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Abstract

Objective: To explore the nature and management of needle-related distress in children and adolescents with cystic fibrosis (CF). **Design:** Qualitative study using semi-structured interviews.

Methods: Fourteen child-parent dyads took part. Children (5 male; 9 female) had a mean age 12.4 years (range 7-17) and were mostly diagnosed with CF at birth ($n = 11$). Frequency of needle procedures ranged from once to six times a year. Parents (3 male; 11 female) had a mean age of 41.5 years and were from a variety of socio-economic backgrounds. Interviews were transcribed and analysed using thematic analysis. **Results:** Most participants identified previous needle experiences and pain as related to their needle anxiety. Over half of parents and children considered 'taking control' to be the optimum coping strategy. The majority of parents and children thought inhaled nitrous oxide gas during needle procedures was helpful in managing needle-related distress. Parent and staff influences on needle-related distress are also examined.

Conclusions: Needle-related distress in children with CF has a substantial impact on children and their parents, and may lead to management problems and treatment refusal. Psychological and pharmacological interventions could reduce distress and aid management.

Keywords: Needle distress, anxiety, cystic fibrosis, children, parents.

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Until recently, cystic fibrosis (CF) was classified as a terminal childhood illness (Carpenter & Narsavage, 2004). Advances in research and improved treatment have significantly increased life expectancy and children with CF can now expect to live into adulthood, often into their forties (Cohen & Larson, 2006). CF treatment involves several approaches that range from taking enzymes, vitamins, medication, physiotherapy, adhering to dietary regimes and attention to hygiene (Havermans & De Boeck, 2006). Regular needle procedures are an important part of treatment for CF. Children with CF undergo regular blood tests to identify those at risk of developing complications and take appropriate action. Furthermore, children with CF are typically hospitalised on a regular basis, often every six months depending on the severity of the case (Wilmott & Fiedler, 1994), where they may receive two-week courses of intravenous (IV) antibiotics.

It is common for children with CF to exhibit distress and behavioural problems during invasive procedures (Duff, 2001). The complex combination of invasive procedures with strict medication and physiotherapy regimes can decrease adherence rates to treatment (McClellan, Cohen, & Moffett, 2009; Modi et al., 2006). Effective management of needle distress in children with CF is therefore critical. Pharmacological management involves analgesics during or after the injection, which can be applied to the skin (e.g. EMLA cream) or taken orally (Lander, Weltman, & So, 2006; Moore, Straube, & McQuay 2009; Zempsky, 2008). However, the use of analgesics by healthcare professionals is variable (Howard, 2003). More rarely, inhaled nitrous oxide gas has been used to reduce pain and distress in children during procedures such as lumbar puncture, bone marrow aspirate, venous cannulation or dressing changes (Kanagasundaram, Lane, Cavalletto, Keneally, & Cooper, 2001). This has also been used during needle procedures with children with CF and a small pilot study found that 14 out of 15 children with CF evaluated it positively (Williams, Riley, Rayner, & Richardson, 2006).

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Predictors of needle-related distress in children with CF have not been examined.

However, research into children's pain during a range of invasive or painful procedures shows increased pain is variously associated with younger age, previous painful experiences, being female, and expectations that a procedure will be painful (Cheng, Foster & Hester, 2003).

However, a recent review concluded that the evidence is inconsistent (Cheng et al., 2003). This may be due to the wide range of procedures and samples studied. For example, factors that influence distress during immunisations may be different to those during needle procedures for chronic illnesses such as CF. Furthermore, whilst research has been conducted into children with chronic conditions such as cancer, CF is incurable and requires regular clinical surveillance. Therefore throughout sufferer's lives they will encounter regular needle procedures whilst healthy and ill. There is also evidence to indicate that if not well managed, needle distress can lead to reduced adherence to treatment which is paramount to good clinical management of CF (Jones, DeMore, Cohen, O'Connell, & Jones, 2008; Zambanini & Feher, 1997). It is therefore important to study procedural distress in different clinical contexts to aid understanding of how to reduce distress within that unique clinical situation (Blount, Piina, Cohen & Cheng, 2006).

Parents' views of needle procedures for children with CF have not been widely studied. Literature on invasive paediatric procedures suggests parents consider needle procedures to be one of the most distressing procedures in hospital settings, surpassed only by the experience of their child having surgery (Caty, Ritchie & Ellerton, 1989). Nonetheless, the majority of parents want to be with their child during invasive procedures (Pruitt, Johnson, Elliott & Polley, 2008). Parental behaviour during such procedures is associated with their child's distress. Parental anxiety, criticism, apologies and reassurance are associated with increased child distress (Khan & Weisman, 2007; Mahoney, Ayers & Seddon, 2010; Schechter, Zempsky, Cohen, McGrath,

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McMurtry & Bright, 2007), whereas distraction and humour are associated with decreased distress (Schechter et al., 2007).

Needle-related distress may have a significant impact on children with CF. Literature on needle procedures in other samples suggests they are associated with substantial anxiety and distress in children and adolescents. Many children consider needle-procedures as one of the most traumatic experiences of hospitalisation (Cordoni & Cordoni, 2001). Needle-related distress and anxiety can have adverse short- and long-term psychological effects, including anticipatory nausea, insomnia, eating problems, increased fear, anxiety, effects on future pain responses, avoidance, and non-adherence to treatment (Blount, Pira & Cohen, 2003; Kennedy, Luhmann, & Zempsky, 2008; Young, 2005). Needle-related distress may also escalate over time with successive procedures (Ellis & Spanos, 1994; Katz, Kellerman & Siegel, 1980; Young, 2005). Effective psychological interventions for needle-related distress include distraction, hypnosis, and cognitive-behavioural interventions (Uman, Chambers, McGrath & Kisley, 2008).

In summary, CF involves regular needle procedures that may be associated with distress, behavioural difficulties and lack of adherence to treatment. Various pharmacological and psychological interventions are available. However, little research has examined the associations, experience and impact of needle-related distress in children with CF. The current study therefore uses qualitative interviews to explore needle-related distress in children with CF and their parents. It is hoped this may improve understanding about needle-related distress, individual variation in coping, and perceptions of effective treatment for children with CF.

Method

Design

An interview study of children with CF and their parents to explore the nature and management of needle-related distress.

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Participants

A convenience sample was recruited from a CF clinic at a regional paediatric hospital between January and August 2007. Children were eligible to participate if they had been diagnosed with CF for at least 12 months, were seven years of age or older, able to read and speak English fluently, and were accompanied by a parent or guardian. Eighteen families attended the clinic during the recruitment period and 14 of these child-parent dyads agreed to take part (78%). Children (5 male; 9 female) had a mean age 12.4 years (range 7 - 17) and most were diagnosed with CF at birth ($n = 11$). Frequency of needle procedures ranged from 1 - 6 times a year. Parents (3 male; 11 female) had a mean age of 41.5 years and were from a variety of socio-economic backgrounds. Characteristics of children and parents are shown in Table 1.

- insert Table 1 about here -

Measures

A semi-structured interview schedule was devised to examine the nature of needle related distress, causes and impact (see Appendix). Questionnaires were used to measure demographic information and to screen for clinical levels of anxiety in children. Clinically significant anxiety was screened for using the Revised Child Manifest Anxiety Scale (RCMAS; Reynolds and Richmond, 1978), a 37-item self-report inventory with four subscales measuring the level and nature of anxiety. The scale has a range of 0 to 37 and a cut-off of 19 indicates severe anxiety. The RCMAS has established a high internal consistency of .91 (Suvey, 2005).

Procedure

Ethical approval was obtained from the local NHS Research Ethics Committee. Parents of children scheduled to attend a CF clinic were sent information and a letter of invitation one week before their appointment. Potential participants were approached upon arrival at the clinic. If both the parent and child agreed to participate, parental consent and child assent were collected.

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Parents and children were interviewed separately after their scheduled appointments. Interviews were carried out by a researcher (IM) who was not employed by the hospital to ensure that parents and children did not know the interviewer or associate her with their care. All data were stored anonymously with identifying details removed.

Interviews were transcribed and qualitative analysis carried out using systematic thematic analysis (Boyatzis, 1998). Dominant themes were identified through close examination of the data by one author (IM). First, half the interviews (7 child and 7 parent interviews) were analysed using WinMax software to identify emergent themes and subthemes. Themes that were generated by children and parents were similar so were combined to form a draft coding schedule. This draft was then used to develop a final coding schedule through inspection of themes, frequencies, discussion and verification through examination of interview transcripts (IM & SA). The coding schedule clearly defined and elaborated each theme and subtheme, including inclusion and exclusion criteria and examples of quotes. This schedule was then used to recode all interview transcripts. Rater-to-expert reliability (Boyatzis, 1998) was carried out on approximately 20% of codes by printing off a list of quotes from these codes which were then categorised by the research supervisor (SA) with 97% agreement. Quotations are identified using C/P (child/parent); participant number; gender; and age, e.g. 'C1:G:10' means Child participant 1; girl; aged 10. 'P1:Mother' means Parent 1; mother.

Results

Ninety-three percent of children reported needle-related distress (see Table 1), although none of the children were clinically anxious (RCMAS range 0 - 18, mean = 11.2, SD = 5.71). Analysis of interview transcripts yielded six major themes with various subthemes. These are

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shown in Table 2 with the frequency with which themes were endorsed by parents and children.

Themes are outlined and illustrated below.

- insert Table 2 about here -

Perceived causes of needle-related distress – “I had a bad experience and I suppose it stuck”

Previous experiences: Children and parents believed that needle-related distress was caused by negative previous needle experiences, such as blood tests during which medical staff failed to locate a vein or that caused excessive bleeding or bruising.

“I don’t like them [needles]. When I was younger I had a bad experience and I suppose it just stuck” (C10.G.15).

“My son had a couple of IV’s and he was fine. Then there was one that went wrong, no disrespect to anyone, but it went wrong... blood shot out everywhere, all over him. After that he was just awful” (P9:Mother).

“[the usual doctor] wasn’t here. Someone tried to put a line in without any gas and air. It was horrible, I was crying as well. She was never that bad, but since then it’s really put her off” (P10:Mother).

“From the moment he was in hospital, as a newborn baby, he was stuck with needles to find out what’s wrong... knowing that every time someone comes near your cot you’re going to get hurt. It must have an effect on children” (P3:Father).

Pain and anticipatory anxiety: anxiety and distress during needle procedures were attributed to previous experience of pain, fear of pain and anticipatory anxiety, although many children recognised they expected the pain to be worse than it actually was.

“The big thing is it hurts, and telling someone to be brave is just ridiculous when they have no other option” (P14:Mother).

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“It really hurt and from then on I hated needles... I always thought it was going to hurt more than it did” (C12:B:12).

“Yeah, it’s not that it hurts greatly, but it’s the build up, the fear” (C14:G:17).

“It’s a mental thing as well. If it’s bigger you think it’s going to hurt more, even if it doesn’t actually” (C4:B:17).

Reactions to needles – “She’d lash out, bite, pull hair and scream”

Physiological and behavioural reactions: Behavioural reactions included refusing to stay still, crying and screaming, fighting, and the child refusing access to their body. Physiological reactions to needles included becoming pale, sweating, tension, shaking, and hyperventilating.

“You’d have to fight with him, he wouldn’t stay still” (P13:Mother)

“She’d clam up, close her arms, clam her arms into her body so you can’t get access to her without force” (P7:Mother).

“I get tense and I shake...my knees start...I try not to think about it, I clench my fist” (C12:B:12)

Coping strategies – “I have to be in control of what happens”

Taking control: The most commonly mentioned coping strategy was taking control. The majority of parents and children described some element of control as essential in coping with needle procedures. One child used the example of being terrified of medical needles but not frightened when she had her lip pierced. She said

“I think it’s because I have the control. It’s my body and something I wanted to do. If you have a [IV] line, the control is with the other people” (C14:G:17).

“The only thing that’s working for him is to understand that he can control his fear” (P3:Father).

Various strategies were used to increase control, including proactive coping techniques such as telling staff when to start the needle procedure, writing a letter afterwards (for the future) telling

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themselves it is not that bad, and creating a needle-plan and giving it to staff before the needle procedure.

“It helped enormously because I was in control then. The [needle plan] card is good to take control of the situation. Control is very important” (C14:G:17).

“He tells them they have to put the line in when he’s ready. He’ll count to three. He still sweats, but he’s nowhere near how he used to be.” (P13:Mother).

“I remember I used to like write a letter to myself every time after I’d done [needle procedure] saying it was alright. I’d open and read it again before next time” (C5:B:12).

Avoidance: Conversely, some children used avoidance strategies such as not looking at the needle or thinking about it. Avoidance was sometimes so severe that parents found it hard to get their children to come to healthcare settings.

“I don’t want to look at it, I don’t want to think ‘Oh God that has to go in my vein’” (C10:G:15).

“I try not to think about it, because that will make me panic” (C12:B:12).

“There was a point of blank refusal. We couldn’t get him in the car or bus to come down here” (P5:Mother).

Management of needle anxiety – “As long as she has Entonox she’s fine”

Inhaled nitrous oxide: In this CF clinic, needle anxiety is managed using inhaled nitrous oxide gas (Entonox) and play therapy. Nitrous oxide was thought to be effective by 77% of children and 64% of parents. Participants said it reduced anticipatory anxiety, pain and fear of needles.

“If I have to choose one thing I’d choose Entonox, personally” (C14:G:17).

“I like the Entonox so I now look forward to that. Well, not the needles. Entonox” (C5:B:12).

“Without Entonox I’d be scared, but with it I wouldn’t be” (C5:B:12).

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An interesting management technique already mentioned was a needle plan. The child's parent described how the needle plan was developed and used:

“We did work out a strategy. It came from a birth plan. [The child] wrote out a needle plan, and she talked it through at home and worked it out with the psychotherapist here at the hospital. They did a 7-point plan. I think it read: ‘don’t tell me to be brave, I’ve been brave for ten years’ and ‘allow me to scream as much as I like. It helps me’, whereas people would tell her to calm down when she couldn’t. ‘Don’t tell me to turn away, I need to see what you’re doing’ and ‘I’ll tell you when I’m ready, don’t go until I’m ready’. It was just sort of a 7-point plan. She had it written on a card, and every time there was a new nurse or doctor she’d hand the card to them and they had to read it before going near her” (P14:Mother).

Play therapy: Parents also mentioned the benefits of play therapy in managing needle-related distress.

“Children practice injecting into an orange. It took a couple of sessions, but that’s how we got round it in the end” (P9:Mother).

“She did an awful lot of play...every teddy at home had a line in, and she had boxes of syringes” (P14:Mother).

Parent’s role during needle procedures – “Mum holds her hand out and I just look at her”

Support: Children and parents said how important it was that parents support their child during needle-procedures. They provided children with familiarity, reassurance, security and practical support.

“She [mum] usually just holds my hand and cuddles next to me... I know she’s there and it’s just better” (C7:G:9).

“Just being there with her, and try and talk her through it, but I think just being there is it” (P10:Mother).

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“She like says that nothing bad is going to happen, and it will just be about ten seconds...just like that” (C2:G:7).

“I feel safer, don’t know why, I just do” (C13:B:12).

Reactions to child’s distress: However, many parents mentioned how upsetting it is to witness their child’s distress; and trying to conceal this distress from the child. A few parents mentioned being overwhelmed, sometimes to the point of having to leave the room.

“I get upset, but I try not to do it in front of her. She looks at me, and I think she’s the brave one and I’m not. I’ve learned over the years to try not to get upset in front of her because she’s the one she should be worried about, not me. She’s going through it, not me” (P10:Mother).

“It was horrible, I was crying as well” (P13:Mother).

“I had to literally walk off the ward. I couldn’t stand it any longer. Was there no other way forward?” (P11:Mother).

Effect on others: The effect of children’s distress on hospital staff was also raised. Parents could see that it was challenging for staff and also that children might perceive this. However, this was rarely mentioned by children.

“It would take ages and they’d [the staff] all come out of the room all bright red... it was just an awful experience really” (P5:Mother).

“She didn’t think of herself, she kept thinking about the poor doctors and what she was putting them through. She kept thinking of them. She always apologised for it” (P9:Mother).

Staff influences – “I’d rather wait until Monday when the CF team are there”

Familiarity: Staff influences on needle-related distress were mostly mentioned by parents rather than children. Familiarity of hospital staff doing the needle procedure was thought to have a major influence on needle-related distress - to the point where a few children were reluctant to attend hospital if the familiar staff were not on duty.

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“If I actually knew the nurse it would be okay, but if I didn’t I would be like ‘what’s going on? I don’t even know you!’” (C12:B:12).

“If he knows the person who is doing the line or injection he is a lot better. It’s a level of trust he’s built up. Members of staff are very important” (P3:Father).

“If she’s not well at the weekend and I wanted to bring her up she’d say ‘mum, I’d rather wait until Monday when the CF team are there’” (P10:Mother).

Trust: Parents emphasised the importance of trust in needle procedures. A few parents saw being open and maintaining trust as an important part of managing needle-related distress.

“I think it’s actually the person who does it [needle procedure] who needs the confidence of the child...to build up trust and so, especially for younger children” (P11:Mother).

“She doesn’t like things sprung on her, so as long as she is warned. She trusts us all” (P7:Mother).

Physical restraint: Negative influences of staff were nearly all focused on physical restraint during needle procedures. Three parents described having to assist staff in physically restraining their child. One parent believed it was the only way to perform the procedure.

“It took four adults to hold him down at the height of his phobia. It was really the only way he could receive treatment” (P3:Father).

However, two parents found this very distressing and believed the physical constraint contributed to the onset or exacerbation of needle-related distress.

“They wanted me there because I had to help actually hold her down. That was when I thought ‘no, I can’t do this anymore’, and actually walked out” (P11:Mother).

“It came from a lack of control as children are forced into it. They are forced and have no option. The people who love you the most, your mother is holding you down ... I think being constrained, being held down by a number of people made it worse. It was the whole sorry process” (P14:Mother).

Discussion

This study illustrates the nature of needle-related distress in children with CF. Results suggest children with CF experience needle-related distress with associated physiological and behavioural reactions. In keeping with previous research, the perceived factors associated with needle-related distress were previous negative experiences, pain and anticipatory anxiety. (Jones, DeMore, Cohen, O'Connell, & Jones, 2008). Coping strategies mostly revolved around increasing control for the child, although a third of children used avoidance. Parental support, familiar staff and trust were also thought to influence needle-related distress.

These themes were similar for parents and children, which may be due to a variety of factors including the constraints of the structured interview and high levels of congruence between parents and children in this particular sample. However, there was variability in the extent to which some themes were mentioned by parents and children. For example, the effect of distress on others, and the influence of healthcare staff were predominantly talked about by parents. Parents thought familiarity with staff members improved children's feelings of trust and security which, if it is the case, highlights the importance of employing permanent members of staff that children can get to know which may promote child coping (Duff, 2003).

Themes that were raised by more than half the children were pain during needle-procedures, coping by taking control, using nitrous oxide gas and parents support. A variety of strategies to increase control were discussed, including play therapy, writing a letter, needle-plans and controlling the start of the procedure. Interestingly, neither children nor parents directly mentioned using distraction, which is well-established as an effective method for reducing child distress during needle procedures (Blount et al., 2006). Indirectly, three children said that having their parents with them is a form of distraction, which they found helpful.

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The emphasis on control as a positive coping strategy is in contrast to research in other paediatric populations that suggests giving control to the child of when to start a needle-procedure can increase distress (Schechter et al., 2007). Although other research has shown that effortful control strategies, such as consciously regulating attention and behaviour, are associated with less distress (Salmon & Periera, 2002). These inconsistent findings on the use of control strategies during needle procedures may partly be due to differences in the type of control, clinical context and population studied. This highlights the importance of examining needle-related distress and coping under different circumstances, such as for children with CF. It is also important to note that approximately a third of children with CF mentioned using avoidance strategies.

The most frequently mentioned theme by both parents and children was using nitrous oxide gas to cope during needle procedures, which is consistent with previous research on children with CF (Williams et al, 2006). The clinic in which this sample was recruited provide nitrous oxide gas in addition to routine analgesia for children with CF who have (or have had) needle-related distress and associated behavioural difficulties. For example, in this sample, 77% of children reported experience of nitrous oxide gas. However, whilst it is appreciated by children and parents, nitrous oxide is not routinely used in other hospitals and there is little quantitative research available on using it for needle distress. Hence further research is needed to properly examine the efficacy of this intervention for needle distress.

Finally, parental support was mentioned by the majority of children as helping them cope with needle procedures. The frequency of this theme is undoubtedly due to the questions in the interview about the role of parents. However, the content of children's answers indicates that having parents present provided support, security, a familiar person and reassurance to the child. This is broadly consistent with literature on distress during paediatric procedures (Young, 2005),

with the exception of reassurance, which has been associated with increased distress in other populations (Schechter et al., 2007). This finding highlights the need for longitudinal research to examine why some children with CF use strategies such as control, or find parental reassurance an effective way to cope with needle procedures.

Methodological limitations

These findings should be considered in light of methodological limitations of the present study. Firstly qualitative methods aim to provide insight and greater understanding of individual's experiences. These themes should therefore be thought of as illustrative but not necessarily representative. Further quantitative work is needed in larger samples to determine how representative these themes are of the experiences of other children with CF and their parents. Second, the sample and clinical context in this study are quite specific. The sample was a convenience sample of white European families and many parents were highly educated. The CF clinic where the sample was recruited is well established, has clinical staff who have worked there for a long time and uses methods, such as nitrous oxide, that are not widely in use.

In conclusion, therefore, further research is needed to determine whether the themes identified here are representative of other children with CF and their parents. However, the moving nature of parents and children's responses highlight the encompassing effects needle-related distress can have on children themselves, as well as their families and medical staff. While any lasting effects are unclear, this study supports previous findings that needle-related distress in children has significant and immediate effects on medical treatment and psychological wellbeing. Further research is needed to promote a more comprehensive understanding of this phenomenon. Until this is achieved, efforts to prevent initial onset of needle-related distress and appropriate management of needle-related distress are of vital importance to reduce anxiety in children with CF, and ultimately improve the quality of care they receive.

References

- Blount, R. L., Piira, T., & Cohen, L. L. (2003). Management of pediatric pain and distress due to painful medical procedures. In M. C. Roberts (Ed.), *Handbook of Pediatric Psychology (3rd Edition)*; pp. 216-233. New York: Guilford Press.
- Blount, R. L., Piina, T., Cohen, L. L., & Cheng, P. S. (2006). Pediatric procedural pain. *Behavior Modification*, 30, 24-49.
- Boyatzis, R. (1998). *Transforming Qualitative Information: Thematic analysis and code development*. London: Sage.
- Carpenter, R., & Narsavage, I. (2004). One breath at a time: living with cystic fibrosis. *Journal of Pediatric Nursing*, 19, 25-32.
- Caty, S., Ritchie, J.A., & Ellerton, M.L. (1989). Helping hospitalised preschoolers manage stressful situations: The mother's role. *Children's Health Care*, 18, 202-209.
- Cheng, S.F., Roster, R.L., & Hester, N.O. (2003). A review of factors predicting children's pain experiences. *Issues in Comprehensive Pediatric Nursing*, 26, 203-216.
- Cohen, J.C., & Larson, J.E. (2006). Cystic fibrosis transmembrane conductance regulator (CFTR) dependent cytoskeletal tension during lung organogenesis. *Developmental Dynamics*, 235, 10, 2736-2741.
- Cordoni, A. & Cordoni, L.E. (2001). Eutectic mixture of local anaesthetics reduces pain during intravenous catheter insertion in the paediatric patient. *Clinical Journal of Pain*, 17, 115-118.
- Duff A. J. (2001). Psychological interventions in cystic fibrosis and asthma. *Paediatric Respiratory Reviews*, 2, 350-357.
- Duff, A. J. (2003). Incorporating psychological approaches into routine paediatric venepuncture. *Achieves of Disease in Childhood*, 88(10), 931-937.

- Ellis, J.A., & Spanos, N.P. (1994). Cognitive-behavioral interventions for children's distress during bone marrow aspirations and lumbar punctures: A critical review. *The Journal of Pain and Symptom Management*, 9, 96-108.
- Havermans, T., & De Boeck, K. (2006). Cystic Fibrosis: a Balancing Act? *Journal of Cystic Fibrosis*, 6, 161-162.
- Howard, R. F. (2003). Current status of pain management in children. *JAMA: The Journal of the American Medical Association*, 290, 2464-2469.
- Jones, T., DeMore, M., Cohen, L. L., O'Connell, C., & Jones, D. (2008). Childhood healthcare experience, healthcare attitudes, and optimism as predictors of adolescents' healthcare behavior. *Journal of clinical psychology in medical settings*, 15(3), 234-240.
- Katz, E.R., Kellerman, J., & Siegel, S.E. (1980). Behavioral distress in children with cancer undergoing medical procedures: Developmental considerations. *Journal of Consulting Clinical Psychology*, 48, 356-365.
- Kennedy, R. M., Luhmann, J., & Zempsky W. T. (2008). Clinical implications of unmanaged needle-insertion pain and distress in children. *Pediatrics*, 122, 130-133.
- Kanagasundaram, S. A., Lane, L. J., Cavalletto, B. P., Keneally, J. P., & Cooper, M. G. (2001). Efficacy and safety of nitrous oxide in alleviating pain and anxiety during painful procedures. *Archives of disease in Childhood*, 84, 492-495.
- Khan, K. A., & Weisman, S, J. (2007). Nonpharmacologic pain management strategies in the pediatric emergency department. *Clinical Pediatric Emergency Medicine*, 8, 240-247.
- Lander, J. A., Weltman, B. J., & So, S. S. (2006). EMLA and amethocaine for reduction of children's pain associated with needle insertion. *Cochrane Database of Systematic Reviews*. 19;3:CD004236.
- Mahoney, L., Ayers, S., Seddon, P. (2010) The Association Between Parent's and Healthcare

- Professional's Behavior and Children's Coping and Distress During Venepuncture. *Journal Pediatric Psychology*. doi: 10.1093/jpepsy/jsq009.
- McCellan, C. B., Cohen, L. L., & Moffett, K. (2009). Time out based discipline strategy for children's non-compliance with cystic fibrosis treatment. *Disability and Rehabilitation*. 31, 327-336.
- Modi, A. C., Quittner, A. L. (2006). Barriers to treatment adherence for children with cystic fibrosis and asthma: what gets in the way? *Journal of Pediatric Psychology*, 31, 846-858.
- Moore, A., Straube, S., & McQuay, H. (2009). Minimising pain during intravenous cannulation. *British Medical Journal*, 338, 442.
- Pruitt, L.M., Johnson, A., Elliott, J.C., & Polley, K. (2008). Parental presence during pediatric invasive procedures. *Journal of Pediatric Health Care*, 22(2), 120-127.
- Reynolds, C.R., & Richmond, B.O. (1978). What I think and feel: A revised measure of Children's Manifest Anxiety. *Journal of Abnormal Psychology*, 6, 271-280.
- Salmon, K., & Pereira, J. K. (2002). Predicating Children's responses to an Invasive Medical Investigation: The Influence of Effortful Control and Parental Behavior. *Journal of Pediatric Psychology*, 27, 227-233.
- Schechter, N. L., Zempsky, W. T., Cohen, L. L., McGrath, P. J., McMurtry, C., & Bright, S. N. (2007). Pain reduction during pediatric immunizations: Evidence-based review and recommendations. *Pediatrics*, 119, 1184-1198.
- Suvey, C. (2005) Emotion socialisation in families of children with anxiety disorders. *Journal of Abnormal Child Psychology*, 33, 145-155.

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- Uman, L.S., Chambers, C.T., McGrath, P.J. & Kisely S. (2008). Psychological interventions for needle-related procedural pain and distress in children and adolescents (Review). *Evidence-Based Child Health*, 3, 323-398.
- Williams, V., Riley, A., Rayner, R., & Richardson, K. (2006). Inhaled nitrous oxide during painful procedures: a satisfaction survey. *Paediatric Nursing*, 18, 31-33.
- Wilmott, R.W., & Fiedler, M.A. (1994). Recent advances in the treatment of cystic fibrosis. *Pediatric Clinics of North America*, 41, 431-451.
- Young, K. D. (2005). Pediatric procedural pain. *Annals of Emergency Medicine*, 45, 160-171.
- Zambanini, A., & Feher, M. D. (1997). Needle phobia in type 1 diabetes mellitus. *Diabetic Medicine*, 14(4), 321–323.
- Zempsky, W. T. (2008). Pharmacologic approaches for reducing venous access pain in children. *Pediatrics*, 122, 140-145.

Table 1. Sample Characteristics

		% (n)
<u>Children</u>		
Gender	Male	36% (5)
	Female	64% (9)
CF Diagnosis	At birth	79% (11)
	< 6 months old	14% (2)
	< 1 year old	7% (1)
Frequency of needles per annum	2-4 times	79% (11)
	5 + times	21% (3)
Self-reported needle-related distress ¹		93% (13)
<u>Parents</u>		
Gender	Male	21% (3)
	Female	79% (11)
Marital Status	Married	71% (10)
	Separated or single	29% (4)
Education	None	7% (1)
	G.C.S.E's	21.5% (3)
	A-levels or equivalent	14% (2)
	Diploma	21.5% (3)
	Degree or higher degree	36% (5)
Employment	Homemaker	43% (6)
	Full-time employment	57% (8)
Ethnic Origin	White European	100% (14)

¹ Self-reported needle related distress (yes/no) was obtained during the interview

Table 2. Themes identified

Theme	Sub-themes	Frequency in parents % (n)	Frequency in children % (n)
<i>Perceived causes of needle-related distress</i>	Previous experiences	57% (8)	36% (5)
	Pain	43% (6)	57% (8)
	Anticipatory anxiety	50% (7)	29% (4)
<i>Reactions to needles</i>	Physiological	36% (5)	36% (5)
	Behavioural reaction	57% (8)	14% (2)
<i>Coping strategies</i>	Taking control	57% (8)	57% (8)
	Avoidance	21% (3)	36% (5)
<i>Management of needle anxiety</i>	Inhaled nitrous oxide gas	64% (9)	77% (11)
	Play therapy	36% (5)	7% (1)
<i>Parents' role during needles</i>	Support	57% (8)	64% (9)
	Reactions to child's distress	50% (7)	7% (1)
	Effect on others	29% (4)	0% (0)
<i>Staff influences</i>	Familiarity	57% (8)	7% (1)
	Physical constraints	50% (7)	7% (1)
	Trust	50% (7)	0% (0)

Appendix: Interview Schedule (parent version)

Introduction:

Thank you for agreeing to be interviewed today. I'm going to ask you some questions about how your child feels and reacts when he/she has injections and blood tests. You don't have to answer any of these questions if you don't want to – just tell me and we'll move on to the next question. The interview should take between 15 and 30 minutes but you are free to stop the interview at any time.

Theme 1: Exploring the nature of needle-related distress:

What regular medical treatment that involves needles does your child receive?

How do you think your child feels about having injections?

Does your child react like this to anything else?

How does he/she react when they know they will be going to have an injection or blood test?

How does your child behave in the examination room, as they're about to receive an injection?

Have you noticed any physical reactions your child may have when faced with needles?

How long does it usually take him/her to return to their old selves again?

Theme 2.1 (If needle related distress present): Exploring perceived causes of needle-related distress:

When did your child first react like this to needles?

Why do you think he/she reacts this way?

Has anything ever happened to him/her that may cause this reaction to needles?

Was there anything that brought this on?

Theme 2.2 (if needle related distress not present):

What do you think would make injections easier for your child?

How does your child react when there is someone with them when they have an injection?

Do you think they react differently if they are on their own with the doctor/nurse when they have an injection?

Theme 3: Exploring the effect of the parent on the child's treatment involving needles:

Are you usually with your child when they have an injection?

Do you do anything to help your child cope with injections? If so, what?

How do you react if your child becomes upset?

How does it make you feel if they become upset?

What do you think would help your child be more comfortable with injections?

Interview schedule (child version)

Introduction:

Thank you for agreeing to be interviewed today. I'm going to ask you some questions about how you feel when you have injections and blood tests. You don't have to answer any of these questions if you don't want to – just tell me and we'll move on to the next question. If you don't understand a question let me know and I'll try to explain it. The interview should take between 15 and 30 minutes but you can stop the interview at any time.

Theme 1: Exploring the nature of needle-related distress

How do you feel about having blood tests or injections?

Is there anything else that makes you feel the same way?

What is it about blood tests or injections that makes you feel like this?

Have you ever refused to have an injection/blood test when the doctors/nurses said you must have one?

What goes through your mind when you're about to have an injection?

How do you feel afterwards?

Can you think of anything that would make injections easier for you?

Theme 2.1 (If needle related distress appears present): Exploring perceived causes of needle-related distress

Have you always felt this way about injections?

When was the first time you remember feeling this way about injection?

What happened then?

What changes to your body do you notice before you have your injection?

When you see a needle, what is the first thing you feel? And then?

Why do you think injections make you feel uncomfortable?

What is it about injections that make you feel this way?

How do you feel when your Mum/Dad is with you when you have an injection?

How do you feel when it is just you and the nurse/doctor?

How do you think other children feel?

Theme 2.2 (if needle related distress not present):

What do you think would make having injections better?

Is there any part of having injections that you don't like?

How do you feel when there is someone there with you when you have an injection?

How do you feel when it is just you and the doctor/nurse when you have an injection?

How do think other children feel about injections?

Theme 3: Exploring the effect of the parent on the child's treatment involving needles:

Who usually goes with you when you have injection/blood tests?

Does this make a difference to how you feel? If so how?

Does this make a difference to how you act? If so how?

How do you think it makes them feel when you get upset?

What does he/she usually do when you get upset at the doctors?

What usually happens after you've had an injection?

Do you think your mum/dad gets worried when you have an injection or blood test?