

August 2011

Vol. 13 No. 2

www.childpain.org/ppl

Editor: Carl L von Baeyer, carl.vonbaeyer@usask.ca — Please visit website for information on submission and review

© 2011, Special Interest Group on Pain in Childhood, International Association for the Study of Pain®

Website review

The Coping Club: a new user-generated resource for children with pain and other medical conditions

Reviewed by Michelle M. Ernst

Pediatric professionals have a novel, valuable tool that can be shared with patients managing pain and other medical issues. *The Coping Club* (www.copingclub.com) integrates social learning theory with the newest development in interactive web communities, user-generated internet content, to enhance children's self-efficacy, coping skills and adjustment. The project is led by Dr. Bryan Carter, a pediatric psychologist and professor of child psychiatry and pediatrics at the University of Louisville School of Medicine and director of the Pediatric Consultation-Liaison Service at Kosair's Children's Hospital, Louisville, Kentucky, USA, in conjunction with Gabe Riggs (Norton Healthcare).

On this award-winning website, children experiencing medical situations post multimedia presentations that they have produced to tell their stories and demonstrate coping. A consistent theme throughout the videos is how these youth have been challenged by a variety of medical situations, but have developed a sense of mastery over their experiences, thus providing peer models of positive adaptation for other children. The efficacy of observational learning for enhancing skill development and self-efficacy is well-accepted (Bandura, 2004), and the use of peer models may be particularly advantageous (van Gog & Rummel, 2010). While the focus of the videos tend to be on chronic illness in general, several of the videos involve children discussing issues related to coping with both acute and chronic pain such as symptom management techniques and the importance of remaining active. The website is designed to be

easily utilized by health care providers working with pediatric populations as well as by the children (and families) independently.

Initiated in 2010, the Coping Club's content consists of brief videos (most less than five minutes in duration) in which children or family members talk about their personal experience with an illness. Some vignettes include coping tips and demonstrations of specific skills (e.g. diaphragmatic breathing, progressive pill swallowing exposure). Alongside each video is written content about the primary illness condition being discussed and a helpful link to Kosair Children's extensive patient-oriented health information library (www.nortonhealthcare.com/healthinfo). The videos vary in style; some are simple captures of a person talking, while others are heavily edited (with child input) including visual graphics and additional sound. Thus, the website utilizes effective components of health education such as multimedia presentation, developmentally appropriate content and cued instruction (de Koning et al., 2009; von Gog & Rummel, 2010). There is a search function that allows for easy site navigation (e.g. search terms "pain", "stress" and "relaxation" all identify some videos related to pain issues). There is also an opportunity on the website for viewer comments.

The content of the videos have been reviewed by pediatric psychologists and reflect pediatric psychology evidence-based approaches, such as cognitive-behavioral skills for pain management (Palermo et al., 2010). In one video, an adolescent

with Crohn's disease discusses positive self-statements she uses to handle pain ("It won't last forever") that can counter the catastrophic thinking so detrimental to effective coping with pain (Vervoort et al., 2006). Another child, confronted with procedural pain, tells herself "it is worth it!", ascribing an adaptive meaning to what might be interpreted as a threatening event. In addition, specific exercises such as diaphragmatic breathing and progressive muscle-relaxation are reviewed in multiple videos (9-year-old Amber is a particularly dynamic teacher of belly breathing), as well as the use of distraction and the benefit of self-monitoring. The children also consistently relate the importance of not letting pain or other illness symptoms interfere with valued activities. This highlights the maintenance of quality of life, adaptive functioning, and pursuit of goals central in Acceptance and Commitment Therapy-based approaches (Wicksell et al., 2009). The videos are also useful for exposure therapy: one child demonstrates giving herself an injection, a video which could be used in a desensitization strategy for anticipatory anxiety (Patel et al., 2005).

Because the videos are brief and focused, they can easily be incorporated into a range of treatment settings and by a variety of health care professionals. For example, a nurse who is working with a patient to cope with injections could review the procedural pain vignette with the patient at the bedside, discussing how the videotaped child coped and identifying tips that the patient could try. A physical therapist doing pain rehabilitation with a child could teach breathing exercises to cope with painful movement by starting the session with a video in which diaphragmatic breathing is presented. Sharing the website with colleagues across disciplines can increase their understanding and use of these brief evidence-based interventions.

While the videos are clearly intended to be of help to viewers, the act of generating the material likely benefits the models as well. The act of simply watching their skill demonstration in their own vignette can enhance skill refinement (van Gog & Rummel, 2010). The emotional disclosure literature suggests that the act of thinking about and writing out their narrative (e.g. developing their script) may be beneficial to these youth (e.g. Wallander et al.,

2011). In addition, research on user-generated material suggests that some of the key motivators to create are to establish identity, enhance self-expression, leave a mark on the world, and build confidence (Leung, 2009; Shao, 2009). These concepts are poignantly illustrated by the experience of one of the videotaped children who asked that her tape be sent ahead when she was transferred to another hospital so that the staff there would know her. This child subsequently passed away, and her parents expressed much gratitude for having the DVD as a remembrance (B. Carter, personal communication, June 2011). Enhancing identity clarification and desiring to have agency in the world is developmentally appropriate for children and also may be particularly meaningful in end-of-life experiences. In addition, the videos may reduce the isolation many chronically ill children experience (Forgeron et al., 2010).

There are other excellent professionally-developed multimedia resources for professionals and families to use which offer health information and review/demonstrate evidence-based tools, such as Leora Kuttner's ground-breaking videos about effective pediatric pain management (e.g. Kuttner, 2010). In addition, internet coping interventions have been described in the literature (e.g. Palermo et al., 2009; Trautmann & Kröner-Herwig, 2010). However, these types of material must be purchased, or are only available to research participants. There are some freely-available websites on the internet related to children's pain, but finding ones that appeal to children is difficult. Sites most readily retrieved by a Google search are either marketing sites for hospital-based pain management programs or informational sites geared to professionals or parents. Searching YouTube (www.youtube.com) retrieves similar sites and necessitates navigating inappropriate content. The StressFreeKids channel on YouTube has engaging, animated cartoon videos of relaxation strategies geared toward younger children, but no peer modeling (www.youtube.com/user/StressFreeKids). The Starlight Children's Foundation sponsors a user-generated web community for youth with chronic illness (and siblings), but only teenagers are allowed to access it, making it difficult to screen videos (www.starbrightworld.org). My Google search was

unable to find any examples of children talking specifically about how they manage their pain or demonstrating any skills.

Unfortunately, my search did not retrieve the Coping Club website either, which speaks to the need for the developers to increase their web presence and make the site more searchable. In addition, some of the videos have a strong religious coping emphasis – prescreening might be important before recommending certain videos to some families. Finally, while there are enough videos to speak to a large number of concerns about pediatric illness, a greater variety of videos will enhance its therapeutic application.

Given the likely benefit to both the youth who post to it and the children and families who view it, I highly recommend that pediatric health professionals consider incorporating the Coping Club website into their own practice. The theoretical grounding, use of evidence-based techniques, and involvement of peer models make it

an ideal tool. The website developers are actively soliciting videos from children outside of their institution and wish to expand the topics that are presented (B. Carter, personal communication, June 2011). The website has uploading features that are easy to use, and the developers can assist with editing. Thus, whether encouraging chronically ill children to watch the material or assisting them in producing their own video, the website is immediately available to be an innovative, effective component of pediatric health interventions across a multitude of settings.

Michelle M. Ernst, PhD

Division of Behavioral Medicine and Clinical Psychology, Department of Pediatrics, Cincinnati Children's Hospital Medical Center, University of Cincinnati College of Medicine, Cincinnati, OH, USA

email: michelle.ernst@cchmc.org

References

Bandura A. Health promotion by social cognitive means. *Health Educ Behav* 2004;31:143-164.

www.pubmed.gov/15090118

de Koning BB, Tabbers HK, Rikers RMJP, Paas F. Towards a framework for attention cueing in instructional animations: guidelines for research and design. *Educ Psychol Rev* 2009;21:113-140.

Forgeron PA, King S, Stinson JN, McGrath PJ, MacDonald AJ, Chambers CT. Social functioning and peer relationships in children and adolescents with chronic pain: a systematic review. *Pain Res Manag* 2010;15:27-41. www.pubmed.gov/20195556

Kuttner L. No Fears, No Tears [DVD]. Bethel, CT: Crown House, 2010.

Leung L. User-generated content on the internet: an examination of gratifications, civic engagement and psychological empowerment. *New Media Soc* 2009;11:1327-1347.

Palermo TM, Eccleston C, Lewandowski AS, Williams AC, Morley S. Randomized controlled trials of psychological therapies for management of chronic pain in children and adolescents: an updated meta-analytic review. *Pain* 2010;148:387-397.

www.pubmed.gov/19910118

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

Patel MX, Baker D, Nosarti C. Injection phobia: a systematic review of psychological treatments. *Behav Cogn Psychother* 2005;33:343-349.

Shao G. Understanding the appeal of user-generated media: a uses and gratification perspective. *Internet Res* 2009;19:7-25.

Trautmann E, Kröner-Herwig B. A randomized controlled trial of Internet-based self-help training for recurrent headache in childhood and adolescence. *Behav Res Ther* 2010;48:28-37. www.pubmed.gov/19782343

van Gog T, Rummel N. Example-based learning: integrating cognitive and social-cognitive research perspectives. *Educ Psychol Rev* 2010;22:155-174.

Vervoort T, Goubert L, Eccleston C, Bijttebier P, Crombez G. Catastrophic thinking about pain is independently associated with pain severity, disability, and somatic complaints in school children and children with chronic pain. *J Pediatr Psychol* 2006;31:674-683. www.pubmed.gov/16093515

Wallander JL, Madan-Swain A, Klapow J, Saeed S. A randomized controlled trial of written self-disclosure for functional recurrent abdominal pain in youth. *Psychol Health* 2011;26:433-447. www.pubmed.gov/20419562

Wicksell RK, Melin L, Lekander M, Olsson GL. Evaluating the effectiveness of exposure and acceptance strategies to improve functioning and quality of life in longstanding pediatric pain – a randomized controlled trial. *Pain* 2009;141:248-257. www.pubmed.gov/19108951