

The Chronic Illness Model

5 Characteristics of Trauma & 6 Characteristics of Development that Make Sense of Chronic Illness

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in *Tumbling the Stone: a chronic illness blog*

June 16, 2014

Introduction

There are a lot of unanswered questions about chronic illness. Why do so many of us develop our diseases after periods of stress, for example? Why are we then unable to recover by addressing, removing or reducing the stress in our lives? Why do some people with type 1 diabetes, or chronic fatigue, or other chronic illnesses have a sudden onset, such as after an infection, while others with the same illness have a slow onset with no observable cause (like me)? For that matter, why is there such a variation in the first symptoms people have, even when they have the same disease, as is so eloquently described in the onset stories on the blog [Rheumatoid Arthritis Warrior \(RAW\)](#)?

I believe that periods of stress occur before the onset of all kinds of different chronic illnesses, including my own. But I don't think that a particular stressful event is the cause of most chronic illnesses. Rather, I think it is more like the last straw in a series of events.

I'm going to describe the theories I've been developing in the past decade in this post. It's long, but I want to touch on all the key points in one place at one time. Most of these paragraphs will eventually become one or more posts with lots more detail.

So as not to overwhelm myself (and possibly you, too!), I will only list a few of the most readable references in this post. I'll present more in the future. For anyone who wants the whole shebang and the full description of the model now, I have two published, academic-style, densely-written papers with tons of references. You can see or download the [Journal Article](#) [1], where I explore how the model applies to type 1 diabetes, or the longer [Book Chapter](#) [2]. The chapter presents more details about type 1 diabetes and looks at the relevance of the model to two additional chronic illnesses: inflammatory bowel disease and asthma. I'll list the references, including these two with links for downloading, at the bottom of the post.

Patterns

The answers to the questions we have about chronic illness lie, I believe, in our nervous systems. Our nervous systems are much, much more adaptable to our unique, individual environments than we ever imagined. The term used to describe this quality is that they are *plastic*.

Our brains and nervous systems are also much more sensitive, and dependent, on our environments than we have realized. Interactions between our bodies and our physical, emotional and psychological environments are what shape the patterns our nervous systems develop as we grow.

Nature and Nurture

One example of interactions between environment and developing physiology happens at birth. Being born through the vaginal canal is actually designed to serve many purposes. It squeezes fluid from our lungs in

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preparation for the great shift that enables us to start breathing air for the first time. It inoculates us with healthy bacteria from our mothers, which populates our guts. After birth, the nervous system activity that was high during the birth process is designed to shift and settle when babies find their ways into the arms of their mothers and fathers. There is often a quiet period at this time, which allows for bonding, resting, and recovering. These are examples of life events that affect how our nervous systems learn to regulate. This is how we, as a part of Nature, are designed to grow and develop through interactions with Nurture.

Two Fields of Research that Provide Great Insight

Two areas that have given me the best insight into origins of chronic illness come from research in the fields of *Trauma* and *Development*.

Trauma

Trauma is an experience that is perceived as both life-threatening and inescapable and can lead to posttraumatic stress disorder (PTSD). Trauma can happen when we go to war, when we're in a car accident, or during natural disasters. It can leave tremendous, life-altering physical wounds. But we have been greatly underestimating the impact of trauma - as a culture, as a population, in medicine - on the nervous system, on the psyche, on behavior, and on our emotions. What we've been learning through research is significant. Here are five of the main characteristics of trauma that I think are remarkably applicable to helping us understand chronic illness. Two books that provide good overviews of trauma are Peter Levine's [Waking the Tiger](#) [3], and Robert Scaer's [The Trauma Spectrum](#) [4].

1. Prior Trauma. Soldiers are at higher risk of developing posttraumatic stress disorder following a traumatic event when they have a history of prior, unresolved trauma, such as trauma from life before joining the military. This is part of the reason that not everyone who serves in a war (or is in an accident or goes through medical training), gets PTSD. Similarly, not everyone who experiences trauma, or the stress of divorce, job loss, or a severe infection develops a chronic illness.

2. Compounding. The effect of multiple traumas over time is additive. In the trauma literature, this is referred to as "compounding." Studies throughout the chronic illness literature find that there have been more stressful life events in those of us who develop a physical disease, compared to our peers who do not.

3. Latency Periods. There is generally a delay between a traumatic event and the onset of symptoms of PTSD. The time period can vary from weeks to months or longer, and is referred to as a "latency" period.

Most of us with chronic illness had intermittent symptoms, just like those of our diseases, months or years before the full onset.

Researchers looking at chronic illnesses have noted latency periods. In illnesses where antibodies have been identified, they are being found to precede the onset of symptoms. In lupus, it has been by as much as 7 years. In type 1 diabetes, antibodies are sometimes present at birth. Unidentified factors affecting risk for Alzheimer's are believed to occur as much as 30 years prior to onset.

4. Triggers. Stressors that cause exacerbations of PTSD are called triggers. The more intense the experience of trauma, the bigger the impact, and the more quickly the pattern gets stabilized. This can lead to an earlier onset of symptoms. Triggers are unique to the individual and to the way a traumatic event was perceived. What constitutes a trigger is therefore different for everyone.

This is similar to chronic illness, where the kinds of stressful events that precipitate the same chronic illness in different people varies. The trigger for one person may be an infection, while for others it is exposure to chemicals, to trauma and other difficult life events, among others. I suspect that what these stressors have

in common is the ability to stimulate existing patterns of nervous system reactivity in a particular individual, rather than to trigger a particular disease through one time exposures. The more frequent or intense the traumatic events, the earlier the age of onset of chronic illnesses.

5. Buffers. Buffers are resources that support healthy patterns of nervous system functioning. They reduce risk of experiencing an event as traumatic, enable greater recovery when patterns arise, or may reduce risk of symptoms of PTSD altogether. Whether a nervous system pattern leads to PTSD depends on the timing and interaction between trauma and buffers.

As in PTSD, buffers also reduce risk for chronic illness. In some babies who are born with antibodies associated with type 1 diabetes, for example, these antibodies disappear and they do not get the disease. I suspect this is the result of factors such as buffers, and shows why so many people with traumatic life events, or who seem predisposed to risk from family histories or other factors, never develop a chronic illness.

Development and Relationship

As with trauma, we've also greatly underestimated the importance of timing, life events, and relationships. The next 6 factors all play key roles in affecting the shaping of the nervous system. The book [From Neurons to Neighborhoods](#) [5], by the National Research Council, is an excellent resource. I will list several other books that I have greatly appreciated for informing me about specific fields of developmental research, in context, below.

1. Critical Periods. Exposure to toxins during pregnancy is known to affect organs developing at the time of exposure, leading to such problems as birth defects. This occurred with [thalidomide](#), which interrupted the growth of limbs and other organ systems when taken early in pregnancy, specifically between days 20 and 36.

The degree of organ system sensitivity depends on the speed at which an organ is growing and the stage of development it is in (early, late etc). This is known as a *critical period*.

Birth is an example of a critical period because such significant changes are happening. They are also taking place in a very short period of time. The heart, digestive system and lungs, for example, undergo dramatic shifts in preparation for disconnection from the mother's support system to independently being able to metabolize food and breathe air.

Studies find that there are critical periods in the development of risk for chronic illnesses. If a person isn't exposed to risk factors for MS before the age of 15 or 16, for example, researchers suspect that they don't develop the illness even if they might be at risk. An increasing number of researchers are also beginning to suspect that initiation of risk for chronic illness, such as type 1 diabetes, begins before birth.

2. Prenatal Stress. Prenatal stress can decrease organ size and size at birth while also increasing risk of prematurity, among other effects. These factors, in addition to stress and trauma at birth and in the first few weeks of life, have been identified with risk for many physical diseases in adults. There have been decades of research in this area, including in one field known as the Adult Origins of Health and Disease. An overview can be found in [Life in the Womb](#) [6].

3. Perinatal Events. The time frame just before, during and after birth is referred to as the perinatal period. Close proximity between parent and baby after birth facilitates bonding and helps to regulate a newborn's immature physiology. Holding newborns skin to skin, referred to as [kangaroo care](#) in hospital settings, helps sick premature babies better regulate body temperature and heart rate and enables them to grow and recover more quickly. Separation of parents from their newborns, which remains common practice in hospital care, affects the parent-infant bond and regulation of a baby's nervous system. The

duration of separation tends to be longer with difficult or complicated deliveries, including cesareans. My favorite book on bonding and the effects of early separation is [Maternal-Infant Bonding](#) [7], which has an updated version I just learned about called [Parent-Infant Bonding](#) [8].

Many studies find that individuals who develop a chronic illness had more interventions, stressful events, and longer separations at birth.

4. Ancestors. The degree of nurturing behavior a mother rat gives her offspring affects its genes during the first week of life through the process of epigenetics. Life experiences in our ancestors' lives, including trauma during the formation of the embryo in a pregnant woman's baby, affects future generations. Nova has a documentary about a discovery that the stress of famine in one European village increased the risk for diabetes in the population's grandchildren. Here's a [link to the first 10 minutes](#) of the 5 part series on youtube.

5. Early Life Events. Trauma that is inflicted by other human beings, who are supposed to care for and protect us, is among the most intense kinds of stress that we can experience. The effects are most severe with children, because they are the most vulnerable among us. The [adverse childhood events \(ACE\) studies](#) find that trauma in childhood is associated with risk for chronic illness in adults. The higher the number and types of exposure, the greater the risk. This is an example of compounding of trauma occurring during critical periods of development.

6. Attachment. Insecure attachment between children and their parents is associated with greater risk for anxiety, depression and other mental health conditions. A [36-year prospective study](#) [9], which is still ongoing, is finding that it also increases risk for physical health problems in adults [10].

The Chronic Illness Model

The following is my premise about chronic illness. For another, similar point of view, see the book by Gabor Mate, a former family physician. It's called [When the Body Says No](#) [11].

Initiating Events

Chronic illness arises when our nervous system gets interrupted and learns a reactive pattern from which it is unable to shift. A series of traumatic events, from accidents and abuse, to emotional unavailability and mis-attunement in parent-child relationships, are important initiators and contributors to the development of altered patterns of nervous system regulation. The initiation of patterns leading to chronic illness occurs during critical periods of development, and probably happens very early in life, most likely before birth. Patterns are shaped and influenced, at least in part, by parental emotional and physical environments.

Perpetuating Events

Trauma and triggers, whether emotional, physical, or psychological, perpetuate and strengthen a pattern once it has begun, creating something like a conditioned response. After a pattern begins, it starts to affect our physiology. It causes occasional symptoms, such as anxiety and depression, fatigue and pain, a rash that is later recognized when lupus is diagnosed, or the formation of antibodies etc. These symptoms, and triggers, are unique to the person, their experiences to date, and to the pattern.

When there are sufficient buffers, including the treatment of trauma and repairs in the parent-child relationship, patterns may never arise, or may soften or even resolve. Patterns emerge and progress when traumatic events during critical periods outweigh buffers.

Precipitating Events

The final stressor that occurs before a chronic illness is a precipitator, not a cause. It unmasks an existing conditioned response pattern that has been developing, often over a long period of time. There may be years or decades between the initiation of the pattern, which likely began before birth or earlier, and the onset of chronic illness. This is known as a latency period.

Symptom Variability

Symptoms and exacerbations are affected by the same types of stressors and triggers that created, perpetuated, and intensified the pattern before the illness ever began. They are therefore unique to each person, rather than to the chronic disease.

Interactions between Mind, Body and Emotions

Chronic illnesses of all kinds, including chronic fatigue and other "psychosomatic illnesses" such as fibromyalgia, asthma, and irritable bowel syndrome, are not attempts to get attention or "play the victim." Chronic illnesses are the result of an interplay between our brains and bodies, thoughts and emotions, and the environment. The patterns that lead to chronic illness occur outside of conscious awareness. They are not created by will. Symptoms that cannot be measured or understood are not "all in your head." Life experiences, including stress, trauma and family dynamics play an important role in the formation of unconscious patterns that can affect our risk for chronic illness.

The Small Stuff is Important

An emphasis I want to make in this model is that we've been failing to understand, and therefore notice, the little traumas and life events that happen every day and in the most subtle of ways in people's lives. These experiences are often considered normal. Or they are minimized. But they, too, affect and shape our nervous systems. I believe that the small events play a very important role in affecting risk for chronic illness. Possibly even more important than the large, overt events we commonly think of as trauma.

Treatment

Reducing stress can resolve some chronic illnesses for some people. [Dean Ornish](#) is a physician who believed that stress reduction and lifestyle changes could heal heart disease. He couldn't get funding for his initial studies because no one believed it was possible to reverse heart disease, let alone treat it through such simple interventions as lifestyle changes. He proved them wrong in study after study after study. So, this is one approach that really works for some.

Leaving medicine, taking a year off and greatly reducing my stress did not improve my fatigue. In fact, my symptoms worsened. The very definition of chronic illness is that it is unrelenting, and that there is no cure. But some people recover some of the time from chronic illnesses of all kinds. These "anecdotes" are overlooked and often denigrated by many of our current approaches to research, science and medicine, but they are worth their weight in gold. What did these people do to recover? Can any sense be made of their stories? What can we learn from them?

Tony Madrid, Ph.D. is a psychologist in California who stumbled upon an [approach for addressing asthma in kids](#) by treating trauma. The youngest children in his studies recover fully. The older they get (after about 9 years of age), the less fully they recover, although his treatment approach is still often helpful in reducing their symptoms. The most fascinating aspect of his research, though, is that he doesn't treat the kids. He treats their MOTHERS for their wounds that made it impossible for them to bond with their babies (see his book [The Mother and Child Reunion](#) [12]). He helps them resolve the traumatic experiences they had during pregnancy, labor and delivery, and when their kids were young. Their babies' and kids' asthma often resolves over night. He's been finding that when he helps moms repair their trauma wounds, the innate, underlying impulse parents have to bond with their kids is restored. And that's when the asthma

resolves or improves. I find his work to be a remarkable statement about the role of trauma and bonding in chronic illness. He's a pretty remarkable person too, and has become not only a colleague but also a friend.

Research

I do not believe that it is a specific event or a single risk factor that leads to a specific chronic illness. Nor that a single cause, such as "trauma" leads to one particular chronic illness. Instead, I have come to believe it is more about patterns. Patterns that are affected by both 1) the *timing* of trauma, which determines the organ system(s) affected, the type of pattern(s) that develop, and therefore the predisposition to a specific illness; and 2) the way events are *experienced*, which leads to either the perpetuation or resolution of that particular pattern.

The research I've been doing looks at studies others have done in multiple disciplines, which are usually very distinct and separate. There are studies of all kinds that look at the influence of events in our ancestors' lives, as well as in prenatal, birth and early life that find a relationship to later physical health.

I am also finding studies showing links between life events and individual chronic illnesses. Most of these studies are done by different researchers, each looking for causes in different areas and time periods. The following slide shows some of the studies I've found in multiple sclerosis (MS) using perspectives from this chronic illness model. Most of them find an increased risk for MS in the areas we've been looking at in this chronic illness model.

There is a tremendous amount of research supporting this chronic illness model in many different diseases. In addition to research in MS, I've been finding studies that support this model in asthma, type 1 diabetes, inflammatory bowel disease (such as Crohn's and Ulcerative Colitis), chronic fatigue and fibromyalgia, lupus, multiple chemical sensitivities, Parkinson's, and rheumatoid arthritis, as well as with autism and schizophrenia, among others. Studies in the [Adult Origins of Health and Disease](#) have also been finding relationships between prenatal stress and many diseases in adults ranging from the metabolic syndrome (high blood pressure, cholesterol, weight, and sugar; heart disease, type 2 diabetes, and stroke) to celiac disease, inflammatory bowel disease, and osteoporosis; to autism and asthma. I'll be adding references, including many of those listed in these last slides, in future posts.

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