

Book Review

Review of Stories of children's pain: linking evidence to practice

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Carter B, Simons J (2014). *Stories of children's pain: linking evidence to practice*. London: SAGE, 249 pp. ISBN 978-1-4462-0760-4 (Hardcover: \$144.00 USD; Paperback: \$48.00 USD).

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Every child experiences pain at some point in their life – whether as a preemie or newborn receiving necessary medical care, a child experiencing pain from a fall, or a child in hospital undergoing multiple procedures and surgeries. These painful events lead to challenges for everyone trying to help assess and manage pain. This includes the child themselves, their parents, nurses and other health care providers – striving to do their best to help children at times when they are experiencing pain, and yet often feeling distress when working with children in pain. In this book, the authors address the multiple different types of pain that children experience by using real life stories. The stories are powerful, and help the reader understand the painful experience from the storytellers' point of view. The use of narratives in health care is an important tool which helps us understand the whole experience, allows us to be with the child, and permits us to be open to the suffering that accompanies the experience. Stories help paint a picture of the experience that can at times be hard to hear, yet is so necessary in order for us to improve pain care for children and their families.

The authors are both well known in the field of children's pain. Bernie Carter is a professor in children's nursing in the UK. She has written extensively on the use of stories and narratives to understand children's pain. She was made a fellow of the Royal College of Nursing in recognition of her work in this area. Joan Simons is assistant head in the Faculty of Health and Social Science Care at the Open University. She has worked in the area of children's pain for over 20 years and has published several papers discussing nurses' management of children's pain.

In the Introduction, the authors remind us that hearing stories helps us connect with people and understand experiences from their point of view. They explain how the book came about – how they sought out and received stories from around the world. They discuss the process they undertook to put the stories together in a way that allows us as readers to take care of the stories, learn from them and grow in our practices.

The book is organized into fifteen chapters – each chapter beginning with the story. For some chapters, there is one story, and for others there are two or even three stories with a common theme. Some stories were written by children, some by their parents, and some by their health care providers. However, all stories were personalized by including the child's name. Following the story, the authors provide context, a review of the current evidence-based literature, a conclusion and key points. Each chapter includes a section on additional resources and references. Fourteen of the chapters

are accompanied by drawings, figures or tables that provide clarity to the reader.

The first chapter begins with two stories from nurses, involving premature infants undergoing painful procedures. In both of the stories, the nurses share how they used evidence to help the babies cope with the painful procedures. The authors then use the stories as a springboard to discuss the assessment and management of pain in neonates.

The second chapter presents a story shared by a home care nurse. The child in the story had undergone surgery and was discharged home with very little instruction to the family on how to manage the child's pain over the weekend. Communication gaps in the transition from hospital to home were identified as a source of frustration for the parents and the home care nurse. The authors review current recommendation guides for assessing and managing children's acute and postoperative pain including the Royal College of Nursing and the Association of Pediatric Anaesthetists guidelines. They address knowledge gaps in uptake of this information. They also review the challenges faced by parents in assessing their child's pain. Key points include the need for nurses to be proactive in managing pain and to provide parents with clear information to manage pain at home.

In the third chapter three stories are presented addressing procedural pain management. The first one describes a mother's anguish over witnessing her child suffer from multiple attempts to start an IV. The second and third stories were written by nurses; both focus on the providers' distress and how they would change things if they could return to these situations. The chapter then reviews the literature on procedural pain management – including the long term effects on children when procedural pain is managed poorly. This chapter includes several helpful tables in addition to the text on how to best manage procedures using both pharmacological and non-pharmacologic strategies.

The fourth chapter includes two stories on pain related to sickle cell disease. One of the stories was written by a teenager and addresses not only pain, but cultural differences in how pain affected the teen's life. The authors then provide a review of painful vaso-occlusive episodes in sickle cell

disease, reviewing current guidelines from American Pain Society, NICE and Royal College of Nursing for managing pain related to sickle cell crisis.

In chapter five we are introduced to three different stories related to managing common pain conditions pain at home. One is from a 5-year-old with a tummy ache, and two are from parents, focusing on time limited, acute pediatric pain experiences. The chapter then reviews how parents assess and treat every day pain at home, and the worry of when to seek help for the pain.

Chapter six demonstrates why stories are so powerful. Janet and Erik's story was written by a pediatric intensive care unit (PICU) nurse, who recalled an event that occurred when she was a new nurse in the 1990's. The chapter, titled *Existential pain and the importance of place and presence*, reflects on the suffering of not only the child, but of the nurse who cared for him over several shifts. She reflects in the story on how often she has wished things could have been done differently, and how her practice has been shaped by this experience. The authors then review the literature on nursing presence and the provision of compassionate care. I suspect many of us can share a similar story from our careers.

Several chapters focus on pain assessment. Chapter seven was written by a care provider about a child in the PICU, and the challenges in assessing pain in children who are sedated due to critical illness. The authors review pain assessment tools and include a table of the Comfort B (Ambuel, 1992) scale. Both pharmacological and non-pharmacological methods to manage pain are reviewed. They then address the distress often faced by nurses in caring for these critically ill children. In chapter eight we are introduced to the challenges of assessing and managing pain in children with cognitive impairments. The story, written by a mom, reflects multiple different types and episodes of pain experienced by her 13-year-old daughter. The authors then define cognitive impairment; review the common types of pain often experienced by these children such as gut pain, positional pain, and pain related to equipment. There is a very good overview of the tools which can be used to assess

pain including a helpful figure which overlays the different tools with the different types of pain.

Chapter nine addresses children's understanding of pain, and how their imaginations are powerful. In the first story, we learn about a child's fear of pain in a PICU setting, and how understanding the child's perspective is important for clinicians. The second story presents diary excerpts from a father of his son's pain over a one-year period. The chapter then provides a nice overview of child development from a theoretical view to help readers understand children's views of pain. Authors then review the literature on children's fears related to pain and hospitalization, and discuss the importance of addressing these fears at the child's developmental level.

In chapter ten the story addresses the transition from acute pain to chronic pain in a 10-year-old who underwent a day surgical procedure with poor wound healing. The authors reviewed the current literature on the challenges faced by parents in assessing and managing their child's pain at home, and the lack of literature on chronic postsurgical pain in children. There is an extremely brief review of the effects of chronic pain on children which only touched on a few studies, despite the large body of literature on pediatric chronic pain. The authors chose to include a section on the use of one multidimensional tool, the Adolescent Pediatric Pain Tool, which is not a commonly used tool in clinical practice. This chapter could have been improved with the inclusion of additional evidence on the transition to chronic pain.

Chapter eleven has three stories from children, explaining their pain in their own words and in pictures. This is an important chapter on how children express pain, because as the authors state, "until pain is expressed, it is hidden" (p. 164). There is a good review on how pain language develops, from crying in an infant, through words and utterances, and the use of pictures and drawings as pain expression. There is a brief section on translation which could have been enhanced by including the available translations for the Faces Pain Scale revised on the IASP website (www.iasp-pain.org/Education/Content.aspx?ItemNumber=1519). The chapter concludes by stressing the

importance of listening, and taking children's little words seriously.

Chapter twelve covers the pain associated with minor injuries and wounds so often experienced by children as they go through childhood. The story is written by a 10-year-old girl recalling a fall and is accompanied by a picture. The authors then review nociceptive pain related to injuries, and discuss wound pain management in detail, including the effect on children of removing bandages and cleaning sites.

In chapter thirteen, two stories are shared by nurses about episodes in children's wards whereby children's pain was relieved by addition of non-pharmacological methods including guided imagery and breathing exercises. The authors then review guided imagery and massage to relieve pain as related to Wall and Melzack's gate control theory (1965). The key message addressed the importance of the therapeutic relationship and good nursing practice in using these methods. I must admit when reading this chapter I was struck by the need to even include this material, and felt saddened that we nurses need to be reminded that these are important aspects of care that we must provide. These were key nursing competencies when I began my career, and I wondered when we stopped providing these pain methods, as the nurses in the stories seemed to question their own abilities to use these methods.

In chapter fourteen we are introduced to the story of a young man with a longstanding history of neuropathic pain related to a disease process. The story is told by the father, who shared the consequences of this painful condition on his son and on the family. The authors then provide a robust review of neuropathic pain including definition, physiology, diagnosis, assessment and treatment approaches. They then briefly address the effects on adolescent growth and development, the parents, and coping strategies.

The final chapter begins with a story shared by the parents of a young man, and reflects their struggles over poor pain management practices at the end of life, and their attempts to advocate for not only their child, but for better care for all children. Both parents are in health care (the mom is a children's nurse!) and the chapter reflects the failure to provide good pain management. It is a

story that needed to be bravely told, as the mom stated “warts and all” (p. 221). The authors then review available literature on the status of pediatric palliative care in several countries, including guidance from the World Health Organization literature. The chapter discusses the inadequate treatment of pain and suffering at the end of life for many children by reviewing many barriers including organizational, geographical, and individual levels. Available clinical guidelines for best practices are discussed, and the authors end by challenging all to ensure this story does not repeat.

The book concludes with a brief discussion of the common threads in the stories, including engagement, power, and leadership to provide effective pain management.

Overall, I found this book to be wonderful read for nurses (and other health care providers) who care for children with pain. The stories bring such an important human element to each chapter

and I found myself reflecting on similar experiences and stories for each chapter. The stories are hard to read at times, as they often reflect the suffering of the child, of the parent, and the moral distress of the staff. Not surprisingly, there were few good stories – times when it all went well! Yet there were hopeful stories, and some humor in a few of the children’s anecdotes. One drawback to the book is the cost - \$125 Canadian (and not easily available in all countries). Sadly, this may put it out of reach of many nurses who would like to read this.

If you do come by a copy, read it. Reflect on the stories told, and most importantly, use the presented evidence to make a difference so that the stories don’t repeat.

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