parents of children with clubfoot had different concerns in relation to the child's gender, age and the severity of the disease. Only four out of nineteen parents (of all boys) did not report any concerns about their child's future. Three families were worried about possible relapses and physical development. The mothers of four girls reported concerns about shoes, difference in sizes of their feet, fashion issues and the possible impact on

their child's confidence. Thus two participants commented:

I think he will adapt to whatever the situation is. Obviously my concern . . . is how he will physically develop. And will he have some problems with his knees and hips when he gets older? He can walk, but will this walk help him to get better? D12
I do have concerns, especially once she's had this plates put in and how this is gonna affect her, well how successful it's gonna be and would she have a limp, or . . . And now when she's become a young lady and she's obviously aware when she goes swimming or anything, where she's kind of marked that she has a scar on her leg. But she's coped well. She is a normal girl, at that kind of age. M7

Some parents worried about their child's developing body image and having to deal with looking different and feeling different, resulting in the need to provide reassurance and answer difficult questions:

As she gets older I still have to reassure her . . . especially because she has a scar and one leg is slimmer than the other. When she is conscious of that she needs reassurance. Because even a couple of nights ago she's saying will this leg ever catch up with the other? I don't know it will so I can't lie to her. I'm honest with her ... M8

In two cases parents were worried about the potential for their child to be bullied when he starts school:

His right foot isn't growing right, I'm a bit worried. If it will catch up with the other when he is older, or if he gets bullied at school because of that. M13

Discussion

Diagnosis of a congenital disease in a child is emotionally difficult for parents and associated with mixed feelings (Brett, 2002; Ellis et al., 2002; Landsman, 2003; Lowoko and Soares, 2004). In this study we explored parents' experiences of having a child with clubfoot and identified three key themes from participants' accounts: (a) emotions and perceptions associated with the diagnosis of CTEV; (b) parenting a child with CTEV; and (c) parents' concerns about the child's future.

An important finding was that participants may experience shock, anger and depression; similar to emotions experienced by parents of children with what are considered to be more disabling conditions. Nevertheless, we also found parents who were relieved when their baby was born with CTEV because from antenatal screening they had perceived that he/she may have a much more serious condition. Our findings also suggest that postnatally parents may go through a process of self-blame, considerable feelings of guilt and, finally, adaptation and that this may be a highly gendered process. Such negative emotions and perceptions may be increased by a lack of parental knowledge about CTEV and misinformation, e.g. about the cause of the disorder, as well as a lack of attention from health care professionals to the emotional impact on parents whose child has been diagnosed with clubfoot.

In the early stages of postnatal care emotional challenges and difficulties in coping with the treatment was common. Thus, as well as the physical and mental challenges of becoming a new parent (Janisse et al., 2009), being a parent of a disabled child requires adaptation of daily routines to accommodate the child's special needs and demands (Britner et al., 2003). Application of plaster casts, weekly visits to the hospital, problems with clothes, breastfeeding, sleep disruptions, not being able to bath the newborn and uncertainty about the future were just some of the difficulties that parents faced. Pain, restriction in movement and not being able to undertake popular activities also impacts upon the child and their family (STEPS).

Parenting a child with CTEV has an impact on psycho-social functioning of the family. Very few parents used professional child care, possibly due to the child's condition, feeling unfair to the child, being uncomfortable with babysitters/nurseries and guilt about leaving their child in someone else's care (Pelchat et al., 2003; Sen and Yurtsever, 2007). From our participants' accounts it is clear that this puts increased pressure on parents (primarily mothers) who often have no break in caring for their child which can lead to feelings of stress, exhaustion and at times isolation. The majority of parents also had concerns about their child's future — not only their physical development but the impact on their psychological and social well being — but most also felt that their child would adapt and be able to cope in the long term.

Our findings suggest that meeting with other parents who have an affected child was sought after by parents and could result in increased parental confidence, knowledge, well being, and better communication with clinicians (Bridgens and Kiely, 2010). Although many families who share their experience of having a child with clubfoot,

seek advice and support from Internet resources (STEPS), our data suggests that a significant group of parents are not comfortable with using such online resources but may benefit from more local provision of support. Thus our findings indicate that the development of local support groups for parents could be a beneficial support mechanism.

Our findings also support Russel (2003) who suggests that parents of children with disabilities deserve better information, advice and support from medical and social staff, family and other support networks in order to relieve the burden of their new role — being a parent of a different child. The provision of antenatal meetings between parents and their child's surgeon together with parental information packs and a designated nurse/physiotherapist as a point of contact for parents during treatment may improve parents' experience. Such targeted information and support should increase parental interest in treatment, have a positive impact on their satisfaction and may result in a decrease of non-compliance due to lack of knowledge and support (Bridgens and Kiely, 2010).

Study strengths and limits

This study provides one of the first accounts of the experience of parenting a child with CTEV in the UK. It draws upon the strengths of using qualitative interviews to gain in-depth insights into participants' views and experiences. The age range of the participants' children was quite wide, enabling us to explore issues across the childrens' development stages. However, further research into individual stages is needed. Arguably there were a small number of participants but this number is thought adequate for a qualitative study of this kind (Mason, 2002) and is in the range reported by other studies exploring health care users' experiences (Tak, 2006). Furthermore, whilst our sample was drawn from a period over 14 years our data did not reflect any notable differences in parents' experiences of their child's Ponseti treatment and professional support within this timeframe. However, it should be acknowledged that a larger sample may have reflected differences in treatment and parental support over this time. Given that 15/17 families who were invited by the clinician took part it is also possible that we experienced a form of 'gratitude bias' (Ovretveit, 1992).

The sample is also unrepresentative of the wider UK population because all participants were Caucasian and their children received their main treatment in a teaching hospital. All interviews were conducted within working hours, hence the majority of the families were represented by mothers only. Further work should be undertaken to explore fathers' views of parenting a child with clubfoot and any differences between homemakers and working parents' experiences. As we did not collect in-depth data about participants' educational backgrounds, future research would also benefit from collecting the accounts of different populations in different settings.

Conclusion

This qualitative study provides insights into the psycho-social aspects of parenting a child affected by CTEV. The findings suggest that management of clubfoot should be centred more on the concerns and needs of parents and their children. Of particular importance was our finding that participants experienced a range of negative emotions and perceptions similar to those experienced by parents of children with what are considered to be more disabling conditions. This indicates that more attention should be paid by healthcare professionals to the emotional impact on parents of their child's CTEV diagnosis and treatment. Given that parents are responsible for home treatment, in particular compliance with bracing, health professionals need to ensure that the necessary emphasis on the role of bracing does not extend to inappropriate criticism of parental efforts to comply. Furthermore, parents should not identify failure of bracing with personal parental failure because, even under conditions of optimal compliance, bracing is not always successful. Another important finding was that parents may not receive the most appropriate form of support and/or information about their child's diagnosis/treatment at the right time for them and this issue is worthy of further attention. As a consequence, the provision of antenatal meetings between parents and their child's surgeon together with parental information packs and a designated nurse/physiotherapist as a point of contact for parents during treatment may improve parents' experience and these approaches merit further study. Our data also suggest that a significant group of parents were not comfortable with using internet resources but may benefit from a more localised provision of support. Socialisation with other parents in a similar situation during a support group meeting should result in increased parental confidence, knowledge, well being and better communication with clinicians.

Ethical statement

The study was approved by the regional (Grampian) NHS Research Ethics Committee.

Role of funding source

This study was part of an MSc in Health Services and Public Health Research and as such resourced by the University of Aberdeen. There was no external funding.

Conflict of interest statement

There are no conflicts of interest. Simon Barker was the clinician treating the patients with CTEV. He invited parents to be interviewed. However parents replied to the first author (who is not connected to the health services) and she conducted the interviews independently. Mr. Barker only saw the thematic analysis, not the individual transcripts of the interviews, nor any names of interviewees.

Acknowledgements

This research led to an MSc degree for MPM. The authors would like to thank all the parents who spoke about their experience of parenting their child with CTEV and to SPARKS for funding our research into clubfoot.

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