A Case Study: Acceptance and Commitment Therapy for Pediatric Sickle Cell Disease

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Objective Sickle cell disease (SCD) negatively impacts patients’ functioning and quality of life. Acceptance and Commitment Therapy (ACT) promotes acceptance of difficult sensations, emotions, and thoughts when doing so facilitates living a values-based life. This study describes ACT for improving functioning and quality of life for an adolescent with SCD and his parents. Methods A 16-year old with SCD and his parents attended an eight-session ACT program. Process (adolescent psychological flexibility, parent acceptance) and outcome (adolescent social anxiety, pain, functioning, quality of life; parent distress) measures were conducted prior to and following treatment and at 3-month follow-up. Results and Conclusions Improvements were evident, especially at follow-up. Process measures suggest adolescent psychological flexibility and parent acceptance might explain positive effects. Anecdotal comments support these findings and provide additional evidence that ACT might effectively promote functioning and quality of life in adolescents with chronic diseases.

Key words acceptance; commitment therapy; parents; sickle cell disease.

Sickle cell disease (SCD) is an inherited disorder of the hemoglobin in red blood cells, affecting primarily people of African descent. In the United States, 1 out of every 600 African-American newborns has SCD and approximately 72,000 people are currently living with the disease [National Heart, Lung, and Blood Institute (NHLBI), 2006]. Despite advances in medical and psychosocial treatment, there is no cure for SCD. Medical complications of SCD are common, including chronic pain, pulmonary and cardiac problems, neurocognitive deficits, and stunted growth (e.g., Edwards et al., 2005). Of those, unpredictable and severe pain is the most common reason for hospitalizations for patients with SCD (Woods et al., 1997). SCD is found to be associated with a host of negative outcomes, such as functional disability (e.g., frequent medical visits, school absences, poor peer relationships; Gil et al., 2000; Palermo, Schwartz, Drotar, & McGowan, 2002), negative affect (Alao & Cooley, 2001), social anxiety (Wagner et al., 2004), and diminished quality of life (QOL; Panepinto, Mahar, DeBaun, Rennie, & Scott, 2004).

The parents of pediatric patients with SCD are also subject to greater psychological distress (Brown et al., 1993; Wallander & Varni, 1998). This is in part due to adjustments and sacrifices associated with parenting a youth with SCD, such as missed days of work and neglected self-care. Considering the parents’ well-being is important in its own right and also because parents play a significant role in pediatric patient care (Kazak, Rourke, & Navsaria, 2009; Wicksell, 2007).

Given the multifaceted impact of the disease, pediatric patients with SCD are typically treated in a multidisciplinary setting receiving a combination of medical and psychosocial interventions (e.g., Forseth & Gran, 2002). The psychosocial strategies, such as relaxation, coping skills
training, and social support typically focus on symptom management and treatment adherence (Chen, Cole, & Kato, 2004). Unfortunately, literature reviews suggest that these approaches provide varying success in symptom management and treatment compliance, and that they do not effectively address poor daily functioning and QOL of patients or their parents (Anie & Green, 2002, updated 2009; Chen et al., 2004; La Greca & Bearman, 2001). It should be noted that symptom management and adherence, when excessive and exclusive, might actually interfere with the daily functioning (e.g., peer interactions) and QOL of pediatric patients with SCD (Barakat, Lutz, Smith-Whitley, & Ohene-Frempong, 2005).

Acceptance and Commitment Therapy (ACT, Hayes, Strosahl, & Wilson, 1999) might be particularly effective for youth with SCD. ACT emphasizes the promotion of daily functioning and QOL while teaching a willingness to experience difficult and possibly unavoidable private events (e.g., pain, discomfort, fatigue, anxiety) without defense when doing so serves valued ends (Hayes, Luoma, Bond, Masuda, & Lillis, 2006). Based on its behavioral roots, ACT posits that functional disability and diminished QOL is typically characterized by the domination of inflexible attempts to modify the form, frequency, or situational sensitivities of unwanted private events (e.g., anxiety, pain). For example, a pediatric patient with SCD might be taught to engage in (e.g., hydrate) or avoid (playing outside on a cold day) in order to minimize SCD symptoms. However, if these behaviors become dominant, excessive, or rigid, they might interfere with daily functioning (making a friend, socializing with peers, studying, having part-time work). Behaviorally, many of these negatively reinforced behaviors can be rule-governed, which are under the stimulus control of aversive private events (e.g., fatigue) and verbal rules associated with these events (e.g., “I can’t do anything when I am unmotivated.”). It should be noted that these behaviors can be reinforced by others (e.g., parents, physicians). In ACT, the maladaptive behavioral pattern of attempting to alter the form, frequency, or situational sensitivity of private events (e.g., thoughts, emotions) are generally called experiential avoidance (EA), and the stimulus control of verbal antecedents that excessively or improperly regulate EA are called cognitive fusion (Hayes et al., 2006).

ACT does not negate the importance of symptoms management (e.g., hydration, healthy diet, regular exercise, medication adherence) in treatment of pediatric SCD. Rather, ACT simply intervenes on the processes (e.g., EA and cognitive fusion) when these lead to long term detrimental effects (e.g., interference of daily functioning) for the individual. ACT posits that discomfort and pain might be unavoidable and persistent in some contexts, and that experiencing them openly without defense and engaging in value-consistent behaviors are likely to promote greater functioning and QOL. Thus, symptom management is important when it leads to living a more flexible and ultimately more meaningful life; however, symptom management is not the end-goal and some forms of symptom management might in fact interfere with living a values-based life.

Preliminary evidence indicates that ACT promotes health behaviors and constructive living among adults with a wide range of behavioral and health concerns (Hayes et al., 2006), including Type II diabetes (Gregg, Callaghan, Hayes, & Glenn-Lawson, 2007), epilepsy (Lundgren, Dahl, Melin, & Kies, 2006), and idiopathic pain (McCracken, Vowles, & Eccleston, 2005). ACT might be beneficial to pediatric patients and their parents (see Greco & Hayes, 2008), but research in this area is sparse. In fact, Greco and Hayes (2008) write that ACT for children and adolescents “has only recently begun to be explored” (p. 4). A review of the literature reveals one case study indicating that ACT is effective for an adolescent with anorexia (Heffner, Sperry, Eifert, & Deterweiler, 2004), a case study of ACT for an adolescent’s chronic pain (Wicksell, Dahl, Magnusson, & Olsson, 2005), a small pilot study of ACT for 14 adolescents with idiopathic chronic pain (Wicksell, Melin, & Olsson, 2007), a randomized trial supporting ACT for adolescents with complex chronic pain (Wicksell, Melin, Lekander, & Olsson, 2009), and a small sample within subjects design study demonstrating that ACT is beneficial for parents of children with autism (Blackledge & Hayes, 2006). Given these preliminary data that ACT can benefit parents as well as adolescents with chronic conditions as well as the importance of involving the entire family system in children’s health care (e.g., Kazak et al., 2009), a family-based ACT intervention might be particularly useful to children struggling with the management of a chronic illness.

Case studies allow researchers to highlight new approaches for clinical populations in medical settings (Drotar, 2009). Thus, the purpose of this case study was to describe and obtain preliminary data for family-centered ACT therapy tailored to the needs of an adolescent with SCD and his parents. It was expected that ACT would help improve the QOL and functioning of the patient and parents. Process measures were employed to explore whether ACT processes (e.g., psychological flexibility) might be associated with any beneficial changes in therapy.
Case Description

Participants and Setting

Appropriate institutional approval was obtained prior to the initiation of the study. The study was conducted at Aflac Cancer Center and Blood Disorders Service of Children’s Healthcare of Atlanta (CHOA), which is one of the largest centers in the country annually treating over 1,600 pediatric patients with SCD. The two ACT-trained cotherapists (AM, LC) presented the ACT model to the SCD medical treatment team, who approved of this therapeutic approach.

To protect the family’s confidentiality, the identifying information was altered. The primary patients were “David Smith,” a 16-year-old African American adolescent male diagnosed with sickle-cell anemia (HbSS) since birth, and his parents, “Mr and Mrs Smith.” Given work conflicts, Mr Smith could only attend the third and final two sessions.

The family was referred to CHOA psychology because of ongoing psychosocial concerns raised by Mr and Mrs Smith, which included the patient having frequent complaints of pain and fatigue, apprehension about socializing with peers, and poor study habits and grades. The patient had not responded to prior approaches to these issues (e.g., relaxation training for pain control). The medical treatment team informed the therapists that the family tends to minimize difficulties, especially with unfamiliar people. The ACT approach appeared especially well-suited to this patient because: (a) David did not respond to initial therapeutic interventions (e.g., relaxation); (b) the physicians reported that acceptance would be a good approach given that a number of David’s symptoms (e.g., fatigue, pain) could not be further mitigated via available medical interventions (e.g., medications); and (c) he reportedly was engaging in EA (e.g., he tries to sleep when he feels pain) and cognitive fusion (e.g., he stated, “Why should I ask my teacher for help? She won’t be able to help me.”).

David was a junior in high school, living with his parents and his older sister, who took classes at a local college. The annual family income was approximately $75,000. David and Mrs Smith attended the initial intake session. David was reserved and reported that he had no difficulties other than the SCD symptoms of pain and fatigue. Mrs Smith reported that her primary concern was that David was “irresponsible” and “too relaxed,” especially around his schoolwork. She reported the recent deterioration of his academic performance (i.e., “C” average) and said that he had to “stay on top of him” to complete his homework. According to Mrs Smith, David usually reported fatigue when he came home from school and he often took a long nap (e.g., 2 hr) before dinner. After waking and having dinner, David typically watched TV or played on the computer. David also reported poor sleep hygiene, and he often stayed up past midnight. Mrs Smith had secondary concerns regarding David’s minimal peer relationships, and his low energy and fatigue. Mr Smith said that he suspected that David’s low energy and motivation were not related to sickle cell fatigue symptoms, and that David needed to “take more responsibility for his life.”

David’s presenting concerns were characterized by the behavioral deficits of adaptive behaviors, such as studying, socializing with peers, and having a part-time job combined with the behavioral excesses of inattentiveness and inaction (e.g., taking a long nap after school, playing on the computer). These inactions were hypothesized to be subtle forms of EA (e.g., avoidance of the distress associated with doing schoolwork) and related to cognitive fusion (e.g., “If I am tired, I cannot do any homework”), Given David’s and his parents’ reports, the low levels of these appropriate behaviors were likely to be due to a maladaptive stimulus control, rather than skills deficits. Finally, it appeared that Mr and Mrs Smith unknowingly reinforced the absence of proactive behaviors (e.g., not doing homework until told by Mrs Smith) and inactions.

Measures

Measures were administered 1 week prior to the beginning of therapy (pre-treatment), 1 week following the last session (posttreatment), and 3 months following the last session (3-month follow-up). Assessment focused on both process (David’s psychological flexibility; Mrs Smith’s acceptance) and outcome (David’s social anxiety, pain, functioning, and quality of life; Mrs Smith’s distress) indices.

Psychological Inflexibility

David completed the Avoidance and Fusion Questionnaire for Youth (AFQ-Y; Greco, Lambert, & Baer, 2008), a 17-item questionnaire that assesses psychological inflexibility. The scale measures the degree of being fused with the content of private events (e.g., “The bad things I think about myself must be true”), EA (e.g., “I push away thoughts and feelings that I don’t like”), and inaction or behavioral ineffectiveness in the presence of unwanted internal experiences (e.g., “I can’t be a good friend when I feel upset”). Scores range from 0 to 68 with higher scores indicating higher psychological inflexibility. The AFQ-Y has good internal consistency with Cronbach’s coefficient α’s ranging from .89 to .91 and has demonstrated validity via associations in predicted directions with other measures of similar processes, such as acceptance, mindfulness, and thought suppression (Greco et al., 2008).
Social Anxiety
David completed the Social Anxiety Scale for Children-Revised (SASC-R, La Greca & Lopez, 1998; La Greca & Stone, 1993), a 22-item measure of anxiety in adolescents in the context of social interactions. The scale uses a 5-point Likert scale, ranging from 1 (Not at all) to 5 (All of the time). Eighteen items are used for a composite score, ranging from 18 to 90. A study with pediatric patients with SCD (Wagner et al., 2004) revealed internal consistency to be high for the composite score (Cronbach’s $\alpha = .86$).

Pain
David and his mother completed the Varni/Thomson Pediatric Pain Questionnaire (PPQ; Varni, Thompson, & Hanson, 1987). Using the anchor from 0 (no pain) to 100 (a whole a lot of pain), the measure assesses the experiences of current pain, worst pain, and average pain over a week. The PPQ has been shown to be both a reliable and valid measure of pediatric patient (Cohen et al., 2008).

Functional Disability
David and Mrs Smith (proxy report) completed the Functional Disability Inventory (FDI; Walker & Greene, 1991) to measure David’s functioning. The measure contains 15 items that assess interference with daily activities in youths with chronic pain, using a scale of 0 (no trouble) to 4 (impossible), and greater scores suggest greater functional disability. The FDI has sound psychometrics (Palermo et al., 2008) and has been shown to be internally consistent with a population of adolescents with chronic pain and their parents ($\alpha = .85-.93$) (Cohen, Vowles, & Eccleston, 2010).

Quality of Life
The PedsQL (Varni, Seid, & Kurtin, 2001) was used to measure David’s self-reported QOL. The PedsQL contains 23 items assessing a child’s functioning in physical (eight items), emotional (five items), social (five items), and school (five items) domains. Using a 5-point Likert scale, with 0 indicating “never a problem” and 4 indicating “almost always a problem,” each subscale assesses how much of a problem the child has had over the previous 1 month in these specific functional domains. The responses for each item are reverse scored. The domain and total scores are derived from summing the items and linearly transformed to a 0–100 scale with greater scores reflecting better QOL in specific domains. The PedsQL is a psychometrically sound instrument (Palermo et al., 2008) and has been found to be valid and reliable with pediatric patients with SCD (McClellan, Schatz, Sanchez, & Roberts, 2008; Dampier et al., 2010).

Parent Acceptance of Child Chronic Illness
Mrs Smith completed the Parent Acceptance of Pediatric Illness Questionnaire (PAPIQ), which was developed for the study to measure parents’ acceptance of the child’s chronic condition (e.g., “Despite my child’s illness, we are able to do things that are important to us”). The PAPIQ is a 31-item self-report measure, which is based on the Chronic Pain Acceptance Questionnaire (CPAQ; McCracken, Vowles, & Eccleston, 2004). In the present study, the items of CPAQ, which are designed to measure an individual’s acceptance of one’s own pain experience, were modified to reflect the degree to which a caretaker is willing to accept the child’s chronic illness and also pursue value-directed actions for him/herself and promote this in the child. Conceptually, psychological acceptance is construed as the inverse of avoidance and cognitive fusion (Hayes et al., 2006). Diminished acceptance is suggestive of greater cognitive fusion (“My child can live a good and happy life only when his/her illness and symptoms are controlled”) and avoidance (e.g., “I try to avoid the difficult feelings that are related to my child’s illness”). Using a 7-point Likert-scale ranging from 0 (never true) to 6 (always true) for each item, participants’ responses to the 31 items were summed, with greater scores indicating greater acceptance of the child’s chronic condition.

Parent Psychological Distress
The Brief Symptom Inventory 18 (BSI-18; Derogatis, 2000) was used to measure Mrs Smith’s psychological distress. The BSI-18 contains 18 items and employs a 5-point Likert scale ranging from 0 (not at all) to 4 (extremely). The global severity index score is derived from the sum of all item scores, ranging from 0 to 72 with greater scores suggesting greater psychological distress. The BSI has been shown to be a reliable and valid instrument (Derogatis, 2000).

Acceptance and Commitment Therapy
Six processes of change are theorized to be at the core of ACT (Hayes et al., 2006): acceptance of private events (experiencing those events willingly and without defense), cognitive defusion from the literal content of thoughts (not necessarily believing them or acting on them), present moment awareness of one’s experience, a sense of self-as-context or perspective, clarification and induction of valued directions for life, and committed action (building patterns of overt behavior in valued directions).

The treatment protocol was largely drawn from existing ACT manuals (e.g., Hayes & Smith, 2005).
Modifications were made to reflect issues specific to SCD and the present case. Therapy consisted of eight 60-min consecutive weekly family sessions. As mentioned above, David and Mrs Smith attended all eight sessions and Mr Smith attended the third and final sessions. Each session typically started with a 5–10 min review of David’s daily activities and medical concerns and the parent(s) concerns about David and their own lives. ACT-specific content (e.g., acceptance, mindfulness, and values clarification) was typically introduced in a didactic fashion early in the session and then used to address the family’s issues, with this aspect of therapy spanning 30–40 min. During a few sessions, David and the parent(s) were seen separately when particularly personal issues were discussed. The final 10–15 min of the sessions focused on helping David and his parents set specific values-based goals. Implementation and rationale for the four overarching ACT intervention components are described below.

Perspective Modification
Given the model of psychological flexibility, it was crucial for David and his parents to shift their perspective from excessive and exclusive attempts to avoid and control unwanted psychological events (e.g., pain, discomfort, fatigue, anxiety) to values-focused living. This was a primary focus during the early sessions. To help shift their perspective, the family discussed the inevitable, often unpredictable, and pervasive nature of SCD symptoms (e.g., pain, fatigue) despite careful symptoms management efforts. This was followed by a discussion of the futility and excessive and exclusive attempts to avoid and control symptoms and made great effort to reduce them (e.g., engaging in values-consistent activities (e.g., anxiety, pain, and fatigue)).

Values Clarification
Values were emphasized in Sessions 3 and 4 in order to firmly establish ACT-congruent treatment goals. David and his parents separately completed values-clarification exercises (e.g., projecting what they would like their life to be like in 5, 10, 15, and 20 years), which are similar to activities described in ACT manuals (e.g., Hayes & Smith, 2005). In addition, the family identified emotional and physiological obstacles that might interfere with values-consistent activities (e.g., anxiety, pain, and fatigue) for David; fear of David’s getting sick or doing poorly in school for Mr and Mrs Smith).

In order to promote the parent(s)’ value-consistent behavior in the area of raising David, as well as more individual domains (e.g., hobbies), the values exercise with the parents started with the validation of the emotional challenges and struggles with raising David (worry about his future). Subsequently, the exercise explored the domain of parenting by identifying their own desires for David’s future (e.g., being autonomous, honest, independent, caring, self-disciplined). The exercise allowed them to clarify the underlying values (e.g., being supportive of David) and value-consistent actions they could take to promote
David’s autonomy and personal growth. In the context of these discussions, David and his parents seemed more open to sharing their own personal challenges with the therapists.

The values-clarification exercise helped David and his parents agree upon concrete target behaviors and the arrangement of contingencies to promote the behaviors in the context of family interaction. For example, David and therapists discussed ways in which David might engage in desirable activities (e.g., playing on the computer, drawing pictures) and also behavior that would lead to future values-based goals (obtaining better grades in school; attending college), such as playing 10 min of a computer game or drawing for 10 min as a reward after completing 30 min of homework. Mr and Mrs Smith also discussed ways of promoting David’s values-consistent behaviors and independence (e.g., not repeatedly checking on this homework progress; rewarding his good grades in school).

Acceptance and Mindfulness

The stance of acceptance and mindfulness was used throughout all sessions, but emphasized in Sessions 2 and 5. Several exercises were implemented to facilitate the family engaging in values-consistent behavior despite SCD symptoms. For example, David identified that his parents’ prompting and checking on his homework progress lead to him feeling “annoyed,” discouraged, and disempowered. In response, Mrs Smith said that she felt anxious that David would not do his work if she did not remind him and monitor his behavior. David and his mother were encouraged to practice increasing their awareness of these thoughts and emotions—to experience these private events—without acting on or trying to change them, and to simultaneously engage in values-based behavior (i.e., independent homework completion for David and encouraging independence and responsibility by not prompting or checking on David for Mr and Mrs Smith). Behaviorally, the goals of acceptance and mindfulness exercises were to alter the EA regulatory function of their private events (e.g., thoughts, perceived SCD symptoms) so that other behaviors, including values-consistent activities, flexibly occurred in the presence of these events.

This same approach of encouraging acceptance of difficult thoughts, feelings, and physical sensations and mindfully engaging in behavior grounded in values was used in other areas. For example, David was able to experience the anxiety and reservation about applying for a job (which had stymied him in the past) while simultaneously applying and securing a job, which was consistent with his goals of obtaining work to increase his social activity, strengthen his college applications, and provide financial support for other socializing. Another example is when David asked a teacher for help while having the thoughts that she would not be able to help him and that she would think he was stupid and experiencing anxiety and apprehension. His behavior was reinforced as the teacher provided supportive assistance in the subject matter.

Commitment to Values-directed Life

Committing to values-directed living was infused throughout therapy, but highlighted in Sessions 5 through 8. This was predominately accomplished by repeatedly identifying David’s and the parent(s)’ values (e.g., education, rewarding profession, independence) and linking these values to distal and proximal concrete goals (e.g., studying to improve grades, obtain a job). The psychological and physical challenges (e.g., uncertainty, fear, pain) experienced by the family when establishing behavioral goals were continuously discussed to normalize the experience, encourage acceptance, and place the primary focus on values-consistent living.

At this point in the therapy, the family was encouraged to revisit their thoughts and concerns about SCD and its symptoms (“I can’t stand this,” “I can’t pursue what I want to be because of SCD”) and to allow themselves to have these thoughts without trying to alter or act on them. These private events were revisited and discussed repeatedly and especially toward the end of therapy because they were likely to remain and could interfere with daily functioning. The family was encouraged to continue to notice these thoughts but to behave and live in accord with their identified values, such as academic learning and socializing with peers.

Results

The results of the present clinical case suggested that social anxiety and pain scores remained relatively unchanged from pre- to posttreatment (Table I). Given that therapy did not directly target these areas, this is not surprising. However, in ACT it is common to see a reduction in anxiety and pain—as a byproduct—when the patient is encouraged to willingly accept these difficult experiences and instead focus efforts on living a more vital life (e.g., Vowles & McCracke, 2008). Further, this type of change is often slow to occur and not found until 6–12 months posttreatment (e.g., Hayes et al., 2006). There was preliminary evidence of this pattern in the 3-month follow-up reduction in social anxiety (Table I). Comparing his scores to other samples, David’s pre- and postintervention scores of social anxiety fell within the average range and his follow-up
score was >1 SD below the mean of the anxiety scores for another sample of pediatric patients with SCD (Wagner et al., 2004). This change was supported by the family’s statements at the 3-month follow-up that David had become more social, that he was spending more time with friends, and that his attendance at school had improved. At 3-month follow-up, David remarked that he still noticed difficult thoughts and emotions in the area of social and peer interaction but that he did not let them dictate his behavior. Given the unpredictable and pervasive nature of SCD pain, it is not surprising to see fluctuating pain scores.

Scores on self-report measures completed by David and his parents reflected improvement in David’s daily functioning and quality of life (QOL) (Table I). The improvement was particularly salient at 3-month follow-up. At postintervention, the mother reported “a little trouble” range of disability on average, followed by “a little trouble” and “some trouble” range of disability at 3-month follow-up. While perceived greater disability in some areas of activities remained unchanged throughout the study, such as “walking the length of a football field” and “running the length of a football field,” a salient improvement was reported in other areas, such as peer relationships (i.e., “doing something with a friend”), self-care (e.g., “walking to a bathroom”), and academic activities (i.e., “being at school all day”). This was consistent with the foci of therapy on social and academic behavior.

Similarly, the improvement of David’s self-reported QOL scores was observed at the 3-month follow-up. Pre- and posttreatment overall QOL scores of 64.1 and 67.4 were comparable with the 65.8 (SD = 17.3) average score found in a sample of 68 children and adolescents with SCD (McClellan et al., 2008). However, David’s follow-up score of 87.8 suggested a substantial improvement in QOL; this score was >1 SD above the comparison sample. He had similar improvements in QOL subscale scores (i.e., health and activities, affect, and peer relationship) at the 3-month follow-up.

Although David’s score on the QOL academic activities subscale was only slightly improved at 3-month follow-up, David and his parents reported improvement in grades from a “C average” to an “A average,” both through the 8-week course of therapy and compared to his grades the prior semester. In fact, David’s overall GPA improved from a pre-treatment 2.8 to a posttreatment 3.1. At the posttreatment assessment and at the 3-month follow-up, Mr and Mrs Smith remarked that this was one of the most substantial changes, especially in light of the fact

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that they had discontinued prompting and checking on him around homework completion.

Related to his goal of increasing independence, there were a number of anecdotal data points. Specifically, David obtained and maintained a job, began keeping a schedule book to plan and monitor his homework, spoke to his teachers more often for assistance, performed searches on admissions criteria for colleges, and was beginning to pursue obtaining a driver’s license. Along with these improvements, Mr and Mrs Smith continued to allow David more freedom and reportedly had completely stopped checking on his homework progress by the end of therapy. It appeared that a positive feedback cycle had begun with his parents providing more freedom and David demonstrating greater responsibility.

It is important to consider the mechanism of change in treatment research, whether the study is of a single case or a large group randomized controlled trial. In ACT, it is assumed that acceptance and psychological flexibility are key agents of change (Hayes et al., 1999). In this case, David’s score on the AFQ (Table I) suggest that his inflexible and avoidant behavioral pattern appeared to be greater relative to his peers (Greco et al., 2008) at pre- and postintervention points. David’s psychological inflexibility, however, was found to substantially reduced at 3-month follow-up. Similarly, the increasing trend of Mrs Smith’s PAPIQ scores from pre-treatment to follow-up suggests that she had increased her acceptance of David’s medical condition and that her focus had shifted from symptom management to encouraging David to have a full and productive life with SCD symptoms. Mrs Smith’s scores on the BSI-18 remained low, suggesting lower distress across the course of treatment. Whether this is a response bias or true perception of stress is difficult to determine.

Although they should be interpreted tentatively, anecdotal comments recorded at the 3-month follow-up support the impact of ACT therapy. For example, Mr Smith stated: “If you sit there just waiting for it to come [sickle cell pain crises], you are just wasting your life away. Before sessions, he waited for it, now he is living his life.” Regarding the commitment aspect of therapy, David said: “When I say something, I try to pursue it best I can. When I make a promise, I try to keep it best I can.” Mr Smith said that the “turning point” in therapy was when David “was opening up, getting comfortable. He used to only talk to his sister, now he is expressing himself to us . . . in front of you [the therapists] . . . and we as parents had to take a look at how we were doing things . . . we also learned some ways to live from this too.”

Discussion

The purpose of this case study was to evaluate a novel approach for working with pediatric patients with SCD. Specifically, the case report describes ACT for improving the functioning and quality of life in an adolescent with SCD and his parents. ACT is a behavioral treatment designed to directly enhance functioning and quality of life via encouraging values-consistent living while willingly experiencing difficult and often unavoidable internal experiences as they are without attempting to downregulate them. The results of the case report suggest that ACT might effectively promote functioning and quality of life in adolescents with SCD and their parents and that it is worthwhile to continue to investigate the application of ACT to youths with SCD and the family.

It should be noted that the potential applications of ACT are broad and that ACT might be applicable to youths with a variety of chronic conditions. This is in part because ACT is not an illness- or diagnosis-specific intervention. Rather, the primary aim of ACT is to expand an individual’s functioning and QOL regardless of the particular stressors, difficulties, or situations. ACT teaches individuals to acknowledge, accept, and even embrace difficult private events (e.g., distress) if doing so facilitates living a life that is closely tied to personally identified values (e.g., being a good friend). This conceptual and therapeutic model of ACT can be applied to a wide range of pediatric cases with diverse chronic illness. It is especially well-suited to patients with chronic conditions because chronic diseases often cannot be cured and there might be ongoing or recurrent symptoms that cannot be controlled. In other words, accepting difficult and unchangeable facets of life while focusing on areas in need of improvement is a framework that should resonate with most any child struggling with a chronic condition.

A challenge of using an ACT-based approach with a chronic illness is that the therapeutic stance acknowledges that some symptoms will not remit or change. Families that are waiting for a cure or a new treatment that will remedy a chronic condition might experience this perspective as asking them to give up hope. This is not the case. In fact, ACT posits that the pediatric patient and the family can have a vital and meaningful life with symptoms being present; hoping for a new treatment would only be discouraged if this behavior interfered with quality of life. In other words, the stance of ACT is in fact hopeful and encouraging. Another challenge of using ACT with adolescents is that it has been predominately developed and used with adults and many concepts and exercises are abstract and sophisticated, often relying on metaphors, and
subtle uses of language. This is purposeful in that ACT seeks to undermine some of the detrimental aspects of language itself (Hayes et al., 1999). However, it will be an ongoing challenge to modify this approach for younger populations. Appropriate training in ACT can ameliorate some of these challenges. Although there is no official credentialing body for ACT, competence might be acquired via a variety of means, such as attending workshops, obtaining supervision, and self-study. Additional information about ACT training can be found on the Association for Contextual Behavioral Science website (http://contextualpsychology.org/act).

Given that this is a case study, interpretations of changes should be made cautiously. For example, therapy might explain some of the positive changes, but other circumstances and factors (e.g., maturation of David, changes in the school setting) might explain improvements. The primary purpose of this study is to provide a description of ACT therapy tailored to the difficulties experienced by an adolescent with SCD and his parents.

In summary, this case study extends existing knowledge beyond what has been reported in the area of acceptance and mindfulness treatments for children and adolescents, by suggesting that ACT intervention can be a useful conceptual and therapeutic addition to the treatment of pediatric patients with SCD and the family. The study provides preliminary but promising data that ACT is a viable approach for improving functioning and QOL for adolescents with SCD and their parents. The process measures suggest that the mechanism of change was the ACT processes of increased youth psychological flexibility and parent acceptance. As this is a case study, conclusions about treatment effectiveness should be made cautiously. Additional research is necessary to replicate these findings across other individuals, examine the impact of the approach in a randomized trial, more closely highlight mechanism of change, identify the key ingredients of the intervention, and determine which individuals and situations might be most appropriate for this treatment. Although findings should be interpreted tentatively, this report highlights a promising alternative approach to working with pediatric patients, rather than symptom control, a focus on acceptance and vital living might prove a valuable psychological method for improving functioning and quality of life in youth with chronic conditions. Given that pediatric psychologists often help patients manage symptoms that are unresponsive to medical interventions, a framework of enhancing functioning and focusing on living a vital life with a chronic condition might prove to be a promising mode of therapy.

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**References**


