

**ACT Now IO2 Theoretical Report Section:**  
**Acceptance and Commitment Therapy for**  
**patients with appearance-affecting conditions and their caregivers**

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### **Defining the patient group**

In the United Kingdom, *visible difference* has emerged as a popular term to describe a physical appearance that lays outside the norm (Rumsey & Harcourt, 2004). This offers a more neutral alternative to the medical term *disfigurement*, which for some is loaded with social stigma (Changing Faces, 2019). Defining the appearance ‘norm’ from which a visible difference deviates is also contentious and subject to interpretation.

We therefore suggest that a more self-explanatory term may be more helpful here: *appearance-affecting conditions*. By ‘conditions’ we refer to any illness, disease, syndrome, congenital anomaly, atypical physical development, injury or medical treatment that affects an individuals’ appearance. Some individuals are born with an appearance-affecting condition, which may be evident from birth (e.g. cleft lip and/or palate, craniosynostosis), or emerge later (e.g. neurofibromatosis). Others acquire an altered appearance, as a result of skin disease (e.g. psoriasis, eczema), trauma (e.g. burns, road traffic accident) or surgery (e.g. for cancer). Medical advances mean there is likely to be an ever-increasing population of individuals with appearance-affecting conditions, as greater numbers survive injury, disease and illness (Williamson et al., 2018).

Historically, the research community focused on this area has tended not to include obesity, eating disorders, physical disabilities or movement disorders within the field of appearance-affecting conditions, owing largely to their additional level of complexity and established research communities already tackling these areas. However, it should be noted that many of the psychosocial challenges and intervention components we will go on to describe apply to these conditions to varying degrees.

### **Psychosocial challenges faced by patients with appearance-affecting conditions**

In the context of a society heavily invested in appearance, it is perhaps unsurprising that individuals with an unusual appearance seem to be at particular risk of developing psychological and social difficulties (Shepherd et al., 2018). Many report social discrimination and intrusive attention. For children and young people this may come in the form of teasing, bullying and social rejection (Feragen et al., 2015). Adults commonly describe strangers staring, asking questions or making comments about their appearance, and/or avoiding their physical proximity (Kleve & Robinson, 1999; Ryan, Oaten, Stevenson & Case, 2012).

Relatedly, psychological difficulties have been reported across a range of appearance-affecting conditions and age groups in at least 13 European countries; these include social anxiety and

avoidance of feared social and public situations, body image dissatisfaction, shame and self-stigma, depression, generalized anxiety, low self-esteem and poor quality of life (Appearance Research Collaboration- in Clarke et al., 2014; Dalgard et al., 2015; Montgomery, Messenger, Norman & Thompson, 2016; Osinubi et al., 2017; Randa, Lomholt, Skov & Zachariae, 2018).

Given their direct relationship to appearance, social (or 'appearance') anxiety and body image dissatisfaction are typically targeted in psychosocial interventions for this group to date (e.g. Bessell et al., 2010; Williamson et al., 2016). Outcomes such as poor quality of life and depression are most likely influenced by individuals' capacity to engage in meaningful social activities (hampered by social anxiety), which in turn is likely influenced by individuals' level of body image satisfaction.

Some patients with appearance-affecting conditions live with symptomatic health problems, which may change over time (e.g. psoriasis), involve chronic pain (e.g. lipoedema) or itching (e.g. keloid scarring), require long-term treatment and decisions about treatment (e.g. cleft lip and/or palate, neurofibromatosis), or provide threat to life (e.g. cancer). These patients must also face the many psychological challenges associated with such conditions, which extend far beyond appearance concerns.

### **Psychosocial challenges faced by family caregivers**

Family caregivers, typically parents, are heavily involved in the care of children and young people who have appearance-affecting conditions. Parents too can experience psychological challenges in adjusting to their child's appearance, including anxiety concerning how their children will be treated by friends, family, other children and the public, and hypervigilance to other people's reactions towards their children (Hlongwa & Rispel, 2018; Rumsey & Harcourt, 2005). Parents too can fear or avoid social or public situations (Klein et al., 2006). Additionally, qualitative research in the UK suggests that some parents of children with cleft lip and/or palate may develop unhelpful parenting strategies as a result of these anxieties, becoming overprotective of their child (Stock et al., submitted).

In caring for their child's health condition, parents take a primary role in making decisions about medical intervention (e.g. surgery in cleft lip and/or palate; Jeffery & Boorman, 2001), and managing care at home (e.g. caring for burns scarring post-hospital discharge; Heath, 2018). This additional pressure and responsibility further burdens parents who may already be dealing with feelings of loss, guilt (e.g. over not preventing a burn injury) and anger regarding their child's condition (Heath et al., 2018).

### **Introducing Acceptance and Commitment Therapy for this group**

Acceptance and Commitment Therapy (ACT) was developed in the 1990s by US-based researchers and applied psychologists (Hayes et al., 1999). ACT is fundamentally a behavioural therapy, as it is concerned with supporting individuals to act with greater intention and clarity in a pattern that leads them towards a more meaningful and rewarding life. For this reason, ACT is read as the word *Act*, rather than letter-by-letter (A-C-T).

The higher-order psychological mechanism that promotes such life-enriching behavior in ACT is called 'psychological flexibility'. This describes an individual's ability to focus on their present situation with openness and awareness, and flexibly adopt behaviours that help them live in line

with their personal values (Hayes et al., 2006; Kashdan, 2010). Three interdependent therapeutic tools are utilized in ACT to promote psychological flexibility: value clarification, mindfulness, and committed action.

### *Value clarification*

In order for people to understand what is meaningful to them, i.e. intrinsically rewarding, ACT invites individuals to clarify their values via verbal representations. Values refer to what individuals consider to be the most desirable characteristics of life, towards which they would ideally like to focus their energies. Values answer the question “What do you want your life to be about?” Examples include ‘family’, ‘kindness’, ‘ambition’, ‘courage’, and ‘loyalty’. Individuals can select their own values, or if they prefer, a list of values may be offered from which to choose.

Once an individual clarifies their values, these can serve as a guide, or internal ‘compass’ to direct individuals’ behaviour in a valued direction. Values can inform both the planning of value-oriented goals, and decisions about how best to act at any one moment. For example, a patient with burns scarring who holds a value of ‘friendship’ may set a goal of meeting an old friend, despite feeling worried about how their friend may judge their appearance. Alternatively, if the patient were to spot an old friend while walking locally, they could bring their ‘friendship’ value to mind when deciding whether to approach and greet the friend, or avoid them (Zucchelli et al., 2018).

For some patients with appearance-affecting conditions, attentional resources can become fixated on appearance, and how others may respond to their appearance (Appearance Research Collaboration, 2014). Asking such patients to deeply consider which values matter to them should therefore also help them reconnect with life areas that may have become neglected due to preoccupation with appearance, and in so doing, help to broaden their aspirations beyond appearance concerns (Stock et al., in submission).

### *Mindfulness*

Mindfulness has been defined as the capacity to pay sustained attention to one’s present experience, with an attitude of openness and acceptance (Bishop et al., 2004). The subject of this attention could be any internal experience: physical sensations, emotions, thoughts, sounds, sights, smells or taste.

Two aspects of mindfulness are of particular interest in ACT, and these connect to two central concepts in the ACT model. The first has to do with thoughts. *Cognitive fusion* describes the common tendency to interpret thoughts as facts and act upon them as if they were (Hayes, 2006). There are specific mindfulness techniques that target this process, by learning to observe one’s own thoughts, and recognizing them as language constructions that may or may not be true. In doing so, patients are able to mentally detach themselves from the thoughts, or *defuse* from them.

Some distressing thoughts may actually appear objectively true for people with an appearance-affecting condition, for example, “People are staring at my skin” or “I look so different to everyone else here”. Defusion does not involve trying to disprove such thoughts, as in traditional Cognitive Behavioural Therapy (CBT), but rather by adopting a more detached relationship to the thought, one gains more control over how to act. This allows one’s decisions to be determined more by values, and less by the content of thoughts.

The second central ACT concept is *experiential avoidance*. This refers to a natural human coping style of trying to avoid, get rid of, or change painful internal experiences (i.e. emotions, thoughts etc.), even when doing so ultimately impinges quality of life (Hayes, 2006). Experiential avoidance is maintained via the immediate relief associated with reducing the intensity of painful internal experiences, such as the relief gained by leaving a feared social situation ('negative reinforcement' in behavioural psychology terms; Kent, 2000). In sum, gaining short-term relief can prevent gaining long-term quality of life. The more an individual can practice paying attention to their internal experiences in an open and accepting way through mindfulness training, the more control they will have in choosing how to act when painful internal experiences do arise. This includes making the more 'difficult' choice when it aligns with one's values, rather than seeking immediate relief via avoiding a situation.

Cognitive fusion and experiential avoidance combine to cause rigid, avoidant behaviour. Therefore developing experiential acceptance and cognitive defusion together via mindfulness training helps to develop more flexible responses to situations. For example, an individual with an appearance-affecting condition who is fused with the thought "People are staring at me" at a party which is of value to them to attend, would be more likely to focus attention on the thought as a fact, and this would likely cause them to feel anxious and self-conscious. A tendency towards experiential avoidance would then increase the likelihood of them leaving, to get rid of anxiety. Alternatively, if they had developed stronger cognitive defusion, they may be less preoccupied by the "People are staring at me" thought, and more able to enjoy the party. Equally, if they had cultivated a degree of experiential acceptance, they would be able to manage any anxiety or self-consciousness that does arise, and stay at the party that is important to them.

### *Committed Action*

Values give a sense of direction for behaviour, and mindfulness skills help to stay with any painful internal experiences that may follow from valued action. However, to engage in a pattern of value-driven behaviour in the long-term, it is very helpful to systematize one's choices by setting clear goals. To extend the metaphor of values as an internal compass, goals represent destinations that align to those values; one can achieve and 'check off' goals, whereas values endure. For example, a mother of a new baby with cleft lip and palate may set a goal of introducing her child to her friends despite fears of how they will respond, based on her value of 'connecting to friends' (which may be used to set further goals).

Goals may come in the form of short, medium and long-term goals, and, as is understood in the wider behaviour change literature, work best when specific, measurable, achievable and time-limited (Michie, 2014). Psychological barriers are likely to arise from pursuing more challenging goals, which can be addressed through mindfulness skills including experiential acceptance and defusion.

Depending on patients' level of need and health professionals' resources, ACT can be delivered via individual therapy sessions by suitably trained psychological practitioners (e.g. Bacon, Farhall & Fossey, 2014), in manualized group programmes facilitated by health professionals (e.g. Williams, Vaughan, Huws & Hastings, 2014), short educational workshops (Pearson, Follette & Hayes., 2012), or self-help materials (French, Golijani-Moghaddam & Schroder, 2017).

## **A brief review of ACT research relevant to patients with appearance-affecting conditions**

There is emerging evidence that European clinicians choose to adopt ACT for a range of psychological difficulties related to appearance-affecting conditions. In a recent survey of over 100 psychological practitioners across 15 European countries, a third reported using ACT with patients who have appearance concerns (Harcourt et al., 2018). Similarly, UK clinical psychologists working in cleft services spoke favourably about applying ACT principles in an interview study, especially for adolescent and young adults affected by appearance concerns (Stock et al., in submission).

Recent correlational studies have also explored the relationship between key ACT mechanisms and wellbeing in different appearance-affecting conditions. In a group of UK burns patients, Shepherd et al. (2018) found that measures of experiential avoidance and cognitive defusion positively correlated with appearance anxiety, and higher levels of committed action were associated with lower appearance anxiety. In an international sample of female patients affected by lipoedema, a chronic condition characterized by progressive visible fat build-up in the lower body, Dudek, Bialaszek and Ostaszewski (2016) found that psychological flexibility positively predicted patients' quality of life, by using multiple hierarchical regression. However, while lipoedema unquestionably causes profound physical changes that affect body image, it also causes chronic pain. As the quality of life measure did not focus on appearance, we cannot claim to understand how much participants' psychological flexibility related to their experience of appearance concerns.

Montgomery et al. (2016) measured self-reported mindfulness in UK dermatology patients along with dermatological quality of life, social anxiety, anxiety and depression. Controlling for the severity of patients' skin disease, the authors found that mindfulness partially explained variance in each outcome. The mindfulness measure used for this study did not, however, allow for closer analysis of the central ACT components.

Each of these three studies were correlational in design, so we cannot infer any causal relationships between psychological flexibility nor any of its components with quality of life or wellbeing outcomes. We will therefore now briefly summarise the scientific research testing the application of ACT to the most common problem areas encountered by patients who have appearance-affecting conditions: social anxiety, body dissatisfaction and managing health conditions. We will also suggest important considerations regarding the ways in which these problems may uniquely present in this patient group, and how these considerations can be best understood and worked with using ACT.

### *Social anxiety*

Four single-group intervention studies testing ACT for social anxiety reported reductions in social anxiety, as well as favourable changes in measures of pursuit of valuable relationships (Ossman et al., 2006), quality of life (Dalrymple & Herbert, 2007; Dalrymple et al., 2014), depression (Kocovski, 2009; Dalrymple et al., 2014) and rumination (Kocovski, 2009). In all four studies experiential avoidance decreased over the course of treatment as expected, but their conclusions are limited by an absence of control groups.

Three randomized controlled trials (RCTs) have since been conducted. Kocovski et al. (2013) compared a 12-week ACT group intervention (n = 53) to group cognitive behavioral therapy (CBT; n = 53) and waitlist control group (n = 31) for Canadian adults diagnosed with social anxiety disorder (SAD). The authors found clinically significant social anxiety reductions in around 40% of patients in both intervention groups. This suggests equivalent clinical effectiveness between the ACT and CBT group. Surprisingly, process variables including experiential acceptance, mindfulness and valued living did not differ between ACT and CBT groups, meaning the proposed mechanisms of change in

ACT were not uniquely manipulated by the ACT protocol. A mediation analysis was not conducted, so no clear conclusions about the processes of change could be derived. Yadegari et al. (2014) conducted a small RCT (n = 16) in Iranian young people with reported signs of social anxiety, finding those assigned to an ACT intervention had reduced social anxiety symptoms after a 12-week ACT intervention compared to a no treatment control group.

Craske et al. (2014) published an RCT comparing a 12-week individual ACT intervention (n = 29) with CBT (n = 33) and waitlist control (n = 25) in the US. Clinically significant improvements in social anxiety were observed and maintained at 12-month follow-up in both ACT and CBT groups but not the control group. Niles et al (2014) subsequently performed a mediation analysis on Craske et al's data, and found that experiential avoidance was reduced through the course of both ACT and CBT interventions, but that the ACT condition conferred stronger decreases in experiential avoidance. Interestingly, by analysing the ACT programme content against experiential avoidance scores measured throughout treatment, Niles et al. found that working on defusion (e.g. introducing the idea of observing thoughts as thoughts, not facts) had the biggest effect of any ACT component on reducing experiential avoidance. Taken as a whole, the extant empirical research on the use of ACT for social anxiety suggests targeting experiential avoidance in social anxiety leads to positive outcomes, and ACT therefore represents a viable treatment option for individuals with appearance-affecting conditions who experience social anxiety.

One method commonly used in both traditional CBT and ACT social anxiety protocols, graded exposure, requires clarification in relation to ACT and appearance-affecting conditions. Graded exposure involves the patient (supported by a practitioner) entering feared situations in a gradual way, moving through increasingly feared situations in a planned manner (Benito & Walther, 2015). In ACT, graded exposure is done as a form of committed action; that is, it is done so that the individual can take steps towards doing things that they enjoy and give them meaning. The goal of ACT is *not* for the patient to habituate to the environment, thereby reducing their arousal and anxiety levels (as in CBT). This may naturally occur as a by-product of repeated exposure, but it is very important not to teach patients that anxiety is something to get rid of, as this reinforces experiential avoidance.

There is also an important difference between 'typical' social anxiety and the type often encountered by patients with appearance-affecting conditions (and their families). If someone with an unusual appearance attempts to expose themselves to feared social or public situations (for example, using public transport for the first time since an injury), they may genuinely receive unwelcome attention from other people. To manage any difficult interactions that arise, these individuals must feel able to apply social skills confidently, such as dealing with awkward questions or staring. So before asking patients to enter feared social situations, it is vital that they are equipped with the necessary social skills. Specific social skills training for patients with appearance-affecting conditions is available, for example via online interventions Face IT (Bessell et al., 2010), Young Person's Face IT (Williamson et al., 2017) and the charity Changing Faces ([tinyurl.com/y6ydajam](http://tinyurl.com/y6ydajam)). As with graded exposure, social skills training would be offered as an example of committed action in an ACT intervention.

### *Body dissatisfaction*

As reported in a systematic review conducted by Griffiths et al. (2018), a small number of research trials have tested the effects of ACT on self-reported body dissatisfaction, mostly adopting one-day training workshops. In the US, Pearson, Follette and Hayes (2012) randomised overweight and obese women who self-reported with body dissatisfaction into an 8-hour ACT workshop (n = 39) or a waitlist condition (n = 34). Compared to the control group, the participants who took part in the ACT

workshop reported significantly greater reduction in body anxiety, up to two weeks after the intervention. The ACT group also showed greater reductions in experiential avoidance, which suggested the protocol was successful in targeting a key proposed mechanism of change.

In a group of Swedish adults who had undergone bariatric surgery for weight loss, Weineland, Arvidsson, Kakaloudis and Dahl (2012) tested an ACT body image intervention consisting of two face-to-face sessions in a hospital setting, followed by six online sessions supported by weekly telephone calls (totaling 8 weeks). Participants were randomly allocated either to the intervention group (n = 19) or received treatment as usual (n = 20). At the end of the intervention period and 6-months later, the ACT group reported significantly fewer body shape concerns compared with the treatment as usual group. The ACT group also showed reduced weight concern compared to the control group post-intervention, but this difference was lost at 6-month follow-up. In a single group study, Walloch (2014) also applied a one-day ACT workshop to gay men with body dissatisfaction, finding preoccupation with body image and disordered eating symptomology decreased. The author also found experiential avoidance decreased in line with body satisfaction.

Overall, the small number of research trials that have measured changes in some form of body dissatisfaction suggest potential for the application of ACT for this problem area, and, encouragingly, have found that the ACT protocols tested conferred favourable changes in experiential avoidance. Clearly, further large-scale RCTs are needed to bolster the emerging evidence.

As ACT is primarily a behavioural therapy, it is actually most concerned with the behavioural consequences of body dissatisfaction, and especially how these may adversely affect individuals' quality of life. Cash's (2000) established cognitive behavioural model of body dissatisfaction presents two unhelpful (or maladaptive) forms of behavioural coping strategies for dealing with perceived threats to an individual's body image: avoidance of threatening scenarios, and appearance-fixing (which refers to attempts to conceal or otherwise change one's appearance, seek reassurance about one's looks, or spend long periods fixated on one's appearance). In an Australian correlational study, Mancuso (2016) found that female participants who scored higher in a measure of psychological flexibility pertaining to body image were less likely to use these unhelpful coping strategies, even when they reported body dissatisfaction. Though limited by its correlational design, this study suggests that psychological flexibility, the central mechanism of change in ACT, interrupts the assumed direct relationship between body dissatisfaction and unhelpful coping strategies.

The appearance-fixing strategy, and in particular efforts to conceal physical features, requires further consideration in the context of patients with appearance-affecting conditions. From an ACT perspective, using extensive makeup or skin camouflage (e.g. for skin conditions like vitiligo) in order to attend social activities that would otherwise be avoided, could be viewed as a pragmatic strategy facilitating greater engagement in meaningful activities. Indeed, in a systematic review of studies evaluating the effects of cosmetic camouflage for visible skin conditions, Kornhaber et al. (2018) reported significant improvements in dermatological quality of life following camouflage use. In an alternative example, an individual with vitiligo may only feel able to leave their house wearing extensive makeup, which is applied in certain lighting conditions. However, given the time and specific environment needed to apply makeup, this appearance-fixing strategy may prevent some individuals from engaging in spontaneous trips of value to them. The key question for a health professional from an ACT perspective is therefore whether such appearance-fixing behaviour facilitates or blocks a richer, more fulfilling life.

*Managing health conditions*

As mentioned earlier, the many possible causes of altered appearance present a number of potential challenges to managing one's health. Therefore a full review is beyond the scope of this paper. However, a systematic review on the use of ACT in chronic disease and long-term conditions conducted by Graham, Gouick, Krahe and Gillanders (2016) offers some indication of its utility in a relevant field. Although the small number of high-quality RCTs reviewed led the authors to conclude insufficient evidence exists to date to claim ACT as a well-established intervention for chronic disease and long-term conditions, the most promising findings came in disease self-management. Hawkes et al's (2013) high-quality RCT tested telephone-delivered ACT for Australian colorectal cancer survivors versus treatment as usual, finding significant improvements in self-reported weight and diet management as well as activity levels at 12-month follow-up. Gregg et al. (2007) tested a lower-intensity ACT intervention, delivered via a single day education workshop for US diabetes patients, compared to an education-only condition. The ACT group reported better diabetes self-care and control over blood-sugar levels compared to the control group after three months.

A specific yet prevalent traumatic cause of visible difference, burn injury, is commonly associated with chronic pain (Hamed, 2011). The high-quality evidence base for ACT in chronic pain is unrivalled by any other clinical area. Single-group trials have established the effectiveness of ACT in managing chronic pain even up to three years' follow-up (McCracken, MacKichan & Eccleston, 2007; Vowles & McCracken, 2008; Vowles, McCracken & O'Brien, 2011). Two RCTs have shown ACT to be as effective as CBT, the gold-standard treatment for pain, with higher patient satisfaction with treatment in the ACT group (Vowles, Wetherrell & Sorrell, 2009; Wetherrell et al., 2011).

### **A brief review of ACT research relevant to family caregivers of patients with appearance-affecting conditions**

To our knowledge, no research has evaluated ACT protocols that target appearance concerns for parents or other caregivers of patients who have appearance-affecting conditions. However, one small pilot study conducted by Martin et al (2016) has tested a two-day ACT workshop for parents of adolescents and young people who have neurofibromatosis type 1, a genetic condition that commonly produces visible birthmarks, freckles and/or skin growths. Pain management was the focus of intervention and therefore participants were selected on the basis that their child was experiencing chronic pain associated with the condition. Three months after the workshops, parents reported favourable changes to pain interference and pain acceptance. Given that this is a small-scale study, findings are only indicative and larger trials are needed.

ACT has also been tested as an integrated part of established parenting interventions for parents of children with long-term conditions. In one Australian RCT, Whittingham, Sanders, McKinlay and Boyd (2016) tested a combination of ACT and Positive Parenting Program (PPP; Roberts et al., 2006) for parents of children with cerebral palsy, compared to PPP alone, and a waitlist control group. Compared to the waitlist group, the combined intervention conferred increased functional performance and quality of life for parents, and compared to the PPP alone group, the combined intervention led to reduced depression and parental stress. Also in Australia, Brown et al. (2014) compared ACT plus PPP to treatment as usual for parents of children with acquired brain injuries. The authors found significant small-to-medium improvements in family adjustment, parental distress and confidence in managing behaviours in the intervention group up to 6-months follow-up. Taken together, these studies' findings offer early promise that ACT may contribute towards parents' adjustment to their children's long-term health condition.

## **Summary**

To review the application of ACT to the psychosocial challenges commonly experienced by patients with appearance-affecting conditions and their family caregivers, we have defined the patient group and outlined common psychosocial problems experienced by patients and their families, provided an overview of ACT with reference to the patient group, and summarised the most relevant existing research literature. As limited interventional research has been conducted to date on the use of ACT in this population, we have drawn from empirical findings primarily in the social anxiety and wider body dissatisfaction literature to paint a picture of the emerging, largely promising evidence base. Alongside this literature review, we have attempted to acknowledge the key points of potential divergence in how patients with appearance-affecting conditions may experience social anxiety and body dissatisfaction, and offer guidance regarding how ACT can address these areas.

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