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Commentary

Values-based exposure and acceptance in the treatment of pediatric chronic pain: From symptom reduction to valued living

Rikard K. Wicksell

Chronic or recurrent idiopathic pain is relatively common among children and adolescents, with prevalence rates between 15% (Goodman & McGrath, 1991) and 32% (El-Metwally et al., 2004). For a subgroup of these patients, symptoms develop into a refractory state leading to severe disability (Kashikar-Zuck et al., 2000; Palermo, 2000). Pharmacological strategies are often insufficient in alleviating pain and increasing functioning (Aragona et al., 2005). A large number of studies indicate the effectiveness of cognitive behavior therapy (CBT) for adults with chronic pain (Morley et al., 1999), and there is growing empirical support for this type of treatment in young persons with similar symptoms (Eccleston et al., 2002). However, there is still a need to develop methods to increase functionality in severely disabled patients (Eccleston et al., 2002).

To date, there are enough studies to support the idea that pain in itself does not explain disability (Crombez et al., 1999). Traditionally, chronic pain management has, to a great extent, focused on controlling pain and distress in order to increase quality of life and to facilitate physical and social activities (McCracken et al., 2004a). Although CBT has proven to be an important contribution in chronic pain management, the process by which it is effective is still rather unclear (Morley, 2004).

Acceptance and chronic pain

Recent developments within CBT, such as acceptance and commitment therapy (ACT; Hayes et al., 1999a), have promoted an approach that emphasizes acceptance of, or willingness to experience pain and other interfering private experiences rather than trying to control or reduce symptoms. In two studies by McCracken and coworkers, acceptance was associated with less pain, disability, depression, anxiety, as well as with return to work (McCracken et al., 1998; McCracken & Eccleston, 2003). Studies have shown that acceptance accounts for more variance than coping among pain patients (McCracken & Eccleston, 2003) and that it can reliably predict mental well-being (Viane et al., 2003).

Acceptance and commitment therapy (ACT)

ACT is based on learning theory and although it clearly represents one form of CBT, there are certain differences regarding the approach to human suffering (Hayes et al., 1999b). In the behavior analysis of problems, avoidance of unpleasant experiences is emphasized when describing the functional relationship between symptoms and disability. The patient's experienced need to reduce or control symptoms (e.g. anxiety, anger, fear, pain) in order to live a valued life is considered a core

problem since she or he commonly becomes engaged in activities that produce short-term relief but also are less active, stimulating, and potentially, meaningful. As a result, over time behavior patterns become narrow and inflexible. Conceptualizing the detrimental effects of chronic pain seen in many patients requires more than analyzing pain per se. Thus, an ACT model of debilitating chronic pain includes the patient's *unwillingness to have pain*, as illustrated by patients not engaging in valued activities to avoid experiences associated with pain (e.g. fear of pain, failures, disappointments; Robinson et al., 2004).

In treatment, an ACT therapist seeks to assist the patient in identifying personal *values*, that is to say, an important direction in life (e.g. "being a supportive friend"), and to help the patient to direct his or her efforts to achieve this. Commonly, patients believe that pain and discomfort prevent them from behaving in accordance with values (i.e. "I can't do it because I'm in pain"). *Exposure* to previously avoided private experiences is considered the core intervention, emphasizing a wider and more flexible behavior repertoire. In this process, *acceptance* of what cannot be directly changed (e.g. pain, fatigue, negative thoughts, emotions) is emphasized as a means to recognize and change the things that can (i.e. behaviors directed towards a valued life; Hayes et al., 1999). Thoughts ("if I work out, my pain gets worse") are powerful and tend to point in a direction away from the expressed values ("playing soccer, being part of the team"). Therefore, by helping the patient to recognize and acknowledge private experiences for what they are (i.e. thoughts are thoughts), the therapist tries to help the patient to *defuse*, or distance him or herself from the thoughts, not by discussing whether they are correct or not but by functionally analyzing the consequences of acting upon them. Throughout the treatment the patient is taught to be more *mindful*, to gradually learn to notice and acknowledge the unpleasant experiences in a non-judgmental, non-elaborative, and non-controlling way (Hayes et al., 2004). With this skill, patients are then better able to identify and pursue their goals, and not be as regulated by their psychological events (e.g. pain, fear of anticipated pain). The expressed goal of ACT, in contrast to a

symptom reduction approach, is to increase the *psychological flexibility*, in other words, to help patients consistently choose to act effectively in alignment with their values, in the presence of difficult or interfering private experiences, such as pain or fear.

Shifting perspective from symptom reduction to valued living

In ACT, creative hopelessness refers to a process of altering the context in which the experience occurs - from unwillingness to have pain to acceptance of pain (in the service of increasing valued activities). An important part of this process is to collaboratively evaluate the *workability* of previous goals (i.e. reduce pain and distress) and strategies to achieve them (e.g. pain medications, rest, avoiding risk situations). The central questions are "what have you tried and how did it work?" Both short- and long-term effects are emphasized, as well as these strategies' impact on functionality and life quality. Commonly, the patients present with feelings of hopelessness and thoughts like "nothing works". By challenging the previous agenda (i.e. the previous goals and strategies), we want to highlight that it might not be the person or the intervention per se that is "hopeless". Instead, we suggest that the agenda of trying to reduce pain while at the same time live an active life does not appear to be effective (i.e. disability has increased over time without a corresponding decrease in pain). In addition, the clarification of personal values can further illuminate the long-term consequences of avoiding important, but possibly painful, activities. Following the discussion of workability and values, the therapist can introduce the idea of acceptance of a certain amount of pain and distress to enable engagement in behaviors towards an increase in valued life.

Figure 1 is a conceptualization of the patients' dilemma. The illustration was originally invented to facilitate the discussion with young persons regarding the shift in perspective from symptom reduction to valued life. The figure is drawn collaboratively in session and works essentially as an experiential exercise. Contrasting the previous agenda (symptom reduction) and the alternative (valued life in the presence of pain) can be emotionally challenging

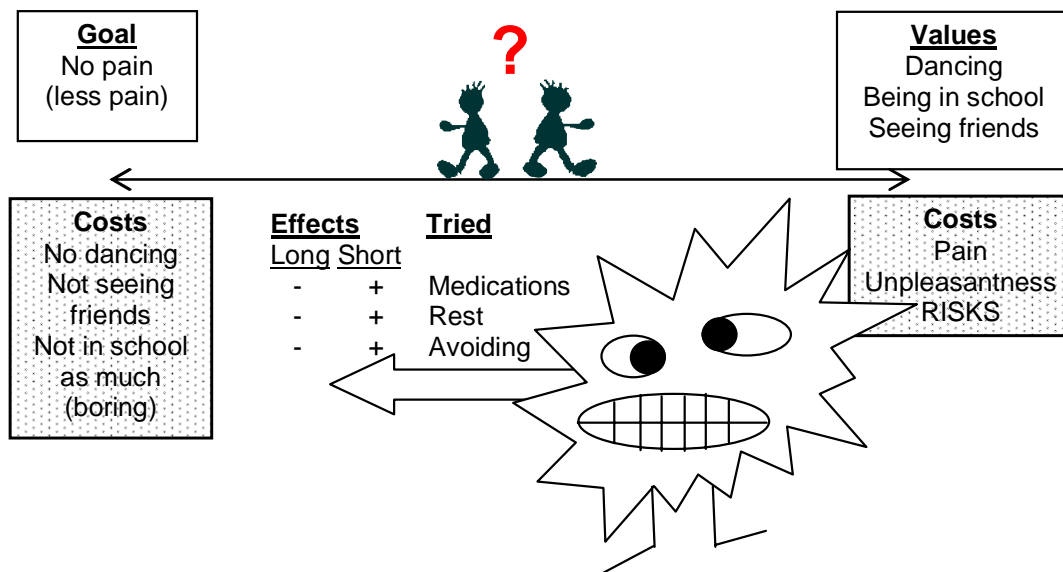


Figure 1. The patient’s dilemma. This illustration is drawn collaboratively with the patient. It is used when discussing the workability of previous strategies to reduce pain, in relation to values-based exposure in order to increase functioning. The pain monster represents thoughts, emotions, and bodily sensations that imply behaving in ways that will reduce pain and distress. © 2007, Rikard Wicksell, reproduced with permission.

for the patient and the parents. The therapist may encounter objections to this conceptualization of the situation. However, given the discrepancy between this and previously tried treatments such reactions are not surprising. The therapist needs to be aware of the emotional challenge and address the concerns in a validating way. To shift perspective and let go of the previous agenda is a process that may take time and, thus, creative hopelessness should be considered a continuous process. Also, the anxiety (e.g. that there might be an unidentified organic cause) experienced by the family may need to be addressed. This may be an even larger barrier to activities engagement than pain itself. Importantly, the therapist’s objective is not primarily to increase the number of performed activities but rather to facilitate the awareness of values-based exposure as an option, in other words to increase psychological flexibility.

Age appropriate considerations and interventions with parents

Patients at the clinic presenting with chronic debilitating pain are normally older than 10 years. Consequently, our clinical model is developed with children above that age. Thus, a future challenge is to adapt the clinical approach to even younger pa-

tients. Working with children implies several age appropriate adaptations and considerations. A more concrete discussion of the central components (e.g. values, acceptance), might be needed. Values clarification should be considered a process of exposure, and this is particularly relevant in the work with younger patients. The therapist may need to start with a concrete goal (e.g. participate in soccer practice once a week), and successively discuss the underlying value of that activity. Sometimes the inability to express values can result from emotional avoidance. “Thinking about what I really would like to do (e.g. study at the university) makes me sad because I’m sure I won’t be able to. Therefore, I better not think about it.” Acceptance of these negative thoughts and emotions may facilitate exposure, for example, thinking about it, discussing it with friends, preparing the application. Important topics, such as the effectiveness of previously used strategies, might need to be repeated more than what is normally done with adults. Setting up a home assignment that clearly builds on what has been discussed in session might help the child to remember the essential information. Also, written materials can be used to improve the processing of the information, for example using a values sheet and pro-

viding the patient with a copy of the figure presented above.

The integration of parents is another important adaptation. Young patients sometimes expect adults to take responsibility for “solving the problem”, for example reducing pain or making arrangements with school. It is important to repeatedly emphasize that the patient him or herself is responsible for, or “in charge of”, the treatment process. Again, home assignments can function to facilitate taking on responsibility, for example, engaging in behaviors not suggested by parents (taking the dog for a walk) or initiating a conversation with friends about plans for the summer break. Thus, this type of home assignments implies that “it’s up to you” while being done in the context of values-based exposure. We normally see the patient and their parents separately. However, using the same figure (see figure 1) with both the patient and their parents facilitates a more open discussion at home. A shared understanding of the new, values-oriented, agenda also increases the probability of more ACT-consistent problem solving strategies. If parents are not seen on a regular basis, it may be a good idea to provide them with a handout of the figure after the session. Furthermore, both the behavior analysis and the following interventions should eventually target the parents’ behaviors and psychological flexibility. This can be done by using the same ACT-approach as previously described; emphasizing exposure to previously avoided private experiences, acceptance, and defusion exercises. By doing this, we can target the emotional barriers that may prevent the parents from acting effectively as good coaches (i.e. in accordance with operant strategies).

Metaphors and illustrations

To clarify concepts such as acceptance and defusion, illustrations and metaphors are commonly used in ACT-oriented treatments. Preferably, these are invented together with the patient and relevant in the child’s context. Again, this type of communication needs to be adapted to the age of the patient. With the youngest children, it is often good to use physical objects. For example, we can write thoughts on paper (“I’m in pain so I can’t go to the dance class”) and put them in an actual box. We can then talk about how this illustrates our ability to

notice an inner experience and then make up our mind about whether we should act accordingly (stay home) or do something different. The pain monster is a metaphor readily used in combination with the figure. It represents thoughts, feelings, and bodily sensations (such as pain) that suggest avoidance. The pain monster is pointing towards “symptom reduction and inactivity”. In treatment we can discuss pros and cons of following the pain monster’s recommendations. “If you want to go to soccer practice and the pain monster wants you to stay home to avoid pain, who should decide?” Importantly, treatment is not about getting rid of the pain monster but rather about acting in accordance with values even when the pain monster is present.

Working in teams

The success of a multidisciplinary team is a shared understanding of the genesis of the pain and other symptoms, the cause of pain-related disability, the treatment objectives, and the type of intervention needed. As previously mentioned, many patients and parents come into treatment with a somatic focus on pain (i.e. there must be something medically wrong). The staff will frequently encounter situations in which they have to agree to decline parental demands for further medical assessments or additional pharmacological strategies. This type of close collaboration is essential when new symptoms emerge or when the family has come across another possible cure. It is, thus, of great importance to present a plausible rationale when discussing this treatment approach with other caregivers. The illustrations and metaphors used with patients and parents have been found useful also when talking to other clinicians involved in the treatment.

A behavior medicine model based on ACT

At the Pain Treatment Service at Astrid Lindgren Children’s Hospital in Stockholm, Sweden, we have since 2001 developed a clinical model based on a behavior medicine perspective on pain and an ACT-oriented approach to treatment. This work is explicitly labeled a “behavior medicine team approach” to illuminate the complex nature of chronic pain and disability and to emphasize the close collaboration needed to support the patient in a values-based exposure process to increase func-

tionality even in the presence of interfering pain and distress. In a behavior medicine perspective on pain, organic factors are taken into account but the interactions between triggering stimuli, pain behavior and reinforcing consequences are emphasized. Furthermore, the behavior analysis provides a good model for understanding the link between pain and disability.

Three assumptions guided the development of the treatment program. First, pain-related avoidance behavior was considered the cause of disability. Second, exposure (i.e. to gradually increase activities previously avoided due to negative private experiences) was considered the core intervention and working mechanism in successful cognitive behavior therapy (CBT) and should therefore be emphasized. Third, increased functioning was given priority over pain reduction because it seemed very difficult to obtain any lasting improvements on symptoms, and because pain intensity reduction did not appear to have a clear causal relationship with functioning (Vlaeyen & Linton, 2000). However, these assumptions resulted in a dilemma. Exposure is expected to be an important intervention with chronic pain patients, but how can this be performed if symptom alleviation does not occur? The integration of acceptance strategies appeared promising to facilitate the exposure process in patients with chronic debilitating pain. The ACT-oriented approach represents a different treatment objective and a different rationale for the exposure intervention than described in traditional CBT.

Treatment studies using acceptance strategies

Although the empirical support for ACT and acceptance-based interventions is still limited, a recently published review illustrates an emerging body of research suggesting that this approach might be beneficial to a wide variety of human suffering (Hayes et al., 2006). To date, there are several clinical studies supporting the use of acceptance-based interventions in adults with chronic pain (McCracken et al., 2005; 2007; Wicksell et al., under review) as well as in people with work absence due to stress and pain (Dahl et al., 2004). In addition, several laboratory studies have presented favorable results when using acceptance for ex-

perimentally induced pain (Hayes et al., 1999b; Gutiérrez et al., 2004; Keogh et al., 2005).

The number of clinical studies investigating the effects of an ACT-oriented approach with pediatric pain patients is still limited. Recently, a pilot study was conducted with 14 consecutive patients between 13 and 20 years suffering from chronic debilitating pain. Following treatment, and retained at 3- and 6-month follow-up, statistically significant improvements in functional ability, school attendance, catastrophizing, and pain (i.e. intensity and interference) were seen (Wicksell et al., 2007). Also, a randomized controlled trial including 32 pediatric patients with chronic idiopathic debilitating pain was recently conducted. In this study, an exposure and acceptance based intervention (10 sessions with the patient and 2 sessions with their parents) was compared with a multidisciplinary treatment including amitriptyline¹. Preliminary results in favor of the ACT-intervention were presented at the International Symposium on Pediatric Pain in Vancouver (Wicksell et al., 2006). In yet another study with 15 adolescents suffering from functional abdominal pain, the utility of ACT in promoting life quality and functional disability was examined. The program included 12 to 14 individual and 2 to 5 parent sessions. The adolescents demonstrated significant improvements regarding life quality, functional ability, and symptom reduction (Greco et al., under review). Furthermore, a case illustration has been published describing the application of an ACT-approach with an adolescent severely disabled by chronic idiopathic pain (Wicksell et al., 2005).

Research issues

The results obtained in ACT-oriented studies with pediatric pain patients are promising. Larger scale studies are still needed to further evaluate the effects of this type of intervention. Furthermore, there is a great demand for studies investigating the working mechanism(s) in successful CBT, including ACT-oriented interventions. Although a comparison between ACT and CBT might seem empirically relevant, my impression is that such a study would not clarify the mechanism(s) of action, since two rather comprehensive intervention packages would be compared. Clearly, effective treatment programs such as CBT need to be dismantled. Also,

intervention(s) should be carefully operationalized (e.g. progressive relaxation to decrease muscle tension and thereby reduce pain) and comparisons should ideally include single interventions (e.g. relaxation vs. exposure). Furthermore, the treatment objective needs to be clearly defined, since pain reduction may not be the only or the most relevant aim of treatment. This accounts for both outcome variables (e.g. quality of life, functional ability, pain decrease) and relevant process variables (e.g. self-efficacy, fear of movement). Interventions based on exposure and acceptance target psychological flexibility rather than symptom decrease. Thus, we need to assess this process to examine the hypothesized mechanism of action. However, this causes another concern. To date, there are unfortunately no empirically-validated measures of psychological flexibility (e.g. acceptance, defusion) for pediatric pain patients. For adults with chronic pain, two measures exist. The Chronic Pain Acceptance Questionnaire (CPAQ; McCracken et al., 2004b) includes subscales for pain willingness and activities engagement. The Psychological Inflexibility in Pain Scale (PIPS; Wicksell et al., in press) consists of subscales to assess avoidance of pain and cognitive fusion. The PIPS has been used clinically with adolescents but no psychometric evaluation has yet been performed.

Conclusion

In conclusion, the central principle in an ACT-oriented approach is the shift in perspective, from a symptom-reduction approach to valued living in the presence of pain and distress. Inflexible avoidance patterns are targeted using exposure and acceptance strategies, in order to help the patient increase valued activities and be mindfully present in the moment even if experiencing pain and distress. In fact, nothing we do in treatment is directly aimed at symptom alleviation. If symptom reduction occurs, that is considered a positive side effect of treatment. Clearly, effective treatments as well as empirical studies for this difficult group of patients are greatly needed. Previous studies based on values-based exposure and acceptance strategies for pediatric chronic pain appear promising but larger scale studies are needed, especially with children and adolescents.

Rikard K. Wicksell, MSc, Doctoral Student
Licensed Clinical Psychologist, Pain Treatment Service, Astrid Lindgren Children's Hospital, Karolinska University Hospital & Department of Clinical Neuroscience, Karolinska Institute, Stockholm, Sweden
email: rikard.wicksell@karolinska.se

Endnote

¹ A tricyclic antidepressant, frequently used in pain syndromes.

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