Letter to the New York Times

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Caring for the Patient With Alzheimer’s

***By** PAM BELLUCK*

In a recent New York Times article, “Giving Alzheimer’s Patients Their Way, Even Chocolate,” I looked at caregiving for people with Alzheimer’s disease and described how scientists and researchers are studying approaches to caregiving that appear to ease some of the most troubling symptoms, like wandering or agitated and aggressive behavior. Certain approaches to caregiving can make life more pleasant for patients, who, research suggests, continue to feel emotions like joy or sadness even if they have no memory of the experiences that caused those emotions. And they can, in turn, make things easier for caregivers, allowing people to care for relatives with Alzheimer’s at home and delay placing them in nursing homes.

In the coming months, issues involving caregiving may be considered for inclusion in a national strategic plan on Alzheimer’s. The plan is part of the National Alzheimer’s Project Act, just passed by Congress and expected to be signed by President Obama. The act would create an advisory council of representatives from all the federal agencies concerned with health, science and aging, and the council would devise a coordinated national plan to ”accelerate the development of treatments that would prevent, halt or reverse the course of Alzheimer’s” and ”improve the early diagnosis of Alzheimer’s disease and coordination of the care and treatment of citizens with Alzheimer’s.”

What kinds of concerns about caregiving in both institutional and home settings do you think a federal advisory panel should focus on?

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Dear Ms Belluck
In response to your question: What kinds of concerns about caregiving in both institutional and home settings do you think a federal advisory panel should focus on?

We applaud you for highlighting individual programs for people with dementia with excellent nonpharmacological interventions, such as the Beatitudes program in Arizona ("Giving Alzheimer's Patients Their Way, Even Chocolate" by Pam Belluck; NY Times; 31 December 2010). Such programs deserve to be complimented for employing dignified and self-fulfilling nonpharmacological interventions that reduce the 4 "A's" of Alzheimer's: anxiety, agitation, aggression and apathy.

There is, however, a major drawback to doing this, namely that the larger unique and positive alternative paradigm (picture) of nonpharmacological interventions in Alzheimer's is reduced to actions that sound simplistic (give people chocolate), obscuring the larger more profound picture and paradigm; the forest is being blocked by the trees. What is that larger paradigm?

1. A DIFFERENT PARADIGM
   Nonpharmacological interventions represent a global paradigm of Alzheimer's treatment; much more than just individual actions such as chocolate, dolls, and environmental design. This paradigm, based on neuroscience theory, applied research, and clinical practice, has been developed by many experts over decades. If this powerful approach to dealing with dementia and reducing symptoms is to be taken seriously, the particulars, no matter how exceptional (such as museum programs for people with Alzheimer's, providing improvisational theatre, or giving chocolate), need to be taken as examplars of a larger way of thinking about Alzheimer's and dementia—a new paradigm—not as ends in themselves.

2. EVIDENCE-BASED PRACTICE
   There is a huge cache of evidence-based knowledge demonstrating how non-pharmacological interventions reduce symptoms and improve daily lives of people living with dementia and their care partners. This research is often discounted and rejected because although it is meaningful and fits the needs of the evaluation being conducted, it does not fit a particular research model—the double blind randomized controlled trial. It is important to assess these data carefully to calculate the statistical effect sizes they represent and thus their impact on people's lives.

3. METHODOLOGY AND METHODS
   Much existing research is discounted by policymakers, researchers, and others because they are convinced that the only evidence worth counting is generated by double-blind randomized controlled trials (RCTs). RCTs represent one important way to generate knowledge; but only one way. Other methodologies contribute substantially to our knowledge of nonpharmacological interventions and need to be taken seriously. It makes little sense to discredit a large body of knowledge that could immensely help policy and decision-making. The following summarizes two alternative ways to think about research methodology.

   The RCT gold standard assumes that 1. It is the highest level of proof, no matter what the research question, 2. It is at the top of a hierarchy of methods where other methodologies are "lower" on the continuum, and 3. That statistical significance is a measure of meaningfulness of a finding.

The alternative gold standard for nonpharmacological and other research assumes that 1. The best methodology for any research question is the methodology that fits the question best--not any particular one, 2. There is no single continuum of methodology and no absolute hierarchy, and. 3. That effect measures are an important addition to statistical significance as a measure of a finding's "meaningfulness."

4. HUMAN RIGHTS
   Freedom to choose, getting what you want, being part of the larger society and taking part in cultural activities are human rights everyone deserves—including those living with Alzheimer's and other dementias. We ought to be shocked at the limits to human rights being imposed daily on those with dementia (no chocolate and no visits to museums) rather than amazed that human rights are being respected in a few places—Arizona, or New York, or Massachusetts or wherever.

   The World Health Organization defines the rights of all people as dignity, independence, self-fulfillment, participation and care. Respecting these for people living with Alzheimer's could well be a rallying cry for those who care about people living with this condition.

5. THE WAY OUT OF THE ETHICAL DILEMMA OF EARLY DIAGNOSIS
   In the name of science and further research, there is a movement taking place to diagnose Alzheimer's disease long before those being diagnosed show any cognitive or behavioral symptoms. Although these tests are presented as limited to research purposes, they are highly likely to be employed in everyday practice. For the millions who will receive this early diagnosis tomorrow and the millions living with this dementia diagnosis today, early diagnosis presents a major ethical dilemma: What to do with a diagnosis if no medications are available that stop the progress of the disease? The nonpharmacological paradigm and its associated interventions represent an ethical way to respond to the call for early Alzheimer's diagnosis since they offer a clear solution to improve the quality of life of people living with dementia.

For these reasons, we urge the Federal Advisory Panel to the National Alzheimer's Project Act just passed by Congress and others administering research programs for dementia to include on an equal basis in all research, both nonpharmacological treatments and pharmacological ones. By nonpharmacological "treatments" we mean all health related activities that research has demonstrated have positive behavioral and health outcomes. These include, among others: engaging activity, exercise, targeted nutrition, music, visual arts, film, drama, museums, an appropriately designed and stimulating environment, memory books, high-touch end of life care, external written cueing, information technology, training family and formal caregivers, counseling, meditation, yoga, tai chi, exercise, poetry, storytelling, pets, and even chocolate.

We also urge the Federal Advisory Panel and those administering Alzheimer's-focused research programs and Alzheimer's-focused intervention strategies to develop and make explicit key performance indicators suited to nonpharmacological interventions. We also urge them to include in research protocols all evaluation methods and methodologies suited to studying the effects of real-world applications of nonpharmacological treatments. We urge that all research involving treatment of dementia, both pharmacological and nonpharmacological interventions, include reporting the clinical significance of effects produced by treatments, as well as statistical significance.

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