

*Modifiable Variables Associated with Better  
(& Worse) PD Outcomes Over Time*

# Mischley Disclosures

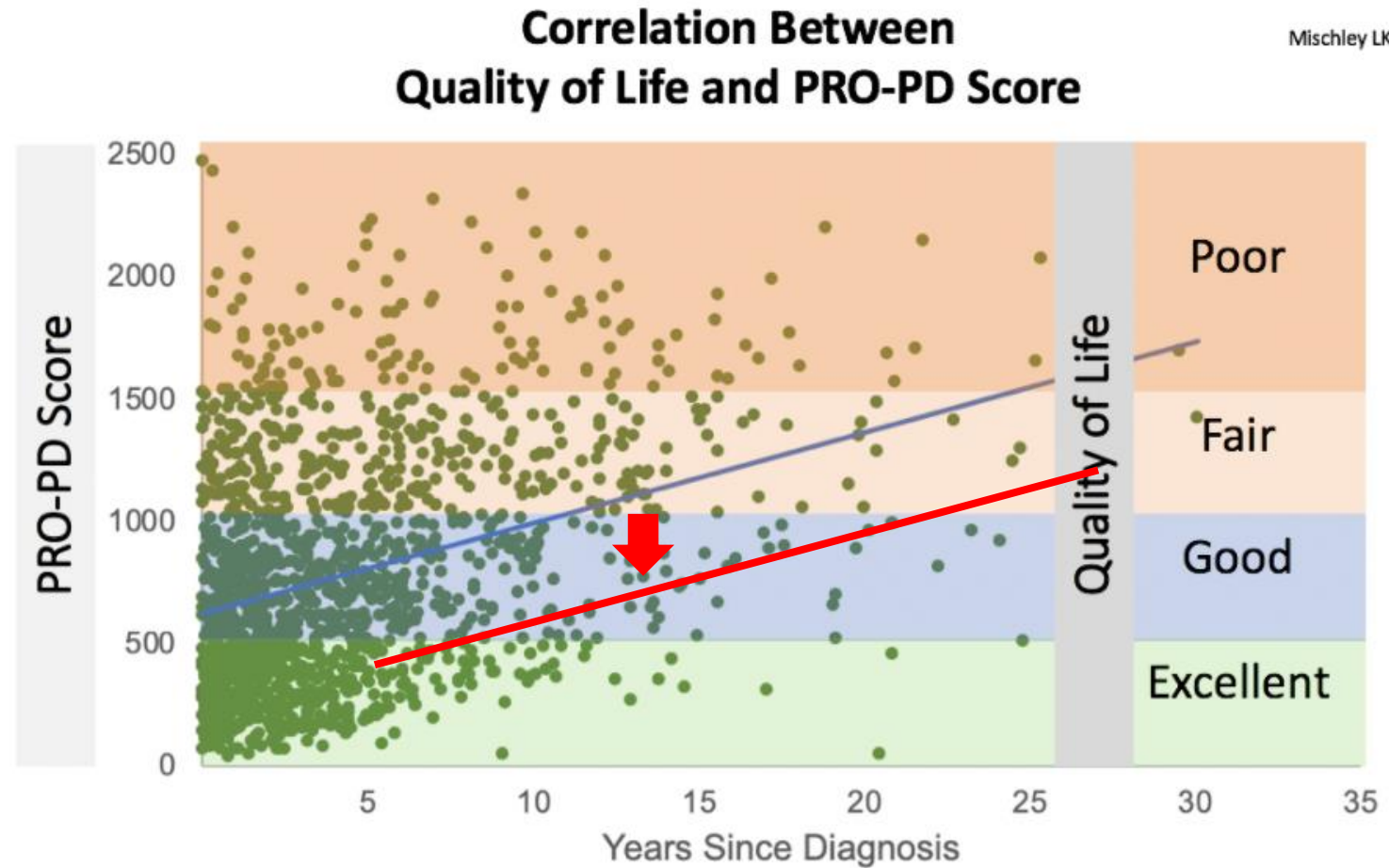
- Founder: ParK-9, Social Purpose Corporation (Canine PD detection); The Brain Cooperative; Online PD School
- Developed the PRO-PD scale
  - Free scores available at [www.PROPD.org](http://www.PROPD.org)
- Institutional Affiliations:
  - Bastyr University Research Institute
  - University of Washington, Dept. of Radiology, School of Medicine
- Clinical Practice: Seattle Integrative Medicine
- Research Funding:
  - Michael J Fox Foundation

# Treating Symptoms vs Stopping Progression

- Offense vs. Defense
  - Know what you're trying to do
  - Know how you'll know if it's working
- Something that treats symptoms could accelerate progression
- Something that worsens some symptoms may stop progression
- A 105 year old should focus on symptoms, not worry about progression!

# What Symptom Reduction Looks Like

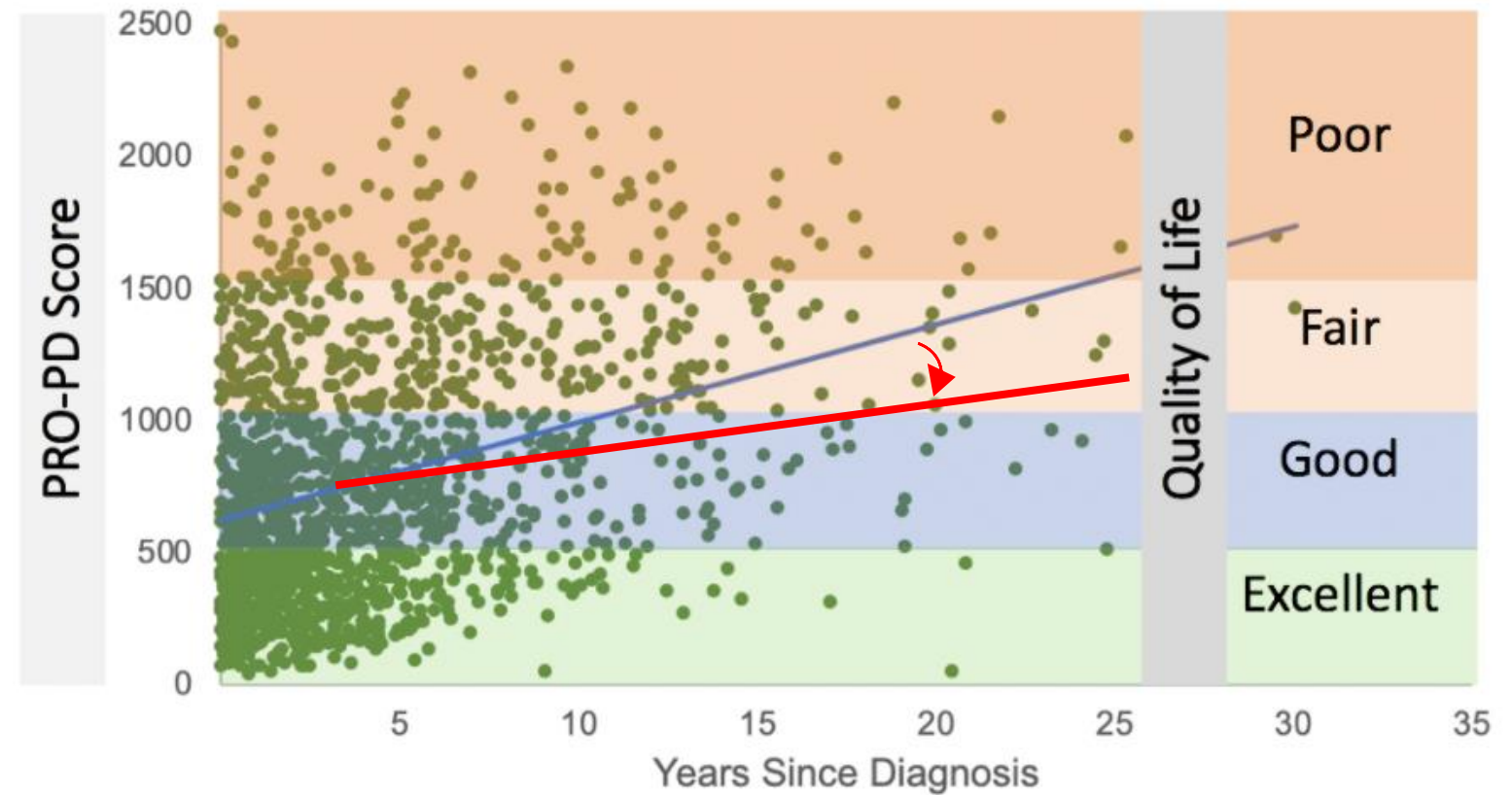
(This is what I'd expect from dopaminergic meds, or dietary changes that allow medications to work better.)



# What Decreased Progression Looks Like

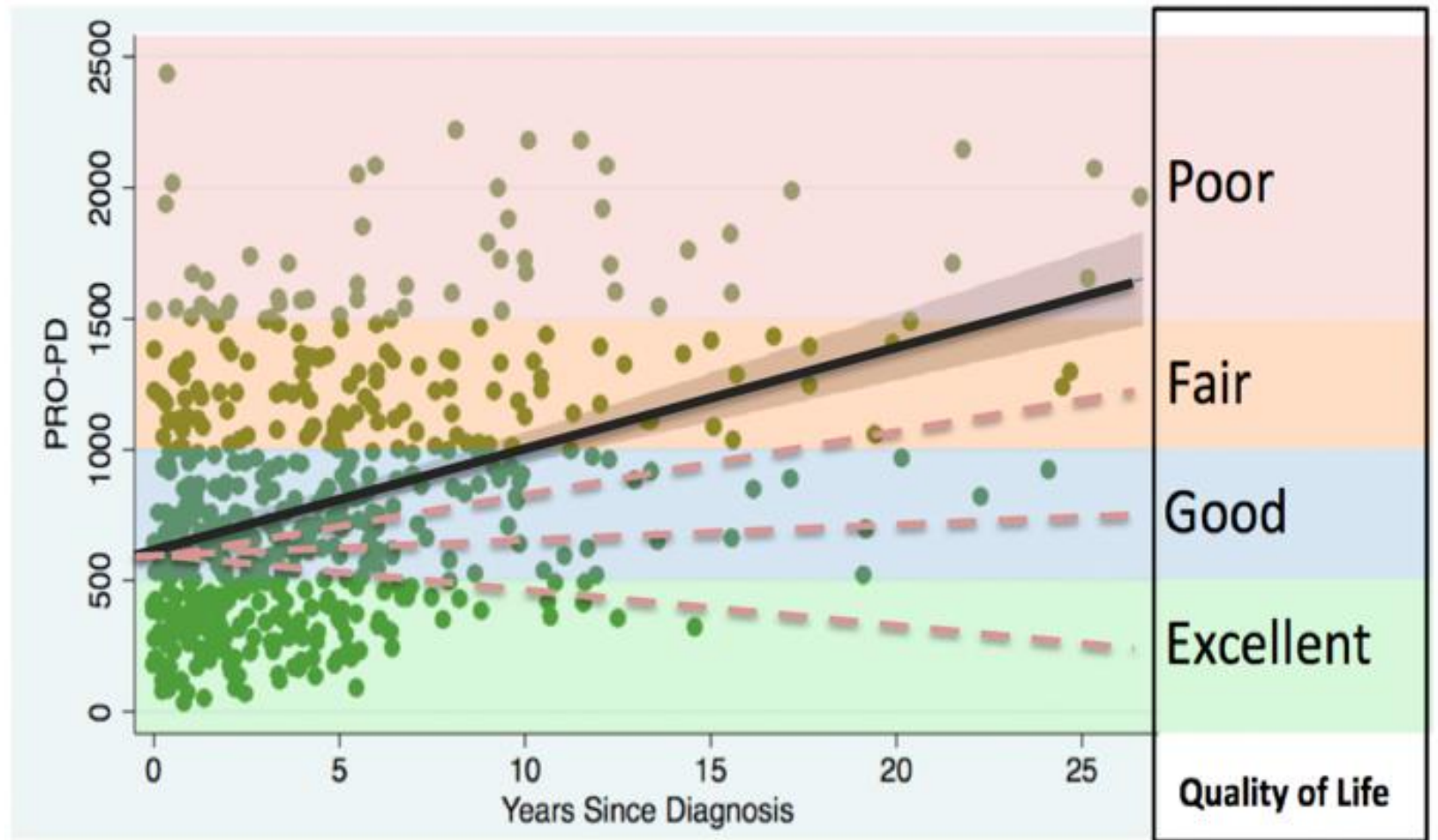
**Correlation Between  
Quality of Life and PRO-PD Score**

Mischley LK 2019



(This is where I'd expect to see  
most of the impacts of nutrition)

# What Decreased Progression Looks Like



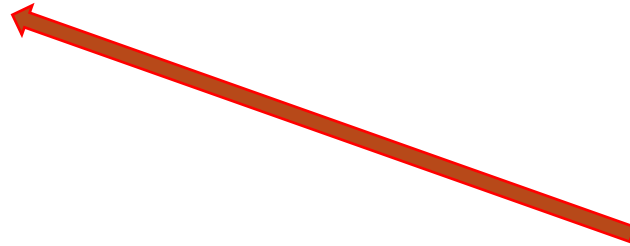
Remember, you may not be able to feel/ appreciate the improvement for the first couple years...

# What Determines PD Outcomes?

- Genes
  - *The hand you are dealt*
- Environment
  - *Those exposures that insult and nourish you.*

# What Determines PD Outcomes?

- Genes
  - *The hand you are dealt*
- Environment
  - *Those exposures that insult and nourish you.*



This is easier to change.

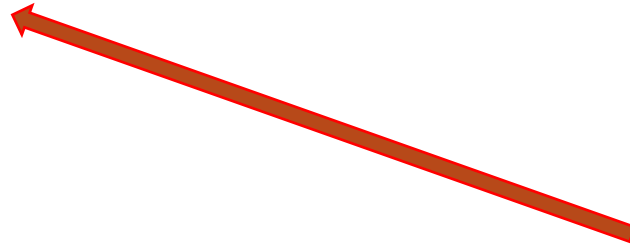


# What Determines PD Outcomes?

- Genes
  - *The hand you are dealt*
- Environment
  - *Those exposures that insult and nourish you.*

CLINICAL EPIDEMIOLOGY

This is easier to change.



# www.CAMCarePD.bastyr.edu

- Past 7 years we've been collecting data on PwP
- Who are you? How are you? What are you doing?

## Complementary & Alternative Medicine Care in Parkinson's Disease (CAM Care in PD)

Status  
Recruiting  
Study area  
CAM Research / Education  
Neurology  
Laurie K Mischley, ND, PhD, MPH  
Project period  
09/01/2012 - 08/31/2021

### Project Overview

Parkinson's Disease is often said to be an incurable, progressive, and degenerative disease.

It is our hypothesis that some of you do not, or will not, have a progressive disease. The goal of this PD study is to collect as much data as possible over a five-year period with the hope of finding dietary and lifestyle factors associated with a slower disease progression.

What are the "Positive Deviants" doing?.

"Positive Deviance is based on the observation that in every community there are certain individuals or groups (the positive deviants), whose uncommon but successful behaviors or strategies enable them to find better solutions to a problem than their peers. These individuals or groups have access to exactly the same resources and face the same challenges and obstacles as their peers.

### TO PARTICIPATE

#### First:

Download and read the Participant Information Sheet. (PDF)

#### Second:

[Fill out this online survey](#)

# Does Diet Matter?

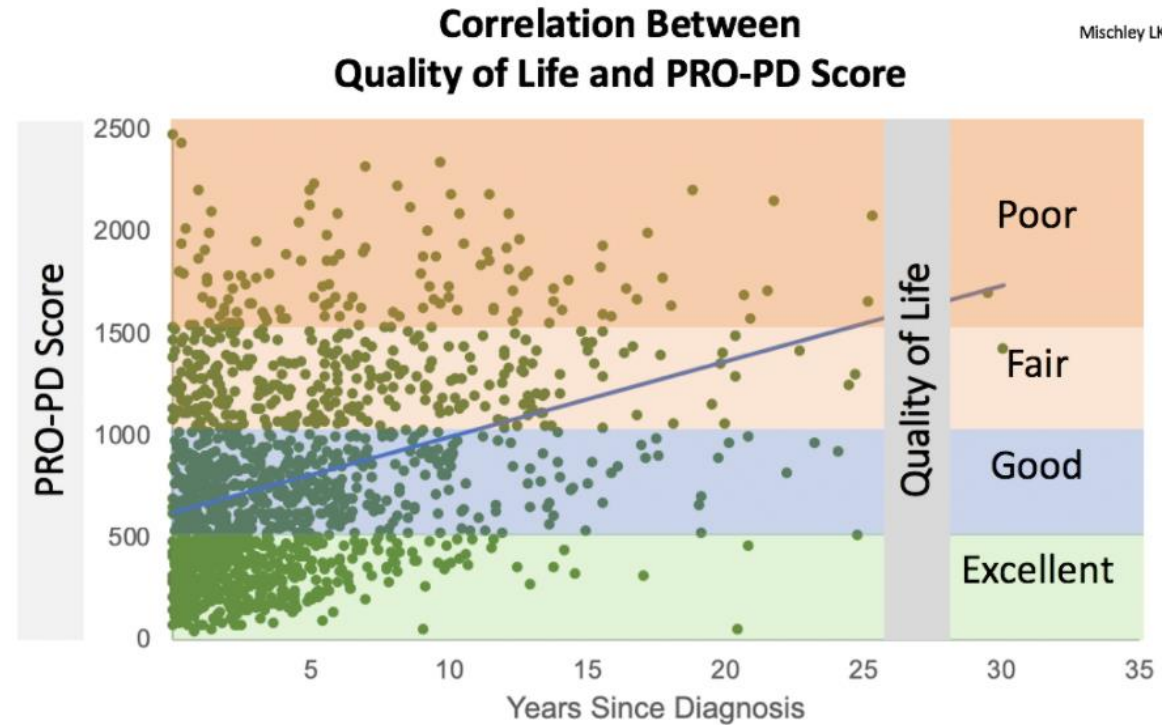
- Following diagnosis, does your choice of breakfast impact your PD symptoms or rate of progression?
- Studies lacking or not possible.
  - *Can't do a double-blind, placebo-controlled study of diet*
- How best to measure PD severity?
- How best to measure diet?
  - Do people know what they're eating?
  - Creatures of habit



# Patient-Reported Symptoms in PD

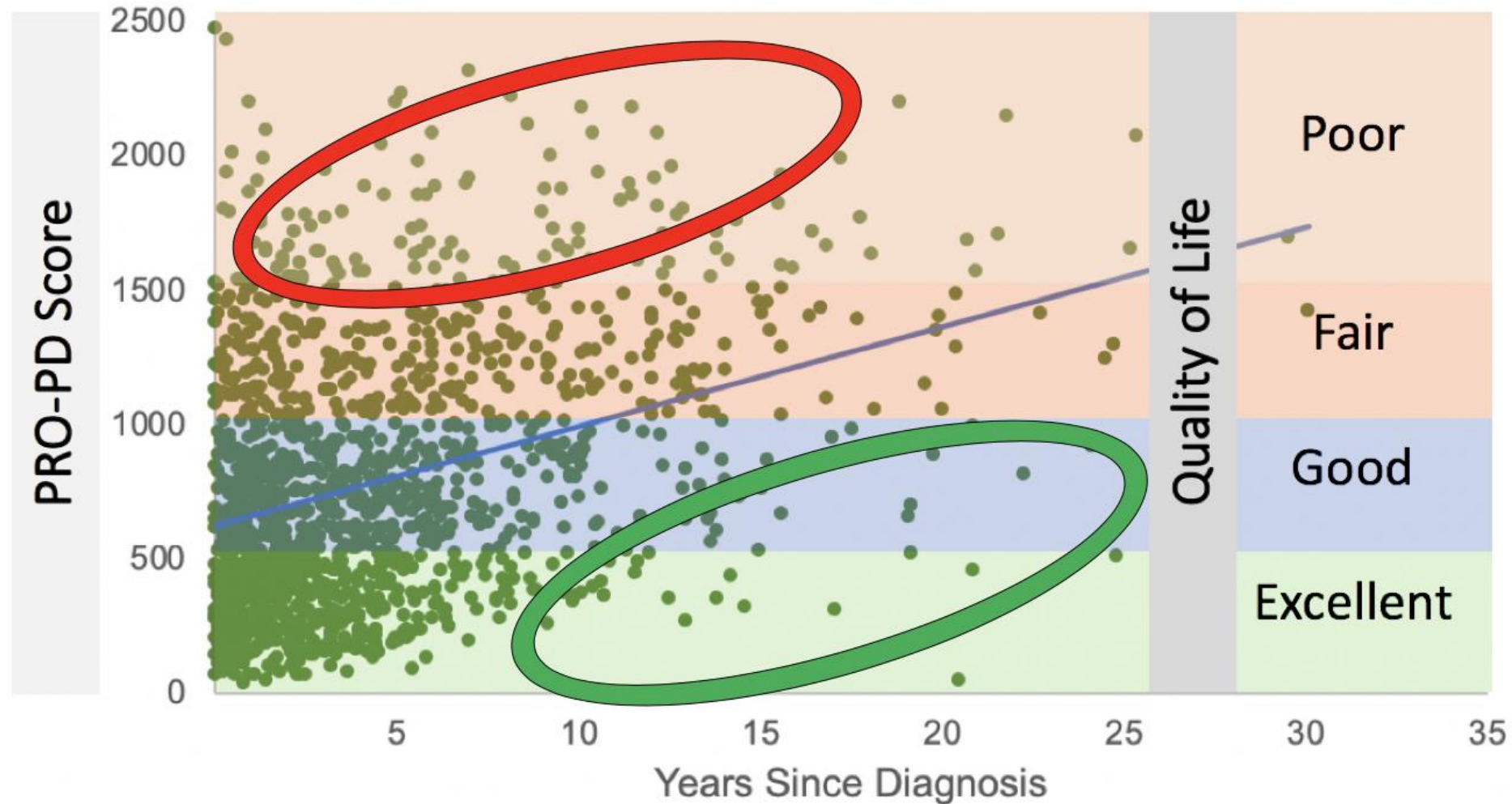
<b>Depression (feeling sad, blues)</b> <small>* must provide value</small>	Mentally healthy    Persistent sorrow    Severe
<b>Loss of Interest</b> <small>* must provide value</small>	Active, engaged    Severely withdrawn
<b>Anxiety</b> <small>* must provide value</small>	None    Severe
<b>Fatigue</b> <small>* must provide value</small>	None    Severe
<b>Daytime Sleepiness</b> <small>* must provide value</small>	None    Severe
<b>Dyskinesia (rocking, writhing, twisting, squirming movements associated with medication.)</b> <small>* must provide value</small>	None    Sometimes, mild    Severe, debilitating
<b>Tremor</b> <small>* must provide value</small>	None    Slight & infrequently present    Severe, debilitating
<small>How it has been, on average, over the past week</small>	
<b>Balance</b> <small>* must provide value</small>	Sturdy, steady    Occasional falls    Lose balance spontaneously

[www.PROPD.org](http://www.PROPD.org)



- Average score at diagnosis: 580
- Typical rate of progression: 40 points per year
- **Everyone can agree: Score of 0 = success**

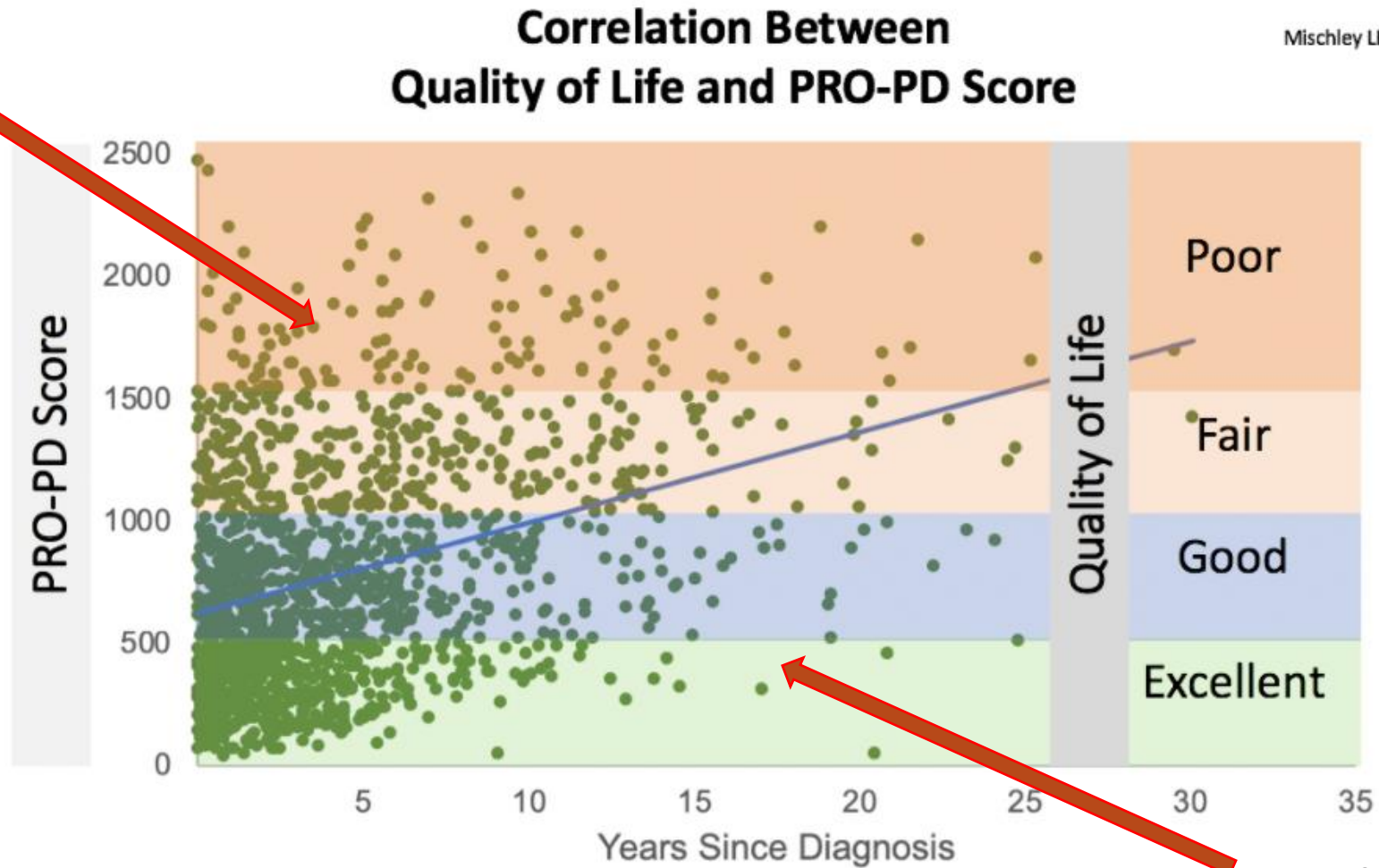
# What Are The Slow/No-Progressors Doing Differently than the Fast Progressors?





# Therapeutic Implications

Don't do  
what these  
people are  
doing.



# The importance of an open mind

Knowledge is power. Education is medicine.

**Informed decision-making.**

“I’d rather spend the rest of my life in this wheelchair than give up ice cream.”

- A patient with MS, c. 2001

# Will changing behavior change your outcome?

WE DON'T KNOW.

Everyone needs to weigh the costs/ benefits of lifestyle modification.



# Symptoms of Parkinsonism

## Getting Patients & Providers on the Same Page

- Providers tend to define PD as:  
**tremor, rigidity, slowness**
- We surveyed > 1000 PwP and the leading symptoms were:
  - **Fatigue**
  - **Impaired handwriting**
  - **Loss of smell**
  - **Memory impairment**
  - **Muscle pain**

<u>Percent of Patients Reporting Symptom</u>	<u>Symptoms</u>
80-85%	Fatigue, Impaired Handwriting, Hyposmia
70-80%	Memory impairment, Muscle pain, Daytime sleepiness, Slowness, Tremor, Sexual impairment, Balance, Urinary dysfunction, Stooped posture
60-70%	Lack of motivation, Insomnia, Difficulty walking, Anxiety, Difficulty rising, Impaired speech
50-60%	Constipation, Difficulty dressing, Depression, Withdrawn, Acting out dreams, Comprehension, Restless legs, Drooling
40-50%	Dizzy on standing, Visual disturbance, Falls
30-40%	Dyskinesia, Freezing
<30%	Nausea, Hallucinations

# The Majority of PD Symptoms are Nonmotor

## Nutrition and Nonmotor Symptoms of Parkinson's Disease

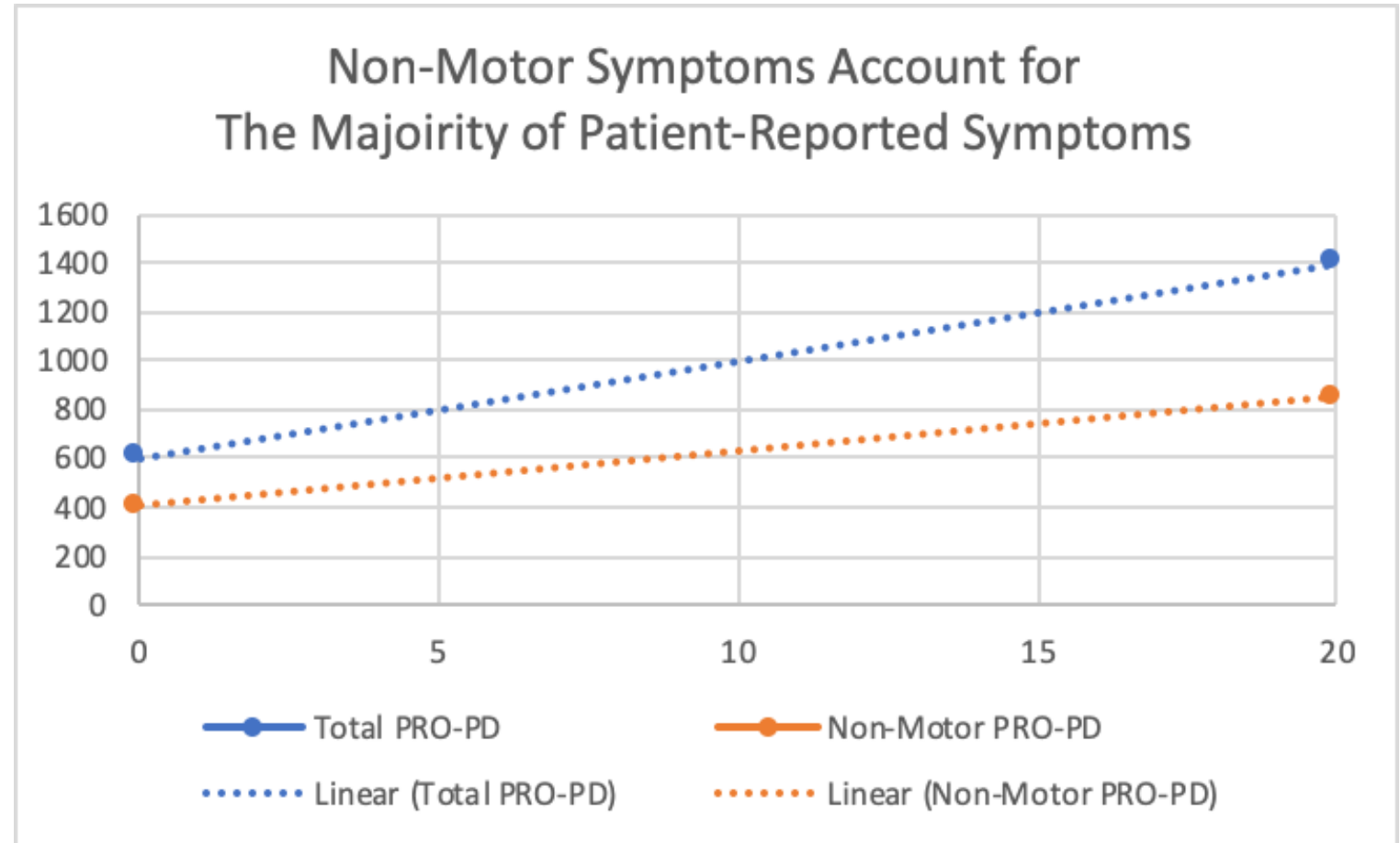
Laurie K. Mischley<sup>1</sup>

Bastyr University Research Institute, Kenmore, WA, United States

<sup>1</sup>Corresponding author: e-mail address: lmischley@bastyr.edu

### Contents

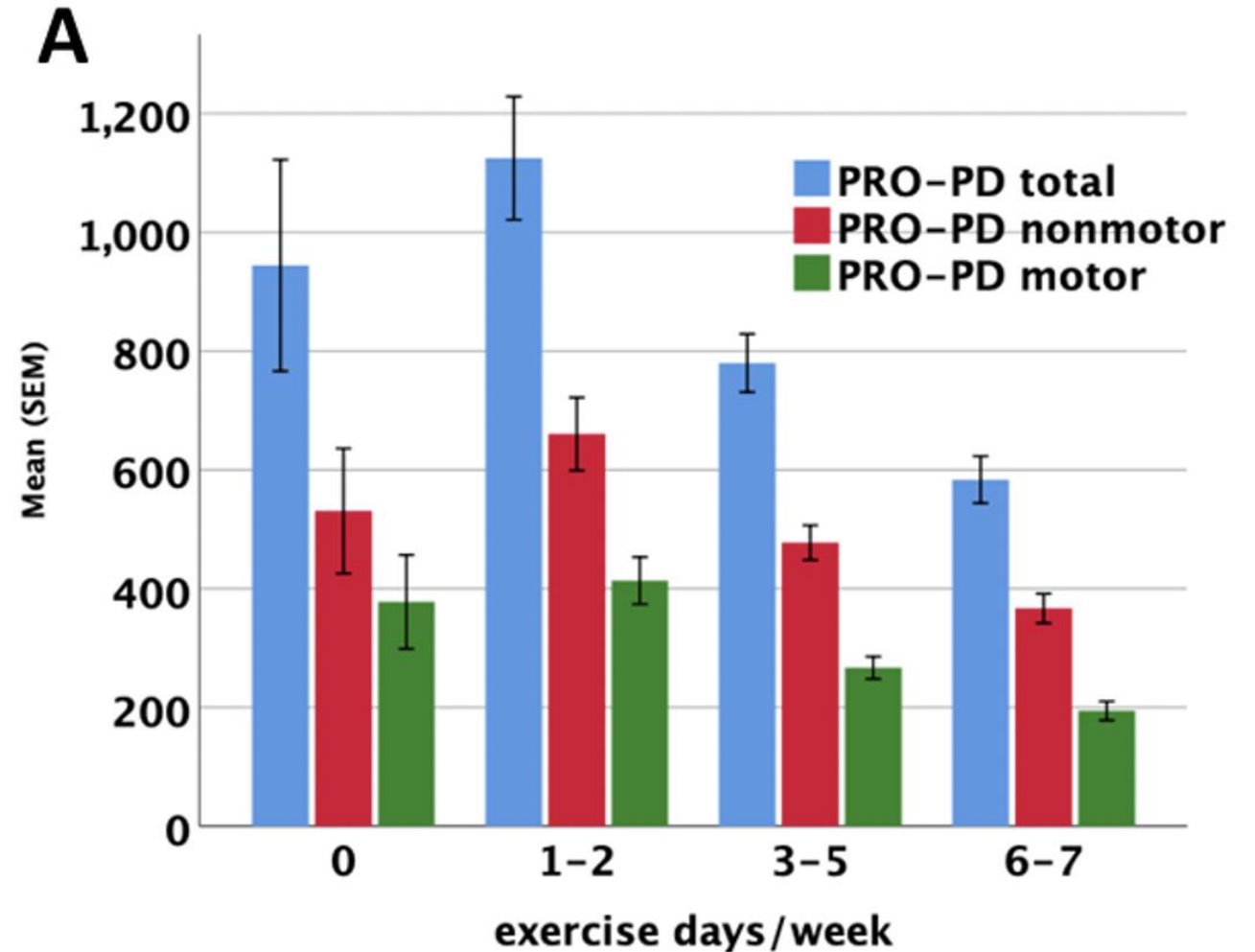
1. Introduction	2
2. Evidence for Nutritional Deficiencies in PD	3
2.1 Coenzyme Q10	3
2.2 Glutathione	3
2.3 Lithium	4
2.4 Thiamine	4
3. PD Increases Risk of Malnutrition	5
4. Diet and Risk of PD Incidence	5
5. An Intestinal Disease That Spreads to the Brain?	6
5.1 Digestive Enzyme Insufficiency	6
5.2 Celiac Disease	7
5.3 <i>Helicobacter pylori</i>	8
6. Symptom-Specific Nutritional Considerations	8
6.1 Constipation	8
6.2 Cognitive Impairment	9
6.3 Depression and Anxiety	9
6.4 Sleep Disorders	10
6.5 Dystonia	11
7. Drug–Nutrient Interactions	11
7.1 Levodopa	11
8. Assessment of Nutritional Status	12
9. Conclusions	13
References	14



Mischley LK, 2019. CAM Care PD Data. N > 2000

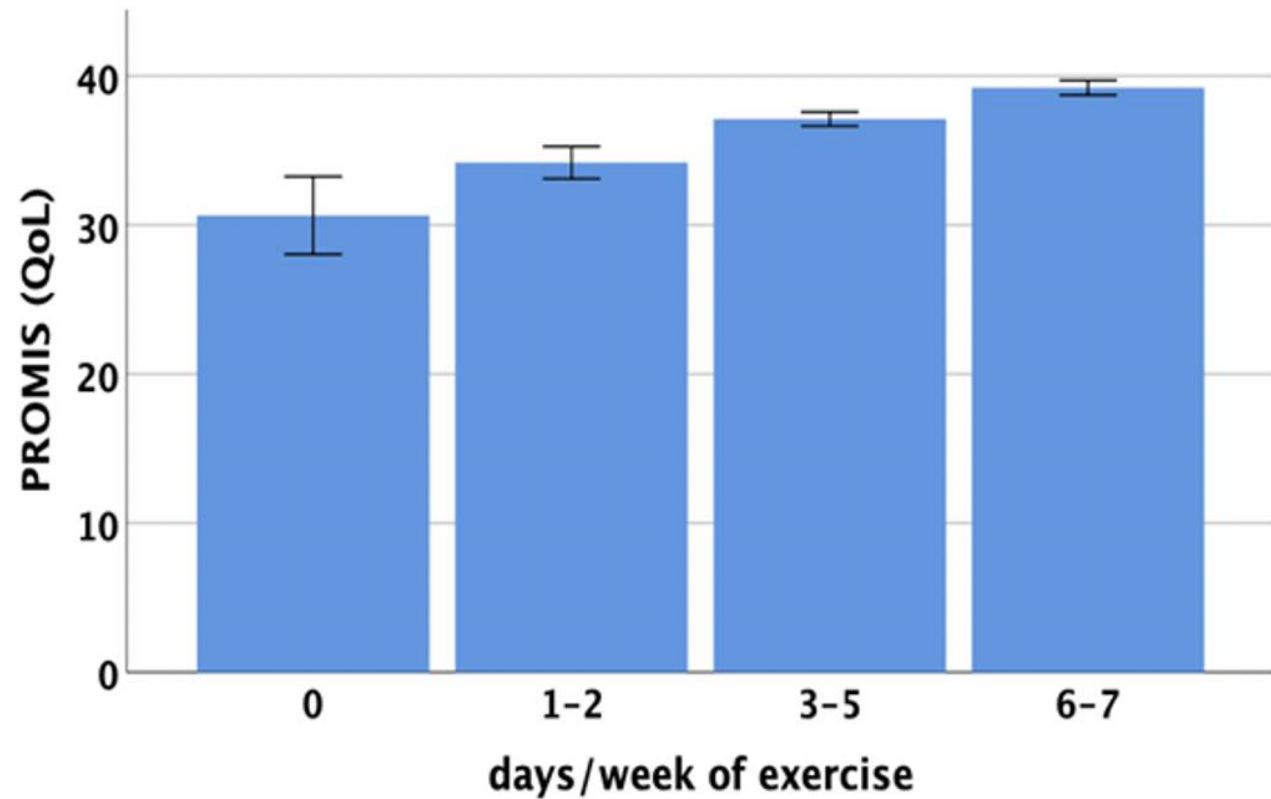
# Exercise & PD Symptoms

- Trend:
  - More exercise is better
- 1-2 d/wk is not associated with symptom reduction
- 3-5 d/wk is good
- 6-7 d/wk is better

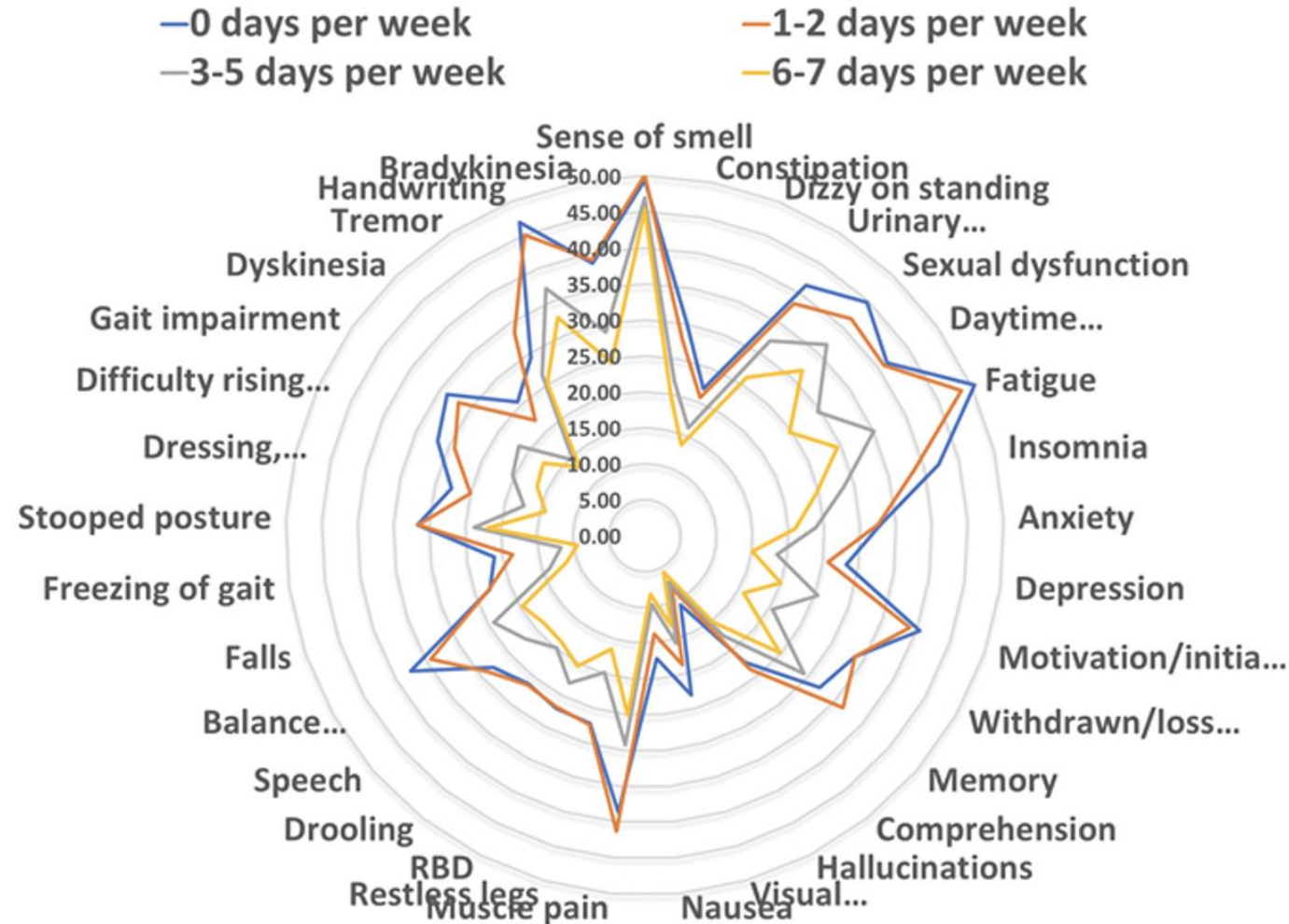


# Exercise & Quality of Life

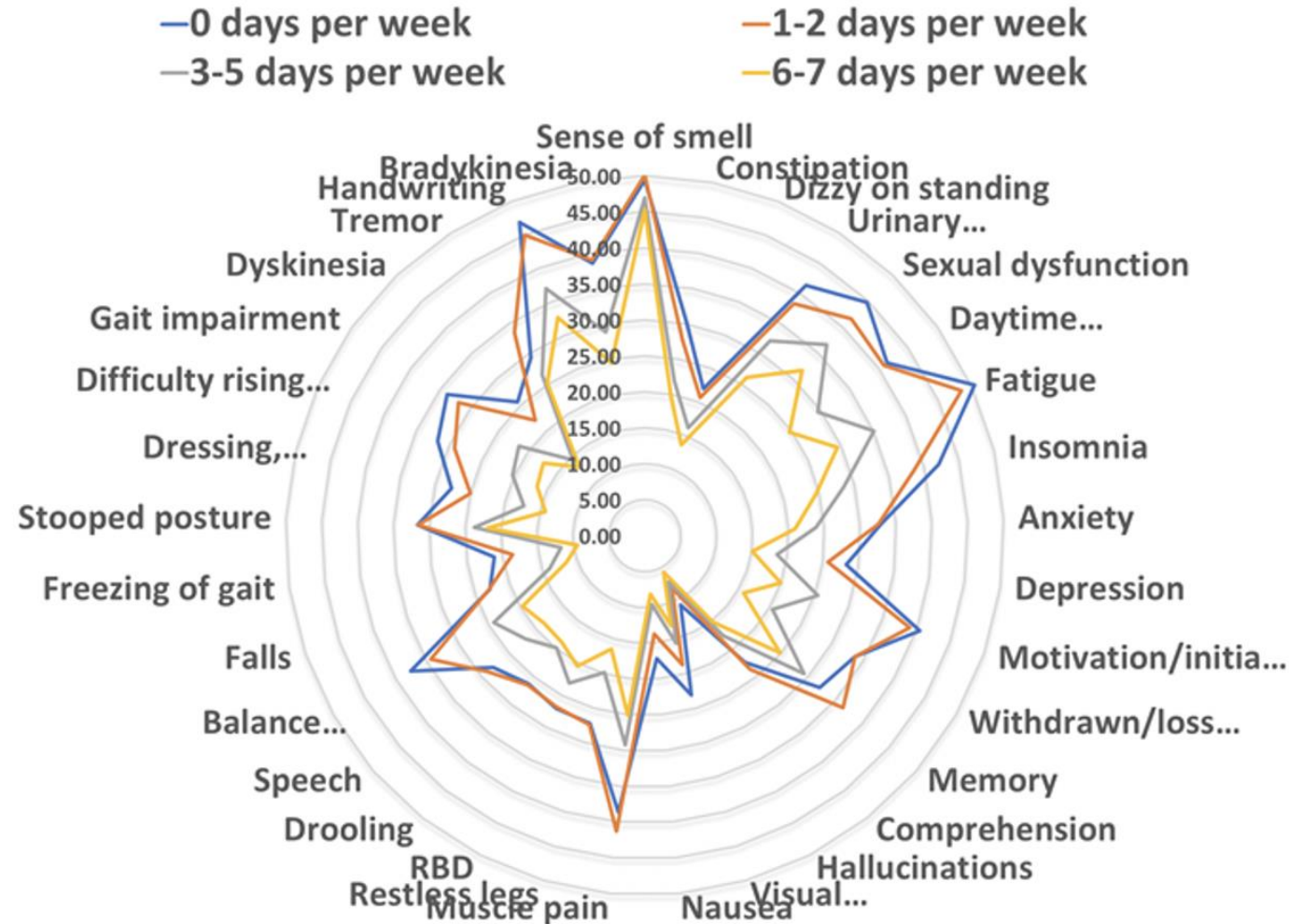
- The more days per week people exercise, the better they rated their quality of life.



# What Symptoms Are Most Strongly Associated with a Sedentary Lifestyle?



# What Symptoms Are Most Strongly Associated with a Sedentary Lifestyle?



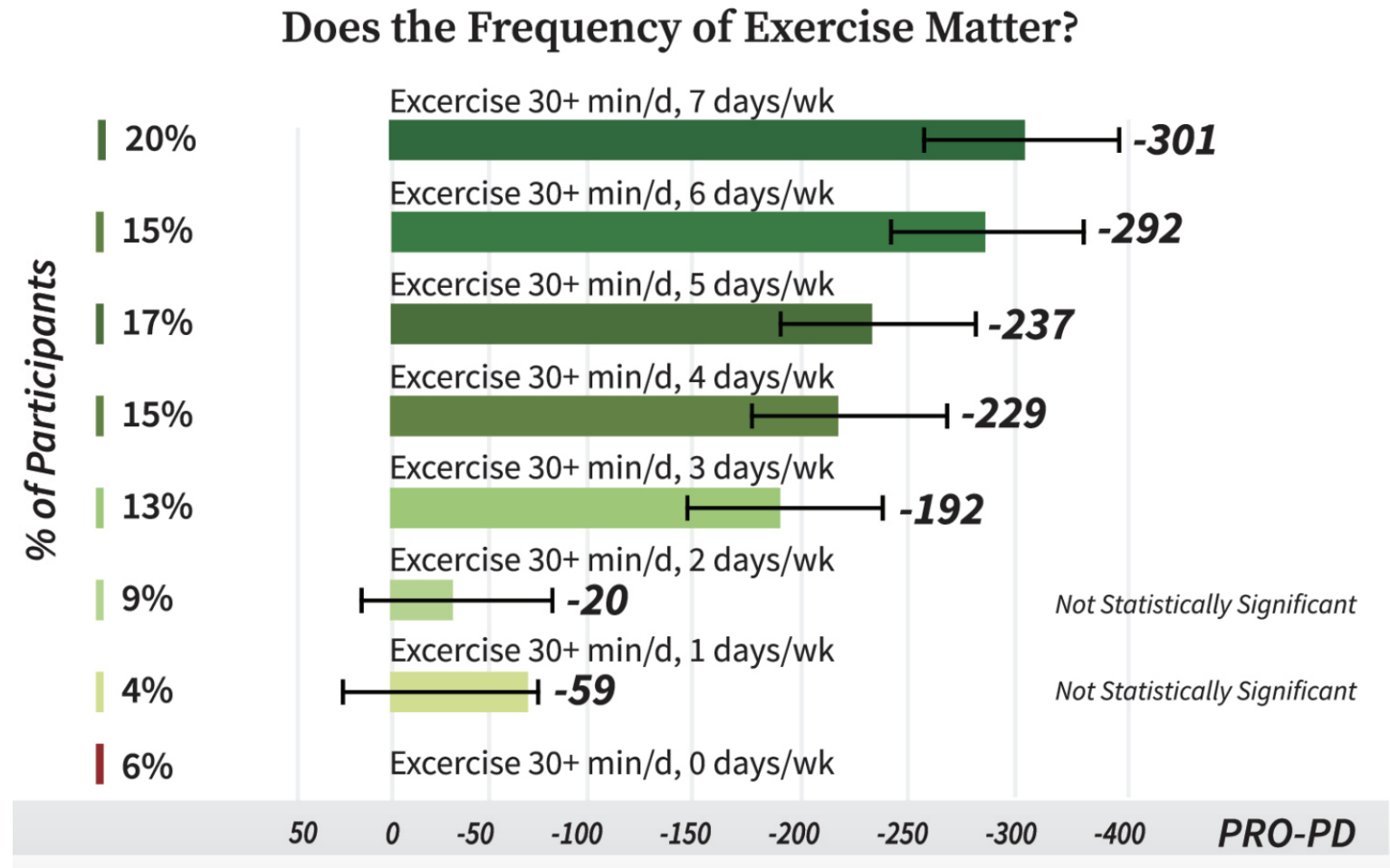
What does an  
“Exercise deficiency  
syndrome” look like in  
PD?

Might some of your  
symptoms be because  
you’re not exercising  
enough?

Are you the grey or  
the yellow type of  
person? 😊



# Exercise is Good & More is Better



# Predictors of Progression:

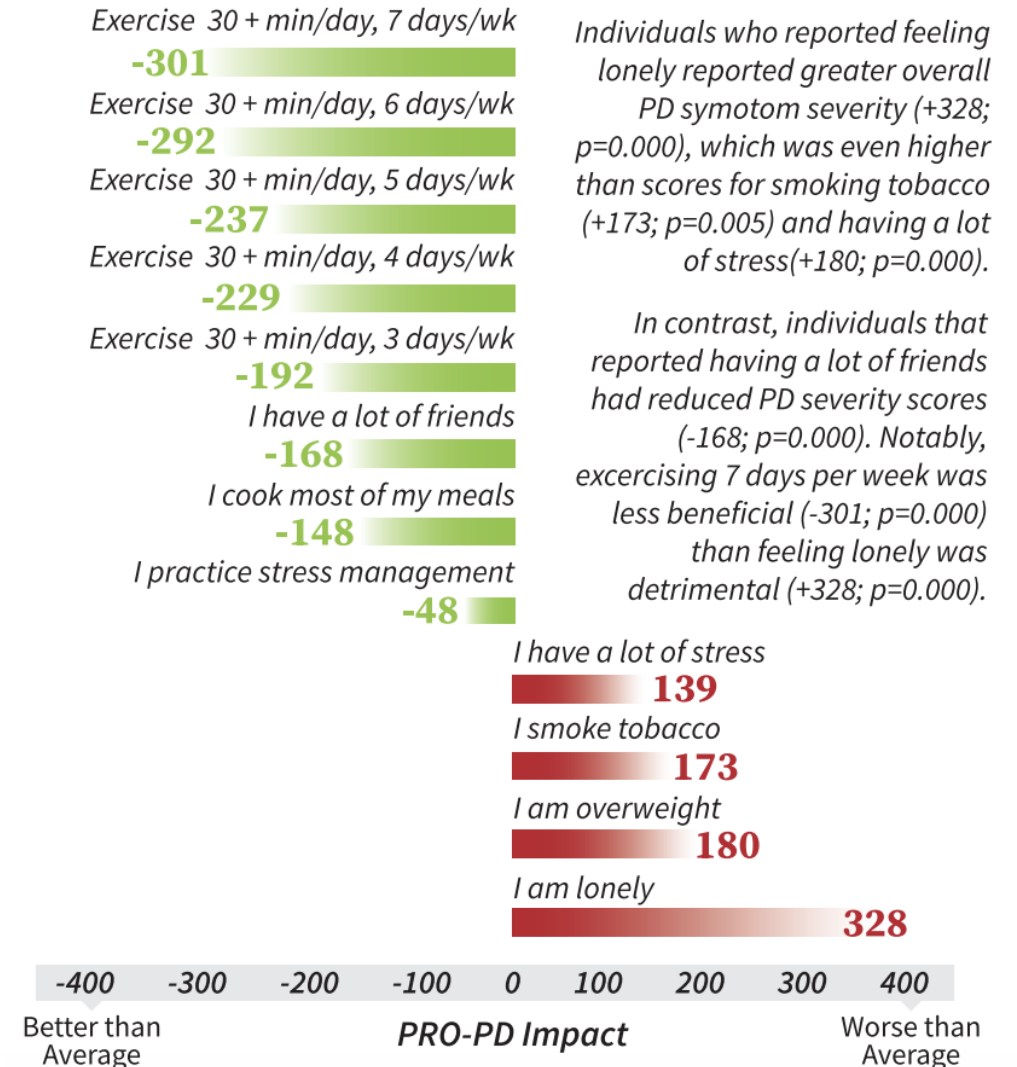
“I am lonely”

“I am overweight”

“I smoke tobacco”

”I have a lot of stress”

## Modifiable Variables Associated with Rate of PD Progression





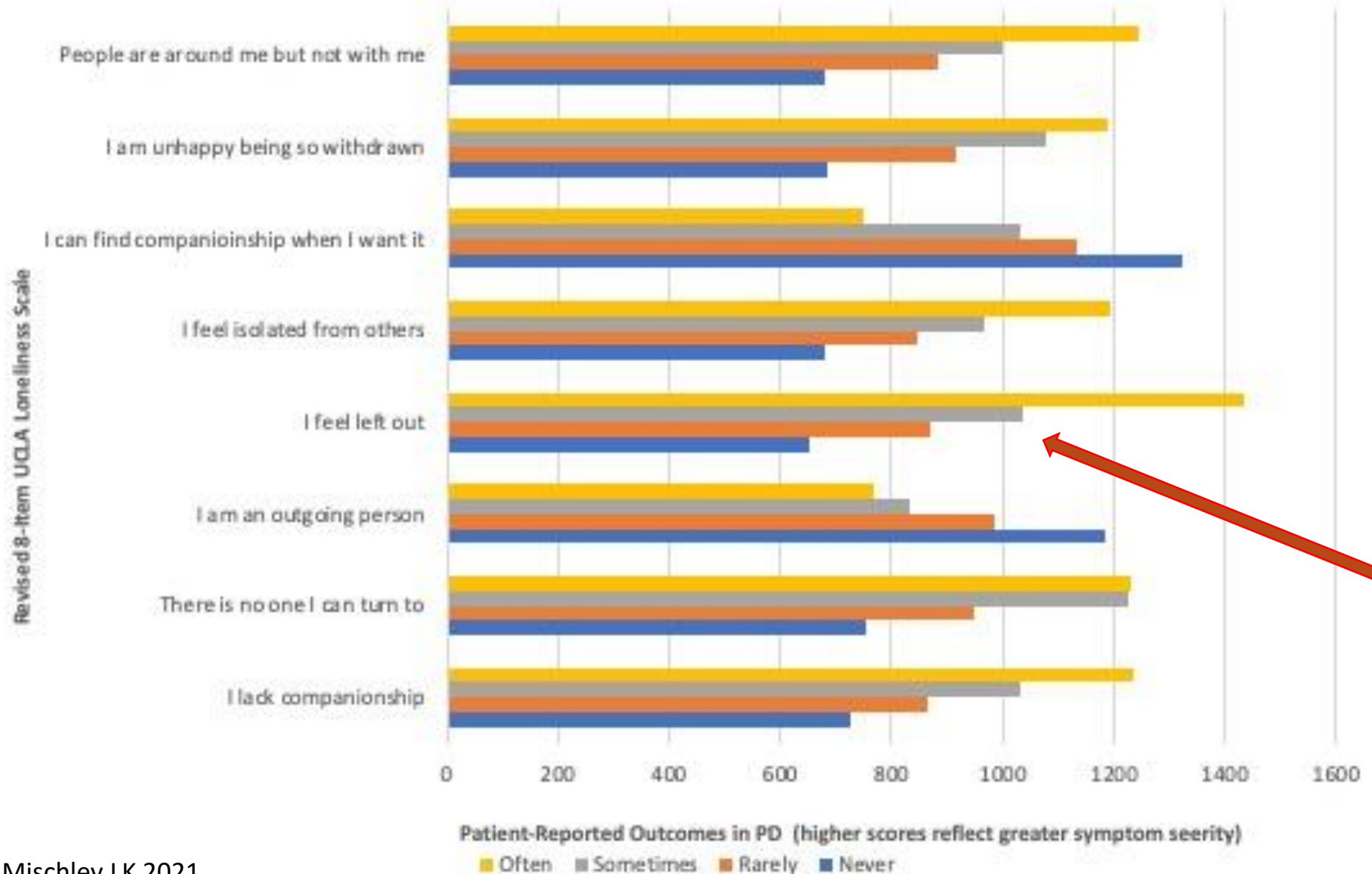
# Social Prescribing

- Gainful employment
  - We all need to be needed
  - Volunteering is therapeutic
- Alcoholics Anonymous as a model
  - The community is part of the solution
- Patient screening in clinic



Providers can ask in clinic,  
“Do you sometimes or  
often feel left out?”

## Correlation Between Parkinson's Disease Symptom Severity and Loneliness



# Non-Motor Symptoms Associated with Malnutrition



- Constipation
- Depression
- Anxiety
- Apathy
- Cognitive impairment
- Dystonia



[Int Rev Neurobiol.](#) 2017;134:1143-1161. doi: 10.1016/bs.im.2017.04.013. Epub 2017 Jun 9.

**Nutrition and Nonmotor Symptoms of Parkinson's Disease.**

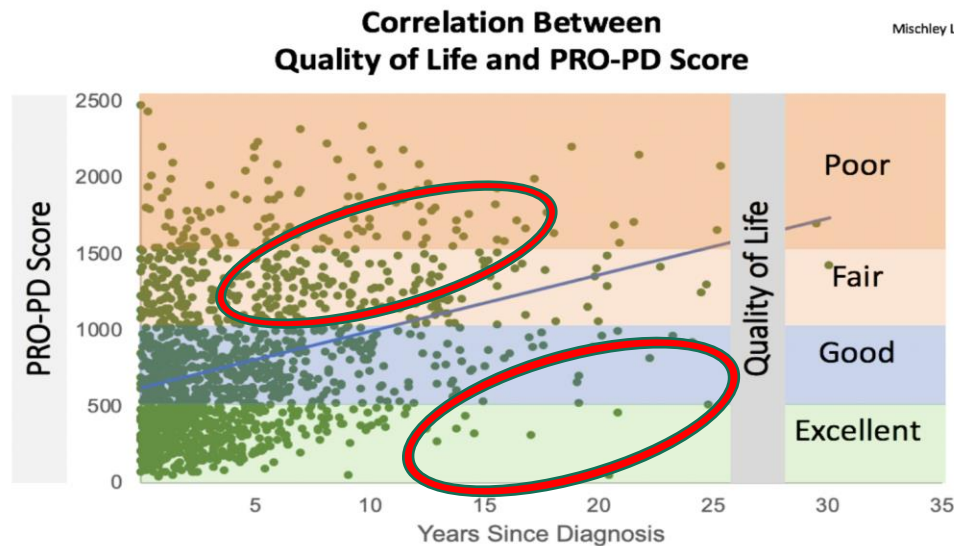
[Mischley LK](#)<sup>1</sup>.

# Diet in Parkinson's Disease PROGRESSION



# Association vs. Causation

- I am NOT saying these behaviors make the disease progress faster or slower.
- I AM saying that people with the fastest progressing disease have different behaviors than those with a more slowly progressing disease.



*It makes sense to me that, if possible, I would try to mimic the lifestyle of those with the best outcomes.*



# Role of Diet and Nutritional Supplements in Parkinson's Disease Progression

Partners that  
Play for Points

Laurie K. Mischley,<sup>1</sup> Richard C. Lau,<sup>2</sup> and Rachel D. Bennett<sup>1</sup>

<sup>1</sup>Bastyr University Research Institute, 14500 Juanita Dr. NE, Kenmore, WA 98028, USA

<sup>2</sup>Oregon State University, 101 Milam Hall, Corvallis, OR 97331, USA

Correspondence should be addressed to Laurie K. Mischley; lmischley@bastyr.edu

4


Oxidative Medicine and Cellular Longevity

TABLE 2: Multiple linear regression model of dietary intake and PD progression. Predicted PD severity score, as measured by the PRO-PD, per unit increase in food intake frequency, intake measured on a 10-point scale: never, <1/month, 1/month, 2-3×/month, 1/week, 2-4×/week, 5-6×/week, 1/day, 2-4×/day, 5-6×/day. \* Adjusted for years since diagnosis, age, and gender. \*\* Adjusted for years since diagnosis, age, gender, and income.

Association between dietary practices and Parkinson's disease progression				
Food item (serving size)	Mean change in PRO-PD score (SE)*	P value (95% CI)*	Mean change in PRO-PD score (SE)**	P value (95% CI)**
Fresh vegetables (1/2 cup)	-53.2 (7.9)	<0.000 (-68.7 to -37.6)	-48.9 (8.3)	<0.000 (-64.7 to -33.1)
Fresh fruit (1/2 cup)	-44.1 (8.5)	<0.000 (-60.7 to -27.5)	-40.7 (8.6)	<0.000 (-57.5 to -23.9)
Nuts (1/4 cup or 2 tbsp spread)	-38.5 (7.5)	<0.000 (-53.2 to -23.7)	-33.2 (7.6)	<0.000 (-48.1 to -18.4)
Fish (4 oz)	-37.1 (8.9)	<0.000 (-54.6 to -19.5)	-29.5 (9.1)	0.001 (-47.3 to -11.6)
Olive oil (1 tsp)	-34.1 (6.8)	<0.000 (-47.4 to -20.8)	-31.4 (6.8)	<0.000 (-44.7 to -18.1)
Wine (6 oz)	-23.6 (5.3)	<0.000 (-34.1 to -13.1)	-14.6 (5.6)	0.009 (-25.5 to -3.7)
Turkey (4 oz)	-20.2 (18.7)	0.281 (-57.1 to 16.7)	-10.8 (19.2)	0.573 (-48.7 to 27)
Coconut oil (1 tsp)	-18.6 (5.5)	0.001 (-29.3 to -7.8)	-20.2 (5.5)	<0.000 (-31 to -9.4)
Fresh herbs (1 tsp)	-14.9 (6.4)	0.02 (-27.4 to -2.4)	-8.9 (6.5)	0.169 (-21.7 to 3.8)
Spices (1/4 tsp)	-14.2 (6.4)	0.027 (-26.7 to -1.6)	-13.4 (6.4)	0.037 (-26 to -0.8)
Eggs (1 egg)	-9.5 (8.2)	0.251 (-25.6 to 6.7)	-9.7 (8.3)	0.241 (-26 to 6.5)

# www.LivingHealthyWithParkinsons.com

← → ↻ 🔒 livinghealthywithparkinsons.com



**Living Healthy With Parkinsons**  
Lifestyle Modification as a Therapeutic Strategy

**'CAM CARE PD' STUDY SITE**

## Food Choices & Parkinson's Disease Progression

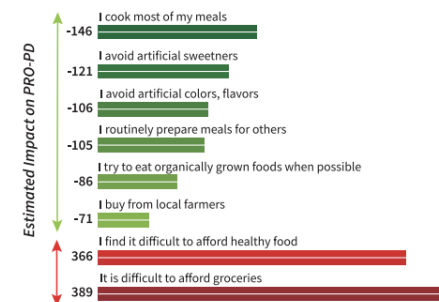
| 2020

LK Mischley et al.

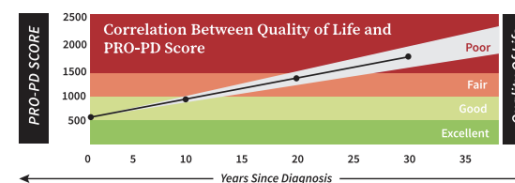
For study details:  
[www.LivingHealthyWithParkinsons.com](http://www.LivingHealthyWithParkinsons.com)

To participate in this study:  
[www.CAMCarePD.Bastyr.edu](http://www.CAMCarePD.Bastyr.edu)

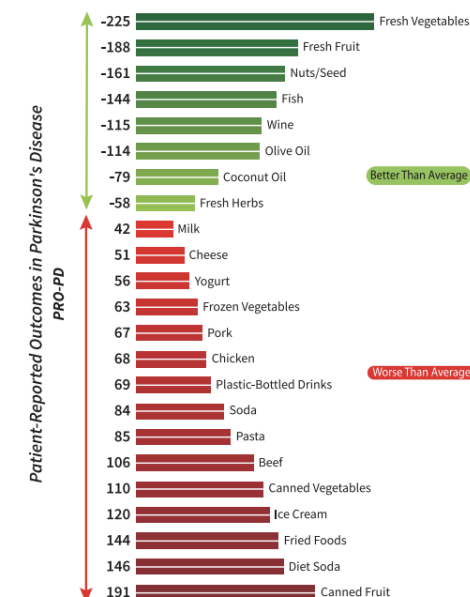
### Impact of Dietary Behaviors on PD Progression



N = 1503-1521 (per question, if answered).  
All regression analyses adjusted for age, gender, income, and years since diagnosis.

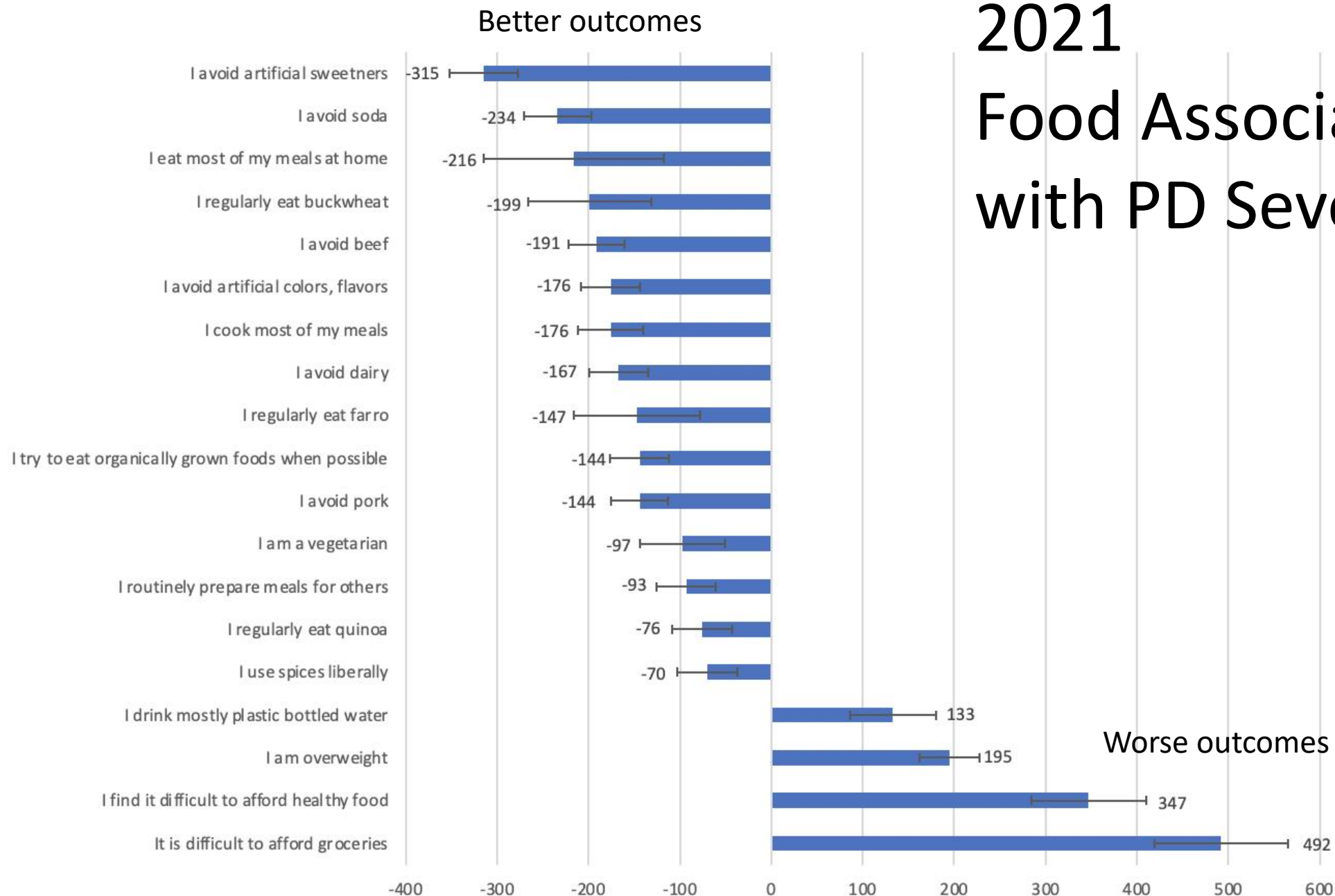


## Impact of 2-4 Servings Per Week on Symptom Severity



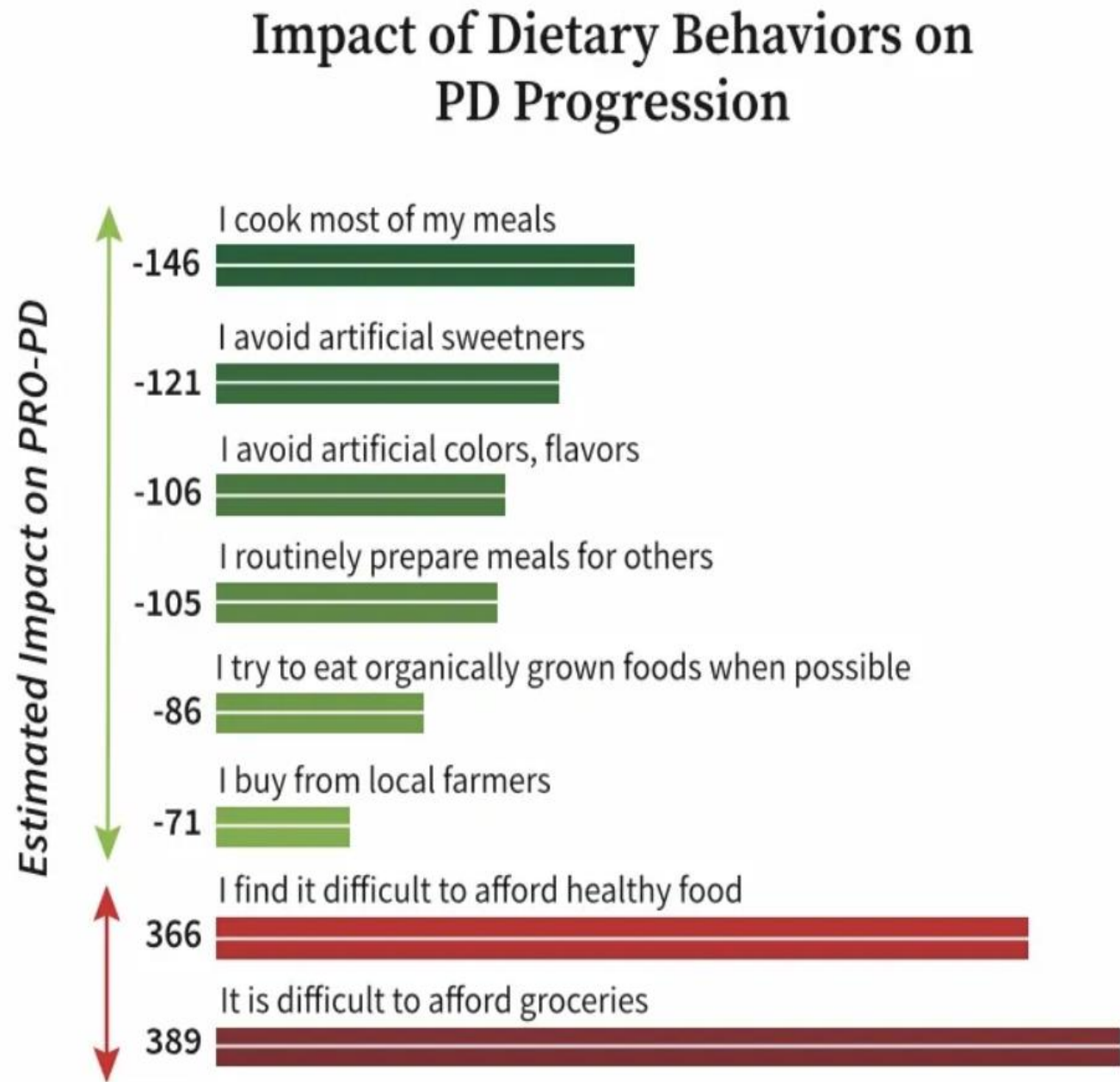
# 2021

## Food Associated with PD Severity





How you Eat  
May Be As  
Important as  
What You Eat



# Does it Matter if It's Organic?

From a public health perspective, finding ways to support access to organic foods may save money and lives.

## DIRTY DOZEN

EWG's 2017 Shopper's Guide to Pesticides in Produce™



**“I try to eat organically grown foods when possible.”**

We surveyed over 1000 PwP. People who responded TRUE had a **PRO-PD score** approximately **75 points lower** than those who don't make the effort (-74.9 (28.1);  $p=0.008$  (-130 to -19.8)).

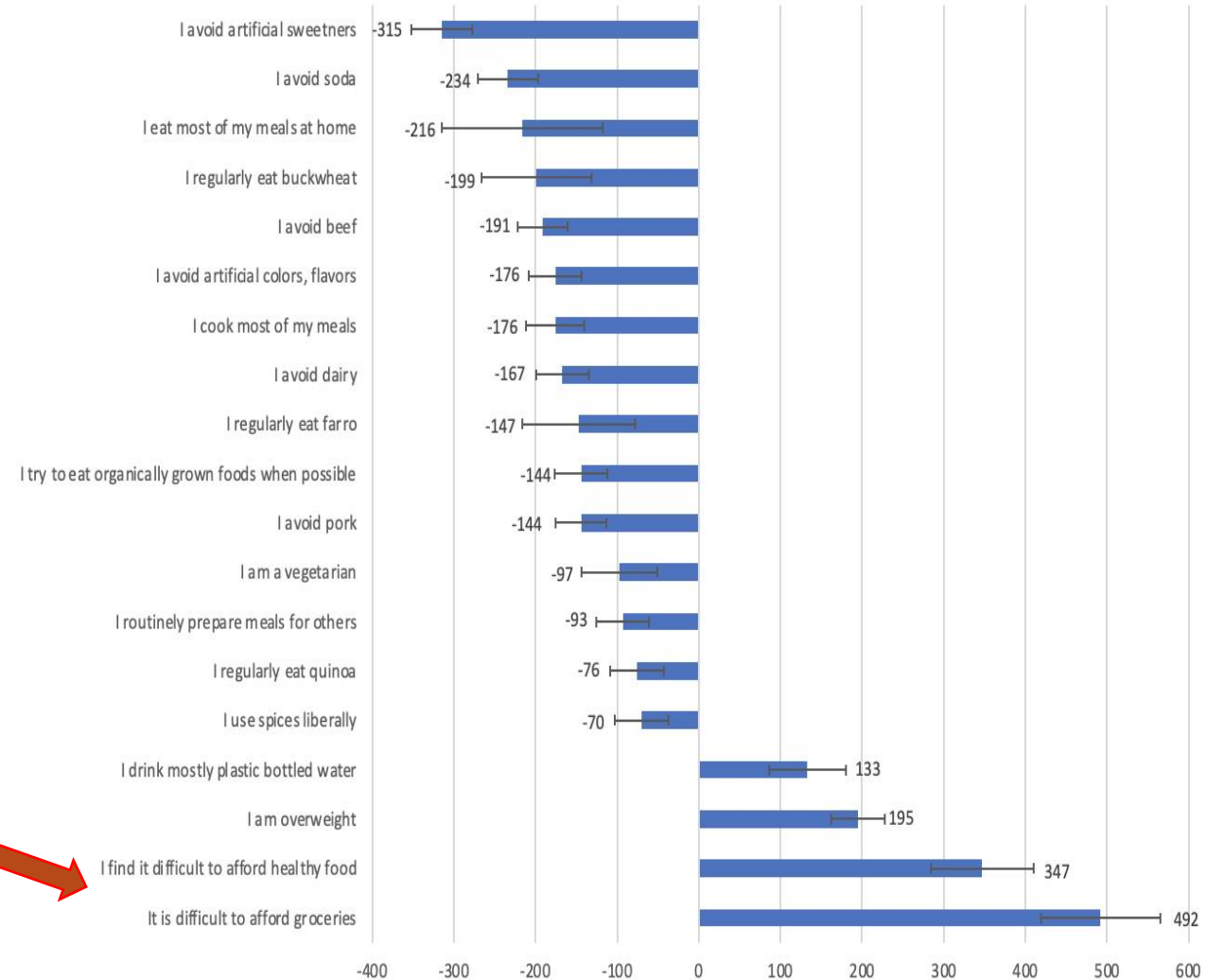
Data after adjusting for age, gender, income, and years since diagnosis. (Mischley et al 2017)

Environmental Working Group

- Dirty dozen
- Clean fifteen

# Poverty & Food Scarcity

From a medical and public health perspective, **finding ways to support financial stability and access to healthy food** may save money and lives.



# Poverty & Food Scarcity

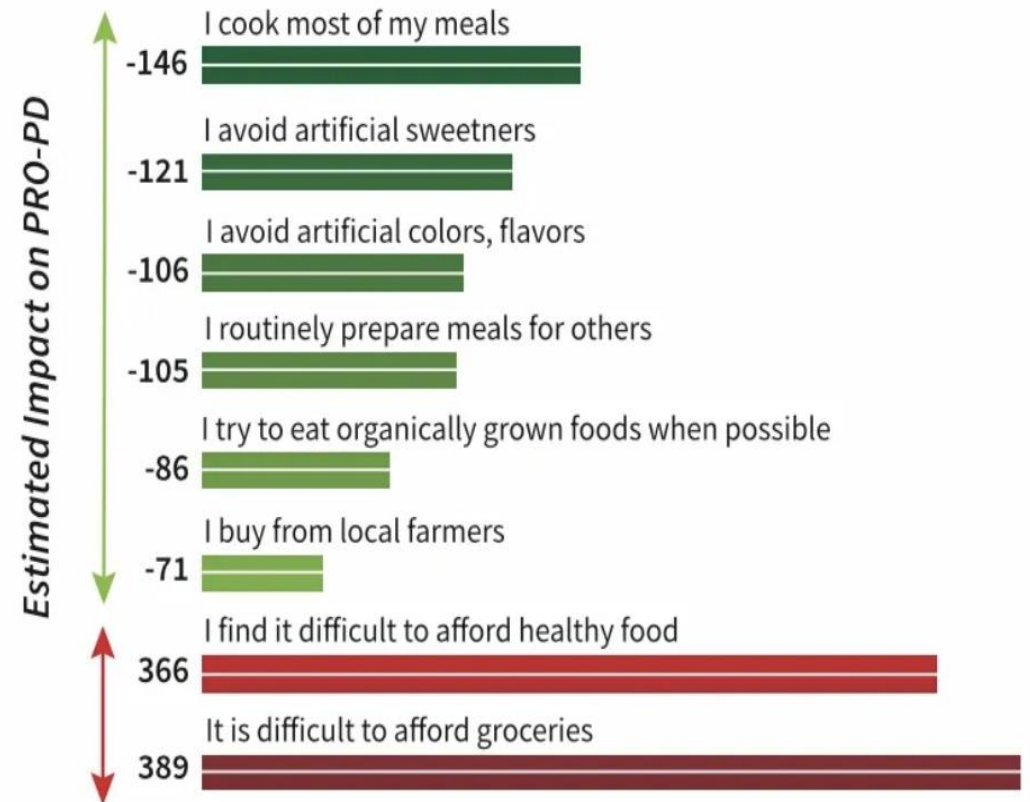
## Philosophical and Practical Questions:

Might malnutrition or the stress/  
lifestyle associated with poverty  
contributing to disease progression?

Income inequality is systemic— how to  
treat?

Might there be a day where patients  
receive a stipend instead of a pill as a  
therapeutic strategy?

## Impact of Dietary Behaviors on PD Progression

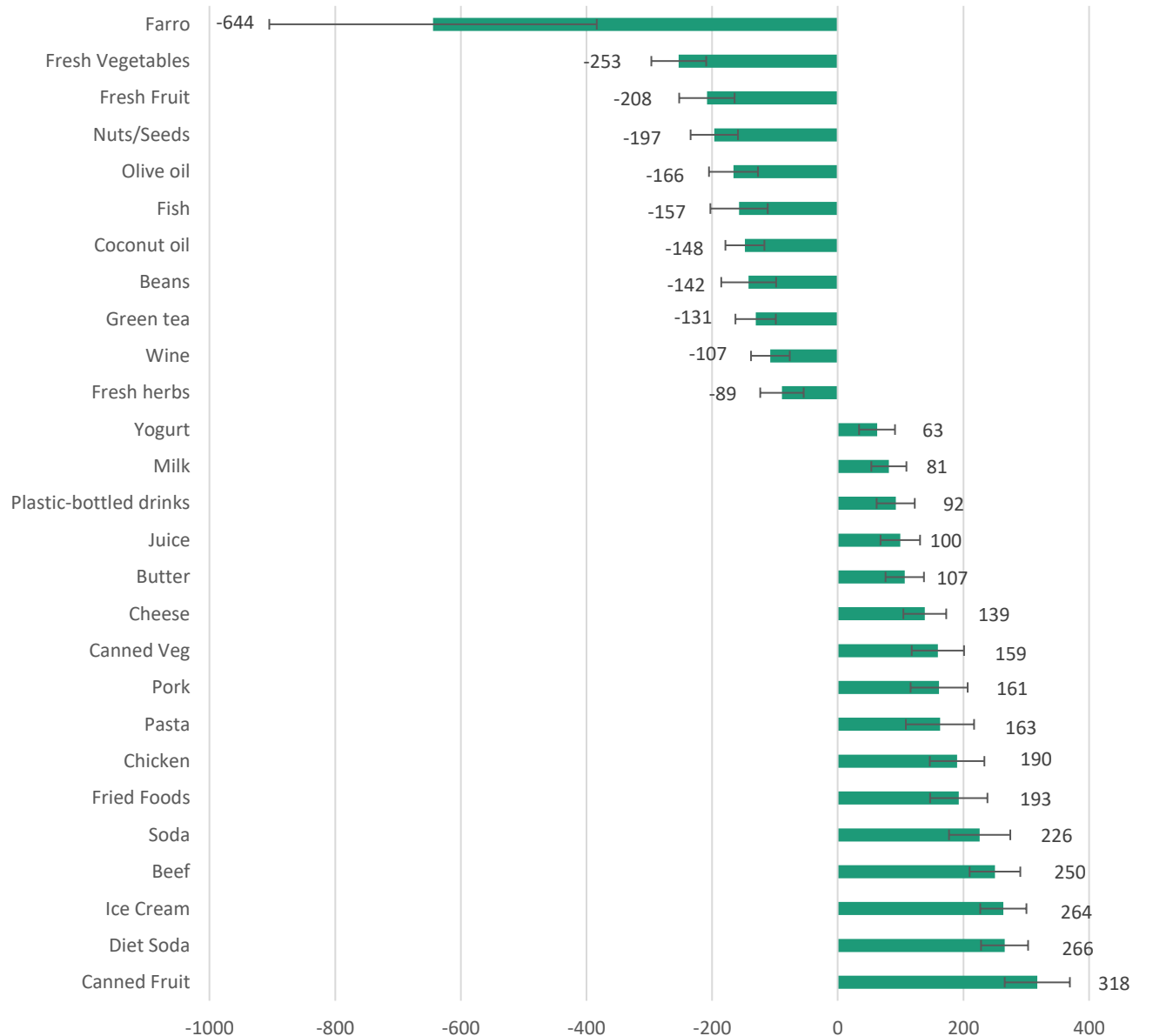


N = 1503-1521 (per question, if answered).

All regression analyses adjusted for age, gender, income, and years since diagnosis.

# 2021 Foods Associated with PD Progression

Mischley LK, Farahnik J 2021




# Teaching Patients to Eat

- Playing for points
  - *The person with the least points each day has to do the dishes.*
- Educational tool
  - *Realize it's easy to get extra points from water, nut butter, etc.*
  - *Impact of farro, sorghum, etc.???*
  - *Realize small 'cheats' add up*
  - *Realize if you have 50 good points, subtracting 2 may not matter so much...*

Name:  
Date:

Version 2021.2

 <b>PARKINSON-PRO DIET</b>			
Foods to Encourage			
	<u>Serving Size</u>	<u>Points per Serving</u>	Tally
Fresh vegetables	1/2 cup	5	
Fresh fruit	1/2 cup	4	
Nuts & seeds	1/4 cup/ 2 Tbsp	4	
Non-fried fish	4 oz.	3	
Coconut oil	1 tsp	3	
Olive oil	1 tsp	3	
Beans	1/2 cup	3	
Green tea	1 cup	3	
Water	8 oz	3	
Wine	1 glass	2	
Fresh herbs	1 tsp	2	
Frozen fruit	1/2 cup	1	
Farro	1/2 cup cooked	13	
TOTAL POSITIVE POINTS:			
Foods to Discourage			
	<u>Serving Size</u>	<u>Points per Serving</u>	
Canned fruit	1/2 cup	-6	
Canned vegetables	1/2 cup	-3	
Soda/ diet soda	12 oz, 1 can	-5	
Fried foods	4 oz	-4	
Beef	4 oz	-5	
Chicken	4 oz	-4	
Pork	4 oz	-3	
Ice cream	1/2 cup	-5	
Cheese	1 Tbsp, 1/2 oz	-3	
Butter	1 tsp	-2	
Milk (from mammals)	1 cup	-2	
Juice	8 oz	-2	
Yogurt	3/4 cup	-1	
POINTS TO SUBTRACT:			
Rx: ____ points per day		TOTAL DAILY POINTS	

There may be several mechanisms responsible to explain the association between PD progression and dairy consumption:

- (1) Dairy intake lowers uric acid [19]. Uric acid quenches peroxynitrite in the CNS, and low uric acid levels are associated with greater PD incidence and faster PD progression [20].
- (2) Dairy consumption is associated with insulin resistance [21]. There is a growing body of evidence that PD and other neurodegenerative diseases are a form of “type III diabetes” [22].
- (3) Lactose intolerance, occurring when the enzyme, lactase, that digests the milk sugar decreases with age, is especially common in individuals of African, Asian, Hispanic, and Native American descent [23]. Consuming dairy in the absence of sufficient lactase may contribute to intestinal inflammation and intestinal permeability.
- (4) Presence of a neurotoxic component or contaminant, for example, pesticides, may be present in dairy [23].
- (5) Introduction of bovine microbiota, facilitating seeding of methanogenic organisms, leads to the development of methane-dominant small intestinal bacterial overgrowth (SIBO) and other forms of abnormal intestinal flora [24–26].

# Dairy: The Quest for a Loophole

- “What about goat/ sheep/ camel cheese?”
- “What about lactose-free?”
- “My butter is from grass-fed cows.”
- “But my ice cream is organic.”
- “Yogurt is my source of calcium.”



# Comparisons Across Studies of PD Risk & Progression

## ENCOURAGE

	<i>Vegetables</i>	<i>Fruit</i>	<i>Nuts</i>	<i>Seafood</i>	<i>Wine</i>	<i>Olive oil</i>	<i>Legumes</i>	<i>Whole Grains</i>	<i>Coconut oil</i>	<i>Egg</i>	<i>Poultry</i>	<i>Dairy</i>	<i>Fresh herbs</i>	<i>Spices</i>	<i>Buy organic</i>	<i>Cook at home</i>
<b>Parkinson-PRO</b>																
<b>Mediterranean</b>												<sup>3</sup>				
<b>MIND</b>	<sup>1</sup>	<sup>2</sup>														
<b>Ketogenic</b>																

## DISCOURAGE

	<i>Red meat</i>	<i>Pork</i>	<i>Chicken</i>	<i>Dairy</i>	<i>Fried food</i>	<i>Soda</i>	<i>Refined Grains</i>	<i>Sweets</i>	<i>Pastries</i>	<i>Pasta</i>	<i>Frozen vegetables</i>	<i>Plastic bottles</i>	<i>Canned food</i>
<b>Parkinson-PRO</b>													
<b>Mediterranean</b>				<sup>4</sup>									
<b>MIND</b>				<sup>5</sup>									
<b>Ketogenic</b>													

<sup>1</sup>Especially green leafy vegetables

<sup>2</sup>Especially berries

<sup>3</sup>Low fat

<sup>4</sup>Full-fat

<sup>5</sup>Butter

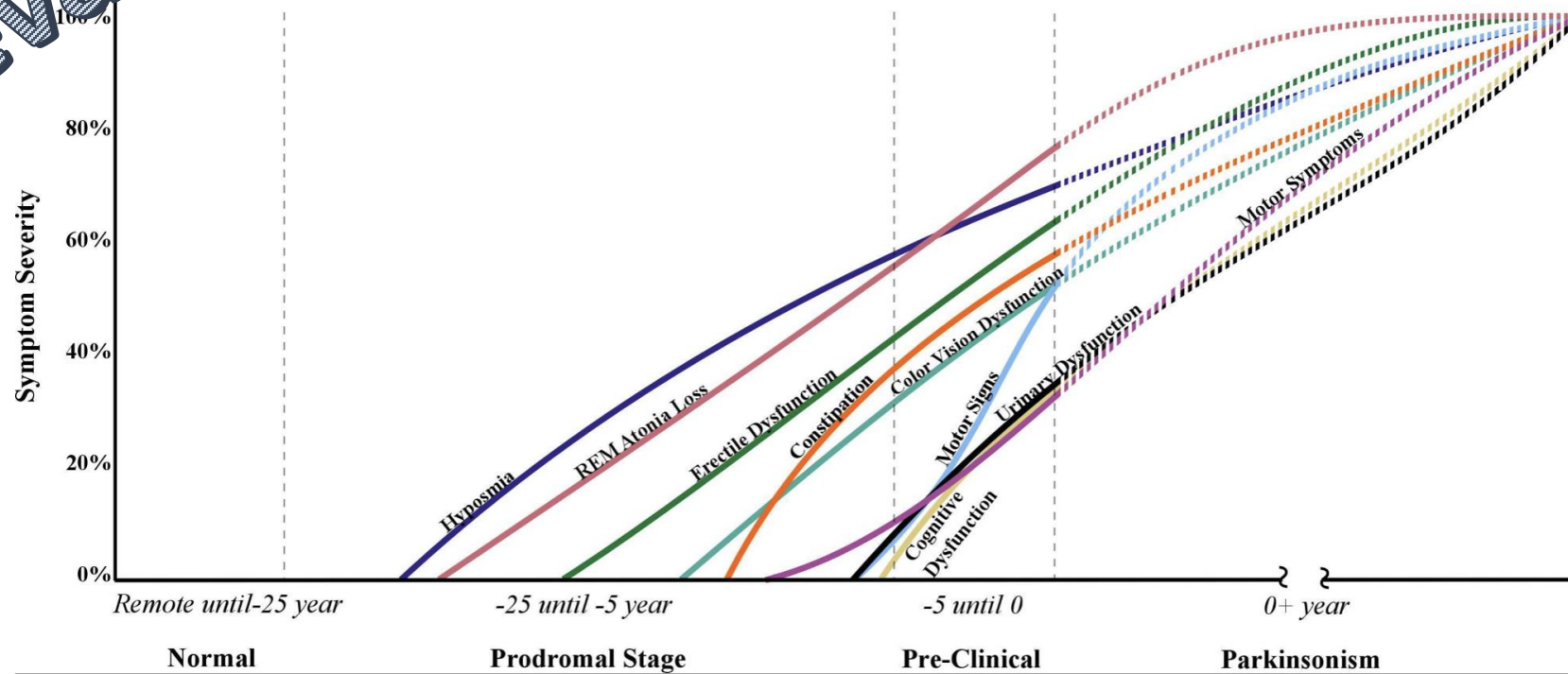


# Association Does Not Mean Causation

- It may be that people who exercise the most eat the most vegetables, and it's not the vegetables- but the exercise- that is responsible for the improved outcomes over time.
- These data do NOT tell us whether or not changing your patterns will change your outcomes.
- These data only tell us what the fast vs slow progressors are doing differently.

Clinical  
Relevance!

## START EARLY

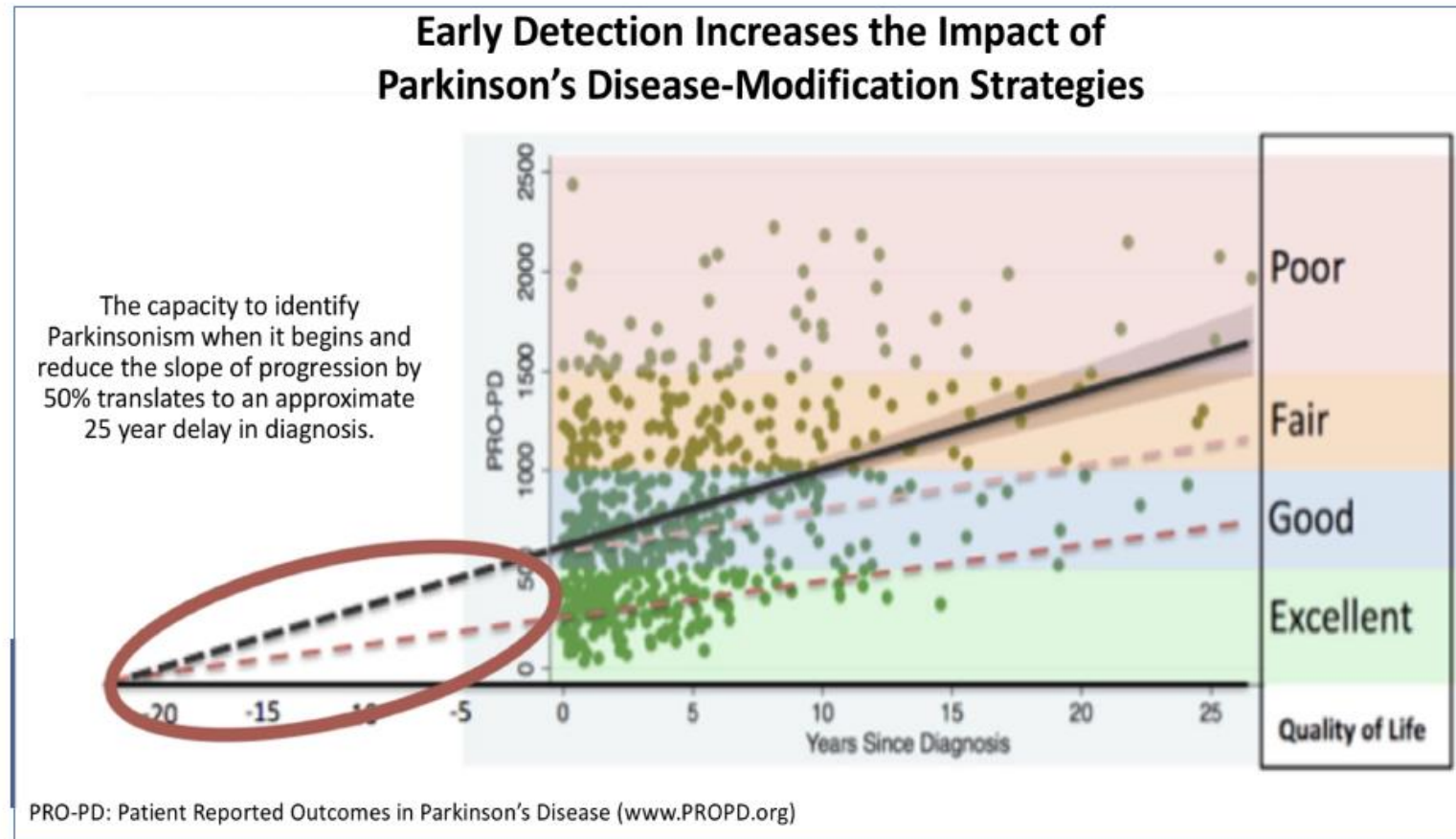


**Parkinson's disease and dementia with Lewy bodies: a prospective study**  
SM Fereshtehnejad, et al. *Brain* 20 May 2019

# START EARLY

There IS evidence the disease can be modified by lifestyle and a host of emerging pharmaceutical, nutraceutical, and activity-based therapies.

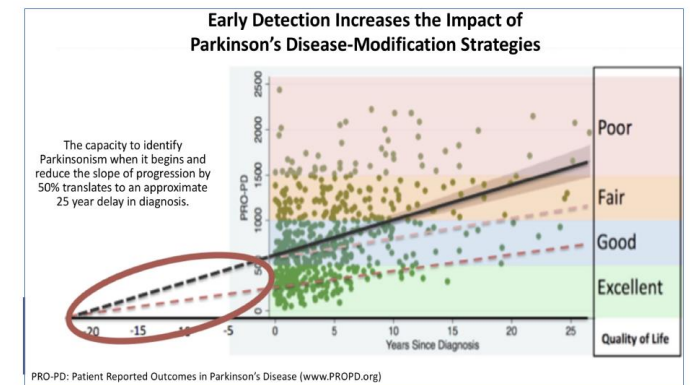
**Clinical  
Relevance!**



# Next Steps

- Ensuring that Canadians, esp. French-speaking, are represented in the research
  - Appoint a Canadian PI
  - Translate to French: [www.PROPD.org](http://www.PROPD.org)  
[www.CAMCarePD.bastyr.edu](http://www.CAMCarePD.bastyr.edu) / **Modifiable Variables in Parkinson (MVP) study**
- Education-Based Public Health Campaign
  - Teach everybody what early PD looks like
    - Loss of smell, sleep issues, fatigue, erectile dysfunction, constipation, acting out your dreams,...
  - Teach everybody that small reductions in slope can translate to major improvements in symptoms over time
  - Make people aware of the association between diet, exercise, social & financial health and PD outcomes.

There IS evidence the disease can be modified by lifestyle and a host of emerging pharmaceutical, nutraceutical, and activity-based therapies.



# Thank You!

[www.LivingHealthyWithParkinsons.com](http://www.LivingHealthyWithParkinsons.com)

[www.LaurieMischley.com](http://www.LaurieMischley.com)