

Commentary

Overcoming common barriers to engagement in psychological services for chronic pain: A one-day intensive pain management workshop for youth and parents

Rachael Coakley and Brittany N. Barber

There is strong evidence that cognitive behavioral therapy (CBT) and biobehavioral interventions are efficacious components of pain management for youth with chronic or recurrent pain (Eccleston et al., 2009; Schurman et al., 2010). These strategies help to decrease pain, improve functioning, and reduce the symptoms of anxiety and depression that often co-occur in youth with pain (Turk et al., 2008). In a recent study conducted at the Pain Treatment Service at Children's Hospital Boston, Simons and colleagues (2010) found that 65% of new patients are referred for psychological treatment; however, less than half of those referred actually follow through with initiating services. The purpose of this commentary is to identify the common barriers that impede access to treatment, discuss expanding models of care that seek to address these barriers, and present the structure, content, and preliminary program evaluation data for a newly developed CBT workshop targeting youth with chronic pain and their parents.

Engagement in psychological services for youth with chronic pain is often hampered by factors such as a lack of available providers, scheduling conflicts, insufficient knowledge of service efficacy, feeling stigmatized by mental health referrals, and financial or insurance constraints (Vona et al., 2009; Gabel 2010; Simons et al., 2010). Parents' beliefs about their child's need for psychological services are also a particularly challenging obstacle in the field of

pediatric pain. Parents seeking treatment for their child's chronic pain may be resistant to a mental health referral when they do not believe their child has a primary mental health concern (Pescosolido et al., 2008). Additionally, parents may be resistant to mental health referrals when they feel the physician referral for mental health services implies their child's pain is psychologically based and therefore not real pain. Research suggests that families are much more likely to follow through with referrals for psychological services if they have a foundational understanding of the benefit and efficacy of CBT for the management of chronic pain prior to a referral (Simons et al., 2010). This suggests that one way to increase engagement in services would be to increase patient education and familiarity with CBT for chronic pain. More broadly, poor adherence to referrals for psychological services in the pediatric chronic pain population highlights the need to create models of care that can be flexible in meeting the time, cost, and limited resource barriers that routinely impede access to care. Additionally, there is a need to provide access to targeted interventions in a non-stigmatizing format.

Expanding models of care to improve engagement in psychologically based interventions

There have been several recent efforts to address barriers to engagement and increase access to psychological services for pediatric pain. For

example, Palermo and colleagues (2009) created an 8-week CBT treatment delivered via the Internet and demonstrated that participants had a significantly greater reduction in activity limitations and pain intensity post-treatment and at a three-month follow-up. Similarly, Hicks and colleagues (2006) designed an Internet- and telephone-delivered CBT intervention for pediatric recurrent headache and migraine pain. This study demonstrated that 70% of participants in the treatment group achieved clinically significant improvement at the one- and three-month follow-ups, which was significantly different from control group peers. Another intervention by Connelly and colleagues (2006) provided psychoeducational CD-ROMs to youth with chronic headaches. This intervention was designed to introduce psychologically-based strategies in a way that minimizes stigma and reduces the logistical and financial demands of working with a mental health provider. A final approach to making CBT and biobehavioral interventions more accessible is the use of a brief group intervention (Morrison, 2001). This approach has the added advantages of providing peer support as well as the personalized experience of working with a psychologist.

Within the pediatric literature, brief (< 6 hours) psychoeducational and CBT group interventions have demonstrated promising gains on variables such as self-efficacy, self-management, family functioning, psychosocial well-being, pain severity, school attendance, and feelings of hopefulness (Barlow & Ellard, 2004). Condensing a brief intervention into a one-day workshop has the added benefits of reducing scheduling demands, increasing the likelihood of attracting families from a greater geographic area, and reducing the likelihood that patients will receive only a partial dose of the intervention, as occurs when patients only attend a subset of recommended group sessions. Implementing CBT in an intensive format, such as a daylong workshop, has proven to be cost-effective, convenient, and efficacious in the adult literature (LeFort et al., 1998; Brown et al., 2000; Morrison, 2001), with some preliminary support in the pediatric pain literature (Logan & Simons, 2010). Moreover, evidence suggests that initial gains for one-day workshops were frequently maintained at

one-month follow-up, and may be maintained for as long as one year (Morrison, 2001; Prytys et al., 2010). Additionally, one-day workshops have a very high rate of satisfaction from participants (Brown et al., 1999; Brown et al., 2004).

Implementing a one-day pediatric pain management workshop

The Pain Treatment Service at Children's Hospital Boston initiated an intensive one-day intervention with the goal of providing a non-stigmatizing, cost and time effective means by which to introduce cognitive behavioral and biobehavioral pain management strategies to youth with chronic pain and their parents. The program, named *The Comfort Ability*, was designed to provide families with a foundation for understanding how psychological interventions (i.e. CBT and biobehavioral skills) facilitate improved pain management. The program goals include: (a) provision of an introductory CBT skill set to encourage improved functioning from both an emotional and physical perspective, (b) opportunity for in vivo practice of basic biobehavioral skills (i.e. diaphragmatic breathing, guided imagery, progressive muscle relaxation), (c) provision of peer-based support for youth and parents, and (d) opportunity for families to consult with pediatric psychologists and obtain resources for continued psychological support as needed.

The Comfort Ability currently runs on a quarterly basis. The program consists of a parent group and an adolescent group that run simultaneously but separately. The program is six hours long and is scheduled on a weekend day to maximize accessibility for families and to minimize school and job interference. Each group includes up to 12 adolescents (ages 10-17 years) and up to 24 parents. The group is staffed by two attending psychologists (one for the parent group and one for the adolescent group), a psychology fellow, and one or two volunteers (e.g. psychology interns, research assistants). There is a program fee of \$120 USD per family. Program referrals primarily come from the multidisciplinary pain clinic, however, the program also accepts direct referrals from other clinics within the hospital (e.g. rheumatology, gastroenterology, neurology, hematology), as well

as outside referrals. Recruitment efforts currently include posting flyers in the hospital, mailing flyers to new patients within the Pain Treatment Service, and posting information about the program on the internal and external hospital websites. All youth between the ages of 10 and 17 years with chronic or recurrent pain are invited to participate in the group. Exclusion criteria include only significant developmental delay or psychopathology that would likely impede group functioning. Additionally, families who are non-English speaking are informed that interpreter services are not available for the day-long program. Youth within the Pain Treatment Service who are assessed to need CBT for pain management are routinely referred to both individual therapy and *The Comfort Ability* group. Families are provided with information about how each modality would benefit their child, and given a choice about which service delivery model to pursue. We are in the process of formally assessing what factors may influence family decisions to select one modality over the other and whether participation in one modality may influence the future acquisition of additional services.

The Comfort Ability youth program includes motivational interviewing strategies to prepare youth for making changes in their health behaviors, cognitive behavioral approaches to pain management, and in-vivo practice of biobehavioral pain management strategies. Specific cognitive behavioral components include psychoeducation about how pain functions in the body (e.g. gate control theory) and interactive discussions using case vignettes and role plays that emphasize adaptive cognitive and behavioral strategies to enhance functional ability. Program topics include school participation, sleep hygiene, exercise routines, peer relationships, and family interactions. Cognitive strategies include practice in the identification and modification of common pain-related negative thoughts (i.e. "This pain will never go away", "I can't do anything until my pain gets better") and psychoeducation about how these thoughts contribute to feelings of fear, hopelessness, and helplessness. Additionally, youth are taught about the symptoms of persistent anxiety and depression and how to obtain further services for these difficulties. Youth are asked to bring a yoga

mat or blanket with them to the program and about one third of the day is devoted to in vivo practice of diaphragmatic breathing, guided imagery, progressive muscle relaxation, autogenic relaxation, and biofeedback on the Stresseraser™ handheld biofeedback device. Youth also participate in an art therapy activity to help boost feelings of self-efficacy. At the end of the day youth create a personalized pain management plan that highlights the individual coping strategies each child preferred during the course of the day. Youth are additionally provided with a pain management tool kit inclusive of a relaxation CD and multiple other tools (i.e. biofeedback card, a blower to use while practicing diaphragmatic breathing, a notebook/pens for distraction, etc.) to use in their pain management regimen.

The parent program includes psychoeducation about pain and an in depth discussion about pain in the context of development. A large portion of the parent program emphasizes strategies that promote a child's return to adaptive functioning in school and home settings. Parents are also introduced to the cognitive and biobehavioral strategies covered in the youth program so that they can help to reinforce these strategies at home. Additionally, there is a parent support group component to the program. All parents and youth are provided with a tailored manual inclusive of psychoeducational materials from the program to solidify the information learned.

How do patients respond to this intervention? Preliminary program evaluation data

Our preliminary goal was to assess feasibility and patient satisfaction with this program. We requested that all participating youth and at least one participating parent anonymously complete a post-treatment survey immediately after completion of the program. Most questions were assessed on a 5-point Likert scale ranging from 1 (*Strongly Agree*) to 5 (*Strongly Disagree*).

Our youth participants ($N = 32$) ranged in age from 10 to 17 years ($M = 13.8$, $SD = 2.1$). Participants were predominately female (84%) which is representative of a chronic pain population (Eccleston et al. 2009; Stanford et al., 2008).

Program evaluation data indicate that all participating youth reported an increase in new knowledge about how pain functions in the body, biobehavioral relaxation strategies, biofeedback, and CBT. Additionally, 85% of youth strongly agreed that they gained the knowledge necessary to practice many of these skills independently, and endorsed having confidence that these strategies would help them to function better.

Participating parents who completed post-treatment surveys ($N = 37$) included 25 mothers, 10 fathers, and two other caregivers. Approximately 50% of our participating families had two caregivers present at the workshop, but in many instances only one participating parent completed a post-treatment survey. Surveys indicated that caregivers were also highly satisfied with this intervention. Most caregivers (91%) indicated that they gained new knowledge about how pain functions in the body, 96% indicated that they gained knowledge about how biobehavioral interventions work to reduce pain, and 87% indicated that they gained knowledge about CBT. The majority of caregivers also reported they learned new ways to respond to their child's chronic pain problem, and indicated that they learned how to better manage their child's pain flares. After completion of the program, 92% of caregivers indicated that they planned to make changes in how they manage their child's chronic pain problem. Importantly, 91% reported that they learned when and how to seek additional psychological services for pain management, and 86% indicated that they obtained the resources necessary to establish these services. An overwhelming majority of parents reported they enjoyed the intensive one-day format and would not prefer weekly sessions or even having the material split into a two-day program.

Challenges and future directions

Addressing the common barriers that limit engagement in psychological services for youth with chronic pain requires creative and flexible treatment options. Even with targeted efforts to increase accessibility and reduce the stigma of mental health referrals, there continues to be challenges. For example, while our fee structure was set to be on par with the average copayment

associated with attending six outpatient therapy sessions (\$20/hr for 6 hours of therapy), the "pay out of pocket" model is too burdensome for a portion of our referrals. To address this concern, we are currently working on strategies to make this program financially accessible to all families who have interest in attending.

Another common problem within the pain population is getting parents to bring a child for treatment when the child is in pain. Within our group program we found that about one third of our confirmed participants did not attend on the day of the program. The majority of these unanticipated cancellations were reportedly due to the child not feeling well on the day of the program. To address this concern, at our most recent group we required a 50% deposit to ensure a place in the program. This dramatically reduced the late cancellations.

Our current program does not include a sibling intervention. Creating a separate sibling group was beyond the scope of the initial workshop agenda, but may be an important future consideration given that chronic pain is well known to have a systemic impact on the family. Additionally, exclusion of siblings may reduce the ability for both parents to participate in this program, given that caregiving responsibilities are often split between parents. Another future consideration would be whether or not families with either highly disabled youth or an inability to travel to the site of the program would be able to participate via an online communications program such as Skype.

We have initiated a study to formally assess outcome data at one week, one month, and three months after program participation. Ultimately, our goals are to demonstrate sustained feasibility and efficacy for this brief CBT intervention. We hope to increase the frequency of this program as needed to meet the demands of our current catchment area, and in the future to transport the program to underserved areas so that we can further increase access to care. Given that this intervention is manualized and highly transportable, we have considered whether or not other professionals (e.g. nurses, other health care providers, para-professionals) could be trained in the administration of this program. However, our experience within the parent and child group thus far suggests that

while this intervention is highly structured, families have many questions that require clinical expertise and novel clinical situations emerge with each new group. Additionally, mental health expertise is useful for helping to identify youth with more significant psychopathology and to assist these families in attaining further intervention. Thus, *The Comfort Ability* intervention greatly benefits from group leaders who are mental health clinicians with training in pediatric pain management and CBT.

The availability of non-stigmatizing, cost- and time-effective approaches to psychological interventions can help to address many of the barriers that prevent families from engaging in psychological services for pain management. For youth with minimal to moderate levels of functional impairment and psychopathology, a brief but intensive intervention such as a one-day workshop may prove to be a sufficient dose of therapy and may provide the resources for helping patients to gain better control of their symptoms. For youth with more severe functional limitations and/or significant anxiety, depression, or other mood-based concerns, this type of intervention may be more of a “foot in the door” approach to obtaining individual psychological services. In other words, the knowledge gained in a workshop such as this may help to reduce the stigma associated with psychological interventions and encourage families to seek additional services. Anecdotally, after the

workshop, several participating families reported that their child was more open to psychological interventions and these families requested referrals to individual providers. We are formally assessing the foot in the door hypothesis by tracking which patients initiate psychotherapeutic services after completion of the workshop. Additionally, it is our hope that we will be able to discern the patient characteristics that predict which patients are likely to benefit from this intervention alone, and which patients may utilize this intervention as a gateway to more comprehensive care.

Rachael Coakley, PhD
Children’s Hospital Boston, Boston, MA, USA
email: rachael.coakley@childrens.harvard.edu

Brittany N. Barber, PhD
Children’s Hospital Boston, Boston, MA, USA

Acknowledgments

The authors thank Richard and Sara Page Mayo for their generous support of this program, which is part of their longstanding initiative to increase access to pain management services at Children’s Hospital Boston. The authors also thank Dr. Deirdre Logan for her contribution to this commentary.

References

Barlow JH, Ellard DR. Psycho-educational interventions for children with chronic disease, parents and siblings: an overview of the research evidence base. *Child Care Health Dev* 2004;30:637-645.

www.pubmed.gov/15527474

Brown JSL, Cochrane R, Cardone D. Large-scale health promotion stress workshops: promotion, programme content and client response. *J Ment Health* 1999;8:391-402.

Brown JSL, Cochrane R, Hancox T. Large-scale health promotion stress workshops for the general public: a controlled evaluation. *Behav Cogn Psychother* 2000;28:139-151.

Brown JSL, Elliot SA, Boardman J, Ferns J, Morrison J. Meeting the unmet need for depression services with psycho-educational self-confidence workshops: preliminary report. *Br J Psychiatry* 2004;185:511-515. www.pubmed.gov/15572743

Connelly M, Rapoff MA, Thompson N, Connelly W. Headstrong: a pilot study of a CD-ROM intervention for recurrent pediatric headache. *J Pediatr Psychol* 2006;31:737-747. www.pubmed.gov/16861397

Eccleston C, Palermo TM, Williams AC, Lewandowski A, Morley S. Psychological therapies for the management of chronic and recurrent pain in children and adolescents. *Cochrane Database Syst Rev* 2009 Apr 15;(2):CD003968. www.pubmed.gov/19370592

Gabel S. The integration of mental health into pediatric practice: pediatricians and child and adolescent psychiatrists working together in new models of care. *J Pediatr* 2010;157:848-851. www.pubmed.gov/20633899

Hicks CL, von Baeyer CL, McGrath PJ. Online psychological treatment for pediatric recurrent pain: a randomized evaluation. *J Pediatr Psychol* 2006;31:724-736. www.pubmed.gov/16093516

LeFort SM, Gray-Donald K, Rowat KM, Jeans ME. Randomized controlled trial of a community-based psychoeducation program for the self-management of chronic pain. *Pain* 1998; 74:297-306. www.pubmed.gov/9520244

Logan DE, Simons LE. Development of a group intervention to improve school functioning in adolescents with chronic pain and depressive symptoms: a study of feasibility and preliminary efficacy. *J Pediatr Psychol* 2010;35:823-836. www.pubmed.gov/20167628

Morrison N. Group cognitive therapy: treatment of choice or sub-optimal option? *Behav Cogn Psychother* 2001;29:311-332.

Palermo TM, Wilson AC, Peters M, Lewandowski A, Somhegyi H. Randomized controlled trial of an Internet-delivered family cognitive-behavioral therapy intervention for children and adolescents with chronic pain. *Pain* 2009;146:205-213. www.pubmed.gov/19695776

Pescosolido BA, Jensen PS, Martin JK, Perry BL, Olafsdottir S, Fettes D. Public knowledge and assessment of child mental health problems: findings from the National Stigma Study-Children. *J Am Acad Child Adolesc Psychiatry* 2008;47:339-349. www.pubmed.gov/18216729

Prytys M, Whittinger N, Coventry S, Idusohan H, Brown J. Psycho-educational CBT insomnia workshops for the general public: an audit of access and clinical outcomes. *J Public Ment Health* 2010;9:8-15.

Schurman JV, Wu YP, Grayson P, Friesen CA. A pilot study to assess the efficacy of biofeedback-assisted relaxation training as an adjunct treatment for pediatric functional dyspepsia associated with duodenal eosinophilia. *J Pediatr Psychol* 2010;35:837-847. www.pubmed.gov/20185416

Simons LE, Logan DE, Chastain L, Cerullo M. Engagement in multidisciplinary interventions for pediatric chronic pain: parental expectations, barriers, and child outcomes. *Clin J Pain* 2010;26:291-299. www.pubmed.gov/20393263

Stanford EA, Chambers CT, Biesanz JC, Chen E. The frequency, trajectories and predictors of adolescent recurrent pain: a population-based approach. *Pain* 2008;138:11-21. www.pubmed.gov/18093737

Turk DC, Swanson KS, Tunks ER. Psychological approaches in the treatment of chronic pain patients: when pills, scalpels, and needles are not enough. *Can J Psychiatry* 2008;53:213-223. www.pubmed.gov/18478824

Vona P, Siddarth P, Sankar R, Caplan R. Obstacles to mental health care in pediatric epilepsy: insight from parents. *Epilepsy Behav* 2009;14:360-366. www.pubmed.gov/19110072