Juvenile idiopathic arthritis (JIA) is an important disease of childhood with far-reaching effects on the child and family. Splinting is a major treatment modality used by occupational therapists for children with JIA. Parents play a central role in whether, when and how splints are used with their children on a daily basis. This paper describes a qualitative research project, which was undertaken to evaluate an occupational therapy service for children with JIA whose treatment had involved splinting. Using semi-structured interviews, the study investigated five mothers’ perceptions of the effectiveness of splinting for their children.

The interviews revealed five major points. First, the informants generally believed the splinting to be effective. Secondly, the children involved generally resisted wearing splints because they were physically uncomfortable and made them feel different to other children. Thirdly, the mothers used a variety of strategies to ensure that their children wore the splints. Fourthly, the perception of having a positive and supportive relationship with the therapist enhanced the mothers’ ability to adhere to splinting. Lastly, the mothers’ grief at having a child with JIA influenced their ability to understand and attend to information about specific interventions such as splinting. Practical responses to these findings are outlined.

The Effectiveness of Splinting as Perceived by the Parents of Children with Juvenile Idiopathic Arthritis

Natalie Schroder, Merrill J Crabtree and Sarah Lyall-Watson

Introduction

Juvenile idiopathic arthritis (JIA) is a disease of childhood with far-reaching effects on the child and his or her family (Bender et al 1994). Occupational therapists have a significant role in the treatment of children with JIA and use splinting as a primary intervention technique. While splinting is widely used and accepted by occupational therapists as a therapeutic modality that aims to maintain or increase joint range of motion and reduce pain, the effectiveness of splinting is insufficiently substantiated (Falcolner 1991).

This study was conducted for the purpose of evaluating the occupational therapy for children with JIA at a major children’s hospital. In particular, the study aimed to explore parents’ perceptions of the effectiveness of splinting, which forms a major part of treatment for children with JIA who experience pain and limitations to joint range of motion. Parents were selected as the focus for the study because clinical observation and the literature (Rapoff 1989, Kroll et al 1999) suggested that parents have the main responsibility for ensuring that their children adhere to the recommended splint-wearing regime.

A phenomenological orientation was chosen to guide the research (Crabtree and Miller 1999), which sought to highlight the essential features of splint wearing from the perspective of parents. The study was guided by the following major research question:

- How do parents determine the effectiveness of splinting for their children?

To focus the study further, a number of more specific questions were asked:

1. Did the parents perceive splints to be effective? And, if so, why?
2. What positive or negative effects, if any, had they seen?
3. What issues were important to the parents when splinting their children?
4. What factors had an impact on the parents’ and the children’s compliance with the wearing regime?

Method

Setting

The study was conducted through the occupational therapy department of a major metropolitan children’s hospital in Queensland, Australia. Children with JIA would typically engage with a team of health professionals at this hospital, including a rheumatologist, a physiotherapist, an occupational therapist and a nurse, and have prescribed
medication, exercise programmes, splints and hydrotherapy as part of their treatment programme. The occupational therapist on the team aimed to assist the parents and the children in adjusting to the disease, to address the functional impact of the condition on the child's self-care, leisure and skill development and to facilitate joint protection. Two major therapeutic strategies used to achieve these aims were splinting and education. The occupational therapist and the physiotherapist also collaborated closely on an exercise programme.

Participants
The study aimed to explore parents’ perceptions of the effectiveness of splinting in order to evaluate the current occupational therapy service offered at the hospital. Consequently, informants were purposefully selected in order to highlight the needs of those children who had intensive occupational therapy involvement. These children had required at least one splint and had experienced a higher level of joint involvement, pain and reduced joint mobility than other children treated at this setting. They were either currently involved with the occupational therapist or their contact had been recent. Additionally, the children identified to participate varied in their experiences of splinting, whereby both positive and negative reactions were represented.

Guided by this sampling method, five children with JIA who had worn splints as part of their treatment were identified. These children represented a balance of gender (three girls and two boys) and a range of ages (3-10 years, with an average age of 6.5 years). Three of the children had systemic juvenile arthritis and the other two had polyarticular juvenile arthritis. The average length of time since the diagnosis of their arthritis was just over 2 years. Two of the children were diagnosed by 2 years of age, two were diagnosed between the ages of 5 and 6 years, and one was diagnosed at 9 years of age. Four children had worn or were currently wearing knee splints and all the children had worn or were currently wearing wrist splints. Three of the children were in remission at the time of the interview and two of the children were in the acute stages of their illness.

While the study aimed to investigate the perceptions of parents, it became clear throughout the recruitment process that, when approached to participate in the study, the mothers in this sample had the most active role in supervising and facilitating the wearing of splints with their children. Therefore, these five women became the primary informants. All five women agreed to participate in the study, were provided with information sheets and gave written informed consent. The women had an average age of 30 years. Three of the women were single mothers, with only one child. The remaining two women were married, with supportive husbands and other children (see Appendix 1).

Data collection
After receiving approval from the hospital ethics committee, audio-taped semi-structured interviews, ranging in duration from 30 to 50 minutes, were conducted with informants. A general interview guide (Appendix 2) was used to gain information about a range of topics that might highlight the parents' perceptions of splinting and provide contextual information to assist in interpreting these perceptions. These semi-structured interviews were designed to be flexible, enabling the informant to talk about what was important and meaningful to her, as well as enabling the researcher to pursue particular issues in greater depth (Patton 1990). At the completion of each interview, the interview guide was refined for use with subsequent informants to enable further exploration of important themes as they emerged. Each informant was interviewed once. In some cases, a follow-up phone call was made in order to clarify important issues.

To increase the trustworthiness of the data, triangulation of data collection methods was achieved through observation during a field visit and the subsequent production of field notes. Field notes were also written immediately following the interviews, summarising the main issues raised and describing the researcher’s impressions and perceptions of the interview. The transcription of the interviews took place at the first opportunity following the interview and the informants were given pseudonyms to ensure confidentiality.

Data analysis
Once all the interviews were completed and transcribed, the data were subjected to a comprehensive thematic analysis through multiple readings of the transcribed interviews and field notes. The data were analysed inductively, whereby patterns, themes and categories of analysis emerge from the data itself, rather than being determined prior to analysis (Patton 1990). Each paragraph of each transcript was analysed and coded, using the QSR NUD*IST (Non-numerical Unstructured Data: Indexing, Searching, Theorising) computer programme to manage the data. Codes were then grouped into broader themes. To enhance methodological rigour, both the first author’s interpretation of the data and a reflexive analysis (Krefting 1991) of her own beliefs and experiences, as well as the possible impact of these on the study and the interpretation of data, were reviewed by and discussed with the second author.

Results
Parents’ perceptions of the effectiveness of splinting
When asked whether splinting was effective, the informants identified both advantages and disadvantages of splints, which each mother had carefully weighed up in determining whether to apply the splints or not. The mothers identified three major beneficial effects of splints. First, they overwhelmingly responded that splinting had a positive effect on joint range of motion by preventing the development of joint contractures and deformities in their children:

Physically, if it had not been for the splints, he would have pulled his knees up and curled up in a little ball and stayed
there, you know ... He's a lot straighter in the legs. He can move his legs. He can walk. He's not curled up in a ball ... his joint range has improved. (Kate.)

Secondly, and to a lesser extent, they felt that the splints were beneficial in reducing pain, particularly during and after sleep. Lastly, all the mothers noted that the functional upper limb splints provided support to joints during handwriting.

All the mothers also outlined negative aspects of wearing splints. They perceived splints to be uncomfortable and restrictive to movement and to interfere with the child's functional development and play:

His splints just get in the way. He can't play with them on. They are too restrictive. He doesn't like wearing his splints at school – he's not a normal child then, he can't do normal things, can't run, can't move, can't bend. (Kate.)

Factors influencing parents' perceptions of effectiveness

The results suggested that the presence or lack of a visible benefit of wearing a splint influenced an informant's belief in the efficacy of the splint. The mothers reported that factors such as periods of remission and negative reactions (discomfort, disruption to sleep and restriction to movement) made it difficult for them to continue splinting their children. However, those mothers who demonstrated a strong belief in the efficacy and long-term benefits of splints had continued to persevere with this therapy in the face of such difficulties. As the following quotes demonstrate, two of the mothers had seen the effects of being without the splints for a period of time on their child's joint range of motion. As a result, they both believed strongly in the efficacy of the splints, despite also having had negative experiences with the splints:

– For a while, a couple of nights in a row, I took his splints off when he first got sick. We were at mum's place for one night and I forgot them, and the second night he was really sore, and he was really distressed so I took them off, and then I think the third night we just plain forgot. And then, by the time the morning came, he had just contracted so much that it was difficult to get the splints back on. So it just made me realise that the 12-15 hour stretch that they get does make a big difference. (Linda.)

–My knowledge of seeing him when he can't walk is enough to get him to wear the splints ... I know that if he didn't have the splints, there would be so much pain when he tried to straighten his legs. (Kate.)

To summarise, the mothers interviewed in this study outlined both positive and negative aspects of splinting and most perceived splinting to have been effective for their child. This perception was particularly strong when they had concrete experiences to draw upon.

Factors influencing adherence to splinting

Parents' difficulty in adhering to splinting regimes has been documented previously (Barlow et al 1998). The informants in this study outlined two factors that influenced their compliance with the recommended splinting regime. These were the child's age and reactions to the splints and the relationship that the informant had with the occupational therapist.

The reactions, age and development of the child

The mothers reported that their children's reactions to and cooperation with the splinting regime was essential to its effectiveness. They said that when the children were young and unable to remove their splints independently, it was easier to comply with splinting. However, as the children grew older adherence to the splinting regime became more difficult because the children often removed their splints when unsupervised.

The data suggested that the children were reluctant to wear splints for two main reasons. First, all the children except one did not like the hard thermoplastic splints because they were uncomfortable, while they did not mind wearing neoprene splints. For one child in particular, the splints caused considerable discomfort and splinting became a difficult and traumatic experience. Her mother, Susan, felt that the discomfort was related to her child's acute inflammation and joint swelling and the number of splints she was wearing. She said of the experience, 'As you can appreciate, if you're putting them on at night ... when she's screaming that she can't stand to have them on anymore too, it's very difficult.' Understandably, this mother did not persevere with splinting.

A second reason that the children were reluctant to wear splints was a fear of 'standing out' as different and a desire to be 'normal'. Three mothers reported that their children felt different from others as a result of wearing their splints. For example, Kathy said, 'Rachel's been a little bit reluctant to wear those I suppose at school initially, because of the thoughts of what the other children might say.' Susan commented, 'I think she found it [difficult] sometimes with other kids ... she was at that age where it did make it a little bit difficult.' Kate also stated:

He's not like everyone else ... The children see that he's different when he wears his splints. He wants to be a normal child ... He walks along the road with the other kids, and takes them off and puts them in his bag ... He doesn't like wearing his splints at school, he's not a normal child then ... kids ask him what they are. They make him stand out and call attention to him and they get in the way. But he knows he has to wear them.

Relationship with the therapist

Another major finding of the study was that a parent's relationship with the occupational therapist was an important influence on compliance with splinting. This finding aligns with other research that has indicated that the quality of the therapeutic relationship has an impact upon adherence with a range of interventions (Cameron 1996), such as splinting (Nicholas et al 1982, Groth and Wulf 1995). All the mothers in this study indicated that they had
experienced a positive relationship with their occupational therapist and stated that this relationship was important to the way that they approached the splinting of their child. The mothers reported that they valued the mutual respect and rapport with their occupational therapist and that these factors were significant in how they felt about the splinting regime:

They have to put a certain amount of heart into it. It can't just be a job. You're dealing with other people's lives and when you're dealing with other people's kids it's even more to the heart. I respect [the occupational therapist]. I think if I didn't respect her, and I didn't think much of her, I probably wouldn't stick with some of the things. (Linda)

A personal approach to therapy was also seen as important by the informants. They appreciated the therapist who took time, communicated care and addressed their needs. The single mothers indicated that their relationship with the occupational therapist was an important form of support. For example, Linda had low levels of support at home and she commented that her occupational therapist and physiotherapist were especially valuable to her as a means of support. She said:

[The occupational therapist] and [the physiotherapist], they were fantastic. I think because we're all the same age ... and we'd all have therapy together, we just had a rapport ... They just became more than therapists.

The mothers' rapport with the therapist and the support gained from the therapeutic relationship assisted them in feeling more positive about the splinting regime, therefore aiding their compliance with the regime.

Parents' strategies for making splinting successful

A previous study revealed that parents struggle with imposing splints, which they know will restrict their child's personal freedom and independence (Kroll et al 1999). The mothers in the study had developed a number of strategies to help them to adhere to the recommended splinting regime. Personal discipline and courage on the part of the mother, especially in the face of negative experiences, as well as taking a team approach with her child were effective ways to ensure that the children wore the splints:

You're not fighting with them to get it on, it's not a 'you versus me' situation. It's a, 'I have to do this, and mum doesn't like doing it either, but we have to do it.' I don't know, I think that he can understand that I don't like to do it, that it's just something he has to do, that we have to do together so that he doesn't get sore. (Linda)

Having the child participate in the fabrication of the splints was also highlighted as an important strategy. One mother's experience demonstrated this. Her child was enabled to participate fully in the fabrication of her splints: choosing materials and colours and decorating her splints. As a result, she was highly compliant with the splinting regime because she enjoyed wearing her splints. Her mother said:

When we got home, she just couldn't wait to show them to her older brother and sister, and they were special and no one was allowed to touch them, and all that sort of thing ... Rachel was able to choose what colours, and with the heart and that. And [the occupational therapist] said to her to come home and decorate them, so we've done that. (Amanda)

The mothers also found that the use of routine in the splinting regime was important, as well as emphasising the benefits of using reward as a reinforcer of compliance (Rapoff 1989).

'Just one more thing'

For occupational therapists, splinting is a major focus. However, for the informants in this study, splinting was just one of a multitude of events and experiences related to having a child with JIA. Consequently, when discussing splinting, the mothers placed it in the context of their own grief at having a child with JIA and their need for support and understanding. For example, one mother discussed the impact of her grief on her acquisition of new information and understanding of the illness and the splinting regime:

Splinting and the discovery that your child has a disease go hand in hand. Everybody in the hospital has got their job to do, but probably the most important thing there is to know and to remember is that they're working together with a parent who's only just found out that their child is long-term ill. (Linda)

The mothers were also concerned about the effects of JIA on the child's social development. During the course of the interviews, it became apparent that the mothers wanted to be able to discuss their experiences of the effect of JIA on their child's general play and development. As Linda explained:

They [other kids] just run around and play and in the water they splash around and their dads and mums throw them around and Neil will just sit there. He loves to watch, but he will just ... he's very nervous around water, and just playing with other kids ... he's really unsure because if he gets knocked over, he doesn't put his hands out, because his wrists are involved. So he's just learned that it's a bit dangerous to play. To him the threat of being knocked over, I think you know just classical conditioning, that he knows it's really going to hurt.

In particular, the mothers were concerned about their child's school attendance and reduced opportunities to learn and participate, as well as the impact on their child's self-esteem and feelings of belonging and acceptance. They discussed how important it was to them to work in collaboration with teachers. Especially important to the mothers were the education sessions conducted by the occupational therapist and the physiotherapist in their children's schools. These sessions were aimed at increasing teachers' and students' understanding of the developmental effects of JIA in order to make school attendance easier for the children.

Having a child with JIA is also a significant source of stress for the family (Bender et al 1994, Kroll et al 1999).
The mothers reported on their significant support needs, which they felt had an impact on the success of the interventions for their children, such as splinting. Those mothers with supportive families appeared to cope much more effectively with the splinting regime:

When you really think about it, and my husband and I have talked about it a lot, and we just have to take each day as it comes and work our lives that way … I couldn’t survive, I couldn’t do it without my husband and the others. (Amanda.)

In contrast to the married mothers, a lack of support emerged as a major issue for the single mothers in this study. They lacked a partner with whom to share their feelings, their grief, and the burden of dealing with a chronically ill child. Linda, a single mother, said of her experience:

It was really difficult. And I think because I’m not the kind of person that lets stress out and I don’t have any … like Neil’s father lives a really long way away … it was just difficult because there’s no kind of outlet.

For the mothers in this study, splinting was just one of a large number of concerns raised by having a child with JIA. These concerns placed extra pressure on the mothers, who benefited from support, either from their partners or from therapists.

Summary of results
This study revealed five major factors relating to the perceptions of splinting of mothers who have a child with JIA. First, while the mothers in this study outlined both positive and negative aspects of splinting, they generally perceived it to be effective. Secondly, they generally reported that their children did not like wearing hard thermoplastic splints because they were uncomfortable and made them feel different and, consequently, they often removed them if they could. Thirdly, the mothers used a number of strategies to encourage their children to wear splints, including personal discipline and courage, taking a team approach, developing a routine, rewarding their children when they wore the splints and involving the children in the fabrication and decoration of the splints. Fourthly, they reported that a positive relationship with the occupational therapist helped them to adhere to splinting when it was difficult and through which they felt supported. Lastly, the mothers approached splinting from a context dominated by their own grief at having a child diagnosed with JIA.

Discussion and recommendations
The struggle for parents
The data collected in this study presented an overwhelming sense of struggle on the part of the informants. These mothers often had to apply splints to their children knowing that they were uncomfortable and made them feel different. Some of these mothers were juggling the demands of a household with other children in addition to caring for a child with a demanding medical condition, while others lacked support. They also struggled with their own grief at having a child diagnosed with a major debilitating illness, which impeded their reception of information and ability to comply with treatment.

Implications for therapy and research
While the sample used in this study was purposely chosen to provide one particular occupational therapy department with feedback on the service it was providing, some general recommendations for therapy may be deduced from the findings; readers are encouraged to make comparisons with their own context and determine the relevance of these findings for their own work. One outcome of this research for the particular service in which it was undertaken was that changes were made to improve its educational strategies for parents, including the appointment of a social worker to the team.

When developing an intervention regime, such as splinting, an awareness of the intensity of parents’ struggle may be useful. Interventions that require implementation in the child’s daily life may be enhanced by taking into account the parents’ adjustment to the condition, their perceptions of that intervention and the likely impact of the intervention on the whole family. Interventions like splinting are ‘just one more thing’ in living with a child with a chronic illness.

In this study, it appeared that the mother’s own discernment about the needs of her child always ‘triumphed’ over any instructions given by the treating team. Therefore, engaging with parents in a problem-solving partnership may be a useful approach. Therapists may also be an important source of support for parents. Being ‘more than just therapists’ meant understanding the experience of JIA for the child and his or her family and acknowledging their struggle. It also meant providing practical support when it was required.

This study focused primarily on the perceptions of parents and dealt with a small number of mothers whose children represented the clients of a service with reasonably high splinting requirements. Future studies using a sample of children that are more representative of the population of JIA clients would be useful to further the understanding of splinting with these children.

Specifically, this study sought to explore parents’ perceptions of splinting for their children with JIA. While the mothers generally perceived splints to be effective, a flexible research methodology allowed exploration in greater depth of the struggle that parents faced in trying to make splinting work for their children. Readers are encouraged to compare the results of this study with their own settings and make conclusions about the relevance of these findings to their practice.

References
Appendix 2. Interview guide

Introduction
Introduce self
Explain study
Read information sheet together
Read through consent form together and sign
As we go through the interview, if you have any questions at any time, please feel free to ask; are there any questions before we begin?

Background details
Name of child and parent
Age of child and parent
Family members/siblings
Living situation
School

Child
Diagnosis and date of diagnosis
Current stage of illness
When they were first splinted
Types of splint prescribed
Period of splint wear
Stage of illness during splint wear

Past
What they were told about the splints
Child’s reactions
Child’s level of understanding
Benefits seen from splints
Negative effects of splints

Present
Current splint usage
Why they are wearing/not wearing splints
Difference splints have made; if so, when the difference was noticed
Social impact
Physical impact
Pain
Function
Home
School
Child’s reaction now
Knowledge of splinting now

Future
Expected splint usage and outcome of splint usage
What would you have liked to have known at the beginning that you now know?
What would have made the process of splinting easier at the beginning?

Appendix 1. Characteristics of the five informants

<table>
<thead>
<tr>
<th>Characteristics</th>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mother’s name</td>
<td>Linda</td>
<td>Susan</td>
<td>Kate</td>
<td>Kathy</td>
<td>Amanda</td>
</tr>
<tr>
<td>Mother’s marital status</td>
<td>Single</td>
<td>Single</td>
<td>Single</td>
<td>Married</td>
<td>Married</td>
</tr>
<tr>
<td>Name of child</td>
<td>Neill</td>
<td>Tammy</td>
<td>Billy</td>
<td>Rachel</td>
<td>Kylie</td>
</tr>
<tr>
<td>Age of child</td>
<td>3 years</td>
<td>10 years</td>
<td>7 years</td>
<td>6 years</td>
<td>8 years</td>
</tr>
<tr>
<td>Gender of child</td>
<td>Male</td>
<td>Female</td>
<td>Male</td>
<td>Female</td>
<td>Female</td>
</tr>
<tr>
<td>Type of JIA</td>
<td>Systemic</td>
<td>Polytarcticular</td>
<td>Systemic</td>
<td>Systemic</td>
<td>Polytarcticular</td>
</tr>
<tr>
<td>Age at diagnosis</td>
<td>12 months</td>
<td>9 years</td>
<td>5 years</td>
<td>6 years</td>
<td>2 years</td>
</tr>
</tbody>
</table>