Food, Water & Supplements: Does Nutrition Play a Role in PD Symptoms or Progression?

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Disclosures

- Research support: Michael J. Fox Foundation and community donors.

- Significant interest in the following companies:
  - ParK-9, Social Purpose Company (PD screening test)
  - Parkinson’s School (online program)
  - Laurie K Mischley, ND PhD MPH (clinic)

- Developed the PRO-PD rating scale (freely available at www.PROPD.org)

- Stock in Acorda.

- Not paid by any pharmaceutical or supplement company.
Nutrients provide nourishment.
Food may be a source of nutrients, or anti-nutrients.

Nutrition: the study of the human dependence on our environment.
Non-Dietary Sources of Nourishment

- Take these away, human health suffers:
  - Water
  - Air
  - Social connection
  - Gravity
  - Microbiome
  - Sleep

- **Nutrition**: Can we provide targeted nourishment and improve health?
Our data suggests identifying with the statement, “I am lonely” is worse for you than 7 days per week of exercise is good for you!
Exercise is a Nutrient

The more days per week PwP reported exercising, the fewer their PD symptoms over time.

Modifiable Variables Associated with Rate of Parkinson's Progression

AIHM Poster: Subramanian, Farahnik, Mischley 2019
Sleep

• Impaired sleep affects more than 50% of PwP and is associated with progression and depression. (MD Gjerstad, 2006)

• From the PPMI study, the following symptoms predicted faster PD progression: (KM Tsiouris, 2017)
  • Frequently disturbed sleep (REM sleep disorder)
  • Falling asleep while watching TV
  • Falling asleep as a car passenger

AIHM Poster: Subramanian, Farahnik, Mischley 2019
According to our “CAM Care PD” study of > 2000 PwP, which of the following is associated with the fastest rate of PD progression:

A) Not exercising
B) Poor sleep
C) Being lonely
How to Study Nutrition in PD

- Symptoms v. Progression
- Traditional Epi vs. Clinical Epi
- Motor vs. Non-motor
- Implications for study design, outcome measures, etc.
How to Study Nutrition in PD

Symptoms

• L-dopa for tremor.

• Fish oil for dyskinesia.

• Melatonin for interrupted sleep…

Progression

Increase Frequency of Getting (Incidence)

Accelerate Disease Progression (Rate)

Decrease Frequency of Getting (Incidence)

Slow Disease Progression (Rate)

TRADITIONAL EPIDEMIOLOGY
Well suited for acute conditions e.g. infectious diseases, heart attack, trauma.

CLINICAL EPIDEMIOLOGY
Well suited for chronic, progressive conditions, e.g. neurodegenerative diseases
How to Study Neurodegeneration

TRADITIONAL EPIDEMIOLOGY

Well suited for acute conditions
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CLINICAL EPIDEMIOLOGY

Well suited for chronic, progressive conditions,
e.g. neurodegenerative diseases
E.g., 5 studies suggest a link between dairy consumption and risk of later being diagnosed with PD.

E.g., 1 study suggests a link between dairy consumption and faster rate of PD progression.

**TRADITIONAL EPIDEMIOLOGY**

*Well suited for acute conditions e.g. infectious diseases, heart attack, trauma.*

**CLINICAL EPIDEMIOLOGY**

*Well suited for chronic, progressive conditions, e.g. neurodegenerative diseases*
Prodromal Parkinsonism

Parkinson’s disease and dementia with Lewy bodies: a prospective study
SM Fereshtehnejad, et al. *Brain* 20 May 2019
Studying PD Risk & Progression

Parkinson’s disease genetics research and Lewy bodies: a prospective study.

Well suited for acute conditions, e.g., infectious diseases, heart attack, trauma.

Well suited for chronic, progressive conditions, e.g., neurodegenerative diseases.
How to Study Prevention

1. Early Detection
   - Screening tests
   - Known risk factors

2. Slope Reduction
   - Continuous scale
   - Effective interventions
Early Detection + Slope Reduction = Prevention

1. Early Detection
   - Screening tests
   - Known risk

2. Slope Reduction
   - Continuous scale
   - Effective interventions

Early Intervention Makes Disease-Modification More Meaningful
How to Study Disease Modification

[Diagram showing the relationship between PRO-PD scores and Quality of Life over years since diagnosis, with categories for Poor, Fair, Good, and Excellent.]
Patient-Reported Outcomes

Use of a self-rating scale of the nature and severity of symptoms in Parkinson’s Disease (PRO-PD): Correlation with quality of life and existing scales of disease severity

Laurie K. Mosley\(^1\), Richard C. Lau\(^2\) and Noel S. Weiss\(^3\)

[Graphs and tables illustrating PRO-PD scores and their correlation with quality of life over years since diagnosis.]

Poor
Fair
Good
Excellent
Are Patients Accurate?

**ARTICLE**  
**OPEN**  
Use of a self-rating scale of the nature and severity of symptoms in Parkinson’s Disease (PRO-PD): Correlation with quality of life and existing scales of disease severity  
Laurie K. Mischley¹, Richard C. Lau² and Noel S. Weiss³

www.PROPD.org (scores are free)

PRO-PD correlates with existing measures of severity (UPDRS, HY)
Clinical Epi: Who are the Outliers?
Foods Associated with PD Progression

*Unpublished data from CAMCarePD study. N = 1600. 2013- April 2019*
2020 Update
N > 1500 PwP

For information about the study:
www.CAMCarePD.Bastyr.edu
Foods Associated with PD Progression

LK Mischley, J Farahnik 2020; updated analysis using previously published methods.
https://doi.org/10.1155/2017/6405278
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/ slow progressors are doing differently.
When to Implement?

Option A: Tell patients, “Do nothing until there is a placebo-controlled, randomized clinical trial of diet and progression.”

Option B: Advise people, “The currently available evidence suggests diet is associated with rate of progression. Eat more fresh fruits, fresh vegetables, nuts and seeds, non-fried fish, olive & coconut oil, wine, and green tea. Avoid canned fruits & vegetables, fried food, soda, dairy, beef, chicken, pork, pasta, & frozen vegetables.”
Implementation & Recommendation

**Encourage**
- Fresh fruit
- Fresh vegetables
- Nuts & seeds
- Non-fried fish
- Olive oil
- Coconut oil
- Wine
- Fresh herbs

**Avoid**
- Canned fruit
- Canned vegetables
- Fried food
- Soda
- Dairy
- Beef
- Pork
- Chicken
- Pasta
- Frozen vegetables
- Plastic-bottled drinks
Quiz #2

If a person with PD were to improve their diet, would we expect to see improvement in:

A) Motor symptoms
B) Nonmotor symptoms
C) Rate of progression
Special Diets: What’s Popular?

Ketogenic

Wahl’s

Mediterranean

Calorie Restriction
Calorie Restriction

• CR diets being studied for potential neuroprotective interventions
  - 12-14 hour fast ever night
  - Stop eating the 3 hours before bed.
  - Don’t eat in the morning until you’re hungry

• Individuals that are underweight need to consult a physician.
  • Orthorexia
  • Anorexia, sarcopenia, weight loss, malabsorption
Weight Loss

• Weight loss is associated with greater loss of dopaminergic function on DaTScan. (K Pak et al, 2018)

• In a large population study, weight loss occurring within 1 year of diagnosis was associated with loss of independence, dementia, and death. (K Cumming, et al 2017)

• Maintaining adequate daily calories is essential.
• Emphasize calorie-dense, nutrient-dense foods.
Sarcopenia (loss of muscle mass)

- **Sarcopenia**: age-related progressive loss of muscle.

- 1 in 5 patients with PD met diagnostic criteria. Sarcopenia was associated with PD severity. (DL Vetrano, et al. 2018)

- Ensure adequate calories, protein, absorption, etc.
- Do NOT let yourself become malnourished.
- Exercise muscles.
Hyposmia (loss of smell)

- **Exercise your sense of smell**
  12 weeks olfactory training using 4 odors 2x/day
  → improved sense of smell! (A Haehner et al, 2013)

- Smell is part of digestive process, tells body to start making appropriate digestive enzymes.

- Smell is involved in ability to taste. Impaired smell makes food less pleasurable—instead of adding sugar for flavor, add fresh herbs & spices.
Quiz #3

For PwP that are underweight and trying to add a few pounds:
Which macronutrient is the most calorie-dense?

A) Fat
B) Protein
C) Carbohydrates
D) Alcohol
Why Didn’t My Neurologist Tell Me That?
Borrowing from the Technology Adaption Curve

Unfounded wave of enthusiasm

Most people

Innovators

Laggards

Estimated 17 year time lag
For translation of research

ZS Morris, et al, 2011

https://www.cobloom.com/blog/crossing-the-chasm#
Nutrition Education in Medical School

• Average physician is getting about 19 hours of nutrition education during their entire medical school curriculum. (KMBW Adams, 2015)

• Difficult to patent natural substances, so fruits and vegetables don’t have the same industry funding for research, development, and educational events. Less awareness.

AIHM Poster: Subramanian, Farahnik, Mischley 2019
Supplements

• Not all nutrients come from food. Supplementation not always oral.

• B12— GI-related reasons why elderly people can’t absorb B12, require IM shots.

• Vit D-- some people spend too much time indoors, live too far from the equator, cover too much skin, etc.

• Iodine– some people live in regions of iodine insufficiency, government iodizes salt to prevent deficiency.
Supplement Dangers

- Bad idea to run out to the local supplement store and start buying all the supplements I mention!
- Cost
- Drug-Nutrient interactions
- Without baselines, won’t know what’s working
- Other conditions may make some of this contra-indicated
Supplements Associated with Progression

People taking these were more likely to report worse symptoms over time:

• Iron
• Melatonin*
*(association disappears after adjusting for bad sleep)

People taking these were more likely to report better symptoms over time:

• Glutathione
• Fish oil
• Coenzyme Q10
Supplements Associated with Progression

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- Glutathione
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- Coenzyme Q10

DON’T RUN OUT TO THE SUPPLEMENT STORE!
Supplements are much safer than pharmaceuticals, so they don’t require physician supervision.

A) True
B) False
Take Home

Don’t Wait to Implement potentially helpful interventions that have few risks associated with them.

→ Mediterranean diet (Plant-based, fish, olive/ coconut oil, wine, tea)
→ Exercise daily
→ Nurture relationships. Reach out to your community.
→ Protect your sleep
→ Discuss supplementation with a provider trained in nutrition & PD.

Nourishing yourself should occur all throughout your day, every day. Be thoughtful of the air, food, water, and friends you provide.
Contact: Info@EducationIsMedicine.com
PD GENEration: Flagship Program for Parkinson’s Genetic Testing

Who: People with PD
What: Free genetic testing and genetic counseling for 7 Parkinson’s linked genes
Where: Pilot program at 6 Centers of Excellence
Goal: 600 participants (pilot)
15,000 participants (national expansion in 2021)

❖ Pre-register online at: www.Parkinson.org/PDGENEration

✓ To schedule an appointment at a pilot site above, call/email the site
  Contact info available at: www.Parkinson.org/pdgeneration/sites
✓ Help us reach 600 participants to accelerate national expansion

Coming soon: Cleveland Clinic (Ohio, Florida)
What’s New in Professional Education?

Physical Therapy Faculty Program

THREE PROGRAMS THIS SUMMER

- Boston University: May 18–21st
- Washington University: June 15th–18th
- OHSU: August 3rd–6th

Applications Now Open!

parkinson.org/ptfaculty

Edmond J. Safra Nurse Faculty Program

SIX PROGRAMS THIS YEAR

This 50-hour accredited Nurse Faculty Program trains and educates nurse faculty across the country in PD care.

Applications Now Open!

parkinson.org/EdmondJSafraNursing

Advanced Allied Team Training for Parkinson’s (ATTP®)

ATTP ALUMI EXCLUSIVE

ATTP Cognition:
San Diego, CA
July 31–August 1, 2020

Registration is now open.

parkinson.org/attp
2020 Care Partner Summit | Cumbre Para Cuidadores
Planning for the Unpredictable Path of Parkinson's Caregiving

Miami, FL | May 16th, 2020

Join us live in Miami, at one of the many viewing parties around the world, or at home on your personal computer.

Visit Parkinson.org/Summit for more information.
Expert Briefings Topic Survey

Help Choose Topics for Our Upcoming Expert Briefings!

Whether you are a person touched by Parkinson’s disease or a health care professional, the Parkinson’s Foundation Expert Briefings offer the opportunity to learn more about PD symptoms, progression, treatments and management during our free, live and archived webcast program.

Click here to take the survey.
Resources

National Helpline
Specialists answer calls about all aspects of Parkinson’s in addition to helping you locate your local PD trained allied health professional therapist.
1-800-4PD-INFO
Helpline@Parkinson.org
Mon- Friday 9 am to 8 pm ET

Podcast: Substantial Matters
New episodes every other Tuesday featuring Parkinson’s experts highlighting treatments, techniques and research.
Parkinson.org/Podcast

Fact Sheets and Publications
Get the resources and information you need to start living a better life with Parkinson’s.

Aware in Care Kit
Includes tools and information for people with PD to share with hospital staff during a planned or emergency hospital stay.
Parkinson.org/Awareincare