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Pain. Author manuscript; available in PMC 2010 November 1.

Published in final edited form as:
Pain. 2009 November ; 146(1-2): 15–17. doi:10.1016/j.pain.2009.05.009.

Parents of children and adolescents with chronic pain

Tonya M. Palermo, PhD[1] and **Christopher Eccleston, PhD**[2]

[1] Department of Anesthesiology & Perioperative Medicine, Oregon Health & Science University, Portland, OR 97239 USA

[2] Centre for Pain Research, School for Health, The University of Bath, Bath, England, UK

Keywords

pain; chronic pain; children; parents; parenting

1. Introduction

> "You can't make it better. I think that's the hardest thing I found: that Mummy couldn't make it better"[11]

For many, becoming a parent is a significant life-changing event and a defining feature of adult life. Learning how to parent effectively is generally considered demanding. However, being a parent of the child with chronic pain is a particularly daunting and challenging role. In this topical review we focus on a neglected but critical aspect of pediatric chronic pain management: the caregiving parent.

Parents have a strong influence on children's experience of pain and disability, and a renewed research focus on the family of the child in pain has been recently promoted[17]. Our interest here is explicitly on parents; both as adults inhabiting a chronically stressful environment, and as critical behavioral agents influencing the child in pain and distress. First we review examples of research about the effect that living with, and caring for, a child in chronic pain has on parents. Second, we review selected literature about the effect that parent functioning has on child adjustment to chronic pain. Third, we summarize the cognate literature of parental adjustment and reaction to severe childhood chronic medical conditions other than chronic pain. Finally, we focus on critical gaps in the literature on parenting the child in chronic pain, and explore implications for research and clinical practice.

2. Parents of Children and Adolescents with Chronic Pain

Rare are studies that focus specifically on the mental health of adults exposed to the chronic stress of living with, caring for, and parenting a child in persistent pain. Palermo[18] reviewed the potentially devastating impact of chronic pain on parents, drawing research attention to the widespread social, relational, emotional and financial impact. In clinical samples of youth with chronic pain, high levels of parental role stress, anxiety and depressive symptoms, and social impact were commonly reported by parents[7] [10]. Case control studies [3] have shown that

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Correspondence and requests for reprints to: Tonya Palermo, PhD, Department of Anesthesiology & Perioperative Medicine, UHN-2, Oregon Health & Science University, 3181 SW Sam Jackson Park Rd., Portland, OR 97239, USA, E-mail: palermot@ohsu.edu.

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mothers of children with chronic pain have higher rates of anxiety, depression, and somatoform disorders compared to mothers of controls.

In one of the few qualitative studies in this area, Jordan et al[11] interviewed 17 parents of youth with chronic pain about their experience, finding that parents reported being engaged in a struggle for control over their lives, involving the desperate search for a cure and the strain of being unable to help their child in pain. They also reported a fundamentally changed life, one unplanned and unexpected. Interestingly, they reported feeling suspended in an earlier parenting pattern, aware that they were parenting their children in a developmentally inappropriate manner, but unable to change.

The limited research on parental reaction to caring for a child with chronic pain indicates that high levels of stress, feelings of frustration over an inability to effectively help, and psychological distress are common.

3. Parental Effects on Child Adjustment to Chronic Pain

There is a small literature on the association between parental functioning and child adjustment to chronic pain. For example, an early study in children with juvenile arthritis found that greater emotional distress of the mother was related to higher levels of child reported pain[21]. Similarly, higher levels of parental psychological distress[14] and less healthy family functioning[19] have been associated with greater pain-related disability in youth. The parent-child relationship has emerged as important; in a clinical study of adolescents with chronic headaches, lower levels of age appropriate independence were associated with increased headache-related disability[19]. Family and parent factors have also been found to moderate child adjustment. For example, one study found that increased risk of poor child functioning was present only in disruptive family environments [14].

Unlike research into other childhood chronic medical conditions, for chronic pain there has been a focus on learning factors and social reinforcement in maintaining pain and disability. Working within an operant behavioral model, Walker and Zeman[25] introduced the term ‘illness behavior encouragement’, arguing that more solicitous responses from parents toward their children’s pain behavior (e.g., frequently attending to pain symptoms, granting permission to avoid regular activities) increased sick role behaviors in children with recurrent pain. Studies to date have found relationships between parental protective or solicitous responses and child outcomes, suggesting that individual child factors, such as emotional distress, moderate risk of poorer adjustment [4;20]. These parental behaviors are conceptualized as operant factors that serve to either increase or decrease adaptive child behaviors. Psychological interventions for the management of pediatric chronic pain have involved parents in treatment using this conceptualization, e.g., teaching parents techniques to increase adaptive child behaviors such as rewarding the child for school attendance[23].

4. Parental Adjustment and Reaction to Childhood Chronic Medical Conditions

Childhood chronic medical conditions such as cancer, diabetes, and traumatic brain injury also pose significant stressors and demands on parents, and there is a relatively large body of literature on the lives of parents in the context of caring for children with such conditions[1; 6;13]. Traditional conceptualizations of stress and coping have revealed common stressors experienced by parents, specifically stress related to the child’s treatment, medical adverse effects, changes in daily activities, disruption of social and family roles, and burden associated with adhering to a treatment regimen[6]. The everyday demands of parenting and managing employment, finances, and a household are greatly increased. Parents use a range of adaptive

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coping resources to deal with these stressors such as seeking social and emotional support [15].

The lives of parents of children with chronic medical conditions are often characterized by increased parental distress and negative affectivity[6], in both mothers and fathers[16]. Parental physical and psychosocial well-being consistently predicts poorer child adjustment across a range of chronic health conditions[6]. Specifically, significant relationships have been found between parental, especially maternal, self-reports of mental and physical health and the functional status and psychological adjustment of their children[5;9], implying that the quality of a parent's functioning is interwoven with his or her child's functioning. Longitudinal studies have demonstrated that parental distress decreases over time in the context of certain childhood medical conditions, such as cancer, where parents are especially at risk of experiencing psychological distress during the first year following the child's cancer diagnosis[16]. However, persistence or intensification of distress over time has been found for parents of children with other medical conditions such as diabetes[2].

Parental distress is constructed as a normal emotional response to the stress of the child's chronic medical condition rather than an indication of psychopathology. Even subclinical levels of parental distress are thought important as they may negatively impact on child emotional, physical, and family functioning, and interfere with decision-making about the child's treatment. Helping parents reduce emotional distress after their child is diagnosed with a chronic medical condition is, therefore, considered vital, and a normal part of pediatric practice. Interventions have been specifically developed to reduce emotional distress in parents of children with chronic medical conditions. For example, a problem-solving skills intervention was trialed for mothers of children with newly diagnosed cancer, producing significant attenuation in negative affectivity [22].

5. Implications for Research and Practice

Several clinical and research implications emerge from this consideration of parental stress and influence. First, it is interesting to consider why, in chronic pain research, there has been little examination of the impact of parenting the child with pain on the parents themselves, a topic that is well developed, indeed considered crucial, in research of other chronic medical conditions. The reason for this omission lies perhaps in the predominance in the early literature of studies of youth with headache or abdominal pain. Unlike medical conditions such as cancer, both headache and abdominal pain are clinically characterized by intermittent and recurrent symptoms, are typically of unknown origin, and are highly reactive to stress and social influence. Data on the enduring pattern of persistent pain and disability associated with such conditions only emerged later. In this context, parenting was considered primarily as a set of behaviors in response to the child's specific complaints of pain. Parenting practices rather than a consideration of parental emotional needs might understandably have taken prominence as the focus of the research in pediatric chronic pain management.

However, this relegation of interest in parental distress has left several major unanswered questions about the lives of parent caregivers of children with persistent pain. Parents living in a context of chronic stress might themselves be a population with significant mental health needs. This is more than simply unfortunate collateral damage to a primary pediatric problem given the negative effects of parental distress on child health outcomes[6]. Understanding how to treat or manage parental distress may address the problem of how to more effectively manage children's pain and disability.

Several major omissions perforate the chronic pain literature offering opportunity for further study. A primary research task concerns a more complete characterization of parental emotional

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functioning, parental coping and adjustment, and parent-child relationships. Multiple approaches and methods are needed to increase understanding of common parental reactions, parental coping styles, and ways that parent-child relationships change. It will be important to characterize differences between mothers' and fathers' adjustment and coping and how this may impact the parent-child relationship at different developmental periods during childhood and adolescence. This will require the longitudinal study of parents and children over time. Prospective analyses may help to clarify developmentally relevant causal pathways linking the presence of persistent pain with parental distress and children's adjustment.

Perhaps the most pertinent question is how to intervene with parents who are distressed in ways that produce lasting positive effects for both adults and children. To date, psychological therapies have been focused primarily on pain control, and on building children's coping skills, with promising but preliminary results[8]. However, where parents have been involved in treatment it has been to modify the presumed effects of parental behavior on child function rather than to reduce parental distress. There has been no intervention developed specifically to treat parental negative affectivity in the context of pediatric chronic pain, despite the ubiquity of parent training programs for caregivers of children with other medical or behavioral conditions [12;24]. Testing of interventions developed specifically for parents will increase understanding of how effectively to reduce negative affectivity in parents, and how to augment child treatment with parental content.

Practice implications are also evident. First, we recognize that parental and family assessment is not uncommon in case formulation; however, this assessment, we suspect, does not normally lead to parental intervention. We argue that an increased understanding of the emotional and support needs of parents translated into shared treatment plans will benefit both child and adult. Second, although much has been learned about particular styles of parenting behavior, their relationship with child behavior, and optimal methods of behavior modification, we need now to develop a comprehensive model of the inter-relationship of child and parent coping patterns. Third, taking a developmental perspective will offer opportunities for understanding how to support parents to encourage their child's attainment of developmental milestones and relate to their child's experience with pain.

Such research takes time. But, while we wait for a comprehensive model to be developed, tested, and treatments designed and refined, remedial action is possible. For example, parents will likely benefit from the provision of education and support around their own adjustment and reaction to the child's persistent pain, where such material is focused on stressing the normalcy of their experience of stress and burden, as well as providing developmentally specific information on how to best support their child.

To conclude, we argue that a renewed research focus on parents of children and adolescents with chronic pain is warranted. In addition to the existing investigations on the influence of parents on the development or maintenance of child pain and disability, we suggest research on the experience of parents struggling to cope with and be effective in parenting the child with chronic pain. Discovery of optimal methods of intervening with parents, individually or as part of existing child focused treatments, hold the promise of major advance in this field, where effective treatments remain frustratingly rare.

Acknowledgments

There are no financial or other relationships that would lead to a conflict of interest.

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