

Hyperarousal in Fragile X Syndrome: Transitions, IEPs and Childhood Issues

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Outline of Presentation

- What are transitions?
- What is hyperarousal?
- Transitions may cause hyperarousal.
- Strategies for coping with hyperarousal caused by transitions.
- Importance of the IEP.

Transitions

Transitions are movements or changes between environments, activities, people, stages or states.

Transitions

Transitions are inherently aversive because they involve shifting set, or moving from a current comfortable state to a different and uncertain state.

Transitions

- All children endure transitions throughout the day.
- Transitions occur at home, in school & during play.

Examples of transitions that occur within the home:

- Bed to bathroom
- Bathroom to kitchen
- Undressed to dressed
- Playing to eating
- Waking to sleeping
- Parents to babysitter

Examples of transitions that occur at school

- Home to bus to school
- Classroom to class or therapy room
- Classroom to cafeteria or gymnasium
- Teacher to teacher, therapist or para
- Class lesson to lesson or activity
- School to bus to home

Examples of transitions that occur anywhere

- Morning to afternoon
- Day to night
- Weekday to weekend
- Inside to outside activities

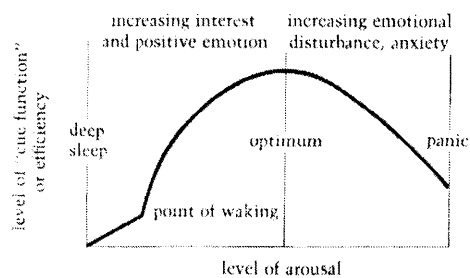
Examples of transitions that occur between stages of life

- Childhood to adolescence
- Adolescence to adulthood
- School to vocational program
- Home to residential program
- Loss of parents or friends

Arousal

A general state of nervous system activation that is reflected in one's behavior, physiological activity and emotional experience.

Arousal vs Performance Efficiency



Hyperarousal

“Hyperarousal” refers to a state of excessive nervous system activation that interferes with the production of effective organized behavior.

Hyperarousal

People with Fragile X Syndrome:

- are unable to normally regulate their arousal
- are hypersensitive to stimulation
- remain highly aroused after stimulation ends

Hyperarousal

Poor self-regulation of arousal, and the resulting hyperarousal, are important characteristics of Fragile X Syndrome, and underlie many of the behavior problems associated with it.

Typical Signs of Hyperarousal

- Hyperactive, impulsive, distractible
- Covering eyes or ears
- Flush ears or neck
- Wet (sweaty) palms
- Hand biting
- Aggression towards self or others
- Rocking, flapping, stereotypic behaviors

Examples of reactive strategies for dealing with unavoidable hyperarousal when it occurs

- Identify and reduce the source of stimulation.
- Remove the child from the overstimulating environment.
- Provide an alternative non-stimulating sheltered environment.

Examples of reactive strategies for dealing with unavoidable hyperarousal when it occurs

- Do not try to establish eye contact.
- Do not reprimand the child
- Understand that the child is having difficulty self-regulating.

Transitions and Arousal

- Transitions are inherently arousing, and are therefore very difficult for individuals with Fragile X Syndrome.
- Although all individuals experience some form of arousal during transitions, individuals with Fragile X Syndrome experience greater degrees of arousal than others at those times.

Interaction with other sources of arousal

- Transitions are more difficult if one is already aroused from other sources.
- Therefore, try to avoid arousing activities prior to anticipated transitions, and prepare for difficult transitions with arousal-lowering strategies such as muscle fatigue-inducing tasks, brushing, deep pressure, etc.

Coping with Transitions

- There are many strategies for helping children cope with transitions by reducing the uncertainty about new activities or environments.
- It is also important to allow a child to plan and mentally (and physically) rehearse the sequential motor activities required to move to, or perform, a new or unfamiliar activity.

Examples of proactive strategies for preventing hyperarousal during routine transitions

- Create a picture schedule to help the child mentally prepare for the various activities and transitions that will occur during the day.
- Review the child's schedule each day to alert him to any potential breaks in routine, and inform parents about a child's daily transitions so they can also help prepare him for the day's activities.

Examples of proactive strategies for preventing hyperarousal during routine transitions

- Avoid unnecessary arousal by allowing the child to move between teaching or therapy areas when the environment is least stimulating, for example by avoiding the crowded hallways between class periods.
- Pair the child with a friend who will provide assistance, and create more continuity, when transitioning between teaching areas.

Examples of proactive strategies for preventing hyperarousal during routine transitions

- Distract the child from transitions, for example by singing or by telling jokes to make him laugh and to grab his attention.
- Have the child carry something as a form of work between places so that his mind will be on that task, and on the ultimate approval he will receive.

Examples of proactive strategies for preventing hyperarousal during routine transitions

- Exercise is always a good method to help ease transitions, and it also provides a myriad of health and psychological benefits.
- Decide (with an occupational therapist) the best forms of exercise and sensory input that will help the child regulate his arousal during the day.

Examples of proactive strategies for preventing hyperarousal during breaks in routine transitions

- Whenever possible have the child become acquainted with a new teacher, therapist or para before that person actually takes over.
- Visit a new environment with a familiar and liked teacher during quiet times so the child can see and experience it in advance.

Examples of proactive strategies for preventing hyperarousal during breaks in routine transitions

- Create a picture story about a new place so the child can become familiar with its layout and personnel.
- Encourage parents to keep a schedule in the home that provides their child with activities that will keep him engaged, and not looking for things to do.

Examples of proactive strategies for preventing hyperarousal during breaks in routine transitions

- Help the child practice how to talk to and interact with a new person by role playing various conversations that may occur between them.
- Role play all different forms of transitions, and the activities one performs during such movements.

Examples of proactive strategies for preventing hyperarousal during breaks in routine transitions

- Carol Gray stories may provide good models of typical situations. You can use them to let the child know what will happen and how he may respond in those situations.
- He can then use that information to guide his own behavior.

Examples of proactive strategies for preventing hyperarousal during breaks in routine transitions

- Children with Fragile X Syndrome easily copy the behavior they observe in others. This makes video modeling a good method to introduce impending changes in their routine.
- The videos can be transferred to a smart phone or IPAD to allow the child to review them whenever he has the time.

Examples of proactive strategies for preventing hyperarousal during routine transitions

A child can be helped to control his arousal, and make him less prone to disruption by transitions, by incorporating Occupational Therapy activities into his daily schedule.

- Consider the child's "sensory diet".
- Provide muscle fatigue-inducing tasks.
- Deep pressure, brushing, weighted vest.
- Provide oral motor stimulation.

Individualized Education Program (IEP)

- For school aged children with disabilities, the process of developing an appropriate educational program for each child starts with the IEP.
- The IEP's goals and provisions are determined by a child's specific needs, as identified by his teachers, therapists and parents.

Individualized Education Program (IEP)

- The IEP represents a contract between the school system and a child's parents.
- It specifies the skills to be acquired within a specified time, as well as any special accommodations that the child requires.
- e.g., Specific therapies may be mandated in order to help a child meet his IEP goals.

Individualized Education Program (IEP)

- Improving transitions between school activities may be included among a child's IEP goals.
- Appropriate IEP goals that would facilitate improved transitions include:
 - Improving self-regulation
 - Improving planning skills
 - Improving initiating skills

Individualized Education Program (IEP)

Because hyperarousal can greatly influence an individual's performance, ability to learn, and ability to function independently, relevant information about the causes and effects of hyperarousal should be included in the IEP of any child with Fragile X Syndrome.

Individualized Education Program (IEP)

The IEP should contain mandates to assure that a child's teacher understands the triggers for hyperarousal, and is able to apply proactive strategies to help the child regulate his arousal throughout the day, especially during potentially arousing times, such as transitions.

In Conclusion

- Transitions are a necessary part of everyday life, but they can be especially stressful for children with Fragile X Syndrome, and may lead to hyperarousal.
- Attention to the arousing causes and effects of transitions can help to reduce hyperarousal in these individuals, and the behavior problems associated with it.