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American Journal of Alzheimer's
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**Ecopsychosocial Interventions in Cognitive Decline and
Dementia: a new terminology and a new paradigm**

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Review

Ecopsychosocial Interventions in Cognitive Decline and Dementia: *a new terminology and a new paradigm*

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 Alzheimer's—a condition associated with aging. The number of persons with Alzheimer's and other forms of dementia in the world is expected to increase from 36 million people at the present time to 115 million in 2050. Consequently associated costs are anticipated to increase from an estimated \$655 billion dollars annually worldwide at the present time to nearly \$2 trillion dollars annually at mid-century.¹ While investments are being made in the search for a pharmacological solution to Alzheimer's—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.²

Nonpharmacological interventions that have been developed for persons with Alzheimer's include: cultural events, such as guided museum programs for persons with cognitive challenges³; community efforts, such as alerting residents to the needs of persons with dementia living in their community; designing environments with recognizable landmarks that help persons with dementia find their way⁴; creative projects, such as group story writing that provides a sense of achievement⁵; and educational efforts, such as teaching family members to better interpret behaviors of their loved ones.

Initiatives such as those described above and many others with similar purposes, aim to replace maladaptive behavioral symptoms such as the four "A"s of Alzheimer's⁶—anxiety, agitation, aggression, and apathy—with socially engaging behaviors. Consequently *nonpharmacological* interventions are on the front line of support for the improvement of the quality of life of persons with Alzheimer's. In this publication, we propose that *nonpharmacological* interventions for persons with Alzheimer's deserve formal recognition and support and therefore ought to be identified by a more positive nomenclature. A more proper and positive nomenclature for this field of research and practice will ultimately assist in achievements such as the reduction of conditions which lead to care in much more costly, and frequently, much less satisfying, health-care environments⁷. 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 the society. If *nonpharmacological* interventions reduce the global monetary costs of care for persons living with Alzheimer's today by only 5%, this saves governments, health systems, and individuals world-wide nearly \$33 billion dollars annually.⁸

The *ecopsychosocial* approach

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5 There are important reasons why global investment in research into these
6 humanistically valuable and potentially cost-effective “nonpharmacologic” approaches
7 lags so far behind investment in pharmacologic treatments. We believe one reason is
8 the lack of a clear, positively formulated definition of this field of research and
9 intervention. Other reasons for the relative paucity of research investment may include
10 significant methodological challenges to carrying out *nonpharmacological* research and
11 the fact that *nonpharmacological* interventions often have little commercial viability.
12 Exploratory studies that indicate positive outcomes of *nonpharmacological* interventions
13 are often underfunded and subsequently discounted as not rigorous enough.
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17 To overcome the first of these challenges—lack of a clear, positively formulated,
18 definition—we propose to introduce the positive and inclusive term—*ecopsychosocial*—
19 to replace the term “*nonpharmacological*” in both research literature and common
20 parlance. Instead of defining this research area in terms of what it is not—not
21 pharmaceutical—the term *ecopsychosocial* incorporates the full breadth and complexity
22 of this area of inquiry and practice which is not clearly specified by the term
23 “*nonpharmacological*.” Use of the term *nonpharmacological* raises ethical and practical
24 issues as well as being conceptually inelegant; it is a commonly accepted shortcut that
25 does not adequately describe the phenomena it refers to; a short cut, to continue the
26 metaphor, that may create more problems for the entity it seeks to describe than a more
27 direct and apposite description.
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31 **The Challenges Created by Labeling**

32 Labeling an intervention *nonpharmacological* means simply that it does not include
33 pharmaceuticals in its protocol, framing such interventions in negative terms—as what
34 they are not—rather than identifying the nature of what the intervention actually is.
35 While the term *nonpharmacological* is gaining traction in the professional literature,
36 employing it to describe a wide range of evidence-based programs such as caregiver
37 training to assist in the understanding of the dementia process⁹, adaptive technologies
38 that help the person communicate, the effects of personal care staff wearing street
39 clothes instead of uniforms¹⁰, and interactive improvisational drama programs which
40 engage persons’ creativity¹¹, is both imprecise and undervalues the positive nature of
41 the interventions.
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45 Use of the label *nonpharmacological* to describe major shifts in the social milieu through
46 counseling and support to assist family members to understand and live with the effects
47 of dementia¹², activity based drama and art interactions in which residents choose their
48 own subject matter¹³, and environmental interventions, such as creating home-like
49 settings to help residents adapt more easily to change¹⁴, fails to recognize that these
50 interventions may be of greater significance and effectiveness in comparison with
51 existing pharmacologic treatments¹⁵, and are at the very least complementary to
52 conventional treatment. In treatment of behavioral and psychological symptoms of
53 dementia (BPSD), so called *nonpharmacological* interventions can reduce or even
54 eliminate the use of potentially harmful medications^{16 17 18 19 20 21}.
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5 Ethical and practical questions raised by the use of the term *nonpharmacological*
6 include: How does the use of a nonspecific and inexact label limit financial resources for
7 research? Does such a label make it unnecessarily difficult to acquire and compare
8 potentially significant research data and evidence? Does using a negative label limit
9 access to treatments that might provide those with dementia and their partners a higher
10 quality of life?
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13 The term *nonpharmacological* is increasingly used in medical research literature.
14 Scholarly and professional articles appear regularly on a range of *nonpharmacological*
15 interventions to treat health conditions such as recovery from heart transplants²²,
16 gastrointestinal disorders²³, fibromyalgia²⁴, premenstrual syndrome²⁵, hypertension²⁶,
17 and children's postoperative pain²⁷.
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20 A similar increase in interest in nonpharmacological approaches is evident in dementia
21 research, an example of which is a recent article by Cohen-Mansfield in which she
22 employs the acronym "NPHI" for Nonpharmacological Interventions²⁸. Other recent
23 articles on *nonpharmacological* interventions in dementia include studies of agitation²⁹
24 ³⁰, the effects of music³¹, delirium³² and Huntington's related dementia³³. As the term
25 *ecopsychosocial* is increasingly adopted, it will be imperative to cross-reference the two
26 terms *nonpharmacological* and *ecopsychosocial* in future publications
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29 30 **Finding a Better Name**

31 Often employed interchangeably with *nonpharmacological*, the term *psychosocial* refers
32 to outcomes of interventions aimed at improving a person's psychological state or social
33 situation. However, many effective *nonpharmacological* interventions imply
34 mechanisms which are beyond the boundaries of this terminology. For example, the
35 effect of exercise to reduce obesity and dementia risk is a biological treatment. The
36 term *bio-psychosocial* has also been used³⁴ but it implies a more circumscribed view of
37 biology (molecular and pharmacological) whereas *ecopsychosocial* implies a macro
38 view including the environment and the public health context.
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41 The terms *psychosocial* and *bio-psychosocial* clearly do not encompass the broad array
42 of what are now being called *nonpharmacological* interventions. While intergenerational
43 charter schools where elders with dementia teach and learn from younger students,³⁵
44 and museum visit programs where those with dementia look at and discuss works of art
45 in normal settings, improve the quality of life for persons with dementia and have
46 *psychosocial* effects, such programs encompass much more. Environmental contextual
47 change is integral to such actions and programs. The impact of such interventions is on
48 context and environment and not simply on the individual living with the disease.
49 Notions of context and the broader impact of change are missing from current
50 nomenclature. *Psychosocial*, for example, describes some effects of some
51 interventions on individuals but the terminology does not adequately address the impact
52 of contextual changes brought about by access to safe therapeutic gardens or
53 introducing a new object such as a "memory book" into the setting with structured visual
54 memory-jogging material³⁶, employing computer tablets for communication, or
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5 introducing music and art appreciation as a way to engage people with dementia in
6 meaningful discussion.
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8 9 ***Ecopsychosocial*—a Term to Cut the Gordian Knot**

10 Using the prefix *eco-*, as employed in the term *ecological*, begins to resolve the insular
11 terminology dilemma. “Ecological” refers to “the interrelationship of organisms and their
12 environment” and to the study of “the relationships between a group of living things and
13 their environment.”³⁷ Frequently employed in biology, sociology, and psychology to
14 include contextual factors, the term “eco-,”—etymologically rooted in the Greek term for
15 house or household (*oikes*)³⁸—rectifies the current terminological deficiency. Since
16 many interventions presently considered *nonpharmacological* are concerned with
17 changing the context or environment of persons with dementia, it is clear that a
18 reference to “context” is advantageous if not essential in defining this approach.
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22 We believe that the term *ecopsychosocial* (EPS) provides a significant improvement
23 over the present term *nonpharmacological*. The new term positively delimits an
24 expanding category of therapeutics and serves to draw together for research purposes
25 a broad group of interventions to treat dementia.
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28 The value of the *ecopsychosocial* terminology for the scientific community is that
29 identifying a field with clear and, in this case, potentially broader boundaries and
30 components should result in more fruitful professional discussion while providing a
31 vehicle for structured research support. As the field of *ecopsychosocial studies* of
32 cognitive decline and dementia is increasingly recognized, subject matter, academic
33 curricula, and research protocols particularly suited to the field are likely to emerge.
34 Similarly, results of related research projects can more easily be compared—thus
35 contributing to a critical mass of comparable data to be used in resource allocation and
36 policy making.
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39 40 **Defining the Range of “*ecopsychosocial*” (EPS) Impacts & Outcomes**

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

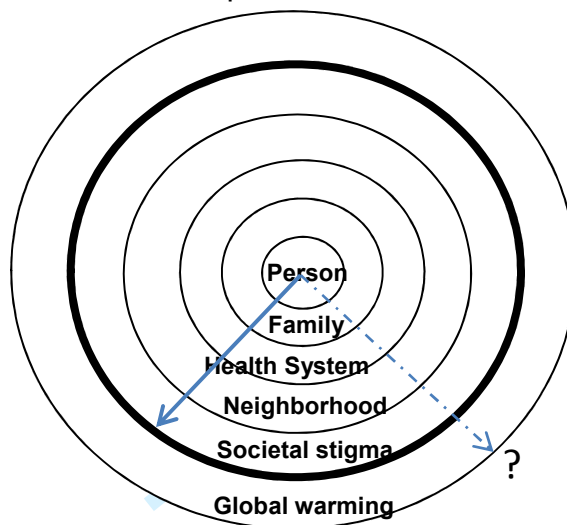


Figure 1: Environmental Range of Ecopsychosocial Interventions in

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 this condition is less of 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 exist. The argument can also 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. Every concept, including *ecopsychosocial*, needs to evolve through debate, research, and government action. 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 positive language to describe this growing field. While 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

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5 and positive nature of a broad range of interventions in the lives of those living with
6 dementia.
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8 *Ecopsychosocial* is a practical and conceptually elegant term to replace the term
9 *nonpharmacological* in dementia and other studies. *Ecopsychosocial* avoids defining
10 phenomena by what they are not and, more significantly, includes the broad range of
11 subject matter and research interest actually included in the overall term, especially
12 contextual issues and environmental design. We urge and welcome the professional
13 community's adoption of the new recommended terminology as well as ongoing
14 commentary and study of these matters.
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21 ¹ World Health Organization (WHO) & Alzheimer's disease International (ADI) (2012),
22 *Dementia: a public health priority*, World Health Organization, Geneva, Page 2, ISBN:
23 9789241564458.
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25 ² According to the National Institute of Health's Research Portfolio Online Reporting tools
26 (RePORT), 1659 grants were awarded under the NIH spending category of dementia in fiscal
27 year 2013. In a random sample of 100 of these awards only 2% of grant awards and only 1.6%
28 of monetary funding (\$468,345 of \$29,741,932 for the 100 studies) was awarded to
29 nonpharmacological studies (the remaining \$29,273,587 for the 100 studies awarded to basic
30 science and pharmacological research.) The total award amount for all 1659 awards was
31 \$648,317,093 with an extrapolated expenditure of 1.6% for 33 studies of nonpharmacological
32 subject matter totaling \$10,054,549. *Report.nih.gov/categorical_spending.aspx* (accessed June
33 26, 2014)
34
35

36 ³ MacPherson, S., Bird, M., Anderson, K., Davis, T. & Blair, A. (2009) "An art gallery access
37 programme for people with dementia: 'You do it for the moment'" *Aging & Mental Health*, Vol.13,
38 No 5, 744-752.
39

40 ⁴ Zeisel, J., Silverstein, N. M., Hyde, J. Levkoff, S., Lawton, M. P., & Holmes, W., (2003)
41 "Environmental correlates to behavioral health outcomes in Alzheimer's special care units."
42 *Gerontologist*, Vol.43, No.5, 697-711.
43
44

45 ⁵ Fritsch, T., J. Kwak, (or K. Jung?) S. Grant, J. Lang, R. Montgomery, & A. D. Basting, (2009)
46 "Impact of TimeSlips, a creative expression intervention program, on nursing home residents
47 with dementia and their caregivers." *Gerontologist*., Vol. 49 No 1, 117-127.
48

49 ⁶ Zeisel, J. (2009) *I'm Still Here: A New Philosophy of Alzheimer Care*. Penguin-Avery, New
50 York. 39-41
51

52 ⁷ Long KH, Moriarty JP, Mittelman MS, Foldes SS. (2014) Estimating the potential cost savings
53 from the New York University Caregiver Intervention in Minnesota." *Health Affairs*. 2014 Vol. 33
54 No 4, 596-604
55
56
57
58
59

⁸ This calculation is drawn from the global figure of \$655 annual world-wide present expenditures in World Health Organization (WHO) & Alzheimer's Disease International (ADI) (2012), *Dementia: a public health priority*, World Health Organization, Geneva, Page 2, ISBN: 9789241564458.

⁹ Reisberg, B., Kenowsky, S., Boksay, I., Golomb, J., Heller, S., Ghimire, S., Salam, M., Qureshi, S., Kumar, M., Torrosian, C., and Vedvyas, A. (2013) Memantine and Comprehensive, Individualized, Person Centered Management (CI-PCM) of Alzheimer's Disease (AD): A randomized controlled trial, *Alzheimer's & Dementia*, 9(4) supplement, 295-296.

¹⁰ Charras, K., Gzil, F. (2013). Judging a book by its cover: uniforms and quality of life in special care units for people with dementia. *American Journal of Alzheimer's Disease and Associated Disorders*, Vol. 28, No. 5, 450-458.

¹¹ Benson, S. (2009) "Ladder to the Moon: interactive theatre in care settings." *Journal of Dementia Care*, Vol. 17, No 4, 20-23.

¹² Mittelman, Mary S; Haley, William E; Clay, Olivio J; Roth, David L. (2006) "Improving caregiver well-being delays nursing home placement of patients with Alzheimer disease." *Neurology*. Vol. 67, No. 9: 1592-1599

¹³ Caulfield, S., "Establishing an Alzheimer's-Competent Evidence-Based Museum Program" in P.E. Hartman and A. La Rue (eds.) *Enhancing Cognitive Fitness in Adults: A Guide to the Use and Development of Community Based Programs*, Pages 311-320, DOI 10.1007/978-1-4419-0636-6_6, Springer Science+Business Media LLC, New York (2011).

¹⁴ Cohen, U. & Weiseman, G. (1991) *Holding On to Home: Designing Environments for People with Dementia*, Johns Hopkins, Baltimore.

¹⁵ Reisberg, B., Kenowsky, S., Heller, S., Boksay, I., Golomb, J., Ghimire, S., Torossian, C., Lobach, I., Addition of a Comprehensive, Individualized, Person Centered Management Program, to Memantine Alone Produces a 900% Increment in a Pivotal Trial Global Measure over Medication Treatment Alone in Advanced Alzheimer's Disease, *Neuropsychopharmacology*, 38, S423-S424, 2013.

¹⁶ Woollorton E: (2002) Risperidone (Risperdal): increased rate of cerebrovascular events in dementia trials. *CMAJ*;167:1269--1270.

¹⁷ Schneider LS, Dagerman KS, Insel P: (2005) Risk of death with atypical antipsychotic drug treatment for dementia: meta-analysis of randomized placebo-controlled trials. *JAMA* 294:1934-1943.

¹⁸ US Food and Drug Administration: FDA Public Health Advisory: deaths with antipsychotics in elderly patients with behavioral disturbances. <http://www.fda.gov/cder/drug/advisory/antipsychotics.htm> (accessed April 13, 2005).

- 1
2
3
4
5
6¹⁹ Wang PS, Schneeweiss S, Avorn J, Fischer MA, Mogun H, Solomon DH, Brookhart MA:
7 (2005) "Risk of death in elderly users of conventional vs. atypical antipsychotic medications." *N*
8 *Engl J Med* 353:2335--2341.
- 9
10²⁰ Stephen PJ, Williamson J: "Drug-induced parkinsonism in the elderly". (1984) *Lancet* 2:1082--
11 1083.
- 12
13²¹ Reisberg B, Saeed MU (2004),: "Alzheimer's disease"; in Sadovoy J, Jarvik LF, Grossberg
14 GT, Meyers BS (eds): *Comprehensive Textbook of Geriatric Psychiatry*, ed 3. New York, W.W.
15 Norton, pp 449--509.
- 16
17
18²² Conway, A., V. Schadewaldt, R. Clark, C. Ski, D.R. Thompson, K. Kynoch & L. Doering.
19 (2014) "The Effectiveness of Nonpharmacological Interventions in Improving Psychological
20 Outcomes for Heart Transplant Recipients: A Systematic Review." *European Journal of*
21 *Cardiovascular Nursing*; Vol. 12, No. 4, 393-399.
- 22
23
24²³ Lahner, E., S. Bellentani, R. De Bastiani, C. Tosetti, M. Cicala, G. Esposito, P. Arullani & B.
25 Annibale on behalf of the Study Group Primary Care in Gastroenterology of the Italian Society of
26 Gastroenterology. (2013) "A Survey of Pharmacological and Non-Pharmacological Treatment
27 of Functional Gastrointestinal Disorders." *United European Gastroenterology Journal*; Vol. 1,
28 No. 5, 385-393.
- 29
30
31²⁴ Nuesch, E., W. Hauser, K. Bernardy, J. Barth & P. Juni. (2012) "Comparative Efficacy of
32 Pharmacological and Nonpharmacological Interventions in Fibromyalgia Syndrome: Network
33 Meta-Analysis." *Annals of Rheumatic Diseases: The Euler Journal*; Vol. 72, 955-962.
- 34
35
36²⁵ Montazeri, S. (2011) "Nonpharmacological Treatment of Premenstrual Syndrome." *African*
37 *Journal of Midwifery and Women's Health*; Vol. 5, No. 3, 148 – 152.
- 38
39
40²⁶ Sharma, M., W.H. Frishman & K. Gandhi. (2011) "RESPerATE: Nonpharmacological
41 Treatment of Hypertension" *Cardiology in Review*; Vol. 19, No. 2 - 47-51.
- 42
43
44²⁷ He, H.G., R. Jahja, T.L. Lee, E.N. Ang, R. Sinnappan, K. Vehvilainen-Julkunen & M.F. Chan.
45 (2010) "Nurses' Use of Non-Pharmacological Methods in Children's Postoperative Pain
46 Management: Educational Intervention Study." *Journal of Advanced Nursing*; Vol. 66, No. 11,
47 2398–2409.
- 48
49
50²⁸ Cohen-Mansfield, J., B. Jensen, B. Resnick & M. Norris. (2012) "Knowledge of and Attitudes
51 Toward Nonpharmacological Interventions for Treatment of Behavior Symptoms Associated
52 With Dementia: A Comparison of Physicians, Psychologists, and Nurse Practitioners." *The*
53 *Gerontologist*; Vol. 52, No. 1, 34-45.
- 54
55
56
57
58
59
60²⁹ Janzen, S., A.A. Zecevic, M. Klooseck, & J.B. Orange. (2013) "Managing Agitation Using
Nonpharmacological Interventions for Seniors With Dementia." *American Journal of Alzheimer's*
Disease and Other Dementias; Vol. 28, No. 5, 524-532.

- 1
2
3
4
5
6³⁰ Wierman, H.R, W.R. Wadland, M. Walters, C. Kuhn & S. Farrington. (2011)
7 "Nonpharmacological Management of Agitation in Hospitalized Patients with Late-Stage
8 Dementia." *Journal of Gerontological Nursing*; Vol. 37, No. 2, 44-48.
9
- 10³¹ Narme, P., A. Tonini, F. Khatir, L. Schiaratura, S. Clement & S. Samson. (2012)
11 "Nonpharmacological Treatment for Alzheimer's Disease: Comparison Between Musical and
12 Non-Musical Interventions." *Geriatric et psychologie neuropsychiatrie du vieillissement*; Vol. 10,
13 No. 2, 215-224.
14
- 15³² Kolanowski, A.M., D.M. Fick, L. Clare, M. Steis, M. Boustani & M. Litaker. (2011) "Pilot Study
16 of a Nonpharmacological Intervention for Delirium Superimposed on Dementia." *Research in*
17 *Gerontological Nursing*; Vol. 4, No. 3, 161-167.
18
- 19³³ Lee, H.M., S.T. Chen, S.J. Chen. (2010) "Nonpharmacological Treatments in a Patient with
20 Dementia Due to Huntington's Disease." *Journal of Neuropsychiatry and Clinical*
21 *Neurosciences*; Vol. 22, No. 2, E17.
22
- 23³⁴ Engel, G.L. (1981) "The Clinical Application of the Biopsychosocial Model." *Journal of*
24 *Medicine and Philosophy*, Vol. 6, No. 2, 101-124.
25
- 26³⁵ Whitehouse PJ, Bendezu E, FallCreek S, Whitehouse C. Intergenerational Community
27 Schools: A New Practice for a New Time. *Educ Gerontol*, 2000, 26:761-770.
28
- 29³⁶ Bourgeois, M. (2013) *Memory Books and Other Graphic Cuing Systems: Practical*
30 *Communication and Memory Aids for Adults with Dementia*, Health Professions Press,
31 *Health Professions Press, Baltimore* (April 2007)
32
- 33³⁷ *Merriam-Webster.com*. Merriam-Webster, (2014) [http://www.merriam-](http://www.merriam-webster.com/dictionary/ecology)
34 [webster.com/dictionary/ecology](http://www.merriam-webster.com/dictionary/ecology). (Accessed June 1, 2014)
35
- 36³⁸ *Merriam-Webster.com* (2014) www.merriam-webster.com/dictionary/eco-
37 [and Wiktionary](http://www.merriam-webster.com/dictionary/eco-) (2014) <http://en.wiktionary.org/wiki/eco-> . (Accessed June 15, 2014)
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Ecopsychosocial Interventions in Cognitive Decline and Dementia: a new terminology and a new paradigm^a

John Zeisel^b, Barry Reisberg^c, Peter Whitehouse^d, Robert Woods^e, Ad Verheul^f

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 ~~Alzheimer's dementia~~—a condition associated with aging. The number of persons with ~~Alzheimer's and other forms of~~ dementia in the world is expected to increase from 36 million people at the present time to 115 million in 2050. Consequently associated costs ~~are anticipated can be calculated~~ to increase from an estimated \$655 billion dollars annually worldwide at the present time to nearly \$2 trillion dollars annually at mid-century.¹ While investments are being made in the search for a pharmacological solution to ~~Alzheimer's 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 far~~ behind.²

Nonpharmacological interventions ~~that have been~~ developed for persons with ~~Alzheimer's dementia~~ include: cultural events, -such as guided museum programs for persons with cognitive challenges³; community efforts, such as training and alerting

^a This paper is part of a two-year series of international consensus symposia organized in Spain and Portugal by the WISDEM network. Members of the symposia included: Jiska Cohen-Mansfield (Israel), Torhild Holthe (Norway), Renata Avila (Brazil), Cameron Camp (USA), Li-Chan Lin (Taiwan), Joel Belmin (France), Anne Basting (USA), Sean Caulfield (USA), Marily Cintra (Australia), Elisabetta Farina (Italy), John Killick (UK), Richard Taylor (USA), Maqda Tsolaki (Greece), Yeunsook Lee (Korea), Maqie Calkins (USA), Mary Marshall (Scotland), Richard Fleming (Australia), Sibylle Heeg (Germany), Kevin Charras (France), Anne Margriet Pot (Holland), Jesus Favela (Mexico), Alex Mihailidis (Canada), Suzanne Martin (Northern Ireland), Topo Päivi (Finland), Maria Parsons (UK), Irina Roschina (Russia), Ken Sakamura (Japan) as well as the authors, John Zeisel (USA), Barry Reisberg (USA), Peter Whitehouse (USA), Robert Woods (UK), and Ad Verheul (Holland).

^b Hearthstone Alzheimer Care & The I'm Still Here Foundation, Woburn, Massachusetts

^c Zachary and Elizabeth M. Fisher Alzheimer's Disease Education and Resources Program, New York University Langone Medical Center, New York

^d Case Western Reserve University, Pittsburgh & Baycrest, University of Toronto

^e Bangor University, Wales, UK

^f 's Heeren Loo, Holland & Founder of Snoezelen Therapy.

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9 residents to recognize and respond to the needs of persons with dementia living in their
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21 ~~Initiatives such as those described above~~ These and many ~~others~~ other initiatives with
22 similar purposes; aim to replace maladaptive behavioral symptoms such as the four
23 ~~"A"s~~ of Alzheimer's⁸—anxiety, agitation, aggression, and apathy—with socially
24 engaging behaviors. Consequently *nonpharmacological* interventions are on the front
25 line of support for the improvement of the quality of life of persons with ~~Alzheimer's. In~~
26 dementia. We assert in this publication, ~~we propose~~ that *nonpharmacological*
27 interventions for persons with ~~Alzheimer's dementia~~ deserve formal recognition and
28 support and therefore ought to be identified by a more ~~positive~~ precise and distinctive
29 nomenclature. A more ~~proper and positive~~ precise nomenclature for this field of
30 research and practice will ultimately assist in achievements ~~such as the reduction of that~~
31 include reducing conditions ~~which that~~ lead to care in ~~much~~ more costly, and frequently,
32 ~~much~~ less satisfying, health-care environments⁹. The more such positive interventions
33 cut the costs of care and increase ~~the~~ satisfaction and psychological and physical health
34 of both persons with dementia and those who care for and about them, the greater the
35 savings for ~~the~~ society. If *nonpharmacological* interventions reduce the global monetary
36 costs of care for persons living with ~~Alzheimer's dementia~~ today by only 5%, ~~this saves~~
37 governments, health systems, and individuals world-wide will save nearly \$33 billion
38 dollars annually.¹⁰
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47 The ecopsychosocial approach 48 The Need for a Distinct Field of Inquiry

49 There are important reasons why global investment in research into these
50 humanistically valuable and potentially cost-effective "nonpharmacologic" approaches
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lags so far behind investment in pharmacologic treatments. ~~We believe one~~ One reason is the lack of a clear, ~~positively formulated~~ definition of ~~this~~ these efforts as a distinct field of research and intervention. Other reasons for the relative paucity of research investment ~~may~~ include significant methodological challenges to carrying out *nonpharmacological* research and the fact that *nonpharmacological* interventions often have little commercial viability. Exploratory studies ~~that indicate~~ indicating 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 ~~clear, positively~~ clearly formulated, definition—we propose ~~to introduce the positive and inclusive~~ 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 ~~which is not clearly specified by~~ as reflected in the ~~term “nonpharmacological.”~~ 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 short cut, to continue the metaphor, that may ~~create~~ lengthen the journey by creating more problems for the entity it seeks to describe than a more direct and apposite description.

The Challenges Created by Labeling: An Epistemological Challenge

Labeling an intervention *nonpharmacological* means simply that it does not include pharmaceuticals in its protocol, ~~framing.~~ Rather than identifying the nature of such interventions ~~—by what they actually are—the term frames the interventions~~ in negative terms ~~—as by~~ what they are not ~~—rather than identifying the nature of what the intervention actually is.~~ While, Although the term *nonpharmacological* is both imprecise and undervalues the positive nature of such interventions, it is gaining traction in the professional literature, employing it increasing the urgency for a new label. The term is increasingly being employed to describe a wide range of evidence-based programs

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such as caregiver training to assist in ~~the~~ understanding ~~of~~ the dementia process¹¹, adaptive technologies that help the person communicate, the effects of personal care staff wearing street clothes instead of uniforms¹², and interactive improvisational drama programs which engage persons' creativity¹³, ~~is both imprecise and undervalues the positive nature of the interventions.~~

~~Use of the~~ The label *nonpharmacological* ~~is also being employed~~ to describe major shifts in the social milieu ~~throughof persons with dementia such as~~ counseling and support ~~to assistof~~ family members ~~to assist them~~ to understand and live with the effects of dementia¹⁴, activity based drama and art interactions in which residents choose their own subject matter¹⁵, and environmental interventions, such as creating home-like settings to help residents adapt more easily to change¹⁶. ~~Such labeling~~ fails to recognize that these interventions may be of greater significance and effectiveness in comparison with existing pharmacologic treatments¹⁷, ~~and are~~ at the very least ~~should be considered~~ complementary to conventional treatment. In treatment of behavioral and psychological symptoms of dementia (*BPSD*), ~~so called nonpharmacological interventions can have been shown to reduce orand~~ even eliminate the use of ~~medications which on occasion~~ potentially ~~harmful medications may have deleterious adverse effects.~~^{18 19 20 21 22 23}

~~Ethical and practical questions raised by the use of the term nonpharmacological 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?~~

~~The term nonpharmacological~~ In dementia research there is increasingly used in medical research literature. Scholarly and professional articles appear regularly on a range of *nonpharmacological* interventions to treat health conditions such as recovery from heart transplants²⁴, gastrointestinal disorders²⁵, fibromyalgia²⁶, premenstrual syndrome²⁷, hypertension²⁸, and children's postoperative pain²⁹.

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10 A similar clearly an increase in interest in nonpharmacological approaches ~~is evident in~~
11 ~~dementia research, an example of which is a recent.~~ A significant article by Cohen-
12 Mansfield in which she employs the acronym "NPHI" for Nonpharmacological
13 Interventions³⁰ is a prime example. Other recent articles on *nonpharmacological*
14 interventions in dementia include studies of agitation^{31 32}, the effects of music³³,
15 delirium³⁴, and Huntington's related dementia³⁵.

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20 The term *nonpharmacological* is also increasingly used in basic medical research
21 literature, not only research related to dementia. Scholarly and professional articles
22 appear regularly describing a range of *nonpharmacological* interventions to treat health
23 conditions such as recovery from heart transplants³⁶, gastrointestinal disorders³⁷,
24 fibromyalgia³⁸, premenstrual syndrome³⁹, hypertension⁴⁰, and children's postoperative
25 pain⁴¹. As the term *ecopsychosocial* is increasingly adopted, it will be imperative to
26 cross-reference the two terms *nonpharmacological* and *ecopsychosocial* in future
27 publications.

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33 Ethical and practical questions are raised by the use of the term *nonpharmacological*.
34 These include: How does the use of a nonspecific and inexact label limit financial
35 resources for research? Does such a label make it unnecessarily difficult to acquire and
36 compare potentially significant research data and evidence? Does using a negative
37 label limit access to treatments that might provide those with dementia and their
38 partners a higher quality of life?

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43 **Finding**A similar shift in terminology with an equally difficult transition for the field is the
44 way researchers and clinicians are avoiding the term "behaviors" when referring to the
45 many, often socially disruptive, ways in which those living with dementia express
46 themselves or communicate their needs.⁴² While this transition is taking time and effort,
47 the shift eventually benefits all those with dementia who are presently being treated as if
48 their "behaviors" have little to do with intent and meaning and are merely phenomena to
49 eliminate with whatever means possible.

Seeking a Better Name

Often employed interchangeably with *nonpharmacological*, the term *psychosocial* refers to outcomes of interventions aimed at improving a person's psychological state or social situation. ~~However, many effective nonpharmacological interventions imply mechanisms which are beyond the boundaries of this terminology. For example, the effect of exercise to reduce obesity and dementia risk is a biological treatment. The term bio-psychosocial has also been used⁴³ but it implies a more circumscribed view of biology (molecular and pharmacological) whereas ecopsychosocial implies a macro view including the environment and the public health context. As noted by Vesse et al⁴⁴, 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"⁴⁵ but there is no similar definition for "nonpharmacological" interventions.~~

The terms *psychosocial* and *bio-psychosocial* ~~are often used interchangeably with the term nonpharmacological, but~~ clearly do not encompass the broad array of what are now being called *nonpharmacological* interventions. ~~While Programs such as~~ intergenerational charter schools where elders with dementia teach and learn from younger students,⁴⁶ and museum visit programs where those with dementia look at and discuss works of art in normal settings,⁴⁷ improve the quality of life for persons with dementia and have *psychosocial* effects, ~~such but these~~ programs encompass much more. Environmental contextual change ~~which~~ 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 and not simply on the individual living with the disease. Notions of context and the broader impact of change are missing from current nomenclature. *Psychosocial*, ~~for example,~~ 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 a new object such as a "memory book" into the setting with structured visual memory-jogging material⁴⁸, employing computer tablets for communication, or

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9 introducing music and art appreciation as a way to engage people with dementia in
10 meaningful discussion.
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14 The name change from *nonpharmacological* to *ecopsychosocial* interventions should
15 also help dissolve the narrow perception that the only hope for quality of life for persons
16 with dementia lies somewhere in a vague future when a cure is discovered. Because
17 the term “nonpharmacological” does not adequately suggest that there are many
18 interventions readily and easily available to individuals and families who provide care for
19 persons with dementia, a new descriptive term reinforces a more user-inclusive
20 approach to care.
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25 ***Ecopsychosocial*—a Term to Cut the Gordian Knot**

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27 Using the prefix *eco-*, as employed in the term *ecological*, begins to resolve the insular
28 terminology dilemma. “Ecological” refers to “the interrelationship of organisms and their
29 environment” and to the study of “the relationships between a group of living things and
30 their environment.”⁴⁹ Frequently employed in biology, sociology, and psychology to
31 include contextual factors, the term “eco-,”—etymologically rooted in the Greek term for
32 house or household (*oikes*)⁵⁰—rectifies the current terminological deficiency. Since
33 many interventions presently considered *nonpharmacological* are concerned with
34 changing the context or environment of persons with dementia, it is clear that a
35 reference to “context” is advantageous if not essential in defining this approach.
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41 We believe in the field of environmental psychology which plays a major role in
42 nonpharmacological treatment for dementia, the work of J. J. Gibson⁵¹ highlights the
43 theory of “affordances” and “niches” in what Gibson labeled “ecological psychology.”
44 Affordances are the opportunities environments offer—from the scale of a teacup to that
45 the of a city and beyond—that are directly perceived and acted upon by users.
46 Niches—ecological niches—represent a set of affordances in which individuals can
47 choose to express their needs or not, according to their abilities and the environmental
48 constraints they naturally face. This approach holds particular hope for people with
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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 the physical environment plays 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"⁵², 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"⁵³, Algase's "need driven behavior model"⁵⁴, and the work of Cohen-Mansfield⁵⁵ provide other critical examples. This body of work provides further justification for including the prefix "eco" in any replacement term for the label nonpharmacological.

Employing 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 (EPS)* provides a significant improvement over the present term *nonpharmacological*. The new term, positively ~~delimits~~delimiting an expanding category of therapeutics and ~~servesserving~~ 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 collaboration and 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.

Defining/Determining the Range of “ecopsychosocial” (EPS) Impacts & 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.

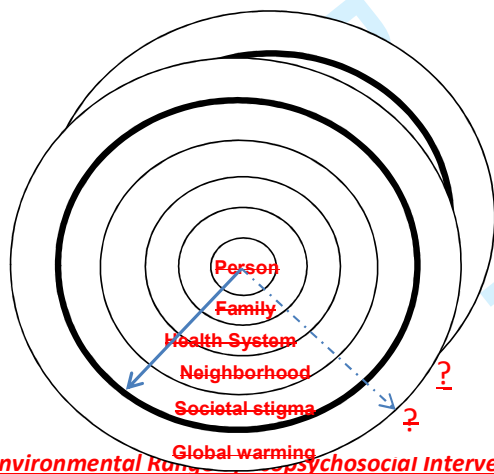


Figure 1: Environmental Range of Ecopsychosocial Interventions in

Figure 1: Environmental Range of Ecopsychosocial Interventions in

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

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practices need to resist the culturally defined social stigma associated with the disability, so that ~~this condition~~ dementia is ~~less of 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 ~~exist~~ live. The argument can ~~also~~ 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. ~~Every concept, including ecopsychosocial, needs to evolve through debate, research, and government action.~~ 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 positive language to describe this growing field. While 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 embodied within~~ the overall term, ~~especially such as~~ contextual issues and environmental design. Every concept, including ecopsychosocial, needs to evolve through debate, research, and in this

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context, regulatory and governmental action. We urge and welcome the professional community's adoption of ~~the new recommended~~this terminology, as well as ongoing commentary and study of these matters.

For Peer Review

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¹ World Health Organization (WHO) & ~~Alzheimer's disease~~[Alzheimer's Disease](#) International (ADI) (2012), *Dementia: a public health priority*, World Health Organization, Geneva, Page 2, ISBN: 9789241564458.

² According to the National Institute of Health'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 (\$468,345 of \$29,741,932 for the 100 studies) was awarded to nonpharmacological studies (the remaining ~~\$29,273,587~~ for the 100 studies ~~was~~ awarded to basic science and pharmacological research.) The total award amount for all 1659 awards was \$648,317,093 with an extrapolated expenditure of 1.6% for 33 studies of nonpharmacological subject matter totaling \$10,054,549. *Report.nih.gov/categorical_spending.aspx* (accessed June 26, 2014)

³ MacPherson, S., Bird, M., Anderson, K., Davis, T., & Blair, A. (2009) "An art gallery access programme for people with dementia: 'You do it for the moment'" *Aging & Mental Health*, Vol.13, No 5, 744-752.

⁴ Zeisel, J., Silverstein, N. M., Hyde, J. Levkoff, S., Lawton, M. P., & Holmes, W., (2003) "Environmental correlates to behavioral health outcomes in ~~Alzheimer's~~[Dementia](#) special care units." *Gerontologist*, Vol.43, No.5, 697-711.

⁵ Fritsch, T., J. Kwak, ~~(or K. Jung?)~~S. Grant, J. Lang, R. Montgomery, & ~~A. D.~~Basting, [A.D.](#) (2009) "Impact of TimeSlips, a creative expression intervention program, on nursing home residents with dementia and their caregivers." *Gerontologist*., Vol. 49 No 1, 117-127.

⁶ [HABIT Healthy Actions to Benefit Independence and Thinking® \(2015\), The Mayo Clinic. Rochester, MN](#)

⁷ [Greenaway M.C., Hanna S.M., Lepore S.W., & Smith G.E. \(2008\) A behavioral rehabilitation intervention for amnesic mild cognitive impairment. *American Journal of Alzheimer's Disease and Other Dementias*. 23\(5\):451-61.](#)

⁸ Zeisel, J. (2009) *I'm Still Here: A New Philosophy of Alzheimer Care*. Penguin-Avery, New York. 39-41

⁹ Long ~~KH, K.H., Moriarty JP, J.P., Mittelman MS, M.S., & Folders SS, S.S.~~ (2014) Estimating the potential cost savings from the New York University Caregiver Intervention in Minnesota." *Health Affairs*. ~~2014~~Vol. 33 No 4, 596-604

¹⁰ This calculation ~~is drawn from~~ ~~represents 5% of~~ the global figure of \$655 [billion](#) annual world-wide present expenditures [indicated](#) in World Health Organization (WHO) & ~~Alzheimer's~~[Dementia](#) Disease International (ADI) (2012), *Dementia: a public health priority*, World Health Organization, Geneva, Page 2, ISBN: 9789241564458.

¹¹ Reisberg, B., Kenowsky, S., Boksay, I., Golomb, J., Heller, S., Ghimire, S., Salam, M., Qureshi, S., Kumar, M., Torrosian, C., and Vedvyas, A. (2013) Memantine and Comprehensive, Individualized, Person Centered Management (CI-PCM) of [Alzheimer's Dementia](#) Disease (AD): A randomized controlled trial, [Alzheimer's Dementia & Dementia](#), 9(4) supplement, 295-296.

¹² Charras, K., Gzil, F. (2013). Judging a book by its cover: uniforms and quality of life in special care units for people with dementia. *American Journal of Alzheimer's Dementia Disease and Associated Disorders*, Vol. 28, No. 5, 450-458.

¹³ Benson, S. (2009) "Ladder to the Moon: interactive theatre in care settings." *Journal of Dementia Care*, Vol. 17, No 4, 20-23.

¹⁴ Mittelman, Mary S; Haley, William E; Clay, Olivio J; Roth, David L. (2006) "Improving caregiver well-being delays nursing home placement of patients with Alzheimer disease." *Neurology*. Vol. 67, No. 9: 1592-1599

¹⁵ Caulfield, S., "Establishing an Alzheimer's ~~Competent Evidence-Based Museum Program~~ [competent evidence-based museum program](#)" in P.E. Hartman and A. La Rue (eds.) *Enhancing Cognitive Fitness in Adults: A Guide to the Use and Development of Community Based Programs*, Pages 311-320, DOI 10.1007/978-1-4419-0636-6_6, Springer Science+Business Media LLC, New York (2011).

¹⁶ Cohen, U. & Weiseman, G. (1991) *Holding On to Home: Designing Environments for People with Dementia*, Johns Hopkins, Baltimore.

¹⁷ Reisberg, B., Kenowsky, S., Heller, S., Boksay, I., Golomb, J., Ghimire, S., Torossian, & C., Lobach, I., (2013) Addition of a Comprehensive, Individualized, Person Centered Management Program, to ~~Memantine Alone Produces~~ [memantine alone produces](#) a 900% ~~Increment~~ [increment](#) in a ~~Pivotal Trial Global Measure~~ [pivotal trial global measure](#) over ~~Medication Treatment Alone~~ [medication treatment alone](#) in *Advanced Alzheimer's Disease* [advanced Dementia disease](#), *Neuropsychopharmacology*, 38, S423-S424, 2013.

¹⁸ Wooltorton E: (2002) Risperidone (Risperdal): increased rate of cerebrovascular events in dementia trials. *CMAJ*;167:1269--1270.

¹⁹ Schneider LS, Dagerman KS, Insel P: (2005) Risk of death with atypical antipsychotic drug treatment for dementia: meta-analysis of randomized placebo-controlled trials. *JAMA* 294:1934-1943.

²⁰ US Food and Drug Administration: FDA Public Health Advisory: deaths with antipsychotics in elderly patients with behavioral disturbances. <http://www.fda.gov/cder/drug/advisory/antipsychotics.htm> (accessed April 13, 2005).

²¹ Wang PS, Schneeweiss S, Avorn J, Fischer MA, Mogun H, Solomon DH, Brookhart MA: (2005) "Risk of death in elderly users of conventional vs. atypical antipsychotic medications." *N Engl J Med* 353:2335--2341.

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²² Stephen PJ, Williamson J: "Drug-induced parkinsonism in the elderly". (1984) *Lancet* 2:1082--1083.

²³ Reisberg B, Saeed MU (2004): "[Alzheimer's Dementia](#) disease"; in Sadovoy J, Jarvik LF, Grossberg GT, Meyers BS (eds): *Comprehensive Textbook of Geriatric Psychiatry*, ed 3. New York, W.W. Norton, pp 449--509.

²⁴ Conway, A., V. Schadewaldt, R. Clark, C. Ski, D.R. Thompson, K. Kynoch & L. Doering. (2014) "The Effectiveness of Nonpharmacological Interventions in Improving Psychological Outcomes for Heart Transplant Recipients: A Systematic Review." *European Journal of Cardiovascular Nursing*; Vol. 12, No. 4, 393-399.

²⁵ Lahner, E., S. Bellentani, R. De Bastiani, C. Tosetti, M. Cicala, G. Esposito, P. Arullani & B. Annibale on behalf of the Study Group Primary Care in Gastroenterology of the Italian Society of Gastroenterology. (2013) "A Survey of Pharmacological and Non-Pharmacological Treatment of Functional Gastrointestinal Disorders." *United European Gastroenterology Journal*; Vol. 1, No. 5, 385-393.

²⁶ Nuesch, E., W. Hauser, K. Bernardy, J. Barth & P. Juni. (2012) "Comparative Efficacy of Pharmacological and Nonpharmacological Interventions in Fibromyalgia Syndrome: Network Meta-Analysis." *Annals of Rheumatic Diseases: The Euler Journal*; Vol. 72, 955-962.

²⁷ Montazeri, S. (2011) "Nonpharmacological Treatment of Premenstrual Syndrome." *African Journal of Midwifery and Women's Health*; Vol. 5, No. 3, 148--152.

²⁸ Sharma, M., W.H. Frishman & K. Gandhi. (2011) "RESPeRATE: Nonpharmacological Treatment of Hypertension" *Cardiology in Review*; Vol. 19, No. 2--47-51.

²⁹ Ho, H.G., R. Jahja, T.L. Lee, E.N. Ang, R. Sinnappan, K. Vehvilainen-Julkunen & M.F. Chan. (2010) "Nurses' Use of Non-Pharmacological Methods in Children's Postoperative Pain Management: Educational Intervention Study." *Journal of Advanced Nursing*; Vol. 66, No. 11, 2398-2409.

³⁰ Cohen-Mansfield, J., B. Jensen, B. Resnick & M. Norris. (2012) "Knowledge of and Attitudes Toward Nonpharmacological Interventions for Treatment of Behavior Symptoms Associated With Dementia: A Comparison of Physicians, Psychologists, and Nurse Practitioners." *The Gerontologist*; Vol. 52, No. 1, 34-45.

³¹ Janzen, S., A.A. Zecevic, M. Kloseck, & J.B. Orange. (2013) "Managing Agitation Using Nonpharmacological Interventions for Seniors With Dementia." *American Journal of Alzheimer's Dementia Disease and Other Dementias*; Vol. 28, No. 5, 524-532.

³² Wierman, H.R, ~~W.R.~~ Wadland, ~~M.W.R.~~ Walters, ~~C.M.~~ Kuhn ~~C.~~ & S. Farrington. (2011) "Nonpharmacological ~~Management~~ management of ~~Agitation~~ agitation in ~~Hospitalized Patients~~ hospitalized patients with ~~Late-Stage Dementia~~ late-stage dementia." *Journal of Gerontological Nursing*; Vol. 37, No. 2, 44-48.

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- 10 ³³ Narme, P., A. Tonini, F. Khatir, L. Schiaratura, S. Clement & S. Samson. (2012)
11 "Nonpharmacological ~~Treatment~~treatment for ~~Alzheimer's~~Alzheimer's Disease: Comparison
12 ~~Between Musical~~between musical and ~~Non-Musical~~non-musical Interventions." *Geriatric et*
13 *psychologie neuropsychiatrie*Psychologie Neuropsychiatrie du vieillissementVieillessement; Vol.
14 10, No. 2, 215-224.
- 15 ³⁴ Kolanowski, A.M., -D.M. Fick, L. Clare, M. Steis, M. Boustani & M. Litaker. (2011) "Pilot
16 ~~Study~~study of a ~~Nonpharmacological Intervention~~nonpharmacological intervention for ~~Delirium~~
17 ~~Superimposed~~delirium superimposed on ~~Dementia~~dementia." *Research in Gerontological*
18 *Nursing*; Vol. 4, No. 3, 161-167.
- 19 ³⁵ Lee, H.M., S.T. Chen, S.J. Chen. (2010) "Nonpharmacological ~~Treatments~~treatments in a
20 ~~Patient~~patient with ~~Dementia Due~~dementia due to Huntington's ~~Disease~~disease." *Journal of*
21 *Neuropsychiatry and Clinical Neurosciences*; Vol. 22, No. 2, E17.
- 22 ³⁶ Conway, A., Schadewaldt V., Clark R., Ski C., Thompson D.R., Kynoch K., & Doering L.
23 (2014) "The effectiveness of nonpharmacological interventions in improving psychological
24 outcomes for heart transplant recipients: A systematic review." *European Journal of*
25 *Cardiovascular Nursing*; Vol. 12, No. 4, 393-399.
- 26 ³⁷ Lahner, E., Bellentani S., De Bastiani R., Tosetti C., Cicala M., Esposito G., Arullani P., &
27 Annibale B. on behalf of the Study Group Primary Care in Gastroenterology of the Italian
28 Society of Gastroenterology. (2013) "A survey of pharmacological and non-pharmacological
29 treatment of functional gastrointestinal disorders." *United European Gastroenterology Journal*;
30 Vol. 1, No. 5, 385-393.
- 31 ³⁸ Nuesch, E., W. Hauser, K. Bernardy, J. Barth & P. Juni. (2012) "Comparative efficacy of
32 pharmacological and nonpharmacological interventions in fibromyalgia syndrome: network
33 meta-analysis." *Annals of Rheumatic Diseases: The Euler Journal*; Vol. 72, 955-962.
- 34 ³⁹ Montazeri, S. (2011) "Nonpharmacological treatment of premenstrual syndrome." *African*
35 *Journal of Midwifery and Women's Health*; Vol. 5, No. 3, 148-152.
- 36 ⁴⁰ Sharma, M., Frishman W.H., & Gandhi K. (2011) "RESPeRATE: Nonpharmacological
37 treatment of hypertension" *Cardiology in Review*; Vol. 19, No. 2 - 47-51.
- 38 ⁴¹ He, H.G., Jahja R., Lee T.L., Ang E.N., Sinnappan R., Vehvilainen-Julkunen K., & Chan M.F.
39 (2010) "Nurses' use of non-pharmacological methods in children's postoperative pain
40 management: educational intervention study." *Journal of Advanced Nursing*; Vol. 66, No. 11,
41 2398-2409.
- 42 ⁴² Cohen-Mansfield, J., Dakheel-Ali, M., Marx, M. S., Thein, K., & Regier, N. G. (2015). Which
43 unmet needs contribute to behavior problems in persons with advanced dementia? *Psychiatry*
44 *research*, 228(1), 59-64. doi: 10.1016/j.psychres.2015.03.043
- 45 ⁴³ Engel, G.L. (1981) "The Clinical Application of the Biopsychosocial Model." *Journal of*
46 *Medicine and Philosophy*, Vol. 6, No. 2, 101-124.

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⁴⁴ : Vasse, E., Moniz-Cook, E., OldeRikkert, M., Cantegreil, I., Charras, K., Dorenlot, P., Fumero, G., Franco, M., Woods, B. & Vernooij-Dassen, M. (2012). The development of quality indicators to improve psychosocial care in dementia: a multinational and multidisciplinary approach. *International Psychogeriatrics*, 24(6), 921-930.

⁴⁵ Rabins, P. V. et al. (2007) APA Work Group on Alzheimer's Disease and Other Dementias. *American Psychiatric Association practice guideline for the treatment of patients with Alzheimer's disease and other dementias*, 2nd edition. *American Journal of Psychiatry*, 164 (Suppl.) 55-56.

⁴⁶ Whitehouse PJ, Bendezu E, FallCreek S, Whitehouse C.-. *Intergenerational Community Schools: A New Practice* community schools: a new practice for a *New Time* new time. *Educ Gerontol*, 2000, 26:761-770.

⁴⁷ Whitcomb, R. (2010) *Art and Alzheimer's: Another way of remembering*. *Pacific Standard*, December.

⁴⁸ Bourgeois, M. (2013) *Memory Books and Other Graphic Cuing Systems: Practical Communication and Memory Aids for Adults with Dementia*, Health Professions Press, *Health Professions Press*, Baltimore -(April 2007)

⁴⁹ *Merriam-Webster.com*. Merriam-Webster, (2014) <http://www.merriam-webster.com/dictionary/ecology>. (Accessed June 1, 2014)

⁵⁰ *Merriam-Webster.com* (2014) www.merriam-webster.com/dictionary/ecology and Wiktionary (2014) <http://en.wiktionary.org/wiki/eco-> . (Accessed June 15, 2014)

⁵¹ Gibson, J.J., (1977). *The Theory of affordances*. In R.E. Shaw & J. Bransford (eds.). *Perceiving, Acting, and Knowing* (pp.67-82). Hillsdale, NJ, US: Lawrence Erlbaum Associates.

⁵² Lawton, M.P., & Nahemow, L. (1973). Ecology and the aging process. In C.Eisdorfer, & M.P. Lawton (Eds.), *The Psychology of Adult Development and Aging* (vi ed.). Washington, DC, US: American Psychological Association.

⁵³ Bronfenbrenner, U. (1979). *The Ecology of Human Development*. Cambridge, MA, US: Harvard University Press. 368.

⁵⁴ Algase, D., Beck, C., Kolanowski, A., Whall, A., Berent, S., Richards, K., & Beattie, E. (1996). Need-driven dementia-compromised behavior: An alternative view of disruptive behavior. *American Journal of Alzheimer's Disease*, 11(6), 10-19.

⁵⁵ Cohen-Mansfield, J., & Warner, P. (1995) Environmental influences on agitation: An integrative summary of an observational study. *The American Journal of Alzheimer's Care & Related Disorders and Research*, 10(1), 32-39

Ecopsychosocial Interventions in Cognitive Decline and Dementia: a new terminology and a new paradigm^a

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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 dementia in the world is expected to increase from 36 million people at the present time to 115 million in 2050. Consequently associated costs can be calculated to increase from an estimated \$655 billion dollars annually worldwide at the present time to nearly \$2 trillion dollars annually at mid-century.¹ While 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 far behind.²

Nonpharmacological interventions developed for persons with dementia include: cultural events, such as guided museum programs for persons with cognitive challenges³; community efforts, such as training and alerting 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

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3 with dementia find their way⁴; creative projects, such as group story writing that provides
4 a sense of achievement^{5 6}; cognitive training efforts that build on procedural learning
5 abilities retained by persons with dementia⁷; and educational efforts, such as teaching
6 family members to better interpret behaviors of their loved ones.
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12 These and many other initiatives with similar purposes aim to replace maladaptive
13 behavioral symptoms such as the four "A"s of Alzheimer's⁸—anxiety, agitation,
14 aggression, and apathy—with socially engaging behaviors. Consequently
15 *nonpharmacological* interventions are on the front line of support for the improvement of
16 the quality of life of persons with dementia. We assert in this publication that
17 *nonpharmacological* interventions for persons with dementia deserve formal recognition
18 and support and therefore ought to be identified by a more precise and distinctive
19 nomenclature. A more precise nomenclature for this field of research and practice will
20 ultimately assist in achievements that include reducing conditions that lead to care in
21 more costly, and frequently less satisfying, health-care environments⁹. The more such
22 positive interventions cut the costs of care and increase satisfaction and psychological
23 and physical health of both persons with dementia and those who care for and about
24 them, the greater the savings for society. If *nonpharmacological* interventions reduce
25 the global monetary costs of care for persons living with dementia today by only 5%,
26 governments, health systems, and individuals world-wide will save nearly \$33 billion
27 dollars annually.¹⁰
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42 **The Need for a Distinct Field of Inquiry**

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44 There are important reasons why global investment in research into these
45 humanistically valuable and potentially cost-effective "nonpharmacologic" approaches
46 lags so far behind investment in pharmacologic treatments. One reason is the lack of a
47 clear definition of these efforts as a distinct field of research and intervention. Other
48 reasons for the relative paucity of research investment include significant
49 methodological challenges to carrying out *nonpharmacological* research and the fact
50 that *nonpharmacological* interventions often have little commercial viability. Exploratory
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3 studies indicating positive outcomes of *nonpharmacological* interventions are often
4 underfunded and subsequently discounted as not rigorous enough.
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9 To overcome the first of these challenges—lack of a clearly formulated definition—we
10 propose the term—*ecopsychosocial*—to replace the term “*nonpharmacological*” in both
11 research literature and common parlance. Instead of defining this research area in
12 terms of what it is not—not pharmaceutical—the term *ecopsychosocial* inclusively
13 incorporates the full breadth and complexity of this area of inquiry and practice as
14 reflected in the many studies being carried out and interventions currently in practice.
15 Use of the term *nonpharmacological* raises ethical and practical issues as well as being
16 conceptually inelegant; it is a commonly accepted shortcut that does not adequately
17 describe the phenomena it refers to; a short cut, to continue the metaphor, that may
18 lengthen the journey by creating more problems for the entity it seeks to describe than a
19 more direct and apposite description.
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30 **Labeling: An Epistemological Challenge**

31 Labeling an intervention *nonpharmacological* means simply that it does not include
32 pharmaceuticals in its protocol. Rather than identifying the nature of such
33 interventions—by what they actually are—the term frames the interventions in negative
34 terms—by what they are not. Although the term *nonpharmacological* is both imprecise
35 and undervalues the positive nature of such interventions, it is gaining traction in the
36 professional literature, increasing the urgency for a new label. The term is increasingly
37 being employed to describe a wide range of evidence-based programs such as
38 caregiver training to assist in understanding the dementia process¹¹, adaptive
39 technologies that help the person communicate, the effects of personal care staff
40 wearing street clothes instead of uniforms¹², and interactive improvisational drama
41 programs which engage persons’ creativity¹³.
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53 The label *nonpharmacological* is also being employed to describe major shifts in the
54 social milieu of persons with dementia such as counseling and support of family
55 members to assist them to understand and live with the effects of dementia¹⁴, activity
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3 based drama and art interactions in which residents choose their own subject matter¹⁵,
4 and environmental interventions, such as creating home-like settings to help residents
5 adapt more easily to change¹⁶. Such labeling fails to recognize that these interventions
6 may be of greater significance and effectiveness in comparison with existing
7 pharmacologic treatments¹⁷—and at the very least should be considered
8 complementary to conventional treatment. In treatment of behavioral and psychological
9 symptoms of dementia, so called *nonpharmacological* interventions have been shown to
10 reduce and even eliminate the use of medications which on occasion potentially may
11 have deleterious adverse effects.^{18 19 20 21 22 23}

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21 In dementia research there is clearly an increase in interest in nonpharmacological
22 approaches. A significant article by Cohen-Mansfield in which she employs the
23 acronym “NPHI” for Nonpharmacological Interventions²⁴ is a prime example. Other
24 recent articles on *nonpharmacological* interventions in dementia include studies of
25 agitation^{25 26}, the effects of music²⁷, delirium²⁸, and Huntington’s related dementia²⁹.

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31 The term *nonpharmacological* is also increasingly used in basic medical research
32 literature, not only research related to dementia. Scholarly and professional articles
33 appear regularly describing a range of *nonpharmacological* interventions to treat health
34 conditions such as recovery from heart transplants³⁰, gastrointestinal disorders³¹,
35 fibromyalgia³², premenstrual syndrome³³, hypertension³⁴, and children’s postoperative
36 pain³⁵. As the term *ecopsychosocial* is increasingly adopted, it will be imperative to
37 cross-reference the two terms *nonpharmacological* and *ecopsychosocial* in future
38 publications.

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40 Ethical and practical questions are raised by the use of the term *nonpharmacological*.
41 These include: How does the use of a nonspecific and inexact label limit financial
42 resources for research? Does such a label make it unnecessarily difficult to acquire and
43 compare potentially significant research data and evidence? Does using a negative
44 label limit access to treatments that might provide those with dementia and their
45 partners a higher quality of life?

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5 A similar shift in terminology with an equally difficult transition for the field is the way
6 researchers and clinicians are avoiding the term “behaviors” when referring to the many,
7 often socially disruptive, ways in which those living with dementia express themselves
8 or communicate their needs.³⁶ While this transition is taking time and effort, the shift
9 eventually benefits all those with dementia who are presently being treated as if their
10 “behaviors” have little to do with intent and meaning and are merely phenomena to
11 eliminate with whatever means possible.
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18 19 **Seeking a Better Name**

20 Often employed interchangeably with *nonpharmacological*, the term *psychosocial* refers
21 to outcomes of interventions aimed at improving a person’s psychological state or social
22 situation. As noted by Vesse et al³⁷, the American Psychiatric Association has a formal
23 definition for psychosocial interventions: actions that “aim to improve quality of life and
24 psychological and social functioning, and to maximize function in the context of existing
25 deficits”³⁸ but there is no similar definition for “nonpharmacological” interventions.
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33 The terms *psychosocial* and *bio-psychosocial* are often used interchangeably with the
34 term *nonpharmacological*, but clearly do not encompass the broad array of what are
35 now being called *nonpharmacological* interventions. Programs such as
36 intergenerational charter schools where elders with dementia teach and learn from
37 younger students³⁹ and museum visit programs where those with dementia look at and
38 discuss works of art in normal settings⁴⁰ improve the quality of life for persons with
39 dementia and have *psychosocial* effects, but these programs encompass much more.
40 Environmental contextual change which is integral to such actions and programs is
41 clearly not included under the umbrella of *psychosocial* effects. The impact of such
42 interventions is on context and environment and not simply on the individual living with
43 the disease. Notions of context and the broader impact of change are missing from
44 current nomenclature. *Psychosocial* describes some effects of some interventions on
45 individuals but the terminology does not adequately address the impact of contextual
46 changes brought about by access to safe therapeutic gardens or introducing a new
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3 object such as a “memory book” into the setting with structured visual memory-jogging
4 material⁴¹, employing computer tablets for communication, or introducing music and art
5 appreciation as a way to engage people with dementia in meaningful discussion.
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10 The name change from *nonpharmacological* to *ecopsychosocial* interventions should
11 also help dissolve the narrow perception that the only hope for quality of life for persons
12 with dementia lies somewhere in a vague future when a cure is discovered. Because
13 the term “nonpharmacological” does not adequately suggest that there are many
14 interventions readily and easily available to individuals and families who provide care for
15 persons with dementia, a new descriptive term reinforces a more user-inclusive
16 approach to care.
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24 ***Ecopsychosocial*—a Term to Cut the Gordian Knot**

25 Using the prefix *eco-*, as employed in the term *ecological*, begins to resolve the insular
26 terminology dilemma. “Ecological” refers to “the interrelationship of organisms and their
27 environment” and to the study of “the relationships between a group of living things and
28 their environment.”⁴² Frequently employed in biology, sociology, and psychology to
29 include contextual factors, the term “eco-,”—etymologically rooted in the Greek term for
30 house or household (*oikes*)⁴³—rectifies the current terminological deficiency. Since
31 many interventions presently considered *nonpharmacological* are concerned with
32 changing the context or environment of persons with dementia, it is clear that a
33 reference to “context” is advantageous if not essential in defining this approach.
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44 In the field of environmental psychology which plays a major role in nonpharmacological
45 treatment for dementia, the work of J. J. Gibson⁴⁴ highlights the theory of “affordances”
46 and “niches” in what Gibson labeled “ecological psychology.” Affordances are the
47 opportunities environments offer—from the scale of a teacup to that of a city and
48 beyond—that are directly perceived and acted upon by users. Niches—ecological
49 niches—represent a set of affordances in which individuals can choose to express their
50 needs or not, according to their abilities and the environmental constraints they naturally
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3 face. This approach holds particular hope for people with dementia because no
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5 cognitive analytic interpretation is necessary to read and negotiate such environments.
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9 The work of prominent gerontologists and environmental psychologists with expertise in
10 the role the physical environment plays in the lives of persons with dementia has led to
11 conceptual constructs demonstrating the effects of the physical environment on the
12 health and well-being of elders with dementia. One of these, Lawton's "environmental
13 press model"⁴⁵, describes how a middle level of environmental support—neither too
14 stressful nor too supportive—provides the healthiest level of challenge to older users.
15 Bronfenbrenner's "ecological model"⁴⁶, Algase's "need driven behavior model"⁴⁷, and
16 the work of Cohen-Mansfield⁴⁸ provide other critical examples. This body of work
17 provides further justification for including the prefix "eco" in any replacement term for the
18 label nonpharmacological.
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28 Employing the prefix "eco" as we suggest, presents a potential conceptual trap. Since
29 "eco" has been so much used by those who promote and defend the natural
30 environment, the use of this prefix may conjure up in some readers' minds images of
31 the outdoors and protesting against global warming. Nevertheless, we suggest its use
32 because of its conceptual elegance and origins.
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38 The term *ecopsychosocial* provides a significant improvement over the present term
39 *nonpharmacological*, positively delimiting an expanding category of therapeutics and
40 serving to draw together for research purposes a broad group of interventions to treat
41 dementia.
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47 The value of the ecopsychosocial terminology for the scientific community is that
48 identifying a field with clear and, in this case, potentially broader boundaries and
49 components should result in more fruitful professional collaboration and discussion,
50 while providing a vehicle for structured research support. As the field of
51 *ecopsychosocial studies* of cognitive decline and dementia is increasingly recognized,
52 subject matter, academic curricula, and research protocols particularly suited to the field
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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 “Ecopychosocial” 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.

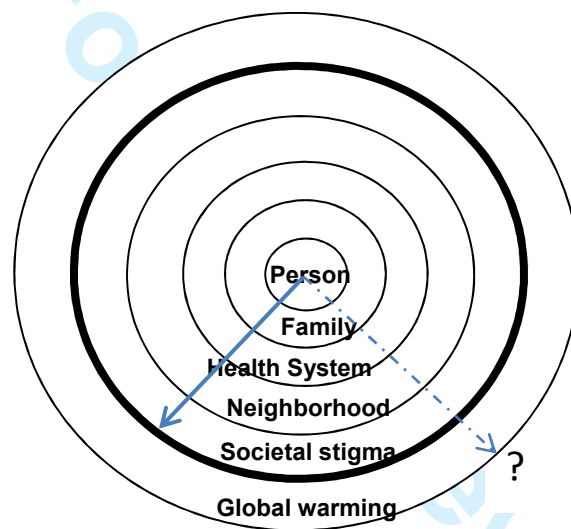


Figure 1: Environmental Range of Ecopsychosocial Interventions in

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.

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3 Local government regulations that affect barrier-free streets, parks, and public transit as
4 well as environmental requirements, codes, and standards for special-needs residential
5 environments are directly relevant to the context within which people with dementia live.
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7 The argument can be made that urbanization, air pollution, the way our food is handled
8 and sold, and global warming are all part of the dementia person's environment.
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10 However, expanding the definition of *ecopsychosocial* context beyond community and
11 society runs the risk of diluting the discipline beyond practical bounds. We propose to
12 include the study of social attitudes toward persons with dementia and the stigma
13 associated with dementia, as well as social policies and investment in dementia, as
14 relevant contextual limits at this time.
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23 In summary, *nonpharmacological* approaches make up a dynamic and expanding field
24 of treatment and research with positive effects on illnesses and diseases including
25 dementia. The scientific and practice communities need better and more positive
26 language to describe this growing field. While the term *nonpharmacological*
27 emphasizes what the field is not and forces the definition to center in and around
28 conventional pharmacological therapies, the term *ecopsychosocial*, incorporates
29 environmental and contextual influences and emphasizes the importance and positive
30 nature of a broad range of interventions in the lives of those living with dementia.
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39 *Ecopsychosocial* is a practical and conceptually elegant term to replace the term
40 *nonpharmacological* in dementia and other studies. *Ecopsychosocial* avoids defining
41 phenomena by what they are not and, more significantly, includes the broad range of
42 subject matter and research interest embodied within the overall term, such as
43 contextual issues and environmental design. Every concept, including *ecopsychosocial*,
44 needs to evolve through debate, research, and in this context, regulatory and
45 governmental action. We urge and welcome the professional community's adoption of
46 this terminology, as well as ongoing commentary and study of these matters.
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7 ¹ World Health Organization (WHO) & Alzheimer's Disease International (ADI) (2012),
8 Dementia: a public health priority, World Health Organization, Geneva, Page 2, ISBN:
9 9789241564458.

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11 ² According to the National Institute of Health's Research Portfolio Online Reporting tools
12 (RePORT), 1659 grants were awarded under the NIH spending category of dementia in fiscal
13 year 2013. In a random sample of 100 of these awards only 2% of grant awards and only 1.6%
14 of monetary funding (\$468,345 of \$29,741,932 for the 100 studies) was awarded to
15 nonpharmacological studies (the remaining \$29,273,587 for the 100 studies was awarded to
16 basic science and pharmacological research.) The total award amount for all 1659 awards was
17 \$648,317,093 with an extrapolated expenditure of 1.6% for 33 studies of nonpharmacological
18 subject matter totaling \$10,054,549. *Report.nih.gov/categorical_spending.aspx* (accessed June
19 26, 2014)

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21
22 ³ MacPherson, S., Bird, M., Anderson, K., Davis, T., & Blair, A. (2009) "An art gallery access
23 programme for people with dementia: 'You do it for the moment'" *Aging & Mental Health*, Vol.13,
24 No 5, 744-752.

25
26 ⁴ Zeisel, J., Silverstein, N. M., Hyde, J. Levkoff, S., Lawton, M. P., & Holmes, W., (2003)
27 "Environmental correlates to behavioral health outcomes in Dementia special care units."
28 *Gerontologist*, Vol.43, No.5, 697-711.

29
30
31 ⁵ Fritsch, T., J. Kwak, S. Grant, J. Lang, R. Montgomery, & Basting, A.D. (2009) "Impact of
32 TimeSlips, a creative expression intervention program, on nursing home residents with
33 dementia and their caregivers." *Gerontologist.*, Vol. 49 No 1, 117-127.

34
35 ⁶ HABIT Healthy Actions to Benefit Independence and Thinking® (2015), The Mayo Clinic.
36 Rochester, MN

37
38
39 ⁷ Greenaway M.C., Hanna S.M., Lepore S.W., & Smith G.E. (2008) A behavioral rehabilitation
40 intervention for amnesic mild cognitive impairment. *American Journal of Alzheimer's Disease*
41 *and Other Dementias*. 23(5):451-61.

42
43 ⁸ Zeisel, J. (2009) *I'm Still Here: A New Philosophy of Alzheimer Care*. Penguin-Avery, New
44 York. 39-41

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46
47 ⁹ Long, K.H., Moriarty, J.P., Mittelman, M.S., & Foldes, S.S. (2014) Estimating the potential cost
48 savings from the New York University Caregiver Intervention in Minnesota. *Health Affairs*. Vol.
49 33 No 4, 596-604

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52 ¹⁰ This calculation represents 5% of the global figure of \$655 billion annual world-wide present
53 expenditures indicated in World Health Organization (WHO) & Dementia Disease International
54 (ADI) (2012), Dementia: a public health priority, World Health Organization, Geneva, Page 2,
55 ISBN: 9789241564458.

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58 ¹¹ Reisberg, B., Kenowsky, S., Boksay, I., Golomb, J., Heller, S., Ghimire, S., Salam, M.,
59 Qureshi, S., Kumar, M., Torrosian, C., and Vedvyas, A. (2013) *Memantine and Comprehensive*,

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Individualized, Person Centered Management (CI-PCM) of Dementia Disease (AD): A randomized controlled trial, *Dementia & Dementia*, 9(4) supplement, 295-296.

¹² Charras, K., Gzil, F. (2013). Judging a book by its cover: uniforms and quality of life in special care units for people with dementia. *American Journal of Dementia Disease and Associated Disorders*, Vol. 28, No. 5, 450-458.

¹³ Benson, S. (2009) "Ladder to the Moon: interactive theatre in care settings." *Journal of Dementia Care*, Vol. 17, No 4, 20-23.

¹⁴ Mittelman, Mary S; Haley, William E; Clay, Olivio J; Roth, David L. (2006) "Improving caregiver well-being delays nursing home placement of patients with Alzheimer disease." *Neurology*. Vol. 67, No. 9: 1592-1599

¹⁵ Caulfield, S., "Establishing an Alzheimer's-competent evidence-based museum program" in P.E. Hartman and A. La Rue (eds.) *Enhancing Cognitive Fitness in Adults: A Guide to the Use and Development of Community Based Programs*, Pages 311-320, DOI 10.1007/978-1-4419-0636-6_6, Springer Science+Business Media LLC, New York (2011).

¹⁶ Cohen, U. & Weiseman, G. (1991) *Holding On to Home: Designing Environments for People with Dementia*, Johns Hopkins, Baltimore.

¹⁷ Reisberg, B., Kenowsky, S., Heller, S., Boksay, I., Golomb, J., Ghimire, S., Torossian, & C., Lobach, I., (2013) Addition of a Comprehensive, Individualized, Person Centered Management Program, to memantine alone produces a 900% increment in a pivotal trial global measure over medication treatment alone in advanced Dementia disease, *Neuropsychopharmacology*, 38, S423-S424.

¹⁸ Wooltorton E: (2002) Risperidone (Risperdal): increased rate of cerebrovascular events in dementia trials. *CMAJ*;167:1269--1270.

¹⁹ Schneider LS, Dagerman KS, Insel P: (2005) Risk of death with atypical antipsychotic drug treatment for dementia: meta-analysis of randomized placebo-controlled trials. *JAMA* 294:1934-1943.

²⁰ US Food and Drug Administration: FDA Public Health Advisory: deaths with antipsychotics in elderly patients with behavioral disturbances. <http://www.fda.gov/cder/drug/advisory/antipsychotics.htm> (accessed April 13, 2005).

²¹ Wang PS, Schneeweiss S, Avorn J, Fischer MA, Mogun H, Solomon DH, Brookhart MA: (2005) "Risk of death in elderly users of conventional vs. atypical antipsychotic medications." *N Engl J Med* 353:2335--2341.

²² Stephen PJ, Williamson J: "Drug-induced parkinsonism in the elderly". (1984) *Lancet* 2:1082--1083.

²³ Reisberg B, Saeed MU (2004),: "Dementia disease"; in Sadovoy J, Jarvik LF, Grossberg GT, Meyers BS (eds): *Comprehensive Textbook of Geriatric Psychiatry*, ed 3. New York, W.W. Norton, pp 449--509.

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- ²⁴ Cohen-Mansfield, J., B. Jensen, B. Resnick & M. Norris. (2012) "Knowledge of and Attitudes Toward Nonpharmacological Interventions for Treatment of Behavior Symptoms Associated With Dementia: A Comparison of Physicians, Psychologists, and Nurse Practitioners." *The Gerontologist*; Vol. 52, No. 1, 34-45.
- ²⁵ Janzen, S., A.A. Zecevic, M. Kloveck, & J.B. Orange. (2013) "Managing Agitation Using Nonpharmacological Interventions for Seniors With Dementia." *American Journal of Dementia Disease and Other Dementias*; Vol. 28, No. 5, 524-532.
- ²⁶ Wierman, H.R, Wadland, W.R., Walters, M., Kuhn C., & S. Farrington. (2011) "Nonpharmacological management of agitation in hospitalized patients with late-stage dementia." *Journal of Gerontological Nursing*; Vol. 37, No. 2, 44-48.
- ²⁷ Narme, P., A. Tonini, F. Khatir, L. Schiaratura, S. Clement & S. Samson. (2012) "Nonpharmacological treatment for Alzheimer's Disease: Comparison between musical and non-musical Interventions." *Geriatric et Psychologie Neuropsychiatrie du Vieillessement*; Vol. 10, No. 2, 215-224.
- ²⁸ Kolanowski, A.M., D.M. Fick, L. Clare, M. Steis, M. Boustani & M. Litaker. (2011) "Pilot study of a nonpharmacological intervention for delirium superimposed on dementia." *Research in Gerontological Nursing*; Vol. 4, No. 3, 161-167.
- ²⁹ Lee, H.M., S.T. Chen, S.J. Chen. (2010) "Nonpharmacological treatments in a patient with dementia due to Huntington's disease." *Journal of Neuropsychiatry and Clinical Neurosciences*; Vol. 22, No. 2, E17.
- ³⁰ Conway, A., Schadewaldt V., Clark R., Ski C., Thompson D.R., Kynoch K., & Doering L. (2014) "The effectiveness of nonpharmacological interventions in improving psychological outcomes for heart transplant recipients: A systematic review." *European Journal of Cardiovascular Nursing*; Vol. 12, No. 4, 393-399.
- ³¹ Lahner, E., Bellentani S., De Bastiani R., Tosetti C., Cicala M., Esposito G., Arullani P., & Annibale B. on behalf of the Study Group Primary Care in Gastroenterology of the Italian Society of Gastroenterology. (2013) "A survey of pharmacological and non-pharmacological treatment of functional gastrointestinal disorders." *United European Gastroenterology Journal*; Vol. 1, No. 5, 385-393.
- ³² Nuesch, E., W. Hauser, K. Bernardy, J. Barth & P. Juni. (2012) "Comparative efficacy of pharmacological and nonpharmacological interventions in fibromyalgia syndrome: network meta-analysis." *Annals of Rheumatic Diseases: The Eular Journal*; Vol. 72, 955-962.
- ³³ Montazeri, S. (2011) "Nonpharmacological treatment of premenstrual syndrome." *African Journal of Midwifery and Women's Health*; Vol. 5, No. 3, 148-152.
- ³⁴ Sharma, M., Frishman W.H., & Gandhi K.. (2011) "RESPeRATE: Nonpharmacological treatment of hypertension" *Cardiology in Review*; Vol. 19, No. 2 - 47-51.
- ³⁵ He, H.G., Jahja R., Lee T.L., Ang E.N., Sinnappan R., Vehvilainen-Julkunen K., & Chan M.F.. (2010) "Nurses' use of non-pharmacological methods in children's postoperative pain

management: educational intervention study.” *Journal of Advanced Nursing*; Vol. 66, No. 11, 2398–2409.

³⁶ Cohen-Mansfield, J., Dakheel-Ali, M., Marx, M. S., Thein, K., & Regier, N. G. (2015). Which unmet needs contribute to behavior problems in persons with advanced dementia? *Psychiatry research*, 228(1), 59-64. doi: 10.1016/j.psychres.2015.03.043

³⁷ : Vasse, E., Moniz-Cook, E., OldeRikkert, M., Cantegreil, I., Charras, K., Dorenlot, P., Fumero, G., Franco, M., Woods, B. & Vernooij-Dassen, M. (2012). The development of quality indicators to improve psychosocial care in dementia: a multinational and multidisciplinary approach. *International Psychogeriatrics*, 24(6), 921-930.

³⁸ Rabins, P. V. et al. (2007) APA Work Group on Alzheimer’s Disease and Other Dementias, American Psychiatric Association practice guideline for the treatment of patients with Alzheimer’s disease and other dementias, 2nd edition. *American Journal of Psychiatry*, 164 (Suppl.) 55–56.

³⁹ Whitehouse PJ, Bendezu E, FallCreek S, Whitehouse C. Intergenerational community schools: a new practice for a new time. *Educ Gerontol*, 2000, 26:761-770.

⁴⁰ Whitcomb, R. (2010) Art and Alzheimer’s: Another way of remembering. *Pacific Standard*, December.

⁴¹ Bourgeois, M. (2013) *Memory Books and Other Graphic Cuing Systems: Practical Communication and Memory Aids for Adults with Dementia*, Health Professions Press, Baltimore (April 2007)

⁴² *Merriam-Webster.com*. Merriam-Webster, (2014) <http://www.merriam-webster.com/dictionary/ecology>. (Accessed June 1, 2014)

⁴³ *Merriam-Webster.com* (2014) www.merriam-webster.com/dictionary/eco- and Wiktionary (2014) <http://en.wiktionary.org/wiki/eco-> . (Accessed June 15, 2014)

⁴⁴ Gibson, J.J., (1977). The Theory of affordances. In R.E. Shaw & J. Bransford (eds.). *Perceiving, Acting, and Knowing* (pp.67-82). Hillsdale, NJ, US: Lawrence Erlbaum Associates.

⁴⁵ Lawton, M.P., & Nahemow, L. (1973). Ecology and the aging process. In C.Eisdorfer, & M.P. Lawton (Eds.), *The Psychology of Adult Development and Aging* (vi ed.). Washington, DC, US: American Psychological Association.

⁴⁶ Bronfenbrenner, U. (1979). *The Ecology of Human Development*. Cambridge, MA, US: Harvard University Press, 368.

⁴⁷ Algase, D., Beck, C., Kolanowski, A., Whall, A., Berent, S., Richards, K., & Beattie, E. (1996). Need-driven dementia-compromised behavior: An alternative view of disruptive behavior. *American Journal of Alzheimer’s Disease*, 11(6), 10-19.

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⁴⁸ Cohen-Mansfield, J., & Warner, P. (1995) Environmental influences on agitation: An integrative summary of an observational study. *The American Journal of Alzheimer's Care & Related Disorders and Research*, 10(1), 32-39

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