

Coping and acceptance in chronic childhood conditions

Jeremy Gauntlett-Gilbert and Hannah Connell look at novel approaches to helping children live with pain and discomfort

Some conditions leave children and adolescents experiencing chronic discomfort, even though there is no ongoing pathology or degenerative change. Passive coping, in the form of avoidance and withdrawal from activities, has been shown to be an unhelpful approach to these experiences. However, research has historically been less clear about which coping styles to promote. Since conditions such as chronic pain and fatigue cannot be easily 'fixed', or 'problem-solved', what is the ideal approach? New research on acceptance and different styles of active coping shows promising data, and emerging clinical traditions of acceptance and mindfulness provide the clinical methods that can support alternative responses to distress.

questions

When is it no longer useful to try to 'problem-solve' distress?

If there was a choice between two incompatible therapeutic outcomes – feeling less discomfort, or living a full, active life – which would you choose?

resources

Harris, R. (2009). *ACT made simple – An easy-to-read primer on acceptance and commitment therapy*. Oakland, CA: New Harbinger.

Acceptance and commitment therapy website:
<http://contextualpsychology.org>

Paediatric psychologists spend much of their time treating children who are experiencing chronic, intractable discomfort. Clinical work in this area has raised important questions: What is the best response to uncontrollable pain or distress? Is it helpful to use cognitive techniques to 'restructure' bleak and negative thoughts about pain? Are there any side-effects to distraction techniques? Is there a role for parents and medical cultures in promoting responses to distress, either helpful or unhelpful?

The coping literature and the cognitive behavioural therapy tradition have grappled with these issues for decades, and the latest thinking in this area – acceptance and mindfulness-based thinking – offers novel and potentially effective answers to these questions. In particular, the field of paediatric pain is devising and testing new therapeutic responses to these difficulties. However, these concepts are applicable to all chronic conditions, particularly to syndromes such as chronic fatigue or irritable bowel, which are disabling and distressing but medically non-malignant.

Paediatric culture and self-management

On visiting a children's hospital or ward, it is easy to be moved by the culture of attentive and supportive care. At the risk of generalisation, paediatric settings and services generally aim to provide assertive medical treatment, reduce suffering, treat pain, and to be supportive to children and families. Paediatric teams are structured

to help children through acute illnesses and to deal with clearly defined, medically threatening chronic conditions.

This culture does not suit every condition, or every therapeutic goal for a young person's life. For example, what happens in conditions that are genuinely chronic and are hard to diagnose or treat medically (for example, chronic pain or fatigue)? These conditions can lead to disability and distress, but are often seen in children who otherwise seem medically 'healthy' – that is, where there is no other medical evidence of pathology. In these situations, the promise of rapid and effective medical treatment can be unfulfilled. Also, does this culture truly support the development of children who can act on their own initiative – without professional help – and cope independently with hardship? Attentive, tolerant and available medical services, whilst desirable, are not necessarily designed to prepare young people to negotiate a school and social life that is not so flexible or forgiving. Indeed, it is possible to characterise a 'paediatricised' child – that is, one who is plucky, apparently assertive, well-liked on the ward, but prefers talking to adults and is at sea in the normal social life of their peers. Preparation for life and for self-management of a chronic condition requires psychological models and techniques.

Living with chronic conditions

Chronic pain in children is a widespread problem, and in a typical hospital children with chronic, non-malignant pain can be found in specialist areas such as gastroenterology (tummy pain), neurology (headache) and rheumatology/orthopaedics (musculoskeletal pain) (Konijnenberg et al., 2005). Decades of neurophysiological research have demonstrated how chronic pain can be present in such conditions, even where there is no evidence of ongoing damage or pathology.

Pain can be a consequence of a

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'wound-up' and sensitised nervous system (e.g. Knowles & Aziz, 2009); thus, pain can persist or be amplified in the absence of damage. This view of chronic pain, whilst commonplace in specialist pain settings, is not universally held. Many clinicians still use a 'psychogenic' model of pain, where the pain experience itself is thought to be strongly influenced by overt or unacknowledged psychological distress or family factors. But this model of chronic pain has been strongly criticised, on conceptual and empirical grounds (Crombez et al., 2009). Instead, it is seen as a genuine, independent syndrome, and psychological factors are seen as important in determining associated distress and disability. This approach treats the pain experience itself as real, which is useful and validating for children and families, whilst acknowledging a critical role for behavioural interventions in helping children and families adapt and function.

How can children and families with these conditions cope well? Here, we will describe the situation for chronic pain, but similar issues apply in other conditions such as chronic fatigue or irritable bowel syndrome. Conventional medical approaches can provide some useful, partial symptom control but independent coping and functional improvement need to be supported by other approaches. Painkillers are usually only partially effective, and all but the simplest ones are used on the basis of clinical experience rather than an established evidence base for their effectiveness in children (Currie, 2006). Standard side-effects include gastric problems and constipation.

Thus, a child and family may have an attentive paediatric team who have no specific and effective medical therapies for



'Acceptance' is promoted in a context of openness, gentleness and humour

their condition. Life now includes fluctuating pain symptoms that are at best partially controllable and often quite unpredictable. There is no clear time frame for cure or the remission of symptoms. Parents have to live with the distressing fact that they cannot 'make it better', and nor can their doctors (Jordan et al., 2009). The challenge is for these children to find a way to develop and progress whilst pain is present (Eccleston et al., 2008).

Although it seems hard to imagine, a child's life *can* be lived well with chronic pain. Data from children's and adults' pain management programmes show that large reductions in disability and distress can be achieved, even where reductions in pain are modest or non-existent (Eccleston et al., 2003; Vowles & McCracken 2009). Also, after appropriate treatment, individuals with pain can come to use medical services much less, being more

confident and reliant on their own ability to cope. How can psychology help to support this?

Coping and cognitions

Psychological research in the field of paediatric pain has investigated a range of 'coping styles'. Active and passive coping have traditionally been distinguished – active coping would include proactive problem solving and seeking support, whereas passive coping might involve withdrawal or avoidance of activities. Passive coping does not usually help (e.g. Walker et al., 1997). However, 'active coping' is complex. Authors have defined this in a range of ways, such as persistence with activities, using problem-solving or using purposeful strategies such as distraction. Contemporary pain researchers split active coping into two forms. 'Assimilative coping' tries to change, alter or solve the

problem at hand, for example, to cure or reduce the pain through medical or non-medical methods. In contrast, 'accommodative coping' tries to adjust to the difficulty rather than change the problem itself (Brandtstadter & Rothermund, 2002). This might involve reducing one's ambitions, accepting disability or reminding oneself that others are worse off. Accommodative coping can represent positive adjustment and can be quite different from passivity or acquiescence. It often promotes better adjustment than other forms of active coping in chronic pain (e.g. Walker et al., 2005).

It is entirely natural to resist pain and suffering. However, it also seems that struggling to change an experience that is uncontrollable and intractable – such as pain – leads to more harm than good. Preliminary data support this conclusion,

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showing assimilative coping to be associated with increased distress and disability (Crombez et al., 2008). There is a growing consensus that treating chronic pain as a problem to be solved, or an experience purely to be avoided, may constitute a problem in itself (Crombez et al., 2008; McCracken & Eccleston, 2003).

Acceptance, mindfulness and living a valued life

There is a current trend in psychological therapies to promote a psychological stance that is open, non-defensive and focused on the present moment. One example of this is mindfulness-based stress reduction (Kabat-Zinn, 1990), which some clinicians are beginning to adapt for paediatric work (e.g. Thompson & Gauntlett-Gilbert, 2008). Here, we focus on acceptance and commitment therapy (ACT), which is an evidence-oriented development of the cognitive behavioural tradition that is well suited to long-term conditions (Hayes et al., 1999, Ruiz, 2010). It assumes that all suffering is partially uncontrollable, and views mind and body in an evolutionary context. Human beings are 'hard-wired' with a pain system, and as such it is always possible that this might malfunction. Similarly, anxiety and fear are essential in evolutionary terms, so it is unlikely that human beings could ever be simply 'free' of these emotions. It is an assumption of the therapeutic model – and a consistent empirical finding – that rigid attempts to control and eliminate suffering are (a) only partially successful and (b) have clear disadvantages, as they attempt to control experiences that are inevitable (Ruiz, 2010). In response, ACT uses methods that help people to be open and focused on the present moment without struggling or attempting to eliminate distress.

Although ACT has been most extensively developed for adult mental health problems, it is highly applicable in

paediatric pain. It develops traditional CBT by providing techniques that help people to openly and willingly contact their difficulties whilst pursuing their goals. Perhaps its greatest innovation is to



ACT is highly applicable to paediatric pain

carefully specify the goals of therapy, seeing symptomatic control – for example, an improvement in mood – as a secondary concern. The role of therapy is entirely to help individuals identify what they value in their lives and to help them pursue this effectively. Therapists in all traditions have endorsed similar goals, but ACT specifically assumes that there is no need to change the presence or frequency of unpleasant thoughts, feelings or sensations in order to achieve this. Although this might seem a purely conceptual point, a therapist's goals and their metric of success infuse every moment of their clinical work; the shift in emphasis is important. Happily, it works (Ruiz, 2010), with incidentally improved mood almost always being a positive treatment outcome.

ACT shows much promise as an approach for children with pain, and their parents. Sometimes, parents respond 'catastrophically' to their child's pain in a fashion that, while quite understandable, does not help (Goubert et al., 2006). Rather than rationalise, restructure or

distract from these thoughts, parents are encouraged to let them be present, observe them as mental phenomena, and keep some of their attention connected to the lived present moment. Children are helped to stop struggling with their pain, and to permit nasty emotions to be present without being overwhelmed by them.

When used clinically, 'acceptance' is promoted in a context of openness, gentleness and humour; attempts to tell children that they 'must' or 'should' accept their difficulties are not consistent with this clinical model. All techniques are deployed in the service of getting on with what matters in life, and minimising any unnecessary and painful struggle in the process. ACT is well suited for children, as most of its therapeutic interventions are metaphorical and experiential, rather than talk-based or didactic. An example of an ACT intervention that explores struggle and acceptance can be seen in 'Walking in the rain' (see box, right). The process of acceptance, and emphasis on experiential learning, are clear in this scenario; however, the therapist would also deal with the whole interaction without challenging thoughts, giving reassurance, information or persuading the patient that wise action will make them feel better.

Most evidence for the construct of 'acceptance', and the effectiveness of ACT, is in the adult literature, and has been reviewed extensively by Ruiz (2010). In adults with chronic pain, acceptance is associated with better functioning and less distress in most domains, and acceptance-based treatment works (e.g. Vowles & McCracken, 2009). In children, an instrument to measure acceptance of pain has recently been published, again showing strong and consistent associations between more acceptance and better physical and emotional functioning (McCracken et al., 2010). Parental acceptance is also associated with better child functioning (McCracken &

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Gauntlett-Gilbert, 2011), which is noteworthy as parental influence on child welfare has historically been hard to demonstrate in the field of pain (Palermo & Chambers, 2005). Outcome data remain scarce, but a high-quality randomised controlled trial and case series show strong positive effects for ACT in paediatric pain compared to 'treatment as usual' controls (Wicksell et al., 2007, 2009).

Acceptance for clinicians and teams

Just as patients naturally try to avoid and eliminate bad feelings, so do clinicians. For example, a clinician might feel upset at a family's distress, and react to this by trying harder to cure a child's pain, or to placate upset or frustrated parents. Authors from medical and psychodynamic perspectives have suggested that unacknowledged, unaccepted emotions in clinicians can lead to poor clinical choices, such as rigid adherence to routine or urges to avoid difficult clinical topics (Meier et al., 2001).

Evidence shows that clinician burnout is also strongly predicted by low acceptance and distance from a valued life (McCracken & Yang, 2008). Paediatric psychologists can help by discriminating – for themselves, and for the medical teams they work in – when it is most useful to 'accept' clinical uncertainty and powerlessness. As in direct clinical work, the concept of 'acceptance' is here used in a context of perspective, gentleness, and releasing struggle and unworkable effort. An example would be a team 'accepting' the limitations on their ability to help medically, and the associated guilt and discomfort, in the service of avoiding clinical traps such as over-treating patients. The role of acceptance concepts in teams and team training is addressed in McCracken (in press).

Genuinely novel?

ACT represents a mixture of acceptance and mindfulness techniques, married to

Walking in the rain

'Imagine you're walking in the rain – it is really chucking down and you are getting wet. You've got a long way to go and you've got no umbrella. It's cold! You are really fed up and miserable about the situation. What kind of physical posture would you be in? Try doing it. Really feel what this posture is like, sense it in your body.'

Now imagine you are in the same rainstorm, just as wet, but this time your attitude is – "OK, I'm getting wet. Nothing to be done about it. Oh well! Wish I'd brought my brolly... yep, I'm still getting wet." What posture would you be in? Again, pay attention to what this feels like.'

This sample clinical technique can provide a vivid physical metaphor of how individuals can react in different ways to discomfort. For the first scenario, people often adopt a hunched forward posture, shoulders up, frowning. With the second, they usually adopt a more relaxed posture. This evokes reflection about which of the two postures is more effort, which involves more suffering, and which is more 'open' to noticing what is going on in the present moment. The second time, the person isn't exactly pleased about getting wet – they are just fighting it less, using less energy and resistance. It doesn't have to involve resignation or 'giving in' – rather, it can just be a degree of acceptance.

It is also useful to raise the question of which time – first or second – the person would get wetter (probably equal). The adoption of a more 'accepting' posture doesn't change the primary source of suffering – i.e. the rain, or pain/anxiety in a clinical setting. This is quite different from, for example, promoting relaxation in the hope that it will reduce anxiety.

traditional behaviour therapy methods that aim to promote valued living. The latter techniques, such as goal-setting, exposure exercises and direct behavioural practice, distance it from more traditional mindfulness approaches, e.g. mindfulness-based stress reduction (MBSR). For example, MBSR values extended periods of meditation as essential for change, and there is no therapeutic time spent on real-life behaviour change, such as exposing oneself to challenging situations. In contrast, 'real-life' challenge and sustained practice in difficult environments are central to the ACT approach. In taking this focus, ACT shows its roots in the behaviour therapy tradition, but expands this tradition by its emphasis on the achievement of full acceptance/accommodation, and the demotion of symptom relief – that is, making people feel better – as a therapeutic goal. Although this article has just focused on acceptance, the model is multifaceted and also includes components around cognitions, attention to the present moment and valued action (Hayes et al., 1999). Some of the techniques used in ACT are quite similar to those seen in CBT or Gestalt therapy, but the therapeutic agenda behind their use seems distinctive.

The exploration of acceptance in paediatric psychology shows that this discipline remains at the leading edge of psychological thinking. The key promise of this approach is that it might liberate people in chronically difficult circumstances. For example, parents are

permitted to feel guilty and worried, without the need for restructuring or behavioural experiment. They will still benefit from choosing wise behaviours – for example, maintaining a consistent and calm approach during a pain flare – but can do this whilst acknowledging and accepting the distress they feel. It can be liberating for psychologists and physiotherapists to treat children without feeling the need to try different 'coping styles' when pain flares or strong feelings emerge. And most importantly, it allows a child to stop spending energy trying to fight something that is uncontrollable. Instead of trying to control or restructure feelings that are inevitable, they can acknowledge all of their difficulty and focus on living a thriving, active life.



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