



Bruno “Bytes” – September, 2017

(Bits and Tidbits from the Post-Polio Coffee House)

Available through a “link” from www.postpolioinfo.com
 (or) directly through <http://www.papolionetwork.org/bruno-bytes.html>

On the topic of PPS Diagnosis (9/11/2017)

Dr. Bruno’s Response: ALL PPS symptoms are diagnosed by exclusion, meaning that all other causes for fatigue, muscle weakness and pain have been rejected. There is no age limit to having PPS symptoms.

Please go to: <http://www.PostPoliInfo.com> for MIA FARROW'S POST-POLIO LETTER.

Click the menu on the left side of the page for information about the cause and treatment of PPS, including Social Security Disability information, surgical and dental precautions and The Post-Polio Library.

On the topic of Healing (9/14/2017)

Dr. Bruno’s Original Post: I think this article has a message for us. As the Buddhists say,

“Pain is inevitable; Suffering is optional.”

“The study found that people on healing journeys created connections with a wide range of helpers, including not only family, friends, and health professionals, but also non-human sources of support, such as pets, spirituality, and personal interests. These relationships proved instrumental in helping participants develop...the ability to reframe suffering in a positive light, the choice to adopt an optimistic attitude, and the capacity to take responsibility for one’s recovery.”



Credit: Sara Warber

This model of the “healing journey” describes how people who are ill re-establish a sense of integrity and wholeness. Researchers’ thematic analysis of patient interviews found that healing is a complex, long-term process facilitated by persistence and trusting relationships.

THE INSTITUTE FOR
INTEGRATIVE HEALTH

Study Provides New Insight Into Patients’ Healing Journeys

Researchers developed model of how people transcend suffering to find healing

Article ID: 681075

September 13, 2017 Source: The Institute for Integrative Health

Newswise — BALTIMORE — Substantial research has established the importance of doctor-patient relationships in facilitating the healing process. But few studies have explored patients’ broader experience of healing and how it can be fostered outside the medical system. Now, a new study, published online this week in *BMJ Open*, sheds light on the complex progression from illness to healing, which the authors call the “healing journey.”

The study is one of few to examine healing from the patient perspective. “The findings are helpful because they show, from the lived experience of people who are suffering, how the winding path of healing happens,” said co-author Kurt C. Stange, MD, PhD, a Distinguished University Professor at Case Western Reserve University and a Scholar of the Institute for Integrative Health, which helped fund the study.

The authors performed thematic analyses of in-depth interviews with 23 patients who had a variety of medical, psychological, and social issues. All had experienced healing, defined as “recovering a sense of integrity and wholeness after experiencing illness and suffering.” Interviews were conducted by the first author, John Glenn Scott, MD, PhD, for an earlier study of healing relationships between doctors and patients.

Using a combination of qualitative methods to analyze the transcripts, the authors identified emerging themes and developed a model illustrating the healing journey. The process it depicts begins with a wounding event, causing suffering, defined as “the experience of distress when the intactness or integrity of the person is threatened.” Its degree and quality are related to the

individual's characteristics, relationships, and stage of life. Through persistence, the suffering person forms safe, trusting relationships with helpers, who in turn, enable the person to gain resources, such as positivity. The cycle of acquiring relationships and resources repeats indefinitely, fostering beneficial attributes, such as self-acceptance. These contribute to a restored sense of wholeness and integrity, which constitutes healing. Transcript analyses revealed that healing was an erratic, long-term process, experienced uniquely by each person with their individual circumstances. The authors wrote: "People in the sample experienced healing journeys that spanned a spectrum from overcoming unspeakable trauma and then becoming healers themselves, to everyday heroes functioning well despite ongoing serious health challenges."

The study found that people on healing journeys created connections with a wide range of helpers, including not only family, friends, and health professionals, but also non-human sources of support, such as pets, spirituality, and personal interests. Crucial to forming connections were a feeling of safety and a sense of trust that connections would be conducive to healing. These relationships proved instrumental in helping participants develop skills and resources through observation and practice, including the ability to reframe suffering in a positive light, the choice to adopt an optimistic attitude, and the capacity to take responsibility for one's recovery from illness.

The authors note that the healing journey was recursive in nature, not step-wise. Mustering persistence and battling despair, people continually formed connections and gained new resources. As a result, they gradually found relief from suffering and began to exhibit emergent characteristics: a sense of hope, self-acceptance, and a desire to help others—the immediate precursors to healing.

Importantly, the authors go on to say that restoring a sense of integrity and wholeness doesn't require the absence of illness. None of the study participants was cured, yet as the authors point out, "they were all able to transcend their suffering and in some sense to flourish."

The authors are hopeful the study will influence a shift in the way patients and health care practitioners think about and approach healing. "By filling a gap in understanding the healing process, the study's findings may offer hope to those who are suffering and guide how they respond to their state of illness," said Dr. Stange. "Likewise, greater understanding of patients' journeys may positively inform the way health professionals, caregivers, and communities support those who are ill."

Other authors include two Institute for Integrative Health Scholars, Paul Dieppe, MD, FRCP, FFPH (University of Exeter Medical School) and David Jones, MD (The Institute for Functional Medicine), as well as Sara L. Warber, MD (University of Michigan Medical School), and John Glenn Scott, MD, PhD (Northeastern Vermont Regional Hospital, Dartmouth Geisel School of Medicine).

In addition to funding from the Institute for Integrative Health, Dr. Jones received some support from the Institute for Functional Medicine, and Dr. Stange received some support from a Clinical Research Professorship from the American Cancer Society.

<http://www.newswise.com/articles/view/681075/?sc=mwhn>

[On the topic of Kinesiology tape and muscle pain](#) (9/18/2017)

Original Post: Kinesiology tape is said to lessen muscular pain and aids circulation and lymph problems. Can I have some advice on using it?

Additional Post: My PT has been taping me for years – I believe in it with her help.

Dr. Bruno's Response: Taping can be very helpful but you have to have a knowledgeable physical therapist assess you and know where to apply the tape.

[On the topic of Prescription Drug Prices](#) (9/19/2017)

Dr. Bruno's Original Post: Looking for cheaper prescription drugs? Some folk didn't have luck with GoodRx. This is worth a look...

**BLINK
HEALTH**

<https://www.blinkhealth.com/>

[On the topic of Radiation for cancer and PPS Fatigue](#) (9/20/2017)

Original Post: I'm having radiation treatments for cancer. I find my fatigue level skyrocketing with more numb/tingling in more places along with more difficulty breathing. I'm only 1/2 way through my treatments for breast cancer. Chemo is up next.

Response from a Cancer Nurse: Chemo and other forms radiation treatments cause everyone tiredness, odd aches and pains, and vulnerability to virus and bacteria. Talk to your doctor about the breathing difficulty. Remind them about your PPS every time you go in. Make sure they track your blood oxygen levels.

Dr. Bruno's Response: I agree with the comment from above. Radiation and Chemo poop out everyone. So how much more would a polio survivor become exhausted? Lots!

Make sure your red cell count is good and that you're eating protein. Lung function studies would be helpful to assess breathing issues. Talk to your physician.

[On the topic of an Old Virus taking on a New Battle](#) (9/21/2017)

Dr. Bruno's Original Post:

NEW INFORMATION ON HOW THE POLIOVIRUS KILLS CANCER WITH A DOUBLE PUNCH ...

Poliovirus Therapy Induces Immune Responses Against Cancer

Investigational therapy directly kills tumor cells and unmarks them to the body's defenses

Article ID: 681262
Released: 18-Sep-2017 10:05 AM EDT
Source Newsroom: Duke Health



"...poliovirus starts by attaching to malignant cells, which have an abundance of...the poliovirus receptor. The modified virus then begins to attack the tumor cells, directly killing many, but not all. By killing the cancer cells, the modified poliovirus triggers an alarm within the immune system, alerting the body's defenses to go on the attack."

Newswise — DURHAM, N.C. — An investigational therapy using modified poliovirus to attack cancer tumors appears to unleash the body's own capacity to fight malignancies by activating an inflammation process that counter's the ability of cancer cells to evade the immune system.

Describing this process in a paper published Sept. 20 in the journal *Science Translational Medicine*, Duke Cancer Institute researchers provide the first published insight into the workings of a therapy that has shown promise in early clinical trials in patients with recurrent glioblastoma, a lethal form of brain cancer. The modified poliovirus received a breakthrough therapy designation from the Food and Drug Administration last year, expediting research.

"We have had a general understanding of how the modified poliovirus works, but not the mechanistic details at this level," said co-senior author Matthias Gromeier, M.D., a professor in the Duke Department of Neurosurgery who developed the therapy. "This is hugely important to us. Knowing the steps that occur to generate an immune response will enable us to rationally decide whether and what other therapies make sense in combination with poliovirus to improve patient survival."

Gromeier, with expertise in cancer biology, collaborated with fellow Duke researcher and co-senior author Smita Nair, Ph.D., an immunologist and professor in the Department of Surgery. The research team elucidated how the poliovirus works not only to attack cancer cells directly, but also to trigger a longer-lasting immune response that appears to inhibit regrowth of the tumor.

Using human melanoma and breast cancer cell lines, and then validating the findings in mouse models, the researchers found that the modified poliovirus therapy starts by attaching to malignant cells, which have an abundance of CD155 protein. The CD155 protein is otherwise known as the poliovirus receptor. The modified virus then begins to attack the tumor cells, directly killing many, but not all. This releases tumor antigens.

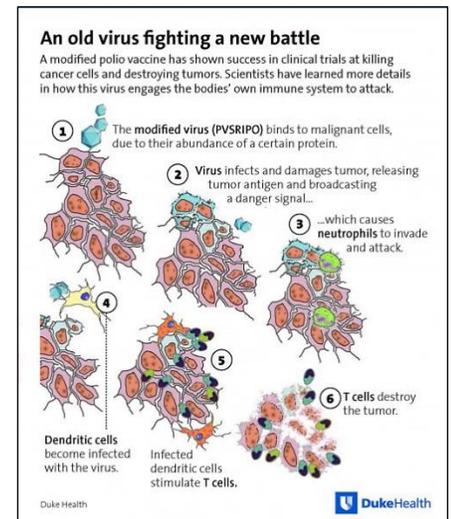
The second phase of assault is more complicated. By killing the cancer cells, the modified poliovirus triggers an alarm within the immune system, alerting the body's defenses to go on the attack.

This appears to occur when the modified poliovirus infects dendritic cells and macrophages. Dendritic cells then present tumor to T cells to launch an immune response. Once the immune system is activated against the poliovirus-infected tumor, the cancer cells can no longer hide and they remain vulnerable to ongoing immune attack.

"Not only is poliovirus killing tumor cells, it is also infecting the antigen-presenting cells, which allows them to function in such a way that they can now raise a T-cell response that can recognize and infiltrate a tumor," Nair said. "This is an encouraging finding, because it means the poliovirus stimulates an innate inflammatory response."

Nair and Gromeier said further studies will focus on the additional immune activity following exposure to the modified virus.

In addition to Gromeier and Nair, study authors include Michael C. Brown, Eda K. Holl, David Boczkowski, Elena Dobrikova, Mubeen Mosaheb, Vidya Chandramohan and Darell D. Bigner.



The study received support the Public Health Services (CA197264, CA124756 and CA190991), the Department of Defense, (W81XWH-16-1-0354); the Lefkofsky Family Foundation, Hope & Gavin Wolfe, and the BLAST Glioblastoma Foundation.

Nair and Gromeier, along with Brown, Chandramohan and Bigner, own intellectual property related to this research, which has been licensed to a company, Istari Oncology, Inc. Gromeier and Bigner are cofounders and equity holders in the company.

<http://www.newswise.com/articles/view/681262/?sc=mwhn>

[On the topic of being Slow to Heal After an Injury](#) (9/26/2017)

Original Post: Do PPS'ers have slower healing with injuries? I fell down my porch steps by tripping over my dog a week ago. My left leg is healing fine but my right leg, which is my weaker leg is still very tender and hurts even when nothing is touching it.

Dr. Bruno's Response: We say polio survivors take twice as long to heal from a fall, sprain or strain. But that's conservative. It could be 2, 3, 4 or 10 times as long. That being said, using the RULE OUT RULE by having some X-rays would be a good idea. You may want to check with your doctor if this continues.

[On the topic of 2018 DME \(Durable Medical Equipment\) Medicare Regulations](#) (9/28/2017)

Dr. Bruno's Original Post:

NEW FOR 2018: MEDICARE WHEELCHAIR & BRACE, DOCTOR & VENDOR REQUIREMENTS.

(Note that doctor and vendor must be enrolled in Medicare.)

Durable medical equipment (DME)

Medicare covers items like oxygen equipment and supplies, wheelchairs, walkers, and hospital beds ordered by a doctor or other health care provider enrolled in Medicare for use in the home. Some items must be rented. You pay 20% of the Medicare-approved amount, and the Part B deductible applies.

Make sure your doctors and DME suppliers are enrolled in Medicare. Doctors and suppliers have to meet strict standards to enroll and stay enrolled in Medicare. If your doctors or suppliers aren't enrolled, Medicare won't pay the claims they submit. It's also important to ask your suppliers if they participate in Medicare before you get DME. If suppliers are participating suppliers, they must accept assignment (that is, they're limited to charging you only coinsurance and the Part B deductible on the Medicare-approved amount). If suppliers are enrolled in Medicare but aren't "contract suppliers," they may choose not to accept assignment. If suppliers don't accept assignment, there's no limit on the amount they can charge you.

To find suppliers who accept assignment, visit [Medicare.gov/supplierdirectory](http://www.Medicare.gov/supplierdirectory) or call 1-800-MEDICARE (1-800-633-4227). TTY users can call 1-877-486-2048. You can also call 1-800-MEDICARE if you're having problems with your DME supplier, or you need to file a complaint.

For more information, visit [Medicare.gov/publications](http://www.Medicare.gov/publications) to view the booklet "Medicare Coverage of Durable Medical Equipment and Other Devices."

Durable Medical Equipment, Prosthetics, Orthotics, and Supplies (DMEPOS)

Competitive Bidding Program: If you have Original Medicare and live in a Competitive Bidding Area (CBA) and use equipment or supplies included under the program (or get the items while visiting a CBA), you generally must use Medicare contract suppliers if you want Medicare to help pay for the item.

Visit [Medicare.gov/supplier](http://www.Medicare.gov/supplier) directory to see if you live in a CBA and to find Medicare-approved suppliers in your area. If your ZIP code is in a CBA, the items included in the program are marked with an orange star. You can also call 1-800-MEDICARE.

For more information visit [Medicare.gov/publications](http://www.Medicare.gov/publications) to view the booklet "Your Guide to Medicare's Durable Medical Equipment Prosthetics, Orthotics, & Supplies (DMEPOS) Competitive Bidding Program."

<https://www.medicare.gov/pubs/pdf/10050-Medicare-and-You.pdf> Section 3, pp: 43-44

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<http://www.papolionetwork.org/bruno-bytes.html>

Scroll down the page (through the Current Month posts).
Previous months are located there, and are available by “clicking” on them, in easily printable PDF format

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