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The Rise of Pseudomedicine for Dementia and Brain Health

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The US population is aging, and with it is an increasing prevalence of Alzheimer disease, which lacks effective approaches for prevention or a cure.[1] Many individuals are concerned about developing cognitive changes and dementia. With increasing amounts of readily accessible information, people independently seek and find material about brain health interventions, although not all sources contain quality medical information.

This landscape of limited treatments for dementia, concern about Alzheimer disease, and wide access to information have brought a troubling increase in "pseudomedicine." Pseudomedicine refers to supplements and medical interventions that exist within the law and are often promoted as scientifically supported treatments, but lack credible efficacy data. Practitioners of pseudomedicine often appeal to health concerns, promote individual testimony as established fact, advocate for unproven therapies, and achieve financial gains.

With neurodegenerative disease, the most common example of pseudomedicine is the promotion of dietary supplements to improve cognition and brain health. This $3.2-billion industry promoting brain health benefits from high-penetration consumer advertising through print media, radio, television, and the internet.[2] No known dietary supplement prevents cognitive decline or dementia, yet supplements advertised as such are widely available and appear to gain legitimacy when sold by major US retailers. Consumers are often unaware that dietary supplements do not undergo US Food and Drug Administration (FDA) testing for safety or review for efficacy. Indeed, supplements may cause harm, as has been shown with vitamin E, which may increase risk of hemorrhagic stroke, and, in high doses, increase risk of death.[3,4] The Alzheimer's Association highlights these concerns, noting that many of these supplements are promoted by testimony rather than science.[5] These brain health supplements can also be costly, and discussion of them in clinical settings can subvert valuable time needed for clinicians and patients to review other interventions.

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Patients and caregivers encounter sophisticated techniques that supply false “scientific” backing for brain health interventions. For example, referring to scientific integrity, Feynman coined the term “cargo cult science” to describe endeavors that follow “…the apparent precepts and forms of scientific investigation, but they’re missing something essential….”[6] Cargo cult science is apparent in material promoting some brain health supplements; “evidence” is presented in a scientific-appearing format that lacks actual substance and rigor. Feynman suggested 1 feature of scientific integrity is “bending over backwards to show how [the study] may be wrong…,” which is a feature that is often lacking when interventions are promoted for financial gain.[6]

A similarly concerning category of pseudomedicine involves interventions promoted by licensed medical professionals that target unsubstantiated etiologies of neurodegenerative disease (eg, metal toxicity; mold exposure; infectious causes, such as Lyme disease). Some of these practitioners may stand to gain financially by promoting interventions that are not covered by insurance, such as intravenous nutrition, personalized detoxification, chelation therapy, antibiotics, or stem cell therapy. These interventions lack a known mechanism for treating dementia and are costly, unregulated, and potentially harmful.

Recently, detailed protocols to reverse cognitive changes have been promoted, but these protocols merely repackage known dementia interventions (eg, cognitive training, exercise, a heart-healthy diet) and add supplements and other lifestyle changes. Such protocols are promoted by medical professionals with legitimate credentials, offer a unique holistic and personal approach, and are said to be based on rigorous data published in reputable journals. However, when examining the primary data, the troubling and familiar patterns of testimony and cargo cult science emerge. The primary scientific articles superficially appear valid, yet lack essential features, such as sufficient participant characterization, uniform interventions, or treatment randomization with control or placebo groups, and may fail to include sufficient study limitations. Some of these poor-quality studies may be published in predatory open access journals.[7]

An argument can be made that even though pseudomedicine may be ethically questionable, these interventions are relatively benign and offer hope for patients facing an incurable disease. However, these interventions are not ethically, medically, or financially benign for patients or their families. While appealing to a sense of hope can be a motivating factor for clinical trials or complementary or alternative practices, the difference is in how these circumstances are framed. Complementary or alternative practices are often adjunct treatments and might not result in direct financial gain by the practitioner recommending the therapy. Further, in clinical trials, there are structured conversations between researchers and participants (such as during the informed consent process) that include research coordinators explaining that any studied interventions are experimental, may result in no gain, and can cause harm. In contrast, pseudomedicine may involve unethical gain for practitioners and manufactured illusion of benefit for patients.

What Can Be Done?

Health care professionals have the responsibility to learn about common pseudomedicine interventions. If a patient or family member inquiries about such an intervention, clinicians can take several steps:

- Understand that motivations to pursue such interventions often come from a desire to obtain the best medical care, and convey that understanding to the patients.
- Provide honest scientific interpretation of any supporting evidence, along with the associated risks and costs. This approach creates a productive dialogue, rather than dismissing any inquiries outright.
- Appropriately label pseudomedicine interventions as such.
- Differentiate testimony from data, and assess whether studies display scientific integrity by "bending over backward" to address any limitations.
- Suggest an exploration of the financial interests behind the intervention (eg, the sale of supplements, out-of-pocket payments to a clinician or organization, book sales). Note that the gain may not only be financial, but also temporary fame that can accompany spearheading a new protocol.[6]
- Provide education on the US Dietary Supplement Health and Education Act that limits FDA testing and regulation of supplements.
- Point out that any effective interventions for common diseases would already be widely used.
- Express a willingness to continue to partner with patients in their medical care even if opinions and interpretations about pseudomedicine differ.

Conclusions

It is disheartening that patients with dementia and their family members are targeted by practitioners and companies motivated by self-interest. Physicians have an ethical mandate to protect patients who may be vulnerable to promotion by these entities. More needs to be done on a national level to limit the claims of benefit for interventions that lack proven efficacy. Clinicians must distinguish testimony and cargo cult science from quality medical research and explain when interventions may appear to represent pseudomedicine. While unethical forces promote the existence of pseudomedicine, an educated community of physicians and patients is the starting point to counteract these practices.

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