The BrightHearts Project: A New Approach to the Management of Procedure-Related Paediatric Anxiety

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ABSTRACT
In this paper we propose a multimedia, biofeedback approach to managing pain and procedure-related anxiety experienced by children undergoing painful recurrent procedures as part of their treatment in primary care settings, based on research currently under way at the Children's Hospital at Westmead, Kids Rehab Dept.

We survey existing approaches to the management of procedure-related pain and anxiety, including recent research utilising Virtual/Augmented Reality Distraction techniques, and then outline an approach that uses a biofeedback controlled interactive artwork as a focus for children to explore how they can regulate aspects of their psychophysiology (autonomic nervous system responses) through a combination of breath and attentive focus.

Our research aims to assess the potential of small, portable biofeedback-based interactive artworks to mediate the perception and performance of the body in paediatric care: as experienced by children undergoing painful recurrent procedures.

AUTHOR KEYWORDS
Biofeedback, Biofeedback Assisted Relaxation Training, Paediatric, Acute, Pain, Distraction, Cognitive-Behavioural, Heart Rate, Temperature, Multimedia, Primary Care

ACM CLASSIFICATION KEYWORDS
H5.m. J.3.b Health J.5.c Fine arts, Information interfaces and presentation

INTRODUCTION
Many children with chronic conditions undergo repeated painful procedures as part of their treatment, the recurrent nature of these procedures can result in a build-up of anticipatory anxiety, causing significant distress to the children. This anxiety can exacerbate the perceived intensity of the painful stimulus, which can sometimes escalate into difficult behaviour in clinic that can also cause significant logistical delays for clinicians. Vasoconstriction caused by extreme distress can further complicate certain procedures (i.e. venipucture for canulation). If left unaddressed - the distress, anxiety and possible trauma associated with these procedures can lead to avoidance behaviours that may stay with an individual into adulthood.

Common approaches to the management of procedure-related paediatric pain and anxiety have focussed primarily on simple distraction methods such as conversation, singing, kaleidoscopes etc. and cognitive-behavioural approaches that help children to reframe and remodel their perceptions and understandings of the situation and procedure they are undergoing, through the use of customised narratives: ("this is what I will see, do, feel, hear" etc.) and the customisation of certain details of the procedure so that children feel 'in control' -i.e. "I like to be sitting up when the tiny straw is put into my arm" the that help to familiarise and normalize the procedure, so that they no longer to feel in control of the situation.

The perceived intensity of painful stimulus is a fundamentally subjective phenomenon, modulated by our perception and attention. Anticipatory anxiety can therefore be determining factor in the level of perceived intensity of a painful procedure, and can increase the perceived intensity of the pain.

With these factors in mind, there is a growing interest across clinical domains from rehabilitation to dentistry, nephrology, oncology and burns treatment in the development and use of techniques for the management of procedure related paediatric anxiety.

Cognitive-Behavioral and Distraction Methods
In modern paediatric primary care many painful procedures use Nitrous Oxide analgesia in combination with a blend of two basic approaches to the management of procedural pain and anxiety: cognitive-behavioural and distraction techniques. There are also situations where it is not safe or possible to use nitrous oxide gas - in which case a combination cognitive-behavioural and distraction techniques will be used.

Distraction techniques are the most common way of managing anxiety and perceived pain intensity

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experienced by children undergoing painful procedures. Distraction techniques work according the gate-control theory of pain perception developed by Mezack and Wall (1965) in which higher-order thought processes are thought to alter a person's perception of pain, due to the diversion of perceptual processing resources away from the site of noxious stimulation.

Cognitive-behavioural approaches are used by clinical staff help children develop a sense of control over their situation, through processes of rehearsal, desensitisation and the customisation of various details of the procedure (i.e. have nitrous oxide gas whilst sitting up, only a few people in the room at start of procedure, siting in parents lap etc.). These approaches lower anxiety by a process of familiarisation and the building of trust.

Systematic Desensitization is another popular related approach - in which the anxiety provoking procedure is broken down into steps that children negotiate via increasing levels of approximation to the actual procedure. Medical Play similarly facilitates a process of familiarisation and mental remodelling - where children work with a Nurse of trained Child-Life Therapist (a.k.a. Play Therapist) and perform a version of the medical procedure on toys enabling the child to build a realistic and safe-feeling narrative and rationale for the procedure, thereby reducing anticipatory anxieties that stem largely from the child's fear of the unknown.

With the increasing ubiquity of mobile multimedia devises like portable video players, mobile phones and tablet computers (i.e. iPads), and the immediate sense of connection that most children demonstrate with these devices, there is now understandably, considerable interest in the use of these recreational and entertainment technologies as Distraction tools for managing paediatric pain and procedure related anxieties.

Malloy and Milling's (2010) systematic review of eleven comparative studies on Immersive Virtual / Augmented Reality distraction, revealed these methods to be effective for reducing experimental pain, as well as the discomfort associated with burn injury care, with studies focussed on needle-related pain providing less consistent findings. They suggest that VR distraction may be a useful tool for clinicians working with a variety of pain problems.

Compared to research on Augmented and Virtual Reality Distraction methods, Biofeedback Assisted Relaxation Training (BART) remains a relatively under-explored set of approaches for paediatric acute pain and anxiety management (as distinct from the many studies focusing on its use in the treatment migraines, headaches and specific psychological problems such as Generalized Anxiety, Panic and Posttraumatic Stress disorders).

BIOFEEDBACK TRAINING: A DEFINITION

Biofeedback training is method by which individuals learn to voluntarily sense and then control some aspect of the physiology, utilizing electronic or electromechanical instruments to measure, process and display information back ('feedback') in such a way that subjects can eventually learn to sense and then influence the behaviour being observed, usually via auditory and/or visual displays. The objective of biofeedback training is to help people develop a greater awareness and voluntary control over physiological processes - first by way of the external displays, and then via internal psychological cue (Schwartz and Olsen, 1995). Biofeedback is not a process of electro-mechanical coercion in which people are 'shocked' or 'brainwashed' into shape - nothing is 'done to' the trainee in the sense of conventional medical treatment – and its effectiveness relies to a large extent on the motivation of the subject to interact with the biofeedback display (i.e. 'play the game').

Biofeedback training supports a philosophy of self-regulation and empowerment that has significance beyond the immediate rehabilitation of the specific functions being trained. Skills gained in the regulation of specific body functions i.e. heart rate, temperature, brainwave activity, muscle control etc. often generalise into an increased sense of self-efficacy - an inner conviction that the individual can make a positive difference to their experience and situation. Such beliefs can in turn generalise into more active mastery over psycho-social problems (Davies, 2003).

We hypothesize that these affirming beliefs and self-representations may have a positive impact on how subjects perceive and manage their experience of procedural pain.

Biofeedback training in paediatric healthcare

While the efficacy of biofeedback for the management of acute pain and anxiety associated with painful procedures has not been established - there is some evidence to support its efficacy in the management of paediatric headache, recurrent abdominal pain, constipation, burns self-catheterization procedures and functional dyspepsia related to duodenal eosinophilia.

Gil et al. (1988) evaluated the effectiveness of a package of biofeedback and behavioural techniques designed to reduce a child's distress associated with learning self-catheterization. The findings suggest that distress associated with medical procedure such as self-catheterization can be reduced by breaking a complex procedure into discrete steps…and that EMG biofeedback can help the child to relax during each step. This case provides an example of biofeedback as an attention-management tool used as part of a larger systematic desensitisation approach.

Schurman et al. (2010) have evaluated the effectiveness of biofeedback assisted relaxation training (BART) for paediatric abdominal pain in children aged 8–17 years over the course of approximately 1 year. Children receiving standardized medical care (SMC) and BART evidenced better pain outcomes (steeper decline in pain intensity and duration, steeper rate of clinical improvement) than children receiving SMC alone. Findings from this study also indicated that both SMC

and SMC+BART interventions can yield improved outcomes on many psychological and social variables, in addition to pain and functioning variables. The authors note that the basic education provided as part of the initial clinic evaluation process may have been sufficient to reduce anxiety in the group of children assigned to receive SMC only and promote effectiveness of medication in the body, although effects sizes indicate a possible stronger effect for children receiving multifaceted treatment.

PROPOSAL: MULTIMEDIA BIOFEEDBACK DISTRACTION – A HYBRID APPROACH

We propose a new hybrid approach that combines visually rich, multimedia 'distraction' with cognitive-behavioural training processes in the form of a biofeedback-based interactive artwork. The aim is to encourage children to explore and learn how to voluntarily influence their autonomic responses by way of heart rate variability and skin temperature biofeedback displays.

Similar to the way that Gil et all (1980) used Biofeedback as part of a larger processes of Systematic Desensitization, this proposal uses biofeedback assisted relaxation training (BART) as part of a Cognitive Behavioural process that focuses on supporting the child to reframe how they respond to an anxiety-provoking situation, whilst at the same time diverting attention away from their procedure-related anxieties.

Our approach builds on previous practice-based creative arts research work undertaken by one of the authors, based around two biofeedback controlled interactive artworks: *Cardiomorphologies* (Khut, 2005) and *The Heart Library Project* (Khut, 2009), that utilised heart and breath rate biofeedback to control interactive sound and video projections: large scale, richly layered visuals that audiences where invited to interact with through a combination of breathing and emotional focus (memories, imagined situations). Accounts of audience members who have interacted with these systems (recorded using video-cued retrospective recall) revealed a consistent focus on themes of agency, self-efficacy, and questions embodiment, intimacy, mortality and psycho-physiological interaction (Khut, 2006, Khut and Muller, 2005, Muller et al., 2006).

We are proposing a way of using biofeedback assisted relaxation training that is not presented to children as a 'treatment' for their anxiety, but rather as an interactive art 'game' in which they are invited to explore with their carers and/or members of the clinical team, ways that they influence the appearance of the work. It differs from other multimedia distraction approaches (i.e. Virtual/Augmented Reality and Tablet games (i.e iPad) in that it is actively involving the children in processes of reflection on and experimentation with their own autonomic nervous system responses.

We hypothesize that this approach could combine some of the immediate benefits of interactive multimedia distraction techniques with the longer-term improvements in psychological and social variables previously noted by Schurman (2010).

Challenges and Misconceptions

Studies into the application of Biofeedback Assisted Relaxation Training (BART) for the management of procedure-related pain anxiety have been few in number. Despite significant improvements in research methodology and growing body of research over the past thirty years, research and implementation of biofeedback training in primary health care settings in general remain extremely limited.

Some factors influencing this situation include: the pseudoscientific claims made by many 'New Age' proponents and distributors of biofeedback equipment; the methodological weaknesses of many studies; the considerable time, space and additional attention required normally required for the training of subjects in the use of these systems (i.e. EMG muscle-tension biofeedback).

Another challenge for this proposal is the tendency to perceive biofeedback as a 'tech fix' - based on the aforementioned misconception of that something is 'being done to' the biofeedback subject, as if the equipment itself was somehow controlling the behaviour, independent of the child and the instruction and motivation provided by the trainer/facilitator. Schurman et al. (2010) in their study of BART treatment for paediatric headaches have remarked on the positive benefits of person-to-person education processes irrespective of specific modalities use (standard medical care vs biofeedback) - this highlights to the continuing importance of inter-personal exchange in the acquisition of pain and procedure-related anxiety management and coping skills.

In relation to the pseudoscientific status of biofeedback training within mainstream primary care, its important to differentiate marketing claims from actual peer reviewed research publications.

The use of EMG (muscle relaxation) and skin temperature (hand warming) biofeedback in the treatment of paediatric and adult headaches has been extensively researched. A systematic review of biofeedback treatments for migraine by Nestoriuc and Martin (2006) published by the International Association for the Study of Pain, identified eighty-six outcome studies, fifty-six of which they were able to include in their review, from they concluded that biofeedback was affective evidence-based behavioural treatment that significantly and substantially reduces the pain and psychological symptoms of migraine patients within the scope of only eleven sessions.

Cost factors need to be weighed against the type of technology required: not all biofeedback training modalities require sophisticated amplifiers and software analysis systems – simple thermometer devices have been used for hand-warming/cooling biofeedback treatment of headaches.

Until recently the cost associated with professional biofeedback systems, together with the time-consuming nature of conventional biofeedback relaxation training methods and the space required do this work in, have been significant and legitimate barriers to prospective

researchers working in primary care. As the cost of computer technologies continue to decline it is inevitable that rich, multimedia-enhanced biofeedback functionalities will soon be able to be embedded in common mobile phone and tablet devices. Technical requirements for BART need to be considered within the context for which they will be used. *Peripheral* biofeedback training modalities (i.e. heart rate pulse-plethysmography, temperature sensors, galvanic skin Response sensors etc.) are much simpler technically (and therefore cheaper to produce) than more complex EMG, ECG or EEG (brainwave) biofeedback systems. Considered within the context of BART based procedure-related anxiety management focus considered in this paper – these simpler peripheral modalities may be all that is required to obtain a basic real-time measure of autonomic nervous system activity (fight-flight, rest-digest responses).

CONCLUSSIONS

A biofeedback-based approach utilising 'immersive multimedia' biofeedback displays in the form on an interactive mobile 'app' artwork, could combine benefits of AR/VR Distraction approaches with cognitive-behavioural training approaches that emphasise the development of coping skills, that may have the benefit of generalising to a broader sense of mastery over subjective impulses and self-efficacy via the learning-by-doing approach exemplified by biofeedback training.

An important design question that has yet to be fully addressed concerns our definition of 'immersive' multimedia, compared to AR/VR - what makes for an a particularly 'immersive' display on a mobile device such as a mobile phone or tablet device (i.e iPad).

We are still in the preliminary stages of this research, collecting interview data with children who undergo painful recurrent procedures, and the clinicians who work with them; observing clinical practices and situations, and prototyping interface concepts and visualisation systems for the biofeedback displays. Our aim is to develop a device and method for its use, based on close examination of user experiences and procedure contexts. A systematic review of literature on biofeedback for pain and procedure related anxiety, and methodologies used and recommended in related studies (i.e. BART for headaches, abdominal pain and non-procedural anxiety problems, VR/AR Distraction methods etc. will also be undertaken in early 2012. We anticipate Pilot Tests with selected children and clinics will take place in early 2012, and a Clinical Trial to measure and assess the efficacy of this systems in clinical settings is scheduled for the second half of that year.

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