

# Ecopsychosocial Interventions in Cognitive Decline and Dementia: A New Terminology and a New Paradigm

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**John Zeisel, PhD, DSc (Hon)<sup>1,2</sup>, Barry Reisberg, MD<sup>3</sup>,  
Peter Whitehouse, MD, PhD<sup>4,5</sup>,  
Robert Woods, MA, MSc, FBPSS<sup>6</sup>, and Ad Verheul, MA<sup>7</sup>**

## Abstract

Dementia is a major medical and social scourge. Neither pharmacological nor nonpharmacological interventions and treatments have received sufficient funding to be meaningful in combatting this tsunami. Because the term—"nonpharmacological"—refers to what these interventions are not, rather than what they are, nonpharmacological treatments face a special set of challenges to be recognized, accepted, funded, and implemented. In some ways, the current situation is analogous to using the term "nonhate" to mean "love." This article presents a carefully reasoned argument for using the terminology "ecopsychosocial" to describe the full range of approaches and interventions that fall into this category. These include interventions such as educational efforts with care partners, social support programs for individuals with various levels of dementia, efforts to improve community awareness of dementia, an intergenerational school where persons with dementia teach young children, and the design of residential and community settings that improve functioning and can reduce behavioral symptoms of dementia. The proposed terminology relates to the nature of the interventions themselves, rather than their outcomes, and reflects the broadest range of interventions possible under the present rubric—nonpharmacological. The goal of this new label is to be better able to compare interventions and their outcomes and to be able to see the connections between data sets presently not seen as fitting together, thereby encouraging greater focus on developing new ecopsychosocial interventions and approaches that can improve the lives of those with dementia, their care partners, and the broader society.

## Keywords

nonpharmacological, Alzheimer's, dementia, terminology, ecopsychosocial

## Introduction

Governments and helping organizations globally are anticipating, with anxiety and trepidation, the enormous cost in both quality of life and currency of what many call the impending tsunami of dementia—a condition associated with aging. The number of persons with Alzheimer's disease and other forms of dementia in the world is expected to increase from 36 million people in 2016 to 115 million in 2050. Associated costs consequently can be calculated to increase from an estimated US\$655 billion annually worldwide in 2016 to nearly US\$2 trillion annually at midcentury.<sup>1</sup> Although investments are being made in the search for a pharmacological solution to dementia—a relatively small financial investment in terms of the dimension of the problem—investment into what are popularly called nonpharmacological interventions lags much farther behind (note 1).

Nonpharmacological interventions developed for persons with dementia include cultural events, such as guided museum programs for persons with cognitive challenges<sup>2</sup>; community

efforts, such as training residents to recognize and respond to the needs of persons with dementia living in their community; designing environments with recognizable landmarks that, by linking to the brain's cognitive map, help persons with

<sup>1</sup> Hearthstone Alzheimer Care, Woburn, MA, USA

<sup>2</sup> The I'm Still Here Foundation, Woburn, MA, USA

<sup>3</sup> Zachary and Elizabeth M. Fisher Alzheimer's Disease Education and Resources Program, Department of Psychiatry, New York University Langone Medical Center, New York, NY, USA

<sup>4</sup> Case Western Reserve University, Pittsburgh, PA, USA

<sup>5</sup> Baycrest, University of Toronto, Toronto, Ontario, Canada

<sup>6</sup> Dementia Services Development Centre, Bangor University, Wales, United Kingdom

<sup>7</sup> Co-founder, Snoezelen-Multi Sensory Environment, Centre De Hartenberg s'Heeren Loo, Ede, the Netherlands

## Corresponding Author:

John Zeisel, PhD, DSc (Hon), Hearthstone Alzheimer Care, Suite 103, 130 New Boston Street, Woburn, MA 01801, USA.

Email: zeisel@thehearth.org

dementia find their way<sup>3</sup>; creative projects, such as group story writing that provides a sense of achievement<sup>4</sup>; cognitive training that builds on procedural learning abilities retained by persons with dementia<sup>5</sup>; and educational efforts, such as teaching family members to better interpret behaviors of their loved ones.

These and other initiatives with similar purposes aim to replace maladaptive behavioral symptoms such as the 4 “A”s of Alzheimer’s disease<sup>6</sup>—anxiety, agitation, aggression, and apathy—with socially engaging behaviors. Nonpharmacological interventions are on the front line of support to improve quality of life of persons with dementia. We assert in this article that nonpharmacological interventions for persons with dementia deserve formal recognition and support and therefore ought to be identified by a positive and distinctive nomenclature. A more precise nomenclature for this field of research and practice will ultimately assist in reducing conditions that lead to care in more costly and frequently less satisfying health-care environments.<sup>7</sup> The more such positive interventions cut the costs of care and increase the satisfaction and psychological and physical health of both persons with dementia and those who care for and about them, the greater the savings for society. If nonpharmacological interventions merely reduce the global monetary costs of care for persons living with dementia by only 5% in 2016, governments, health systems, and individuals worldwide will save nearly US\$33 billion dollars annually (note 2).

## The Need for a Distinct Field of Inquiry

There are important reasons why global investment in research into these humanistically valuable and potentially cost-effective “nonpharmacologic” approaches lags so far behind investment in pharmacologic treatments. One reason is the lack of a clear definition of these efforts as a distinct field of research and intervention. Other reasons for the relative paucity of research investment include significant methodological challenges to carrying out nonpharmacological research and the fact that nonpharmacological interventions often have little commercial viability. Exploratory studies that indicate positive outcomes of nonpharmacological interventions are often underfunded and subsequently discounted as not rigorous enough.

To overcome the first of these challenges—lack of a clearly formulated definition—we propose to introduce the term—*ecopsychosocial*—to replace the term nonpharmacological in both research literature and common parlance. Instead of defining this research area in terms of what it is not—not pharmaceutical—the term *ecopsychosocial* inclusively incorporates the full breadth and complexity of this area of inquiry and practice as reflected in the many studies being carried out and interventions currently in practice. Use of the term nonpharmacological raises ethical and practical issues as well as being conceptually inelegant; it is a commonly accepted shortcut that does not adequately describe the phenomena it refers to, a shortcut, to continue the metaphor, that may lengthen the

journey by creating more problems for the entity it seeks to describe than a more direct and apposite label.

## Labeling: An Epistemological Challenge

Labeling an intervention nonpharmacological means simply that it does not include pharmaceuticals in its protocol. Rather than identifying the nature of such interventions—what they actually are—the term frames the interventions negatively—what they are not. Although the term nonpharmacological is both imprecise and undervalues the positive nature of such interventions, it is gaining traction in the professional literature, increasing the urgency to come up with a new label. The term is being used to describe a wide range of evidence-based programs such as caregiver training to assist in the understanding of the dementia process,<sup>8</sup> adaptive technologies that help the person communicate, the effects of personal care staff wearing street clothes instead of uniforms,<sup>9</sup> and interactive improvisational drama programs that engage persons’ creativity.<sup>10</sup>

The label nonpharmacological increasingly is being used to describe major shifts in the social milieu of persons with dementia such as counseling and support of family members to assist them to understand and live with the effects of dementia,<sup>11</sup> activity-based drama and art interactions in which residents choose their own subject matter,<sup>12</sup> and environmental interventions, such as creating home-like settings to help residents adapt more easily to change.<sup>13</sup> Such labeling fails to recognize that these interventions may be of greater significance and effectiveness in comparison with existing pharmacologic treatments<sup>14</sup>—and at the very least ought to be considered complementary to conventional treatment. In treatment of behavioral and psychological symptoms of dementia, so-called nonpharmacological interventions have been shown to reduce and even eliminate the use of potentially harmful medications.<sup>15–19</sup>

In dementia research, there is clearly an increase in interest in nonpharmacological approaches. A significant article by Cohen-Mansfield in which she uses the acronym “NPHI” for nonpharmacological interventions<sup>20</sup> is a prime example. Other recent articles on nonpharmacological interventions in dementia include studies of agitation,<sup>21,22</sup> the effects of music,<sup>23</sup> delirium,<sup>24</sup> and Huntington’s related dementia.<sup>25</sup>

The term nonpharmacological is increasingly used in basic medical research literature as well, not only in research related to dementia. Scholarly and professional articles appear regularly describing a range of nonpharmacological interventions to treat health conditions such as recovery from heart transplants,<sup>26</sup> gastrointestinal disorders,<sup>27</sup> fibromyalgia,<sup>28</sup> premenstrual syndrome,<sup>29</sup> hypertension,<sup>30</sup> and children’s postoperative pain.<sup>31</sup> As the term *ecopsychosocial* is increasingly adopted, it will be imperative in future publications to cross-reference the 2 terms nonpharmacological and *ecopsychosocial*.

Ethical and practical questions are raised by the use of the term nonpharmacological. These include: How does the use of

a nonspecific and inexact label limit financial resources for research? Does such a label make it unnecessarily difficult to acquire and compare potentially significant research data and evidence? Does using a negative label limit access to treatments that might provide those with dementia and their partners a higher quality of life?

A similar shift in terminology with an equally difficult transition for the field is the way researchers and clinicians avoid using the term “behaviors” when referring to the many, often socially disruptive, ways in which those living with dementia may express themselves or communicate their needs.<sup>32</sup> Although this transition takes time and effort, the shift eventually benefits all those with dementia who are presently being treated as if their behaviors have little to do with intent and meaning and are merely phenomena to eliminate using whatever means possible.

## Seeking a Better Name

Often used interchangeably with nonpharmacological, the term *psychosocial* refers to outcomes of interventions aimed at improving a person’s psychological state or social situation. According to Vasse et al,<sup>33</sup> the American Psychiatric Association has a formal definition for psychosocial interventions: actions that “aim to improve quality of life and psychological and social functioning, and to maximize function in the context of existing deficits.”<sup>34(p8)</sup> There is no similar definition for nonpharmacological interventions.

The terms *psychosocial* and *biopsychosocial* are also used interchangeably with the term nonpharmacological but clearly do not encompass the broad array of what are now being called nonpharmacological interventions. Programs such as intergenerational charter schools where elders with dementia teach and learn from younger students<sup>35</sup> and museum visit programs where those with dementia look at and discuss works of art in normal settings<sup>36</sup> improve the quality of life for persons with dementia and have psychosocial effects, but these programs encompass much more. Environmental contextual change that is integral to such actions and programs is clearly not included under the umbrella of psychosocial effects. The impact of such interventions is on context and environment, not simply on the individual living with the disease. Context and the broader impact of change are missing from current nomenclature. *Psychosocial* describes some effects of some interventions on individuals, but the terminology does not adequately address the impact of contextual changes brought about by access to safe therapeutic gardens or introducing into the setting a new object such as a “memory book” with structured visual memory jogging material,<sup>37</sup> using computer tablets for communication, or introducing music and art appreciation as a way to engage people with dementia in meaningful discussion.

The name change from nonpharmacological to *ecopsychosocial* interventions should also help dissolve the narrow perception that the only hope for quality of life for persons with dementia lies somewhere in a vague future when a cure is discovered. Because the term nonpharmacological does not

adequately suggest that there are many interventions readily and easily available to individuals and families who provide care for persons with dementia, a new descriptive term reinforces a more user-inclusive approach to care.

## Ecopsychosocial—A Term to Cut the Gordian Knot

Using the prefix *eco-*, as used in the term *ecological*, begins to resolve the insular terminology dilemma. The Merriam-Webster online dictionary defines ecological as “the interrelationship of organisms and their environment” and to the study of “the relationships between a group of living things and their environment.” Frequently used in biology, sociology, and psychology to include contextual factors, the term “eco-” —which Wiktionary online defines etymologically as rooted in the Greek term for house or household (*oikos*)—rectifies the current terminological deficiency. Since many interventions presently considered nonpharmacological are concerned with changing the context or environment of persons with dementia, it is clear that a reference to “context” is advantageous if not essential in defining this approach.

In the field of environmental psychology that plays a major role in nonpharmacological treatment of dementia, the work of Gibson<sup>38</sup> highlights the theory of “affordances” and “niches” in what Gibson labeled “ecological psychology.” Affordances are the opportunities environments offer—from the scale of a teacup to that of a city and beyond—that are directly perceived and acted upon by users. Niches—ecological niches—represent a set of affordances in which individuals can choose to express their needs or not, according to their abilities and the environmental constraints they naturally face. This approach holds particular hope for people with dementia because no cognitive analytic interpretation is necessary to read and negotiate such environments.

The work of prominent gerontologists and environmental psychologists with expertise in the role of the physical environment in the lives of persons with dementia has led to conceptual constructs demonstrating the effects of the physical environment on the health and well-being of elders with dementia. One of these, Lawton’s “environmental press model,”<sup>39</sup> describes how a middle level of environmental support—neither too stressful nor too supportive—provides the healthiest level of challenge to older users. Bronfenbrenner’s “ecological model,”<sup>40</sup> Algate et al’s “need-driven behavior model,”<sup>41</sup> and the work of Cohen-Mansfield and Warner<sup>42</sup> provide other critical examples. This body of work provides further justification for including the prefix “eco” in any replacement term for the label nonpharmacological.

Using the prefix “eco” as we suggest presents a potential conceptual trap. Since “eco” has been so much used by those who promote and defend the natural environment, the use of this prefix may conjure up in some readers’ minds images of the outdoors and protesting against global warming. Nevertheless, we suggest its use because of its conceptual elegance and origins.

The term *ecopsychosocial* provides a significant improvement over the present term nonpharmacological, positively delimiting an expanding category of therapeutics and serving to draw together for research purposes a broad group of interventions to treat dementia.

The value of the ecopsychosocial terminology for the scientific community is that identifying a field with clear and, in this case, potentially broader boundaries and components should result in more fruitful professional discussion while providing a vehicle for structured research support. As the field of ecopsychosocial studies of cognitive decline and dementia is increasingly recognized, subject matter, academic curricula, and research protocols particularly suited to the field are likely to emerge. Similarly, results of related research projects can more easily be compared—thus contributing to a critical mass of comparable data to be used in resource allocation and policy making.

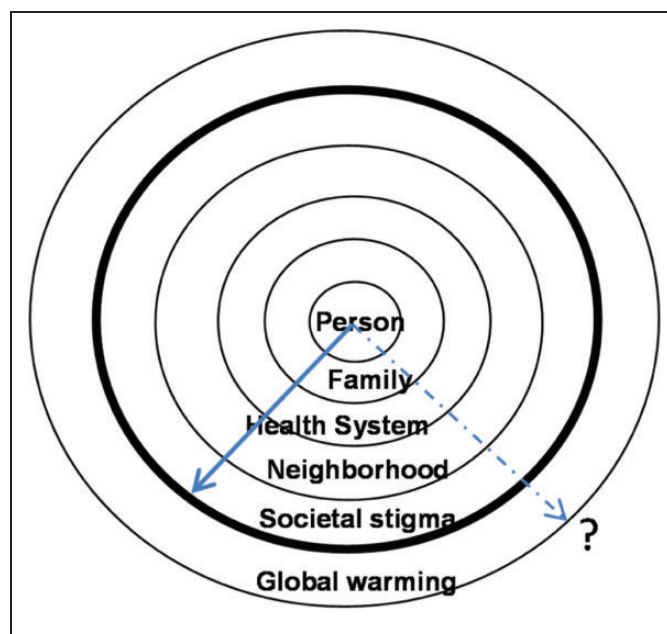
### Determining the Range of “Ecopsychosocial” Outcomes

Including environment as a factor raises the question of what scale or range of environment ought to be considered when defining the environmental context of ecopsychosocial interventions. What is the environmental range of the “dementia problem”? Figure 1 provides a conceptual diagram of the ecopsychosocial approach.

Clearly, the person at the center of the diagram, his or her family, and their health system are part of the “dementia person’s” environment. But what about the neighborhood and larger community? Community resources are important because those living with dementia are more likely to use the physical and commercial environments near their homes and in their community if they feel welcome and if neighbors are trained to understand and respond to their needs. Social policies and practices need to resist the culturally defined social stigma associated with the disability, so that dementia is no longer a barrier to social integration.

Local government regulations that affect barrier-free streets, parks, and public transit as well as environmental requirements, codes, and standards for special-needs residential environments are directly relevant to the context within which people with dementia live. The argument can be made that urbanization, air pollution, the way our food is handled and sold, and global warming are all part of the dementia person’s environment. However, expanding the definition of ecopsychosocial context beyond the context of community and society runs the risk of diluting the discipline beyond practical bounds. We propose to include the study of social attitudes toward persons with dementia and the stigma associated with dementia, as well as social policies and investment in dementia, as relevant contextual limits at this time.

In summary, nonpharmacological approaches make up a dynamic and expanding field of treatment and research with positive effects on illnesses and diseases including dementia. The scientific and practice communities need better and more



**Figure 1.** Environmental range of ecopsychosocial interventions in dementia.

positive language to describe this growing field. Although the term nonpharmacological emphasizes what the field is not and forces the definition to center in and around conventional pharmacological therapies, the term we propose, *ecopsychosocial*, incorporates environmental and contextual influences and emphasizes the importance and positive nature of a broad range of interventions in the lives of those living with dementia.

*Ecopsychosocial* is a practical and conceptually elegant term to replace the term nonpharmacological in dementia and other studies. Ecopsychosocial avoids defining phenomena by what they are not and, more significantly, includes the broad range of subject matter and research interest actually included in the overall term, especially contextual issues and environmental design. Every concept, including ecopsychosocial needs to evolve through debate, research, and government action. We urge and welcome the professional community’s adoption of the new recommended terminology as well as ongoing commentary and study of these matters.

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### Notes

1. According to the National Institute of Health's (NIH's) Research Portfolio Online Reporting tools (RePORT), 1659 grants were awarded under the NIH spending category of dementia in fiscal year 2013. In a random sample of 100 of these awards, only 2% of grant awards and only 1.6% of monetary funding (US\$468 345 of US\$29 741 932 for the 100 studies) were awarded to nonpharmacological studies (the remaining US\$29 273 587 for the 100 studies awarded to basic science and pharmacological research.) The total award amount for all 1659 awards was US\$648 317 093 with an extrapolated expenditure of 1.6% for 33 studies of nonpharmacological subject matter totaling US\$10,054,549.
2. This calculation represents 5% of the global total of US\$655 billion annual worldwide present expenditures indicated in World Health Organization and Alzheimer's Disease International.<sup>1</sup>

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