



Self-Injurious Behavior

by Joy Simpson

Part 1: How science is delivering answers

5-17% of persons with mental retardation and autism do serious harm to themselves by biting, pulling out hair, banging their head or gouging their eyes -- on a regular basis. Unlike psychiatric disorders, this kind of self-destruction is not a suicide attempt. It is a repetitive ritual that causes mutilation, and in the past, was generally stopped with restraints. Because it is so disturbing to the family and difficult to control, a person with SIB (self-injurious behavior) would often have no choice but to live in an institution. Today, most people experiencing SIB live in the community.

Since the 1960's, scientists in medicine, neuroscience, psychology and education have been documenting the reasons for SIB and developing effective treatments. The National Institutes of Health and the Office of Special Education and Rehabilitation Services have been instrumental in funding research at many universities across the United States. Today, we have some significant answers and a few approaches that bring relief.

Here is a sampling of facts from various research fields:

- For some people with intellectual deficits, SIB is a way of communicating that something is wrong or they want to be left alone. Therefore, teaching new strategies for expressing needs and relating to other people is critical – a behaviorist approach.
- Chronic health problems increase the tendency to engage in SIB. It is important to diagnose and treat health conditions that are a constant aggravation, such as difficulty sleeping, inner ear imbalance, and digestive ailments.
- Persons with certain kinds of mental retardation are likely to have chemical imbalances in the brain. Their treatment must include medication.

"To be effective, we must treat the person's medical condition and make changes in the living environment as well," says Stephen Schroeder, retired Director of the Life Span Institute at the University of Kansas. Schroeder believes that researchers from the behaviorist camp and from the disciplines of biomedicine must work together even though their approaches are vastly different. For this very reason, he directed the 1999 Merrill Center conference that brought together leading experts on SIB in the United States. Fifty scholars contributed to the book Schroeder edited with colleagues Travis Thompson and Mary Lou Oster-Granite. *Self-Injurious Behavior: Gene-Brain-Behavior Relationships* is the most comprehensive book on SIB to be released since 1992.

Part 2: Breakthroughs in drug treatment

No drug to date has been created specifically for self-injurious behavior (SIB). To find a medicinal treatment, scientists are testing drugs approved for psychiatric disorders.

Risperidone originally came on the market for persons with schizophrenia. A group of researchers at the University of Kansas obtained permission to run clinical trials on risperidone for the treatment of SIB. Stephen Schroeder, Ph.D. headed the team that included Jessica Hellings, M.D., a professor of psychiatry at the Medical School, and Jennifer Zarcone, Ph.D., a research scientist at the Schiefelbusch Institute for Life Span Studies. Their clinical studies showed that half of the persons who took risperidone experienced a 50% reduction of SIB episodes. In all the patients but one, the drug reduced 25% of the incidents.

Risperidone acts as a modulator adjusting the amount of serotonin and dopamine in the brain. Serotonin and dopamine regulate learning, reward, and emotions. Schroeder decided to pursue risperidone as a remedy because data from animal models showed a link between self-injury and an imbalance of the brain chemistry. His hypothesis is that SIB may be caused by a depletion of dopamine and an excess of serotonin in the basal ganglia region of the brain.

Approximately one-quarter of the persons with SIB do not show long-term benefits from "behavioral" interventions – changes made in the environment, or new learned patterns of behavior. In this instance, medicine plays an especially important role in treatment. Schroeder's study is noteworthy because he restricted participation to those persons who experience repeated, severe bouts of SIB and have not found relief elsewhere. With risperidone, he was able to show a significant reduction in the number of SIB incidents.

A complementary approach has been put forward by Curt Sandman, University of California at Irvine. His research involves the opioid system which regulates the sensation of pain. He has also been successful in treating the most difficult cases of SIB – with drugs called opiate-blockers. Naltrexone changes the brain chemistry in persons with an elevated pain threshold. The inability to feel normal pain is another compelling explanation for SIB.

"It is interesting," says Schroeder, "the opioid receptors for pain are located in the same area of the brain as the dopamine receptors that also influence SIB. It is likely these two systems interact and are part of a larger circuitry of neurons." Some patients may react well to the drug risperidone and others to naltrexone. This may be evidence that persons experiencing SIB don't all have the same diagnosis, according to Schroeder. The success of various treatments may depend on the person's unique brain chemistry.

Part 3: Genetics and the environment – two heads of the coin

"There are many possible genetic causes of SIB. The severe cases may very well be instances where genetics plays a significant role," says Stephen Schroeder. When looking at brain functions and behavior, genetic origins are certainly important. The role of the environment cannot be overlooked either. The circumstances of life ultimately affect the expression of any chemical imbalance in the brain. "Traumatic life events, eating, stress, even learning are all factors that can bring out – or control – a genetic condition like SIB," reports Schroeder.

Many forms of mental retardation are genetic. In certain kinds, SIB is so predictable that it is considered part of the disorder. In fact, scientists learn about SIB just from studying the origins of mental retardation. Mental retardation and SIB are linked in these genetic conditions: Lesch-Nyhan, Prader-Willi, Smith-Magenis, de Lange, and Fragile X.

For example, researchers have pinpointed the origin of the Lesch-Nyhan syndrome. The gene is on the X chromosome and the molecular location is an enzyme called HPRT. The genetic defect causes an overproduction of purine 5, and leads to large amounts of uric acid being stored in body fluids. Scientists also know that a deficiency of HPRT changes the structure and function of the brain, resulting in cognitive and neurological deficits – and perhaps triggering SIB. However, SIB cannot be fully explained by the chemical process; scientists are also looking at the role of neurotransmitters with Lesch-Nyhan syndrome.

Genetic conditions do not destine a person to unrelenting self-abuse. "Treatment is possible and important," says Schroeder. Just as diabetes can never be cured, so too with SIB, the condition persists. But, people with diabetes can live out full lives by changing their eating patterns and taking insulin. With SIB also, education, behavioral supports, and sometimes medicine can change the way the behavior is expressed – says Schroeder – and significantly reduce the number of times it occurs. Because of advances in science, most individuals with SIB are no longer subject to repeated self-mutilation from biting, gouging and head banging. Persons with SIB can often live in community housing or at home with their families.

***Self-Injurious Behavior* is based on interviews with Stephen Schroeder, director emeritus of the Life Span Institute at the University of Kansas. Joy Simpson is a member of the National Association of Science Writers.**

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