Response to the Commentary: A Worldwide Call for Multimodal Inpatient Treatment for Children and Adolescents Suffering from Chronic Pain and Pain-related Disability

Cynthia S. Maynard, PsyD, Adrianna Amari, PhD, Beth Wieczorek, RN, CRNP, James R. Christensen, MD, and Keith J. Slifer, PhD

The Kennedy Krieger Institute and Johns Hopkins University School of Medicine

The commentary by Hechler, Dobe, & Zernikow (2009) that discusses our retrospective review of an inpatient protocol for pain-associated disability (Maynard, Amari, Wieczorek, Christensen, & Slifer, 2009) highlights a number of important points for consideration regarding the worldwide need and standards for multimodal inpatient treatment of children and adolescents with chronic pain and pain-related disability. In their commentary and recent work reporting the results of a similar multimodal inpatient protocol, Hechler, Blankenburg, Dobe, Kosfelder, Hübner, & Zernikowet, (2009) have cogently set forth important standards for future clinical trials of multidisciplinary inpatient treatment for chronic pain and functional disability in children and adolescents. We acknowledged the considerable limitations of a retrospective study in Maynard et al. (2009). We fully acknowledge the need to interpret the results of our study with caution, given its limitations. We have discussed the need for prospective, randomized controlled clinical trials involving multiple centers, and using both a standard protocol and standardized outcome measures. The prospective studies by Dobe, Damschen, Reiffer-Wiesel, Sauer, & Zernikow (2006) and Hechler, Blankenburg, et al. (2009) should be encouraged, and we commend them for their fine work. Our objective in publishing our limited retrospective clinical results was to focus more attention in the field on the relatively untapped potential for multidisciplinary inpatient treatment within a rehabilitation setting to interrupt the downward spiral of pain, avoidance behavior and increasing disability in children and adolescents. Although we conducted a retrospective study, the clinical outcomes seen using our protocol have been encouraging. This along with the increasing demand for a brief inpatient alternative for patients who are not responsive to more typical outpatient pain clinic services seemed worth presenting to our colleagues in pediatric psychology.

As noted in the commentary, we recognize that the sample size of 41 is less than optimal. Again, based upon the available data that we had at our institute, we felt that it was meaningful to present this information despite this relative weakness. We agree with Hechler, Dobe, et al. (2009) that future research studies should obtain larger sample sizes and more complete follow-up data at standard intervals post-discharge. A longer follow-up period beyond our 3-month assessment is critical to evaluating maintenance and generalization of treatment effects.

The need for reporting pain intensity was also discussed in the commentary. Clearly, these data are important and should be included in future studies. Our clinical objective has been to de-emphasize pain ratings relative to functional outcomes with our patients and families. We agree that this does not obviate the need for obtaining pain intensity data. We recommend that the number of times per day that intensity ratings are obtained should be made standard and time based rather than contingent on observed distress. Patients’ subjective pain experience should be acknowledged with both empathy and objectivity, but a contingent association between distress behavior and social attention or termination of therapy demands should be carefully avoided. Subjective pain intensity ratings are obtained on our inpatient unit by the nursing staff at standard times. However, we did not have the research resources to conduct validity and reliability analyses on these pain intensity ratings from our clinical database. Certainly, it is important to obtain these data systematically in any prospective research study, preferably using the core outcome measures recommended by Hechler, Dobe, et al. (2009) and the PedIMMPACT...
(McGrath et al., 2008). It is gratifying that the commentators were able to demonstrate clinically significant changes in pain intensity in the majority of their participants at 3-month follow-up with their multimodal inpatient treatment, and to know that they too have noted the need to study the timing of improvements in subjective pain ratings relative to changes in functional disability. Data demonstrating that decreases in pain intensity can occur in a delayed fashion after function has improved may provide a great deal of encouragement and hope for patients and their families to persist in their efforts to participate in therapy aimed at improving function and utilizing pain coping strategies in the face of apparently unrelenting pain.

We agree that future studies should include standardized outcome measures as recommended by Hechler, Dobe, et al. (2009) and in the PedIMMPACT (McGrath et al., 2008) such as the Functional Disability Inventory (Walker & Greene, 1991), Children’s Depression Inventory (Kovacs, 1981), Revised Child Anxiety and Depression Scale (Chorpita, Yim, Moffitt, Umemoto, & Francis, 2000), PedMIDAS (Hershey et al., 2001; Hershey et al., 2004) and PedsQL (Varni, Seid, & Rode, 1999). Future studies that include recommendations described in the PedIMMPACT guidelines for use of actigraphy (Ancoli-Israel et al., 2003), sleep diaries (Gaina, Sekine, Chen, Hamanishi, & Kagamimori, 2004), or instruments such as the Sleep Habits Questionnaire (Owens, Spirito, & McGuinn, 2000) are to be encouraged.

Interesting discussion was also provided in the commentary about the need for agreement within the field on definitions of chronic pain and pain-associated disability. This is a problem to be grappled with by the entire community of pediatric pain researchers and was well beyond the scope and resources of our retrospective clinical report. The suggestion of combining objective measures of pain behavior and cognitions, functional measures of school attendance, social participation, sleep, analgesic use, and subjective measures of pain location, intensity, and duration is a solid foundation on which to begin. If the research community can agree on standards of defining and measuring pain-related constructs, then, in time, profiles with diagnostic and prognostic significance may emerge.

Finally, the conversation about how to define and measure clinical significance is important and will continue. This will be particularly important to randomized, controlled clinical trials that compare treatment approaches. Perhaps defining clinical significance in terms of disability cutoff scores and indistinguishability from healthy people will be the conceptualization of choice. One consideration is that this approach results in a categorical conceptualization that might discount the importance of gradual and cumulative improvement over time. For example, moving from complete dependence on a wheelchair to ambulating moderate distances might not be valued, because it does not match what the average healthy child could do. However, the value of this level of improvement in terms of motivation and hope for more complete recovery would require more subtle consideration of physical functioning and quality of life. The field of Applied Behavior Analysis began addressing this topic with the work of Wolfe (1978), which focused on the notion of social validation as the ability to demonstrate a level of behavior change that is consistently regarded as satisfactory by clinical professionals and, especially, consumers (in this case children and their families).

Whether consumers of interventions for chronic pain and functional disability value improvements that fall short of complete recovery remains to be studied and consensus about methodology for assessing clinically important success remains to be established. There is no disagreement on our part that this is an important discussion and one that will undoubtedly be demanded by insurance companies tasked with funding intensive inpatient treatment for chronic pain in children and adolescents.

Conflicts of interest: None declared.

Received and revisions received September 9, 2009; accepted September 10, 2009

References


