Prion Disease Raises Questions

How Can I Break Free or Avoid "Freezes"

Algorithm Helps Scientists Identify PD

Gifts of the Season

Holiday Recipe
Message From
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Gifts of the Season
By Jamillah Ali-Rahman
FoP Executive Director

As the holiday season is in full swing there is a certain expectation and excitement in the air. It is a time when we hustle and bustle to accomplish all our goals. With our “wish list” in hand, we go from store to store (or online) looking to fulfill a loved one's dream.

With this excitement comes a higher level of stress that can make us feel overwhelmed with the tasks at hand. And, although we are in a rush to make our deadlines, our mission during this time of year has great rewards. Just imagine the faces of our loved ones “lighting” up as they unwrap their gifts they so impatiently waited for.

There are many reasons we use the holidays for gift giving and only you know, within your heart, the reason. For me, it is a time when we can make a difference in many lives…not only our cherished loved ones, but those in need; especially within the Parkinson’s community.

As CEO and Executive Director of Friends of Parkinson’s, we work hard at bringing knowledge and relief to the Parkinson’s community. Your generosity throughout this year has been most impactful; we could not have done it without you!

As we bring 2015 to a close and enter a new year, we want to maintain the momentum you’ve helped us create. Any donation, no matter how small, makes a BIG difference and we thank you for your generous contributions.

Happy Holidays. Thank you for your continued support.

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Don’t forget to “pay-it-forward” this holiday season.
Researchers have developed a new statistical model that may help to distinguish people with Parkinson’s disease (PD) from those without the disease by analyzing risk factors rather than by measuring movement symptoms. Although the model is not yet accurate enough to be used in the doctor’s office, the hope is that someday this type of approach will help to diagnose people earlier in the course of Parkinson’s disease. The results were published online August 11, 2015 in *Lancet Neurology*.

By the time a person experiences movement symptoms and receives a Parkinson’s diagnosis, the disease has already progressed with as many as 50 percent of the individual’s brain’s dopamine neurons lost or sick. Much research focuses both on finding ways of diagnosing PD earlier and treating this neuron loss more effectively. For example, scientists have focused on uncovering the risk factors and clinical symptoms associated with the early, or prodromal, phase of the disease.

In the new study, Mike Nalls, Ph.D. and researchers led by Andrew Singleton, Ph.D., of the National Institute on Aging in Bethesda, Maryland, set out to develop a statistical model that could be used to distinguish people with PD from healthy controls without relying on observation or measurement of movement symptoms. To develop their model, they used data from a total of 367 people with PD and 165 without PD.

**Results:**
The researchers started out with more than 100 possible risk factors and potential biological measures of PD. After eliminating those that did not help the algorithm, the final prediction model included five factors: smelling ability, family history of PD, age, gender, and a genetic risk score (a composite score that incorporated many different known PD genetic mutations).

Next, the researchers tested their model’s ability to distinguish 825 people with Parkinson’s disease from 261 healthy controls. The model correctly identified 83 percent of people with PD, while it incorrectly classified 10 percent of healthy individuals as having the disease.

**What Does It Mean?**
The new experimental algorithm could pave the way for identifying people with Parkinson’s earlier in the course of their disease, even before motor symptom onset. That said, it is important to keep in mind, the algorithm is still in its early stages.

The current study establishes a model that can separate people with PD from healthy controls with some degree of accuracy. However, the model is not ready for prime time. For example, right now, if it was used in the general population of people aged 60 years and older, it would only correctly predict PD 15 percent of the time, wrote Samuel Goldman, M.D., M.P.H., of the University of San Francisco, in commentary that accompanied the new study. That is, 85 out of 100 people with a positive test would not actually have the disease, meaning it will need work.

He also summed up the results as follows: “What is most striking about these findings is how well olfactory [smelling] impairment [i.e., the inability to smell] was able to distinguish between cases of Parkinson’s disease and controls, and how little was added by the [composite genetic score].

**References:**


Research published recently has identified the first new human prion disease in 50 years. The paper’s lead author, Stanley Prusiner, who won the Nobel prize in 1997 for his discovery that Creutzfeldt-Jakob disease (CJD) could be transmitted by a “misfolded” protein, says this new disease is also potentially infectious.

Prion diseases are a rare class of brain disorders that are transmissible between animals of any species, including humans. The archetypal such disease is kuru, which spread through cannibalistic rituals in the Eastern Highlands of Papua New Guinea.

Rare and Deadly

Kuru affected mostly women and children of the Fore tribe, who ate brains and spinal cords of deceased relatives, and subsequently developed body tremors, balance problems and slurred speech. There’s no cure for kuru and sufferers always died. But it no longer strikes as cannibalism in the region has been eliminated.

Other prion diseases include scrapie in sheep and goats and bovine spongiform encephalopathy (BSE) in cows. When transmitted to humans during the “mad cow disease” outbreak in Europe, BSE resulted in variant CJD (vCJD).

The newly described addition to the prion disease canon, Shy-Drager syndrome (SDS) or multiple system atrophy (MSA), was first recognised in the early 1960s and has many features in common with Parkinson’s disease.

The most important of these is that a protein known as α-synuclein (α-syn) accumulates in the brain, in both Parkinson’s and SDS/MSA. This accumulation is very similar to what happens in CJD, where the prion protein (PrP) accumulates, and also in Alzheimer’s disease and other dementias, where two types of proteins, known as amyloid beta (Aβ-amyloid) and tau, build up in the brain.

The clumps and tangles of these various aggregated proteins cause neurons to degenerate and die. This is a cumulative process which takes between months and decades to manifest as overt disease.

In fact, many of the neurodegenerative diseases of the ageing brain are associated with the accumulation and deposition of specific proteins. It has long been suspected that neurodegenerative diseases in general may all ultimately be caused by this process of proteins getting caught in the wrong process, and misfolding.

This misfolding sets off a cascade of events: the proteins oligomerise...
(a number of identical molecules join together); accumulate; nucleate (form a nucleus or centre); polymerise (combine to build a structure with its components); self-replicate; and eventually, propagate and spread throughout the brain. Many of these protein changes also occur in the usual food cooking process (aggregation of proteins caused by heating) or food preparation (the solidification of proteins in the refrigerator).

Finally, some but not all of these misfolded proteins gain the ability to be transmitted between people and animals. In fact, the word “prion” was coined by Prusiner in 1982 to describe this property of a proteinaceous infectious particle. And we don’t yet know of ways to easily “dis-infect” or kill these proteins. All kinds of chemicals that kill bacteria and viruses do not harm prions.

Scientists have always kept – and still do – an open mind about whether Alzheimer’s disease and other neurodegenerative conditions are transmissible. We’ve known since the early 1960s that amyloid fibrils – the accumulations of Aβ-amyloid in the brain are self-propagating entities.

In diseases involving amyloid protein, the “amyloid enhancing factor”, which causes the disease to progress, is thought to be amyloid itself. In other words, the amyloid is self-replicating and makes copies of itself exponentially.

Infectious Proteins

Scientists have always kept an open mind about whether Alzheimer’s disease and other neurodegenerative conditions are transmissible. We’ve known since the early 1960s that amyloid fibrils – the accumulations of Aβ-amyloid in the brain are self-propagating entities.

We know that the Alzheimer’s disease-causing human Aβ-amyloid can cross-seed Aβ-amyloid accumulation in genetically susceptible rodents. Mice carrying an unstable and genetically modified human protein can then be “infected” by giving them a dose of the human abnormal protein. But there’s still no direct evidence that Alzheimer’s disease is transmissible between people.

Working out whether SDS/MSA is transmissible, at least from humans to genetically susceptible transgenic cell and rodents, is the first step in testing if it’s transmissible from humans to primates, or indeed among people.

As a precautionary measure, the authors of the paper warn we should now take additional safety precautions in the neurosurgical clinics where deep brain stimulation is used to control the tremors caused by Parkinson’s disease. Because of the overlap in symptoms and signs of Parkinson’s with SDS/MSA, it’s likely that some people with the newly described disease have been treated by deep brain stimulation.

It’s important to ensure that cross-contamination of neurosurgical equipment doesn’t occur because we don’t want to inadvertently transmit a disease between humans. Using disposable stimulation electrodes, for instance, will be mandatory in the future. Similar concerns have already been raised about other neurodegenerative illnesses, such as diseases involving misfolded tau protein, which cause frontotemporal dementia.

With the publication of this paper, the spectrum of prion diseases has been enlarged, perhaps considerably. But until it becomes possible to evaluate the role of intra-species transmission, SDS/MSA will have to remain in the category of “hypothetically transmissible to a genetically susceptible recipient”.

It’s premature to classify it as being the same as CJD, which is clearly transmissible within and between species. That has been made apparent by the mad cow saga, which still has years to run due to the long latency from prion infection to overt disease.

Resources: The Conversation

Lead Author: Stanley Prusiner 1997


Colin Masters
Florey Institute of Neuroscience and Mental Health

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The Movement Disorder Specialist

For some people, the problem of freezing can be solved by a simple readjustment of Levodopa. However, for others, mechanical strategies may be needed.

Avoid Known Triggers. Freezing is often triggered by space constraints (e.g., a crowded area or a narrow doorway), and can occur when the person is pivoting or approaching a target. Avoid these situations. Wait for crowds to pass before you begin to walk. Instead, try to execute a pivot and walk in a deliberate circle.

Develop Stepping “Cues.” Because people with PD sometimes have difficulty generating their own internal cues to prompt a step, using external cues may help to end a freezing spell. The cues can be physical, visual or auditory (e.g., an object to step over, a stripe on the floor, or a rhythmic marching tune).

Practice Stepping. Attempt a deliberate, exaggerated step, as if you were deliberately moving in slow motion. Practice stepping, even when you are not experiencing a freezing episode.

The Physical Therapist

A freeze, if not handled properly, can be dangerous. One way to find new strategies for reducing the risk of freezing is physical therapy.

Focus on Yourself …not on the people or things that are around you. Do not worry that you may be delaying someone, or that the elevator may close. Right now, keep your focus on stopping the freeze — and once this is achieved, safely restart movement.

Never “Fight the Freeze.” When your feet feel stuck to the ground, your natural instinct may be to force them to move. Resist this temptation. Instead, as soon as you feel the freeze coming on, try to stop, stand tall and take a deep breath. Shift your weight from one foot to the other until you can take one big, complete step at a time.

Use Your Head and Your Feet …not your hands. Reaching forward during a freeze, or allowing your walker to move too far ahead of you, will move your weight to the balls of your feet, and may lead to a forward fall. Instead, reach backwards, or to the side, to stop yourself.

Stay Within Your Walker. Control your movement by “telling” your feet what to do.

Heather J. Cianci, P.T., M.S., G.C.S., founding therapist, Dan Aaron Parkinson’s Rehabilitation Center, Good Shepherd Penn Partners, Philadelphia, PA.

The Occupational Therapist

Since freezing occurs in part because of the body’s inability to plan movement, try strategies that make your movement more automatic.

Use An Interactive Metronome. This therapeutic tool can be used to establish a unique rhythm for each user. After programming the device, place it on a nearby surface. Then, perform tasks; for example, chores or exercise — to its beat. It will help your movements become more fluid.

Dance. The movements of the waltz and other dances will encourage you to step in various directions, and this will strengthen your muscles and improve both balance and ability to step sideways (even backwards!). Dancing can also establish a rhythm or internal beat that your body can follow automatically. By preparing you to start and stop movement without thinking, dance will help reduce freezing.

Ride A Stationary Bike. Practice interval training, where you change the direction, or rate, of pedaling in two-minute intervals. Work on stopping and starting the pedals after a rest break of five to 10 seconds. These practices will help improve your strength and motor function, which in turn will help to reduce freezing.

Stacy Hodges, O.T., Director, Rehab Services, Virginia Gay Hospital, Vinton, IA.

How Can I Break or Avoid a "Freeze" in Parkinson’s?

INGREDIENTS (yields 2 cakes)
1 (8 oz.) package cream cheese softened 
1 cup butter, room temperature 
1-1/2 cups raw sugar 
1-1/2 teaspoons vanilla 
4 organic eggs 
2-1/4 cups sifted unbleached all-purpose flour 
1-1/2 teaspoons baking powder 
2 cups fresh cranberries (organic) 
1/2 cup chopped walnuts or pecans

DIRECTIONS
Blend together cream cheese, butter, raw sugar, and vanilla. Add organic eggs, one at a time, beating well after each addition. Gradually add 2 cups of organic flour sifted with baking powder. Toss remaining 1/4 cup flour with organic cranberries and nuts, fold into batter. Pour into 2 well greased 9-inch loaf pans. Optional: use mini-pans for several loaves. Cool pan on a wire rack until it reaches room temperature.

Holiday Recipe

CRANBERRY NUT Bread with Cream Cheese

*Preheat oven 350°*
**Bake 1 hr 20 min.**
Check after 50 min. A toothpick inserted in the center should come out clean.
Oven temps & baking times may vary.
**RESOURCES**

DopaMind.org

DopaMind Boxing & Cycling; is non-contact boxing and forced exercise tandem spin classes. Our focus is on the advantageous features of both sports, which have been shown to aid in the regression of Parkinson's symptoms by improving motor function, dexterity, and coordination.

**EVENTS**

**DOPAMIND BOXING & CYCLING,** Tuesdays & Thursdays. These non-contact boxing and forced exercise tandem spin classes have been shown to aid in the regression of Parkinson's symptoms by improving motor function, dexterity, and coordination.

**CALL:** 702-979-8006

**HEALTHSOUTH DESERT CANYON HOSPITAL,** The Parkinson’s Disease Rehabilitation Program provides a full range of rehabilitative services aimed at meeting the global range of medical, psychological and functional needs of Parkinson’s patients. 9175 W. Oquendo Rd., Las Vegas. For additional information please call 702-252-7342.

**EVENTS**

**TAI CHI FOR BALANCE,** Fridays, 9-10am. Desert Breeze Community Center, 8275 Spring Mountain Road, LV, 702-455-8334. Facilitator, Tamalyn Taylor MS.

**DANCE FOR PARKINSON’S,** Wednesdays, 12:30-1:30pm, Las Ventanas (open to the public).

**YOGA FOR THE SOUL,** Yoga class designed for you; no pressure. Starts in January, $10/class. Call Wendy @ 702-750-0850 for details.

**RESOURCES**

**DONATE**

**PLEAS SHOW YOUR SUPPORT FOR THE PARKINSON’S COMMUNITY** and Pledge your contribution to Friends of Parkinson’s to help us continue our serving the Parkinson’s Community.

**THANK YOU**

We appreciate your support!

**CALL:** 702-381-4141
Support Group Meetings

Sponsored by HealthSouth

Our support groups are now sponsored by HealthSouth Caregiver and PwP (Person with Parkinson's Disease)

First Wednesday
HealthSouth
10301 Jeffreys Ave., Henderson
1pm - 2pm

Third Thursday
HealthSouth
9175 W. Oquendo Rd., Las Vegas
11am - 12pm

Fourth Tuesday
HealthSouth
1250 S. Valley View, Las Vegas
1pm - 2pm

More Info: 702-351-4141 • www.FriendsofParkinsons.org
FriendsofParkinsonsLV@gmail.com