False hopes and real risks with Alzheimer’s ‘treatments’

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“What do I have to lose?”

I hear this question regularly from patients who want to try the latest “breakthrough” in Alzheimer’s research featured on television or YouTube. These are typically things that either have been tested in animals with no human studies or supplements that have been tested haphazardly in small numbers of patients and then vigorously hyped.

For example, curcumin is a component of curry that has been tested in animals, with a single small negative study in human subjects, but is well publicized and recommended in the lay media. Bexarotene is a drug approved for skin cancer that showed impressive results in animals and is now in human testing.

A videotape of a single Alzheimer’s patient using coconut oil went viral and has everyone asking about it. A report of a single patient with a great response to the spinal injection of Enbrel has also been widely disseminated, with some physicians wondering if we should be trying this. Intravenous immunoglobulin, or IVIG — a product derived from blood — has been tested in an encouraging study in 36 patients, but it will really take the results of a larger study

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The Layton Aging & Alzheimer’s Disease Center is one of 28 NIH Alzheimer’s Disease Centers in the United States and the only one of its kind in Oregon. Our Center is recognized as a national leader in dementia care and research, and is committed to serving the needs of people throughout the Northwest.
To find out more about our current clinical studies, contact Lisa Loree: 503-494-7615.
(which will be reported later this year) to know whether it can really be recommended.

In each case, the drug is currently available, either as an approved supplement or as a drug which is Food and Drug Administration-approved for other indications. So there is a temptation to try it without real proof that it is effective for Alzheimer's: “What do I have to lose?”

In the case of curcumin and coconut oil, the answer is: “nothing.” I don’t push these treatments. But if my patients ask about them, I tell them: “Go ahead, give it a try.” I wish I could say that they come back with glowing reports, but sadly I have not heard much encouraging news.

My response is very different when I’m asked about Enbrel, IVIG, or bexarotene. In each of these cases, there is the possibility of significant side effects. Each of these requires a doctor and a prescription, and in the absence of good evidence in human subjects, I do not prescribe them.

Even for patients with Alzheimer’s, there is a lot to lose. Our patients have the capacity for a good quality of life for many years after diagnosis, and we can and should promote sensible, simple measures for improving quality of life rather than promote desperate attempts with real risks.

**Brain TLC**

A series of free public presentations on prevention of age-related cognitive decline

**Blood Sugar & Dementia:**

Is Alzheimer’s Type 3 Diabetes?
presented by Joseph Quinn, M.D.
**Wednesday, September 25, 2013 7PM**

OHSU Center for Health & Healing
3303 Bond Ave. Portland, OR 97239
3rd floor conference center

**Walk to End Alzheimer’s**

September 8, 2013, 2PM

The Alzheimer’s Associations Walk to End Alzheimer’s® is the nation’s largest event to raise funds for Alzheimer’s care, support and research. Held every year in more than 650 communities across the United States, people walk with dedication and the desire to make a difference.

This year’s Portland Walk to End Alzheimer’s takes place at Portland International Raceway.

To register for the Walk, visit www.alz.org
Telemedicine plans to bridge distance in memory care

At both Oregon Health & Science University (OHSU) and the Portland Veterans Administration Medical Center (PVAMC) telemedicine is being used to improve care of patients living in remote areas who would otherwise not have access to specialty care in their community.

Thirteen medical centers across Oregon are currently connected to the OHSU telemedicine network, saving rural families the difficulty and expense of traveling to a metropolitan medical center. Specialties now available through the OHSU network include stroke, trauma and psychiatry. The PVAMC also has widely adopted telemedicine to improve care to rural veterans. Mental health, prosthetics and cardiology are some of the specialties that utilize this technology.

Dr. Deniz Erten-Lyons, in collaboration with the departments of geriatric medicine and geriatric psychiatry at the Portland VA hospital, is creating a neurology telemedicine clinic to provide care to veterans with dementia and other cognitive disorders. This will include telemedicine visits through remote site clinics as well as directly from the patient’s home, provided there is a computer savvy caregiver and the availability of reliable internet connection. This will be particularly helpful in care of patients with advanced dementia, since bringing these patients to clinic visits can be challenging. Dr. Erten-Lyons anticipates providing telemedicine services to veterans with dementia across Oregon, Washington, Alaska, and Idaho.

Drs. Jeffrey Kaye and Deniz Erten-Lyons would like to ultimately establish a similar program for the OHSU Memory Disorders Clinic. While the experiences at the VA Tele-Health dementia program will guide the clinical aspects of this program, administrative issues unique to non-VA medical centers, such as insurance reimbursements for telemedicine visits from the patient’s home, need to be resolved.

Remote Monitoring Technology

In recent years, population aging has inspired development of new e-health technologies to support healthy aging and make good use of the limited health workforce. Remote monitoring technology (RMT), one form of e-health technology, is a way to facilitate proactive patient management and remove barriers to the receipt of medical care.

Researchers from OHSU, Intel Corporation, and Portland State University are investigating the use of RMT and how it may improve care access and enable early detection of disease onset. They seek to better understand rural primary care clinician interest in RMTs and to identify the resources necessary to incorporate technology into routine practice. Working in collaboration with the Oregon Center for Aging and Technology (ORCATECH), the team conducted interviews with rural primary care clinicians.

“RMTs may improve the quality of care, reduce access barriers, and help control medical costs,” said Melinda Davis, Ph.D., lead author of the study. “Our study is a first step in addressing this critical gap by exploring rural primary care clinician interest and the resources necessary to incorporate RMTs into routine practice.”

The team plans to continue partnering with clinicians and community members to study the impact of RMT implementation on patient quality of care and provider satisfaction. Dr. Davis noted, “It is critical to build bridges between the great ideas that come from academia and the needs of our on-the-ground partners who will ultimately decide whether or not to use these new technologies to enhance patient care.”
Digital age(ing): in-home monitoring for better health assessment.

Creative, cross-disciplinary teamwork results in new ways to address health needs.

To improve care and better predict changes in health, Layton Center and Oregon Center for Aging & Technology (ORCATECH) researchers collaborate on many technological solutions for continuous, life-pattern monitoring. When it comes to the health issues that develop as we age, infrequent office check-ups may not be the best way for clinicians to detect meaningful changes in an individual’s health. Now, unobtrusive in-home devices that measure every day activity show increasing promise for better health assessment. These devices can assist people to age in place at home, and at the same time, provide important information to health care providers. Tracking daily activity can result in comprehensive information for detecting cognitive and other functional changes, allowing for better preventive or early treatment.

Living Laboratory

For seven years, ORCATECH researchers have collected activity information through motion sensors and computers installed in the homes of study volunteers. Over time, researchers have learned from observing patterns of activity compared to other health and life-change information gathered from volunteers.

For example, study participants complete a weekly on-line health survey. Changes to an individual’s usual activity pattern, such as staying home more, sleep disturbances, or walking speed changes can be detected through sensors. Participants in this “Living Laboratory” have helped researchers discover what patterns to look for in detecting meaningful changes to health.

Walking

Through research, walking speed and variability have been shown to be predictors of cognitive health. OHSU’s Hiroko Dodge, PhD, Layton Center Biostatistics Core Leader explains, “Walking is a complex cognitive and motor task. Loss of motor control, posture, and balance is predictive of declines” in other cognitive abilities. Monitoring at-home walking is one way to detect possible cognitive changes before symptoms are otherwise noticed or reported.

Computing

Tracking time and speed of computer use is another tool that can be used to detect subtle cognitive change. Activity information collected on home computers has shown that, over time, participants with Mild Cognitive Impairment spend significantly less time per session on their computers, use the computer less frequently, and show more day to day variability, compared to cognitively intact participants.

As the use of computers becomes ever more common among older adults, facility with computers can now be considered a typical (or instrumental) activity of daily living – what researchers refer to as an IADL – for measurement of a person’s capacity to live independently. Now nearly universal.

Goals of continuous assessment:

- Be unobtrusive
- Identify highest risk individuals
- Early detection of changes
- Start early treatment
- Prevent acute events & hospitalizations
- Maintain independence
- Efficiently use resources & labor
- Save money
- Better clinical trials

UPDATE: The C. Rex and Ruth H. Layton Aging & Alzheimer’s Disease Center • Summer/Fall 2013
and essential in most American homes, the computer is an ideal tool for monitoring cognitive health as people age in place.

**Socializing**
According to several studies, older adults who have few social relationships are at an increased risk of depression and dementia. In order to learn how social engagement affects cognitive decline or depression, OHSU researchers are using technology that tracks telephone use and also video phones to test the impact of social interaction on the cognitive health of volunteer participants. One study found speech recognition software to be a useful tool for monitoring telephone interactions as a way to study social indicators of cognitive health. In another study, volunteers enjoy regular conversations with researchers, using internet-based video technology. The study aims to find out if persons who engage in daily social conversation improve in cognitive function and mood, over time.

**Taking medication**
Not remembering to take medication correctly, on time, is a problem for many older adults. It also may be a very early signal of cognitive and functional impairment.

An innovative technological device, the Med Tracker, was created by OHSU researchers to collect information about medication taking. Med Tracker is an ordinary pill organizer attached to an electronic device that records the timing of opening the pill box lids, providing valuable information about a patient’s day to day medication adherence.

**Imaging**
New brain imaging techniques help researchers to track a range of physical markers, such as brain volume and diseased structures in the brain.

Through imaging, researchers have identified a latent period of a decade or more during which some people show disease markers in the brain, but do not have symptoms of dementia. Images of a person’s brain may show, for example, the plaques and tangles associated with Alzheimer’s disease, though the person remains very capable of independent living.

Magnetic Resonance Imaging (MRI) scans can reveal bright patches in brain tissue, called White Matter Hyper-intensities (WMHs). WMHs are a marker of vascular disease, also associated with cognitive decline in aging.

Pre-symptomatic detection of these conditions is key for discovery of treatments that may prevent the development of disease.

By comparing imaging information with activity data from continuous monitoring, researchers are able to identify markers that help predict age-related cognitive decline. These technological tools enable providers and patients to become better partners in proactive health care.

For more information about ORCATECH research projects, visit www.orcatech.org

UPDATE: The C. Rex and Ruth H. Layton Aging & Alzheimer’s Disease Center • Summer/Fall 2013
Estate gift fuels the search for a cure

At the dining room table of their sunny, spacious home in Oregon City, overlooking their well-tended vegetable gardens, John and Nancy Dornan recall what it has been like to care for friends and family facing memory loss. "My dad had dementia," said Nancy. "He was a vibrant man, and the dementia took him away from us." The couple also watched a close friend slip away to the disease – forgetting how to drive a car and grasping for words to express his thoughts. "It takes your independence away," said John. "It’s just really sad when that happens to people."

Their empathy for these losses inspired John and Nancy to further help people who are facing dementia or Alzheimer’s. The Dornans chose to include OHSU’s Layton Aging and Alzheimer’s Disease Center in their estate plans and created a bequest in honor of Nancy’s parents, Bud and Lyda Huseman. "We feel strongly that research is very important," says Nancy. "We hope they will find a cure to end dementia as well as preventive measures and new ways to help people better deal with their loss of memory until a cure is found."

The Dornans considered many options to create a legacy for Nancy’s parents and chose to support the Layton Center because of their confidence in OHSU. "The doctors and staff are dedicated and passionate," said Nancy. "And OHSU is not just for the privileged few. We wanted to do something that will help everybody who needs it."

"The Dornans bequest is an investment in brain health for future generations," says Jeffrey Kaye, M.D., executive director of the Layton Center. "Through their generosity, the Dornans have created a legacy for Bud and Lyda Huseman that will advance our understanding of dementia and enable us to improve lives."

For more information how you can include the Layton Center in your estate plans, please contact Sarah Schwarz, director of gift planning, at 503-552-0702 or schwarzs@ohsu.edu.
OPAR 2013-14 grants awarded

The Oregon Partnership for Alzheimer’s Research (OPAR) administers funds donated by Oregonians who designate a portion of their refund as a donation to “Alzheimer’s research” on their tax return form. The volunteer OPAR scientific advisory committee has announced the award recipients for the 2013-2014 budget year. Of the eight proposals received, three grants were awarded:

Amy Henderson, MAIS,
The Geezer Gallery, Portland in collaboration with ORCATECH

Vibrant Elders: An art therapy intervention for seniors with mild cognitive impairment

Jeffrey Iliff, PhD,
OHSU Anesthesiology & Peri-operative medicine

Evaluating age-related failure of perivascular solute clearance pathways

Hiroyuki Nakai, PhD,
OHSU Department of Molecular & Medical Genetics

A novel tau-targeting approach to treat Alzheimer’s disease using adeno-associated viral vectors

You can support grants to new Alzheimer’s disease researchers in Oregon by donating directly to the Oregon Partnership for Alzheimer’s Research. To do so, visit www.opar.ohsufoundation.org.

For more information about the check-off grant program and the Oregon Partnership for Alzheimer’s Research, visit www.ohsu.edu/alzcheck.

Troy Kindy joins clinic to add social work support

The Layton Center Clinic is fortunate to welcome social worker, Troy Kindy, LCSW, who brings a wealth of experience and deep commitment to the service of dementia patients and their families.

Troy attended college in the San Francisco Bay Area and in Beijing, China. Throughout his career, Troy has demonstrated a commitment to making positive systemic change. During 5 years at the Family Caregiver Alliance in San Francisco, Troy supported family caregivers through intake and assessment of care-giving situations, leading family meetings, individual counseling, co-facilitating a caregiver support group, and coordinating respite assistance for caregivers. In 2004, Troy moved to Klamath Falls to help take care of his grandparents. There he served as a medical social worker at a community hospital, as well as starting a community education program on dementia and legal planning, in collaboration with the Alzheimer’s Association. Since 2005, Troy has worked at OHSU. Here, with the support of OHSUs Department of Care Management and Cultural Advocacy Team, he co-created the first state-wide, clinically-focused conference on elder abuse, in April 2012. Troy founded the Sylvia O. Kindy Scholarship in Geriatric Social Work at San Jose State University, named after his inspiring grandmother.

Troy joins the Alzheimer’s clinic excited about the opportunity to help with referrals, crisis intervention, emotional support and practical coping skills for patients navigating the strain that arises when families live with a chronic neurological disorder.

Troy’s expertise is made available to Layton Center patients and families through support from the Barbara Emily Knudson Charitable Foundation and The Holzman Foundation, Inc.
Because everyone deserves the best future.

This year more than ever, it’s important to visit your estate plans to provide for the ones you love and the causes closest to your heart.

A gift to OHSU made through your will, trust, retirement account or life insurance policy supports breakthrough treatments, leading-edge research and compassionate care for all our patients far into the future – the very BEST future.