

Pediatric Pain Letter

Commentaries on pain in infants, children, and adolescents

August 2005

Vol. 7 No. 1

www.pediatric-pain.ca/ppl

Editor: Carl L. von Baeyer, carl.vonbaeyer@usask.ca

© 2005, Patrick J. McGrath & G. Allen Finley

Please visit the website for information on submission and review

Commentary

The impact of pediatric chronic pain on the family

Abbie Jordan

Chronic pain is a significant problem for many children and adolescents. One large study found that 25% of children and adolescents report recurrent or continuous pain for more than three months, while 8% report intense, disabling chronic pain (Perquin et al., 2000). Pediatric chronic pain influences the whole family, and family factors reciprocally affect the child in pain. While the relationship between pain and family factors is bi-directional, in this commentary I will address only the impact of chronic pain upon the family, its members, and affected domains of functioning.

Recent research has focused on the influence of pediatric chronic pain on the family (e.g. Chambers, 2003). Clinical research in pediatric chronic pain has predominantly focused on the experiences of mothers as primary caregivers with some interesting results. For example, in two Dutch self-report studies (Hunfeld et al., 2001; Hunfeld et al., 2002a,b), mothers of children and adolescents with chronic pain reported limitations in social functioning and increased levels of personal strain. Significantly greater impairment was reported by mothers who perceived their child to experience more severe pain. Similarly, results of a qualitative study of mothers of children and adolescents with recurrent abdominal pain found that mothers reported feelings of guilt, inadequacy and the perception that parenting a child with chronic pain challenged their sense of maternal competence (Smart & Cottrell, 2005).

One mixed-methods study has examined the paternal experience of parenting an adolescent with chronic pain. In the qualitative aspect of the study,

fathers reported feelings of frustration, helplessness and inadequacy (Eccleston et al., 2004b). The results of the self-report component conducted with 16 matched mothers and fathers demonstrated that fathers reported significantly lower levels of parenting stress, anxiety and depression than mothers. Such preliminary results suggest that fathers may be affected by pediatric chronic pain to a lesser extent than mothers.

A small number of studies have focused on examining the effects on both parents. One descriptive study of 20 parents of children and adolescents with inflammatory bowel disease investigated the practical impact on parental life. Results demonstrated that 15% of parents reported career restriction as a result of their child's pain condition (Akobeng et al., 1999), suggesting that practical issues associated with parenting a child with chronic pain are faced by only a sub-set of parents.

Parenting a child or adolescent with chronic pain also appears to influence emotional functioning. This was investigated in two UK self-report studies of parents of adolescents with chronic pain. The first study demonstrated that mean scores of parental anxiety and parenting stress were clinically significant prior to treatment (Eccleston et al., 2003). The second study found that parental pre-treatment scores for depression, anxiety and parenting stress were clinically significant in 40%, 62% and 31% of the sample respectively (Eccleston et al., 2004a). These results lend support to the suggestion that parenting a child with chronic pain is

emotionally distressing for a substantial number of parents.

The findings reported so far have been related to the extent to which daily life is disrupted as a result of parenting a child or adolescent with chronic pain. There may, however, also be implications for identifying impaired levels of parental functioning. First, one could argue that evidence of poor parental mental health suggests that parents have their own clinical needs. Second, one could contend that parental distress may influence pain related outcomes in the child or adolescent. Given the dearth of research in this area, it is only possible to speculate about the potential mechanism of such a relationship.

Little attention has been paid to the impact of pediatric chronic pain on siblings, with only three studies identified. The first study included 20 siblings of children and adolescents with inflammatory bowel disease. Results indicated that siblings reported more feelings of anxiety, depression and reduced levels of self esteem than matched siblings of healthy children and adolescents (Engstrom, 1992). Similar results were reported by a self-report descriptive study of 7 siblings of children and adolescents with inflammatory bowel disease. This study found that 57% of siblings worried about 'being kept in the dark' and 14% worried about their sibling's condition (Akobeng et al., 1999). In the third study mothers of children and adolescents with juvenile idiopathic arthritis qualitatively reported that siblings developed a more compassionate and protective role towards their ill sibling (Britton & Moore, 2002). The sibling relationship is especially important for children and adolescents with chronic pain as it involves the development of a relationship akin to a peer relationship. This is significant as many children and adolescents with chronic pain report few meaningful peer relationships.

General literature examining the effects of having a sibling with chronic illness offers further insight into the impact of pediatric chronic pain on siblings. A meta-analysis of 51 published studies demonstrated a modest effect size for children and adolescents with chronically ill siblings compared to individuals with healthy siblings (Sharpe & Rossiter, 2002). The effects were largely negative with chronically ill siblings reporting fewer peer rela-

tionships, reduced levels of psychological functioning and impaired cognitive development (Sharpe & Rossiter, 2002). A review of 43 studies found that 60% of studies reported an increase in sibling risk, 30% reported no elevated risk and 10% reported both positive and negative outcomes associated with having a chronically ill sibling (Williams, 1997). In conclusion, it appears that although siblings of children and adolescents with chronic conditions experience an elevated risk of negative outcomes, positive outcomes are also possible for a small number of siblings.

It is important to consider methodological issues when reviewing the impact of pediatric chronic pain on the family. With the exception of qualitative studies, all reviewed studies have involved the use of self-report inventories. Limitations of self-report methodology include restricted outcomes and subjective reporting. Additional research would benefit from the use of a more diverse range of methodologies, including observational methods. This would enable the objective measurement of a wider range of outcomes such as physiological anxiety and parent-child interaction.

Future research in this field would also benefit from addressing a number of omissions in the research base. First, it is necessary to examine the experiences of a wider range of family members including fathers and grandparents. A second area of interest is the measurement of a more diverse range of positive and negative familial outcomes. As little is known about positive outcomes, exploration of a wider range of outcomes could be achieved using an exploratory qualitative approach (Pope & Mays, 1995). Another topic deserving of further study is the role that parental factors play in the maintenance of child pain and associated disability. Initial studies could usefully focus on the predictive value of parental functional outcomes in relation to child pain-related disability. Additionally, it would be interesting to examine whether the impact of chronic pediatric pain on the family differs according to the characteristics of the study sample (e.g. population versus clinical sample). Finally, considering parallels between the familial experience of pediatric chronic illness and chronic pain (Chambers, 2003), it may be of use to consult the literature on pediatric chronic illness. In this more established

field, models have been developed which could be integrated into the field of pediatric pain to offer a useful framework for further understanding the impact of pediatric chronic pain on the family (e.g. the risk and resistance model; Wallander & Varni, 1992).

In conclusion, the impact of pediatric chronic pain on the family is varied. Parenting a child or adolescent with chronic pain appears to have a significant impact on emotional functioning, with a small number of parents also experiencing effects on other areas of parental life. Studies of siblings of children and adolescents with chronic conditions suggest that siblings are at risk of developing nega-

tive outcomes including symptoms of emotional distress. Further research and use of additional methodologies would enhance our understanding of the effect of pediatric chronic pain on the family.

Abbie Jordan, MSc

Research Officer, Pain Management Unit, University of Bath & Royal National Hospital for Rheumatic Diseases, Bath, UK

e-mail: a.l.jordan [at] bath.ac.uk

Acknowledgement

The assistance of Prof Chris Eccleston is gratefully acknowledged.

References

Akobeng AK, Miller V, Firth D, Suresh-Babu MV, Mir P, Thomas AG. Quality of life of parents and siblings of children with inflammatory bowel disease. *J Pediatr Gastroenterol Nutr* 1999;28:S40-42.

http://www.ncbi.nlm.nih.gov/entrez/query.fcgi?cmd=Retrieve&db=pubmed&dopt=Abstract&list_uids=10204524&query_hl=4

Britton C, Moore A. Views from the inside, part 2: what the children with arthritis said, and the experiences of siblings, mothers, fathers and grandparents. *Br J Occup Ther* 2002;65:413-419.

Chambers, CT. The role of family factors in pediatric pain. In: McGrath PJ, Finley GA, editors. *Pediatric pain: biological and social context*. Seattle, WA: IASP Press, 2003. pp. 99-130.

Eccleston C, Malleson PN, Clinch J, Connell H, Sourbut C. Chronic pain in adolescents: evaluation of a programme of interdisciplinary cognitive behaviour therapy. *Arch Dis Child* 2003;88:881-885.

http://www.ncbi.nlm.nih.gov/entrez/query.fcgi?cmd=Retrieve&db=pubmed&dopt=Abstract&list_uids=14500306&query_hl=17

Eccleston C, Crombez G, Scotford A, Clinch J, Connell H. Adolescent chronic pain: patterns and predictors of emotional distress in adolescents with chronic pain and their parents. *Pain* 2004a;108:221-229.

http://www.ncbi.nlm.nih.gov/entrez/query.fcgi?cmd=Retrieve&db=pubmed&dopt=Abstract&list_uids=15030941&query_hl=17

Eccleston C, Scotford AAJ, Clinch JG, Connell H. Experiences of fathers of adolescents with chronic pain. *Ann Rheum Dis* 2004b;63 suppl 1:430-431.

Engstrom I. Psychological problems in siblings of children and adolescents with inflammatory bowel disease. *Eur Child Adolesc Psychiatry* 1992;1:24-33.

Hunfeld JAM, Perquin CW, Duivenvoorden HJ, Hazebroek-Kampschreur AAJM, Passchier J, van Suijlekom-Smit LWA, van der Wouden JC. Chronic pain and its impact on quality of life in adolescents and their families. *J Pediatr Psychol* 2001;26:145-153.

http://www.ncbi.nlm.nih.gov/entrez/query.fcgi?cmd=Retrieve&db=pubmed&dopt=Abstract&list_uids=11259516&query_hl=23

Hunfeld JAM, Perquin CW, Bertina W, Hazebroek-Kampschreur A, van Suijlekom-Smit LWA, Koes BW, van der Wouden JC, Passchier J. Stability of pain parameters and pain-related quality of life in adolescents with persistent pain: a three-year follow-up. *Clin J Pain* 2002a;18:99-106.

http://www.ncbi.nlm.nih.gov/entrez/query.fcgi?cmd=Retrieve&db=pubmed&dopt=Abstract&list_uids=11882773&query_hl=23

Hunfeld JAM, Perquin CW, Hazebroek-Kampschreur AAJM, Passchier J, van Suijlekom-Smit LWA, van der Wouden JC. Physically unexplained chronic pain and its impact on children and their families: the mother's perception. *Psychol Psychother* 2002b;75:251-260.

http://www.ncbi.nlm.nih.gov/entrez/query.fcgi?cmd=Retrieve&db=pubmed&dopt=Abstract&list_uids=12396752&query_hl=23

Perquin CW, Hazebroek-Kampschreur AAJM, Hunfeld JAM, Bohnen AM, Suijlekom-Smit LWA, Passchier J, van der Wouden JC. Pain in children and adolescents: a common experience. *Pain* 2000;7:51-58.

<http://www.ncbi.nlm.nih.gov/entrez/query.fcgi?cmd=Ret>

http://www.ncbi.nlm.nih.gov/entrez/query.fcgi?cmd=Retrieve&db=pubmed&dopt=Abstract&list_uids=10863045&query_hl=30

Pope C, Mays, N. Reaching the parts other methods cannot reach: an introduction to qualitative methods in health and health services research. *BMJ* 1995;311:42-45.

http://www.ncbi.nlm.nih.gov/entrez/query.fcgi?cmd=Retrieve&db=pubmed&list_uids=7613329&dopt=Abstract

Sharpe D, Rossiter L. Siblings of children with a chronic illness: a meta-analysis. *J Pediatr Psychol* 2002;27:699-710.

http://www.ncbi.nlm.nih.gov/entrez/query.fcgi?cmd=Retrieve&db=pubmed&dopt=Abstract&list_uids=12403860&query_hl=36

Smart S, Cottrell D. Going to the doctors: the views of mothers of children with recurrent abdominal pain. *Child*

Care Health Dev 2005;31:265-273.

http://www.ncbi.nlm.nih.gov/entrez/query.fcgi?cmd=Retrieve&db=pubmed&dopt=Abstract&list_uids=15840146&query_hl=39

Wallander JL, Varni JW. Adjustment in children with chronic physical disorders: programmatic research on a disability-stress-coping model. In: La Greca AM, Siegal L, Wallander JL, Walker CE, editors. *Stress and coping in child health*. New York: Guilford Press, 1992. pp. 279-298.

Williams PD. Siblings and pediatric chronic illness: a review of the literature. *Int J Nurs Stud* 1997;34:312-323.

http://www.ncbi.nlm.nih.gov/entrez/query.fcgi?cmd=Retrieve&db=pubmed&dopt=Abstract&list_uids=9306166&query_hl=47