

## Self-Regulation of Emotion in CHARGE Syndrome

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**“I am starting to be stressed by this article. I wanted it completed some time ago. As my emotions get on edge, I become a bit grumpy, and find that I am less pleasant with the people around me, particularly my co-authors. As I notice my feelings become more aroused, I remind myself that this is a group process, we are all busy, we are making progress, and it will be good. Telling myself these things helps me to relax a bit and calm myself down. I have lowered my level of emotional arousal and am better able to focus on the task at hand. I have self-regulated my emotions”.** (Tim Hartshorne)

The self-regulation of emotions is a process that involves the analysis, control, alteration, or prevention of emotional expression and experiences that are adaptive for a situation. Emotion self-regulation may occur at different times relative to the emotional response. Emotions may be regulated either by manipulating antecedents to emotional response tendencies or by manipulating responses to those tendencies (Gross, 1998).

When focusing on manipulating the antecedents to emotional response, self-regulatory strategies may include situation selection, situation modification, attention deployment, or cognitive change (Gross & Thompson, 2007). Situation selection refers to approaching or avoiding certain people, situations, or environments on the basis of their likely emotional impact. This strategy requires an understanding of emotional responses that can be expected from interaction or lack of interaction with these people, situations, and environments. For example, talking with a certain person always leads to heightened, negative emotion, and so you avoid that person. During situation modification, an individual modifies the environment to alter its emotional impact. If you cannot avoid talking to that person, you might bring a friend along with you to help you stay calm. Attention deployment is turning one’s attention away from something in order to influence emotions. You are in a situation where there is this person you do not want to talk with, and so you make sure that you are constantly engaged in talk with others. Cognitive change refers to the way with which we mentally appraise a situation to alter its emotional significance. This may be done by changing how we think about the situation or about our capacity to manage the demand it poses. Cognitive change requires strong cognitive self-regulation skills. For example, one can mentally prepare for having a conversation with someone and tell oneself that it will be “no big deal.”

When focusing on the emotional response itself, self-regulation strategies include those that intensify, diminish, prolong, or curtail ongoing emotional experience,

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expression, or physiological responding (Gross, 1998). For example, after a challenging conversation with a person, saying to oneself “That is an idiotic position to take, or thing to say, but I do not have to be bothered by it,” could reduce emotional arousal.

It is important to note that emotion regulation is used not only to reduce a negative level of arousal, but also to intensify or prolong. In order to increase one's motivation for doing well on an exam, a person might actively seek to increase emotions of anxiety.

When discussing the self-regulation of emotions, it is important to provide an understanding of what we mean by the term ‘emotion’. Emotions occur when an individual evaluates internal or external emotional cues, and this evaluation triggers a coordinated set of behavioral, experiential, and physiological emotional response tendencies (Gross, 1998). These tendencies may be modulated, and this modulation gives final shape to outward emotional responses. During emotion self-regulation, a person may increase, decrease, or maintain positive and negative emotions (Koole, 2009).

An interesting study conducted by Barrett, Gross, Christensen & Benvenuto (2001) showed that individuals with more highly differentiated and more intense negative emotional experience reported greater emotion regulation, while positive emotional differentiation and intensity were unrelated to emotion regulation. Sometimes our emotions can be kind of a mess and difficult to sort out, but for those individuals who are able to be clear about what they are feeling, particularly in the case of negative feelings, self-regulation appears to be easier. This suggests that the regulation of emotions might be considered separately for positive and negative emotions. This may be because negative emotions tend to have more immediate consequences if they are not dealt with.

Developmental studies have shown self-regulation to play a crucial role in children's social competence (Cicchetti, 1994; Eisenberg, Guthrie, Fabes, Shepard, Losoya, Murphy, Jones, Poulin & Reiser, M. (2000). In other words, impairments in emotion self-regulation affects children's capacity to regulate their emotions, and emotion dysregulation in turn leads to social difficulties. Difficulties with emotion regulation may result in psychosocial problems, such as high levels of negative affect and escalation of anger, aggressive-disruptive behaviors, antisocial behaviors, addictions, suicidal ideations, and mood disorders such as depression (Wyman, Cross, Brown, Yu, Q., Yu, X. & Eberly (2010). Emotion self-regulation recruits less cortical activation in the ventral-prefrontal cortex with age, suggesting that individuals are better able to regulate emotions with age and development (Lamm & Lewis, 2010). Activation of the ventral medial prefrontal cortex is associated with successful suppression of emotional responses to a negative emotional signal (Hänsel & Känel, 2008).

Emotion self-regulation skills closely relate to the other dimensions of self-regulation: physiological, behavioral, and cognitive. According to Saarikallio (2010), the

regulation of emotion is accompanied by the regulation of physiological and behavioral processes related to the specific emotion. Thinking about the situation one is in and what one wants out of the situation, influences the emotional arousal. Thus, improved cognitive self-regulation will result in a greater ability to assess emotional situations, monitor emotional situations, and respond using cognitive or meta-cognitive strategies. In return, a stronger ability to self-regulate emotions will result in a stronger ability to mentally assess a situation, and respond with appropriate behavior.

### **Self-Regulation in CHARGE Syndrome**

It is often difficult for children with severe disabilities, including CHARGE, to develop self-regulation skills, and challenging emotional outbursts are common. Conditions that may contribute to difficulty with emotion self-regulating include multiple sensory impairments, difficulty and delay in language development, executive dysfunction, communication difficulties, and poor health and pain. Communication and sensory information are important for learning how to regulate through experiences and feedback, and it is likely that impairments in these areas contribute to poor self-regulation among individuals with CHARGE. Hearing impairment may cause difficulty processing new information, answering questions, and following directions, while vision impairment may cause difficulty in processing facial expressions, imitating socially acceptable behavior, and focusing on other visual stimuli. Learning how to interpret and express emotions is highly dependent on how the experience is shaped through modeling, which is reduced by communication and sensory problems.

A study by Hartshorne, Nicholas, Grialou & Russ (2007) explored executive dysfunction among children with CHARGE Syndrome using the Behavior Rating Inventory of Executive Function (Gioia, Isquith, Guy & Kenworthy, 2000). The study confirmed the presence of executive dysfunction in over half of children with CHARGE. These children displayed difficulty with items measuring shifting from one activity or focus to another, tracking their own behavior and its effect on others, and controlling their impulses and terminating behaviors as required (Hartshorne et al., 2007). The authors report that about one third of individuals had difficulty on the emotional control scale of the instrument, and half had clinical scores on the behavioral regulation index. Thus it appears that individuals with CHARGE may have some difficulty with self-regulating their emotions. Due to the many challenges faced by these individuals, it may be difficult for someone with CHARGE to understand when they are feeling an emotion, what it is that they are feeling, and how to regulate or control it. As DeGangi (2000) points out, early deficiencies in self-regulation may lead to challenging behavior, and deficits in attention and inhibition.

### **Intervention**

An important step in teaching children to self-regulate their emotions is first teaching those children what it means when they are feeling an emotion. Teaching a feeling vocabulary to a child may be useful here. This could be done using scaffolding techniques, or breaking the process of recognizing and responding to emotions down into smaller, discrete tasks. Modeling of emotions and how to respond in specific situations, as well as using role-play activities, is a useful method when teaching feeling words and how to recognize each feeling. When modeling emotions, mirroring feelings using exaggerated facial and body movements may help children understand how to recognize emotions in other people. The use of differential reinforcement can be very effective in teaching appropriate emotional responses by rewarding positive, appropriate emotions in a situation and reducing negative, inappropriate emotions. It is important to take advantage of opportunities to teach a child feelings when they are noticeably feeling an emotion. When you know that a child is feeling happy, angry, or frustrated, for example, this could be a good time to help them understand that emotion by modeling, and by showing them appropriate responses to that emotion. Concrete aids may help children understand or express emotions as well. Examples of concrete aids may be using a color or face chart to describe feelings, or using a 'traffic light' to describe the strength of the feeling. For children with more significant difficulties, repetition may be important when teaching about feelings.

While teaching the child a feeling vocabulary is useful, strategies for reducing the strong, negative emotions are necessary. When self-regulating emotions, an individual may either alter or avoid triggers that produce an emotional feeling, or alter the emotional feeling after it occurs. By helping children to recognize situations in which they are likely to have a strong feeling, you may begin to teach them how to engage or avoid those situations, or limit their emotional effect. When dealing with a feeling after it occurs, practicing how to respond to feelings with the child or walking them through how to deal with the feeling will likely be helpful. It is also important to teach the child calming techniques when they are feeling a negative emotion. Calming techniques may include breathing techniques, exercise or mindfulness techniques such as meditation, Tai Chi, or yoga, or having attachment or stress reduction objects available. Having a 'safe place' available for the child to go to during an emotional response may help that child calm down. For children with significant difficulties, maintaining a consistent environment and routine may also be important to reducing inappropriate emotional responses. However, it is also important to teach the child how to respond in different situations and with different people, and to help the child form secure stable relationships with as many people as possible. This will help the child's self-regulation skills to generalize to new environments, situations, and people.

### **Case example**

Before starting at a new residential school, Sarah, age 14 and diagnosed with CHARGE syndrome, had been excluded from school for two years as a consequence of her difficult behavior. Some of Sarah's issues were:

- Regular emotional outbursts
- Unable to tolerate being with her peers and being very easily annoyed or upset
- Inappropriate attempts to initiate interactions
- Saying hurtful and inappropriate things to others
- Being very angry with herself, with a negative self-image and self-esteem
- Lack of awareness of her own emotions - Sarah had an analytical understanding but was not able to link this information to what she herself was feeling
- Unable to negotiate or tolerate when things did not go her way
- Difficulty coping with the unexpected
- Difficulty controlling her own behavior and impulsivity (saying "I just want someone to make me stop.")

A full team of practitioners were involved in developing a program to support Sarah, which was regularly monitored and strategies developed or adapted in response. Some strategies developed to support Sarah in this area were:

- Providing Sarah with her own space, with a gradual reintroduction to being in the room with her peers.
- Ensuring a consistent routine, with any changes kept to a minimum and every effort undertaken to prepare Sarah for changes.
- A highly individualized curriculum, using Sarah's strengths and interests to build her confidence and self-esteem.
- Modeling and discussing how Sarah might respond in different social situations. For example, in preparation for attending a local youth club, staff discussed with Sarah what was likely to happen; how to respond if someone said hello; how to initiate a conversation; how to move away if the situation became too much. A picture-board sequence was used to provide a concrete visual cue.
- Sarah struggled during role play, and so plastic characters were used. Social scenes were enacted, exploring different ways a person might respond in each situation. This was also used to re-enact situations that Sarah had found difficult, exploring what might have been a more positive way of managing the situation.
- Weekly yoga was introduced to help Sarah develop and regulate her physiological state more effectively. 'Deep belly breathing' became a useful strategy for Sarah to use independently to help her calm.
- Pet therapy provided Sarah with the opportunity to enjoy caring for and nurturing Darcy the dog.
- Discussing Sarah's own emotional state. Initially she found this extremely difficult, and staff who knew her well, labeled her emotional states for her (e.g. "I think you are feeling a bit frustrated," etc.). A break though came when Sarah was in conversation about a forthcoming trip and suddenly said: "I'm feeling something". Unable to label what she felt, the supporting adult explained she was probably feeling a bit excited and also anxious.

Now 18, it has taken time but Sarah has made huge progress. She is a much happier young lady who is fully included in her class and making real friendships. She is much more socially aware and able to socially engage, sharing a joke and coping with gentle teasing. Sarah is more in touch with her own emotional state and is better able to regulate her emotions and behavior. Very importantly, Sarah is now able to talk about how she is feeling which has proved to be vital as she has undergone a period of ill-health requiring hospitalization and surgery. Overall she has grown in confidence and is looking forward to moving on to college in the near future.

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