

Michael Dobe · Boris Zernikow *Editors*

Practical Treatment Options for Chronic Pain in Children and Adolescents

An Interdisciplinary
Therapy Manual

 Springer

Michael Dobe · Boris Zernikow *Editors*

Practical Treatment Options for Chronic Pain in Children and Adolescents

An Interdisciplinary
Therapy Manual

 Springer

Practical Treatment Options for Chronic Pain in Children and Adolescents

Michael Dobe • Boris Zernikow
Editors

Practical Treatment Options for Chronic Pain in Children and Adolescents

An Interdisciplinary Therapy Manual

 Springer

Editors

Michael Dobe
German Paediatric Pain Centre (GPPC)
Children's and Adolescents' Hospital
Witten/Herdecke University
Datteln
Germany

Boris Zernikow
German Paediatric Pain Centre (GPPC)
Children's and Adolescents' Hospital
Witten/Herdecke University
Datteln
Germany

Chair Children's Pain Therapy
and Paediatric Palliative Care
Witten/Herdecke University
School of Medicine
Datteln
Germany

ISBN 978-3-642-37815-7 ISBN 978-3-642-37816-4 (eBook)
DOI 10.1007/978-3-642-37816-4
Springer Heidelberg New York Dordrecht London

Library of Congress Control Number: 2013944046

© Springer-Verlag Berlin Heidelberg 2013

This work is subject to copyright. All rights are reserved by the Publisher, whether the whole or part of the material is concerned, specifically the rights of translation, reprinting, reuse of illustrations, recitation, broadcasting, reproduction on microfilms or in any other physical way, and transmission or information storage and retrieval, electronic adaptation, computer software, or by similar or dissimilar methodology now known or hereafter developed. Exempted from this legal reservation are brief excerpts in connection with reviews or scholarly analysis or material supplied specifically for the purpose of being entered and executed on a computer system, for exclusive use by the purchaser of the work. Duplication of this publication or parts thereof is permitted only under the provisions of the Copyright Law of the Publisher's location, in its current version, and permission for use must always be obtained from Springer. Permissions for use may be obtained through RightsLink at the Copyright Clearance Center. Violations are liable to prosecution under the respective Copyright Law.

The use of general descriptive names, registered names, trademarks, service marks, etc. in this publication does not imply, even in the absence of a specific statement, that such names are exempt from the relevant protective laws and regulations and therefore free for general use.

While the advice and information in this book are believed to be true and accurate at the date of publication, neither the authors nor the editors nor the publisher can accept any legal responsibility for any errors or omissions that may be made. The publisher makes no warranty, express or implied, with respect to the material contained herein.

Printed on acid-free paper

Springer is part of Springer Science+Business Media (www.springer.com)

Foreword I

This manual is a masterful, compelling, and satisfying read for all professionals in children's pain management. Going beyond the biomedical model, it provides a comprehensive appreciation of the physiology, psychology, pharmacology and familial/social aspects of common paediatric chronic pain syndromes. It emphasizes the broad impact of pain on the lives of children and teens, as well as the complicated process of recovery. Drs. Dobe and Zernikow achieve this by bringing us into the functioning of their inpatient treatment unit in Germany for children and teens with chronic pain. They share their intake procedures, assessment process and instruments, their well-developed decision-making processes, the nuances of their therapeutic program, interdisciplinary team's functioning and their research outcome – a tour de force!

What makes this chronic pain treatment program stand apart is the tight integration of clinical practice with their research program, based firmly within a biopsychosocial framework in the child-family systems context. In fact, they are consistently systems-oriented. A continuous flow-through of research findings informs the clinic's intake and treatment parameters, which in turn feeds their ongoing research. They give considerable attention to the patient's social, emotional, familial and physical systems. You'll note the well-integrated system of trained professionals – nurses, psychotherapists, physicians, psychologists and physiotherapists, and the different forms of psycho-biological treatment regimens to address and relieve pain that the children receive, either as outpatients or inpatients for 6 weeks in their 'Lighthouse' treatment unit.

With a 10-year history of treating some of the most distressed and pain-compromised children and teens in Germany (their patients aged 7–17 years have suffered chronic pain for an average of 3.5 years before starting treatment), the authors discuss their philosophy of care and treatment regimen in considerable detail. Their philosophy is based on principles that we've come to appreciate as critical for the effective treatment of children and teens. This includes principles of transparency, collaboration, requiring the child's commitment to treatment, incorporation of parents at pivotal decision and treatment points, challenging the patient's self-limiting behaviors, providing a well-organized treatment program that requires intensive work on the part of the child, and supporting the child's follow-through with engaging therapeutic relationships and active support to complete the program.

There is clinical brilliance and ingenuity in this intensive treatment program, particularly in the lively, sometimes challenging and strategic nature of their psychotherapy interventions, such as the ‘Three Letters’ in Chap. 6. There are aspects that some North American practitioners may find usual. The authors carefully explain their rationale and care in implementing these practices, their experience and research outcomes. One of these is that a child who does not take on all aspects of the program can be asked to leave. Under certain circumstances they can be invited to re-apply when they deem themselves ready. As part of that application they are required to write a convincing letter about what has changed and how they are now ready to fully engage with the 3-week treatment program.

Other novel practices are the ‘Stress Day’, an individually tailored challenge day, and ‘Pain provocation’ – an established cognitive behavioral strategy which ultimately provides the child with a greater sense of control over his or her pain. All of these techniques are described in sufficient detail for a clear appreciation of their therapeutic benefit. These are not boot camp techniques. They are implemented within empathic relationships and supportive and negotiable contexts, and consistently reflect their treatment approach of encouraging self-management.

Providing psycho-education on pain and ensuring that the children and teens understand it well enough to write about how pain is processed, is emphasized throughout this manual. With humor and transparency Drs. Dobe and Zernikow convey the idea that the doctor “isn’t in charge of your body” and from the outset they change the relationship dynamic by asserting that it is the child who defines what is “the correct” pain perception, not the parents, psychotherapist or physician. A further declaration made early to the child and family is that sustained pain reduction cannot be achieved unless the child engages in learning and using active pain coping strategies. The authors provide detailed case examples of their multi-modal intake and treatment procedures, which makes their treatment system come to life. The child and family are required to make a commitment to this system, and it is evident that this is more than matched by a commitment by skilled personnel at every step along the trajectory towards pain relief.

Contrary to common practices, their treatment process is one that relies heavily and successfully on humor and playfulness as a therapeutic attitude for treating chronic pain. This is summed up by one of the teens in Chap. 4 who asks, “Why did you become a therapist, when you like to laugh so much?” This positive hopeful attitude is supported by a therapeutic focus on enhancing the child’s resources and problem-solving capacity – irrespective of the severity of the pain or symptoms of anxiety, depression or trauma.

Families of children with chronic pain suffer themselves. How to work with these families can sometimes present a particular challenge to the chronic pain team. Drs. Dobe and Zernikow address this from the very start and provide practical recommendations, case examples with dialogue, and strategies that help lay the groundwork for successful family teamwork. The parents, too, are part of the treatment process – and their learning and change provide for a better long-term outcome, once the child is discharged.

The hard truth of treating children and teens with chronic and complex pain is that there is no quick fix. I was heartened to read this statement by Dr. Boris Zernikow: “In a time of limited human resources and a shift to technical medicine the inpatient pain therapy program of the German Paediatric Pain Centre with its personnel-intensive multimodal approach focusing on the child and his/her family may seem to be a relic from the past. However, it is exactly that human approach that makes the program so successful.”

Key, catchy phrases remind families and children of essential concepts in understanding pain, and these are reiterated throughout the treatment process. For example, Drs. Dobe, Kriszio and Zernikow discuss in Chap. 4 the “Three Thought Traps”: 1. “Everything is of pure psychological origin”; 2. “Everything is of pure physical origin”; and 3. “The pain must vanish at all costs”. Debunking these commonly held myths as part of the initial psycho-education builds a solid foundation for the wide range of interventions that are explicated in this groundbreaking manual.

Chapter 6 is the heart of this manual on the treatment of paediatric chronic pain. This chapter alone is worth the price of the book. You’ll be glued, as I was, to the discussion of how to assess and treat children who present with concomitant depression or trauma concurrent with their chronic pain. This is a unique contribution. In the paediatric pain literature to date, there is little research and discussion on children who have experienced trauma and present with chronic pain. We know clinically that their pain will not be successfully resolved without the skillful and sensitive concurrent treatment of the trauma and/or depression. Dr. Michael Dobe is masterful in his systematic exposition on how to engage the traumatized child. He discusses what images and therapeutic strategies are conducive to building psychological flexibility, adaptive cognitions and trust, while not re-traumatizing the child. Imaginative techniques, such as “The Safe Place”, used to provide emotional stability and training in how to self-assess tension levels and use relaxation techniques, are but a few of the cognitive behavioral strategies that are well-described in this chapter.

Drs. Dobe and Zernikow have included in this manual contributions from their team members Drs. Wager, Kriszio, and Hechler. They explain in Chap. 3 the necessity of a comprehensive assessment and the use of standardized multi-modal instruments in determining the full scope of the emotional impact, cognitive, physical, social and familial impact/burden of chronic pain. Drs. Hechler, Dobe and Zernikow conclude the book with a well-written response to the question “Is it all worthwhile? – Effectiveness of intensive interdisciplinary pain treatment” by providing convincing evidence for the effectiveness of intensive interdisciplinary pain programs.

The authors generously provide a list of their questions, materials and in the appendix supply 19 worksheets to explore patients’ resources and their stress factors. These worksheets are very useful and include descriptions with standardized instructions regarding the most important therapeutic interventions. They invite us to take these materials and worksheets with their detailed information and apply them in our own settings, whether in an outpatient or inpatient pain program. We should do so, as there is enough rich material, research, clinical cases and depth of

understanding, whatever one's profession, for this substantial manual to remain a primary resource for pain practitioners for many years to come. It provides an excellent standard of care in the complex treatment of paediatric chronic pain in the second decade of the twenty-first century.

I congratulate Michael and Boris and their team on this superb contribution to the field of paediatric pain, and applaud their generosity in sharing their research, considerable clinical and teaching experience, and their assessment and treatment materials, which all add to the progress in treating chronic pain – one of the most exasperating of all pains.

Vancouver, BC, Canada

Leora Kuttner, PhD, Reg. Psych.

Foreword II

There are a number of textbooks in print on paediatric pain, but very few of them warrant inclusion of the word “Practical” in the title. Michael Dobe’s and Boris Zernikow’s *Practical Treatment Options for Chronic Pain in Children and Adolescents* provides an approach that is above all practical and useful for clinicians caring for children with chronic pain.

The presentation follows a logical progression, through epidemiology, mechanisms, assessment and measurement, therapeutic approaches, and development of a roadmap for clinical decisions about which patients require more routine versus more intensive treatment settings. The authors support many of their recommendations with a superb blend of case discussions, theoretical considerations, and outcome data. The tone throughout is child and family centered. The authors emphasize wellness and fostering a child’s capacity to heal himself or herself.

Those of us who specialize in treatment of chronic pain in children are a relatively small club. There are stylistic differences among our treatment centers that reflect differences in theoretical models, in local expertise and training, in the cultural backgrounds of our patients and families, and in the type of health care system and larger society that surrounds us. Sometimes, a manual or textbook written in one language may translate poorly into another for linguistic reasons or for cultural reasons. As an English-speaking physician in the U.S., I find that Dobe and Zernikow’s book translates very well linguistically, and it also translates well culturally. Among the predominantly English speaking countries, there are widely divergent health care delivery models and very different cultures, and these local factors may lead to modifications of some specific recommendations. Nevertheless, the core themes of the approach outlined in this book are immensely applicable across cultures and languages. I think that clinicians in a wide range of Anglophone countries, including the U.S., Canada, the UK, Australia, and New Zealand, will find the English edition of this book to be among the best “roadmaps” available for guiding treatment of chronic pain in children. In my opinion, this book will be extremely useful for a broad audience, including primary paediatricians, paediatric subspecialists, paediatric psychologists, physical and occupational therapists, child life specialists, nurses and many others worldwide. I salute Dr. Dobe and Prof. Zernikow for their superb and truly practical book.

Boston, MA, USA

Charles Berde, MD, PhD

Introduction

Anouk, a 13-year-old girl, presents at our paediatric outpatient pain clinic accompanied by her mother, after having undergone an extensive diagnostic investigation of her abdominal pain which yielded no pathological findings. Anouk has been suffering from chronic abdominal pain for about 4 years; the pain has been constant over the last 2.5 years. She has undergone various outpatient and inpatient diagnostic procedures, including esophagogastroduodenoscopy with biopsy, laparoscopy, appendectomy, and NMR with angiography, all yielding no clinically relevant findings, histology of the appendix included. During a laparoscopy 1 year ago, adhesions were successfully removed from her lower right abdomen, but she experienced only minimal improvement for a short while; during the last 6 months, the pain has been increasing again. For the last 3 months, Anouk has been unable to attend school due to abdominal pain; 2 months ago, Anouk stayed 4 days at a paediatric clinic for further diagnostic medical investigations. Since then, the intensity of the constant pain has actually increased, now scoring 7–9 on a numeric rating pain scale from 0 to 10 (0=no pain, 10=worst pain). Most of the time, Anouk slacks off and doesn't participate in any family activities, causing her parents to worry. Anouk told us that she was burdened and exhausted and was not able to concentrate anymore. According to her mother, the family burden due to these pain episodes was extraordinary, even impacting close relatives. Consequently, Anouk has feelings of guilt.

Anouk's case illustrates the fact that pain may be so strong and extensive that it severely affects the patient's and his/her family's lives. Pain is a universal experience. Mostly, pain is a sign of muscular tension or of minor injury (e.g., contusion) and will vanish quickly. This is typical of acute pain. But, if pain is present for a longer period of time (6 months in adults, 3 months in children) for at least 15 days/month, it is called chronic pain. Three to 5 % of all children and adolescents report severe chronic pain, also affecting different aspects of their lives (Huguet and Miro 2008).

Some of the children and adolescents (referred to as "children" from now on) will get sufficient help in primary care. But a substantial number of severely affected children remain who are strongly impaired in their daily lives. Most of these children might be effectively treated in an outpatient setting. Unfortunately, suitable paediatric outpatient clinics for children with chronic pain or equivalent treatment options are rare. Thus, it often proves impossible to arrange the indicated measures for children with chronic pain in an outpatient setting. Reasons for the paucity of outpatient treatment centers might be that only recently has attention been brought

to the problem of diagnosing and treating chronic pain and recognizing it as an independent disease. It is only during the last few years that various medical and psychological university faculties and therapeutic medical schools/institutions have specialized in chronic pain and pain disorders in adults and children. As a consequence, a physician unaware of the pain disorder won't offer adequate treatment.

The lack of knowledge of many physicians, paediatricians, and therapists is also reflected in the fact that many children with chronic pain have a wrong diagnosis and receive insufficient treatment. We would like to emphasize that "simple" chronic pain is already of substantial negative impact for the patient's mental and psychosocial development. These children tend to miss school because of their pain. They attend fewer social activities than their healthy peers, and they more frequently show signs of depression (Palermo et al. 2009; Eccleston et al. 2004). Each month of insufficient treatment makes it more probable that the symptom of pain will become independent of physical input and lead to a chronic pain disorder. As seen in the case of Anouk, many patients and their families report a medical odyssey but have never been educated about chronic pain.

As mentioned before, untreated chronic pain frequently leads to pain-related absenteeism from school combined with a high emotional burden for the child and his/her family. Children like Anouk suffer pain disorders, diseases where pain has become an independent disease in such a way that it has a strong impact on thoughts, feelings, behavior, family life, or social activities. If the pain is not too severe, outpatient pain (psycho) therapy may be sufficient. But if the child is severely affected in his/her everyday activities and at school, outpatient pain treatment will in most cases not be effective, and participation in a multimodal inpatient pain therapy program is indicated (Hechler et al. 2009).

How should children with a chronic pain disorder be treated? Only since the end of the 1980s has the medical community engaged in the understanding and treatment of chronic pain disorders. Thus, it is not surprising that a treatment manual or even instruction for clinical practice for the treatment of paediatric chronic pain disorders is not yet available. Another point is the paucity of scientific data on paediatric inpatient pain therapy. So far, the inpatient pain therapy program of the German Paediatric Pain Centre (GPPC) is one of the few scientifically evaluated prospective and randomized inpatient treatment programs for children with chronic pain, irrespective of pain location, underlying cause, or duration of the pain disorder.

With this manual, we intend to integrate the latest scientific knowledge with our longstanding clinical experience in the treatment of children with chronic pain disorders and their families. Along with the explanation and detailed description of our clinical experience, we have included its theoretical background. Following our detailed manual, an experienced psychotherapist should be able to successfully treat children with a chronic pain disorder.

This manual should guide the psychotherapist or the medical doctor through the therapeutic process of treating children with chronic pain. The expert knowledge and therapeutic attitude imparted focus on clinical application and are suitable also in an outpatient setting, as are most of the methods illustrated in Chaps. 4, 6, and 7. Moreover, this manual should allow other inpatient institutions to offer effective inpatient pain therapy to children with a chronic pain disorder. Described in detail

are the setting, inpatient routines, daily routines, as well as therapeutic work, interventions of the nursing and educational team (NET), and the therapeutic approach of including other professions based on the patient's needs. This will also allow minor modifications according to preexisting institutional or therapeutic concepts. We feel that the comprehensive description of the latest scientific knowledge, therapeutic attitude, education, treatment methods preferred by our team, and the institutional structure of the GPPC will help other institutions to successfully establish their own inpatient concept for the treatment of chronic pain in children.

Chapter 1 gives an overview of the latest epidemiological data. Chapter 2 summarizes the scientific state of the art with respect to the background and understanding of paediatric chronic pain. Chapter 3 describes the instruments useful in exploring chronic pain, while in Chap. 4 the necessary basic therapeutic knowledge is outlined in detail. Chapter 5 discusses the criteria for allocating patients to either the outpatient or the inpatient therapeutic setting. Chapter 6 delivers a comprehensive description of the inpatient paediatric pain management concept at the GPPC, not only listing the different tasks of the various professions but also giving practical hints for therapeutic interventions, illustrated by the presentation of sample clinical cases. An extra focus is set on imparting knowledge on working with the patient's family and the implementation of treatment approaches for children with chronic pain disorders concomitantly suffering, for example, psychotrauma or depression. Chapter 7 covers more general aspects of the therapeutic work with children suffering comorbid mental, psychosocial, or physical symptoms. Chapter 8 summarizes results from the latest effectiveness studies especially on inpatient pain treatment.

Chapter 9 includes some material for the clinical work. You will find various worksheets which help to explore patients' resources and psychological stress factors and some sheets just for getting acquainted with the patient. We also include descriptions of the most important therapeutic interventions, with standardized instructions.

We hope that the manual will reflect our enthusiasm for working with children with chronic pain and their families, and we wish the reader success in implementing the therapeutic program.

Datteln, Germany
Datteln, Germany

Michael Dobe
Boris Zernikow

References

- Eccleston C, Crombez G, Scotford A, Clinch J, Connell H (2004) Adolescent chronic pain: patterns and predictors of emotional distress in adolescents with chronic pain and their parents. *Pain* 108(3):221–229
- Hechler T, Dobe M, Kosfelder J, Damschen U, Hübner B, Blankenburg M, Sauer C, Zernikow B (2009) Effectiveness of a three-week multimodal inpatient pain treatment for adolescents suffering from chronic pain: statistical and clinical significance. *Clin J Pain* 25(2):156–166
- Huguet A, Miró J (2008) The severity of chronic pediatric pain: an epidemiological study. *J Pain* 9(3):226–236
- Palermo TM (2009) Assessment of chronic pain in children: current status and emerging topics. *Pain Res Manag* 14(1):21–26. *Pain* 108(3):221–229