

EXPECT THE UNEXPECTED

by

Carol Ann Brady, Ph. D.

As a clinical psychologist it is often my privilege to work with youngsters who have been diagnosed with Tourette's syndrome. Because of diverse, and an often unpredictable range of symptoms and their involuntary origin, my approach must necessarily be different. I must often train myself never to go by the book and, most importantly, to expect the unexpected. Tourette's syndrome is a complex neurobehavioral movement disorder characterized by involuntary movements and sounds called tics. The onset of symptoms must occur between the ages of two and 21, they must wax and wane, and they must be present throughout a period of more than one year. Additionally, most children will exhibit co-existing behavioral problems including obsessive/compulsive disorder, attention deficit disorder with or without hyperactivity, and aggressive and oppositional behaviors. They may also be learning disabled. Although the clinician may expect vocal tics and motor movements to some degree, what often is more subtle and interwoven are the psychological and behavioral problems that co-exist with Tourette's syndrome. These vary by individuals, but again will often include attentional problems, lack of impulse control, irritability, oppositionalism, obsessiveness, and compulsiveness. Also included may be more classic signs of anxiety and depression or over-involvement with sexual content, with all the above leading to not winning friends and influencing people, particularly during the teenage years.

On a day-to-day basis, a Tourette's child is often besieged by a myriad of demands saying to him, "control yourself". So many have despondently retorted, "I cannot". Oftentimes school and parents misunderstand that the associated symptoms are part and parcel of the syndrome. The significance of this is to expect that the child may be able to control or behave as youngsters can in all other areas with the exception of the motor and vocal tics. As I have come to understand from the youngsters who have trained me so well in their disorder, it is all intrinsically interwoven and part of the same syndrome. Interestingly enough, unlike the child who clearly suffers from an emotional problem, the Tourette's youngster may be horrified or otherwise upset that there is absolutely no control. While he or she may have a well-developed conscience, there may be occasions of seeming oblivious to any type of punishment. In essence, these children simply do not react in the usual way to traditional techniques.

For most children with bad behavior, behavior modification will be applied in which a contingency of time-out is given at the onset of inappropriate behavior and then the behavior will remediate. With Tourette youngsters, however, I find that, unless they can finish the thought, deed, or activity they are engaged in, they cannot interrupt that chain to move on to a new one. In the playroom, I often observed this. Often a story is compulsively reported over again many times before the issue can be dropped. This has the feel of a demanding, and sometimes one assumes, spoiled youngster who cannot deal with not getting his or her own way. It is, I think, not so much not getting their own way that drives these children as it is that they cannot give up on an idea or thought until it reaches some natural conclusion.

Unfortunately, sometimes the conclusion is for the grownups around them to become extremely upset to the point where a new problem moves into the arena, that being the upsetness of the parent over-shadowing and overwhelming the child's immediate particular need. Constant reprimands result in a vicious cycle. When thwarted, often a temper tantrum will ensue much to the annoyance of parents and teachers. So many times I have seen these youngsters on the way out the door say, "We must go to the toy store after the session", "We must have a friend over", or "I insist we take an extra sticker".

These are just some examples of what I feel is part of the big picture. By the same token, to expect the unexpected in youngsters with Tourette's syndrome is also to be happily surprised that they can be so responsive. Just when it appears that there is no chance for them to talk about what really is on their minds, they will open up and spill the beans.

Often medication clearly helps with some of the symptomatic behavior. However, frequently I see a parent go from medication to medication in search of a solution only to find subsequently that a new search is needed because the symptoms have changed. This can be a never-ending process, especially when parents reject the necessary but tiring search for the correct medication to accentuate the positive without significant unmanageable side-effects.

While psychotherapy cannot cure a vocal tic or an involuntary motor movement caused by the neurological aspects of this disorder, psychotherapy has its place. Often youngsters, because of associated learning and social disabilities, have problems with self-esteem. They need to have a forum that will provide a chance for them to talk about how painful, psychologically, it is to have so little control over what others seem to come by so easily. Psychotherapy also provides support for the family to change the rules, to not expect what they expect from other youngsters, to capitalize on the unexpected, and, most of all, to not take some of the loud tirades and diatribes too personally. It is not that these youngsters fail to appreciate or care about their parents, rather that, at times, they are helpless victims of a disorder that leads them to tantrum at the drop of a hat. The family, as with any special needs child, needs to come to terms with the fact that their child is on a rollercoaster-like syndrome in which the symptoms will wax and wane and change over time. Although all symptoms will usually worsen during puberty, many will, after adolescence, significantly recover control over their motor and vocal functions. Most will go on to have at least a marked decrease in symptoms. Despite this fact, many of the young adults I have seen who have been down this road still show some problems in judgment and in a sense-of-self, due to an inability to find prospects for themselves supported by misunderstandings about what they and others think and say about the disorder or a tendency to react strongly to minor insults and disappointments. So the legacy of this syndrome may continue in some form or fashion, although more masked from the glaring eyes of the observer and critics in the outside world.

On the positive side, people working with Tourette patients will often be pleasantly surprised. What also is to be expected is a challenging and rewarding involvement with youngsters who show more courage and bravery than ever thought possible. Significant adults need to accept the fact that the behavioral symptoms, tantruming, and repeated instances are a part of the Tourette's syndrome. Take care, caretakers, for with a Tourette's syndrome youngster, only patience and skillful response can counter the behavior and, of course, it helps to expect the unexpected.

Carol Ann Brady, Ph.D. has been on the Tourette Syndrome Association of Texas Medical Advisory Board for over twenty years. She was named one of the "10 Best Child Psychologists in the Country" by *Town and Country Magazine* and is a staff writer for *ADDitude Magazine*.