

Resource List of Articles on Dementia Care and Services

February 2019

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Article Resource List: February 2019

The National Alzheimer’s and Dementia Resource Center has prepared this list of recently published articles covering a range of subjects of interest to Administration for Community Living grantees and partners. This list does not represent a comprehensive examination of the recent literature in any one subject or topic. Links to the publishers’ websites have been included if an article is available for purchase or for free download.

The table below lists the articles by topic: behavioral symptoms; care approaches and interventions; care transitions; cognitive screening, diagnosis, and assessment scales; dementia and diverse populations; dementia with Lewy bodies, frontotemporal dementia, Korsakoff’s syndrome, vascular, and young-onset dementia; family and informal caregiving; intellectual disabilities/Down syndrome; living alone with dementia; and living with dementia. Click on the topic to go to the full citation list including the article abstracts, located beneath the table.

Topic	Articles
Behavioral Symptoms	<ol style="list-style-type: none"> <li data-bbox="462 856 1409 1060">1. Terracciano, A., Islam, M., Mazumder, M., Schwabe-Warf, D., Stephan, Y., & Sutin, A. (2018). Personality changes with dementia from the informant perspective: New data and meta-analysis. <i>Innovation in Aging</i>, 2(suppl_1), 973-973. [Epub ahead of print] https://doi.org/10.1016/j.jamda.2018.11.004  <li data-bbox="462 1075 1409 1278">2. Vernon, E., Cooley, B., Rozum, W., Rattinger, G., Behrens, S., Matyi, J., et al. (2018). Caregiver-care recipient relationship closeness is associated with neuropsychiatric symptoms in dementia. <i>The American Journal of Geriatric Psychiatry</i>. [Epub ahead of print] https://doi.org/10.1016/j.jagp.2018.11.010 
Care Approaches and Interventions	<ol style="list-style-type: none"> <li data-bbox="462 1297 1409 1459">3. Bosco, A., Schneider, J., Coleston-Shields, D., & Orrell, M. (2019). Dementia care model: Promoting personhood through co-production. <i>Archives of Gerontology and Geriatrics</i>, 81, 59-73. https://doi.org/10.1016/j.archger.2018.11.003  <li data-bbox="462 1474 1409 1635">4. Holle, C., Turnquist, M., & Rudolph, J. (2018). Safeguarding older adults with dementia, depression, and delirium in a temporary disaster shelter. <i>Nursing Forum</i>. [Epub ahead of print] https://doi.org/10.1111/nuf.12309  <li data-bbox="462 1650 1409 1812">5. King J., Jones K., Goldberg E. et al. (2019). Increased functional connectivity after listening to favored music in adults with Alzheimer dementia. <i>Journal of Prevention of Alzheimer’s Disease</i>. 6(1), 56-62. https://doi.org/10.14283/jpad.2018.19 

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Topic	Articles
Care Approaches and Interventions (continued)	<ol style="list-style-type: none"> <li data-bbox="459 258 1421 415">6. Leggett, A., Kales, H., & Gitlin, L. (2019). Finding fault: Criticism as a care management strategy and its impact on outcomes for dementia caregivers. <i>International Journal of Geriatric Psychiatry</i>. [Epub ahead of print] https://doi.org/10.1002/gps.5052 <li data-bbox="459 426 1421 625">7. Leng, M., Liu, P., Zhang, P., Hu, M., Zhou, H., Li, G., et al. (2019). Pet robot intervention for people with dementia: A systematic review and meta-analysis of randomized controlled trials. <i>Psychiatry Research</i>, 271, 516-525. https://doi.org/10.1016/j.psychres.2018.12.032 <li data-bbox="459 636 1421 814">8. Meyer, C., Hill, K., Hill, S., & Dow, B. (2019). Falls prevention for people with dementia: A knowledge translation intervention. <i>Dementia</i>. [Epub ahead of print] https://doi.org/10.1177/1471301218819651 <li data-bbox="459 825 1421 1003">9. Teri, L., Logsdon, R., McCurry, S., Pike, K., & McGough, E. (2018). Translating an evidence-based multicomponent intervention for older adults with dementia and caregivers. <i>The Gerontologist</i>. [Epub ahead of print] https://doi.org/10.1093/geront/gny122 <li data-bbox="459 1014 1421 1213">10. Weise, L., Jakob, E., Töpfer, N., & Wilz, G. (2018). Study protocol: Individualized music for people with dementia - improvement of quality of life and social participation for people with dementia in institutional care. <i>BMC Geriatrics</i>, 18(1). https://doi.org/10.1186/s12877-018-1000-3 (free) <li data-bbox="459 1224 1421 1442">11. Zucchella, C., Sinforiani, E., Tamburin, S., Federico, A., Mantovani, E., Bernini, S., et al. (2018). The multidisciplinary approach to Alzheimer's Disease and dementia. A narrative review of non-pharmacological treatment. <i>Frontiers in Neurology</i>, 9. [Epub ahead of print] https://doi.org/10.3389/fneur.2018.01058 (free)







(continued)

Topic	Articles
Care Transitions	<p>12. Burton, J., Guthrie, B., Hapca, S., Cvorov, V., Donnan, P., & Reynish, E. (2018). Living at home after emergency hospital admission: Prospective cohort study in older adults with and without cognitive spectrum disorder. <i>BMC Medicine</i>, 16(1), 231. https://doi.org/10.1186/s12916-018-1199-z (free)</p> <p>13. Cottrell, L., Duggleby, W., Ploeg, J., McAiney, C., Peacock, S., Ghosh, S., et al. (2018). Using focus groups to explore caregiver transitions and needs after placement of family members living with dementia in 24-hour care homes. <i>Aging & Mental Health</i>. [Epub ahead of print] https://doi.org/10.1080/13607863.2018.1531369</p> <p>14. Jacobsohn, G., Hollander, M., Beck, A., Gilmore-Bykovskiy, A., Werner, N., & Shah, M. (2019). Factors influencing emergency care by persons with dementia: Stakeholder perceptions and unmet needs. <i>Journal of The American Geriatrics Society</i>. [Epub ahead of print] https://doi.org/10.1111/jgs.15737</p> <p>15. Jensen, A., Pedersen, B., Olsen, R., Wilson, R., & Hounsgaard, L. (2018). “If only they could understand me!” Acute hospital care experiences of patients with Alzheimer’s disease. <i>Dementia</i>. [Epub ahead of print] https://doi.org/10.1177/1471301218820483</p> <p>16. Lethin, C., Giertz, L., Vingare, E., & Hallberg, I. (2018). Dementia care and service systems – a mapping system tested in nine Swedish municipalities. <i>BMC Health Services Research</i>, 18(1). https://doi.org/10.1186/s12913-018-3592-x (free)</p>

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Topic	Articles
Cognitive Screening, Diagnosis, and Assessment Scales	<p>17. Budgett, J., Brown, A., Daley, S., Page, T., Banerjee, S., Livingston, G., & Sommerlad, A. (2019). The social functioning in dementia scale (SF-DEM): Exploratory factor analysis and psychometric properties in mild, moderate, and severe dementia. <i>Alzheimer's & Dementia: Diagnosis, Assessment & Disease Monitoring</i>, 11, 45-52. https://doi.org/10.1016/j.dadm.2018.11.001 (free)</p> <p>18. Koo, B., & Vizer, L. (2019). Mobile technology for cognitive assessment of older adults: A scoping review. <i>Innovation in Aging</i>, 3(1), igy038. https://doi.org/10.1093/geroni/igy038 (free)</p> <p>19. Umeda-Kameyama, Y., Mori, T., Wada-Isoe, K., Kikuchi, T., Kojima, S., Kagimura, T., et al. (2018). Development of a novel convenient Alzheimer's disease assessment scale, the ABC Dementia Scale, using item response theory. <i>Geriatrics & Gerontology International</i>, 19(1), 18-23. https://doi.org/10.1111/ggi.13552</p>
Dementia and Diverse Populations	<p>20. Lau, B., Lou, V., & Cheung, K. (2018). Exemplary care among Chinese dementia familial caregivers. <i>Healthcare</i>, 6(4), 141. https://doi.org/10.3390/healthcare6040141 (free)</p> <p>21. Milani, S., Marsiske, M., Cottler, L., Chen, X., & Striley, C. (2018). Optimal cutoffs for the Montreal Cognitive Assessment vary by race and ethnicity. <i>Alzheimer's & Dementia: Diagnosis, Assessment & Disease Monitoring</i>, 10, 773-781. https://doi.org/10.1016/j.dadm.2018.09.003 (free)</p> <p>22. Parveen, S., Barker, S., Kaur, R., Kerry, F., Mitchell, W., Happs, A., et al. (2018). Involving minority ethnic communities and diverse experts by experience in dementia research: The Caregiving HOPE Study. <i>Dementia</i>, 17(8), 990-1000. https://doi.org/10.1177/1471301218789558</p> <p>23. Sagbakken, M., Spilker, R., & Nielsen, T. (2018). Dementia and immigrant groups: A qualitative study of challenges related to identifying, assessing, and diagnosing dementia. <i>BMC Health Services Research</i>, 18(1), 910. https://doi.org/10.1186/s12913-018-3720-7 (free)</p>

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Topic	Articles
<p>Dementia with Lewy Bodies, Frontotemporal Dementia, Korsakoff's syndrome, Vascular, & Young-onset Dementia</p>	<p>24. Ducharme, S., Pearl-Dowler, L., Gossink, F., McCarthy, J., Lai, J., Dickerson, B., et al. (2019). The Frontotemporal Dementia versus Primary Psychiatric Disorder (FTD versus PPD) Checklist: A bedside clinical tool to identify behavioral variant FTD in patients with late-onset behavioral changes. <i>Journal of Alzheimer's Disease</i>, 67(1), 113-124. https://doi.org/10.3233/JAD-180839 </p> <p>25. Heirene, R., John, B., & Roderique-Davies, G. (2018). Identification and evaluation of neuropsychological tools used in the assessment of alcohol-related cognitive impairment: A systematic review. <i>Frontiers in Psychology</i>, 9. [Epub ahead of print] https://doi.org/10.3389/fpsyg.2018.02618  (free)</p> <p>26. Kobiske, K., Bekhet, A., Garnier-Villarreal, M., & Frenn, M. (2018). Predeath grief, resourcefulness, and perceived stress among caregivers of partners with young-onset dementia. <i>Western Journal of Nursing Research</i>. [Epub ahead of print] https://doi.org/10.1177/0193945918806689 </p> <p>27. Moheb, N., Charuworn, K., Ashla, M., Desarant, R., Chavez, D., & Mendez, M. (2018). Repetitive behaviors in frontotemporal dementia: Compulsions or impulsions? <i>The Journal of Neuropsychiatry and Clinical Neurosciences</i>. [Epub ahead of print] https://doi.org/10.1176/appi.neuropsych.18060148 </p> <p>28. Mueller, C., Soysal, P., Rongve, A., Isik, A., Thompson, T., Maggi, S., et al. (2019). Survival time and differences between dementia with Lewy bodies and Alzheimer's disease following diagnosis: A meta-analysis of longitudinal studies. <i>Ageing Research Reviews</i>. [Epub ahead of print] https://doi.org/10.1016/j.arr.2019.01.005 </p> <p>29. Slot, R., Sikkes, S., Berkhof, J., Brodaty, H., Buckley, R., Cavado, E., et al. (2018). Subjective cognitive decline and rates of incident Alzheimer's disease and non-Alzheimer's disease dementia. <i>Alzheimer's & Dementia</i>. [Epub ahead of print] https://doi.org/10.1016/j.jalz.2018.10.003 </p>

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Topic	Articles
Family and Informal Caregiving	<p>30. Donnellan, W., Bennett, K., & Soulsby, L. (2018). How does carer resilience change over time and care status? A qualitative longitudinal study. <i>Aging & Mental Health</i>, 1-7. [Epub ahead of print] https://doi.org/10.1080/13607863.2018.1503998</p> <p>31. Jütten, L., Mark, R., & Sitskoorn, M. (2018). Predicting self-esteem in informal caregivers of people with dementia: Modifiable and non-modifiable factors. <i>Aging & Mental Health</i>. [Epub ahead of print] https://doi.org/10.1080/13607863.2018.1531374</p> <p>32. Lee, J., Barlas, J., Thompson, C., & Dong, Y. (2018). Caregivers' experience of decision-making regarding diagnostic assessment following cognitive screening of older adults. <i>Journal of Aging Research</i>, 2018. [Epub ahead of print] https://doi.org/10.1155/2018/8352816 (free)</p> <p>33. Meichsner, F., Töpfer, N., Reder, M., Soellner, R., & Wilz, G. (2019). Telephone-based cognitive behavioral intervention improves dementia caregivers' quality of life. <i>American Journal of Alzheimer's Disease & Other Dementias</i>[®]. [Epub ahead of print] https://doi.org/10.1177/1533317518822100</p> <p>34. Miller, V., Killian, M., & Fields, N. (2018). Caregiver identity theory and predictors of burden and depression: Findings from the REACH II study. <i>Aging & Mental Health</i>. [Epub ahead of print] https://doi.org/10.1080/13607863.2018.1533522</p> <p>35. Quinn, C., & Toms, G. (2018). Influence of positive aspects of dementia caregiving on caregivers' well-being: A systematic review. <i>The Gerontologist</i>. [Epub ahead of print] https://doi.org/10.1093/geront/gny168</p> <p>36. Sakka, M., Goto, J., Kita, S., Sato, I., Soejima, T., & Kamibeppu, K. (2018). Associations among behavioral and psychological symptoms of dementia, care burden, and family-to-work conflict of employed family caregivers. <i>Geriatrics & Gerontology International</i>. [Epub ahead of print] https://doi.org/10.1111/ggi.13556</p> <p>37. Stall, N., Kim, S., Hardacre, K., Shah, P., Straus, S., Bronskill, S., et al. (2018). Association of informal caregiver distress with health outcomes of community-dwelling dementia care recipients: A systematic review. <i>Journal of The American Geriatrics Society</i>. [Epub ahead of print] https://doi.org/10.1111/jgs.15690</p>

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Topic	Articles
Intellectual Disabilities/Down Syndrome and Dementia	<p>38. Ali, A., Brown, E., Spector, A., Aguirre, E., & Hassiotis, A. (2018). Individual cognitive stimulation therapy for people with intellectual disability and dementia: Protocol of a feasibility randomised controlled trial. <i>BMJ Open</i>, 8(12), e022136. https://doi.org/10.1136/bmjopen-2018-022136 (free)</p> <p>39. Hithersay, R., Startin, C., Hamburg, S., Mok, K., Hardy, J., Fisher, E., et al. (2018). Association of dementia with mortality among adults with Down syndrome older than 35 years. <i>JAMA Neurology</i>. [Epub ahead of print] https://doi.org/10.1001/jamaneurol.2018.3616</p> <p>40. Schaap, F., Fokkens, A., Dijkstra, G., Reijneveld, S., & Finnema, E. (2018). Dementia care mapping to support staff in the care of people with intellectual disability and dementia: a feasibility study. <i>Journal of Applied Research In Intellectual Disabilities</i>, 31(6), 1071-1082. https://doi.org/10.1111/jar.12464</p> <p>41. Strydom, A., Coppus, A., Blesa, R., Danek, A., Fortea, J., Hardy, J., et al. (2018). Alzheimer’s disease in Down syndrome: An overlooked population for prevention trials. <i>Alzheimer’s & Dementia: Translational Research & Clinical Interventions</i>, 4, 703-713. https://doi.org/10.1016/j.trci.2018.10.006</p>
Living Alone with Dementia	<p>42. Bloch, F., Lundy, J., & Rigaud, A. (2017). Profile differences of purchasers, non-purchasers, and users and non-users of Personal Emergency Response Systems: Results of a prospective cohort study. <i>Disability and Health Journal</i>, 10(4), 607-610. https://doi.org/10.1016/j.dhjo.2017.01.008</p> <p>43. Johannessen, A., Engedal, K., Haugen, P., Dourado, M., & Thorsen, K. (2018). “To be, or not to be”: experiencing deterioration among people with young-onset dementia living alone. <i>International Journal of Qualitative Studies on Health and Well-Being</i>, 13(1), 1490620. https://doi.org/10.1080/17482631.2018.1490620</p>

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Topic	Articles
Living with Dementia	<p>44. Bosco, A., Schneider, J., Coleston-Shields, D., Jawahar, K., Higgs, P., & Orrell, M. (2018). Agency in dementia care: Systematic review and meta-ethnography. <i>International Psychogeriatrics</i>. [Epub ahead of print] https://doi.org/10.1017/S1041610218001801 ↗</p> <p>45. Lindau, S., Dale, W., Feldmeth, G., Gavrilova, N., Langa, K., Makelarski, J., & Wroblewski, K. (2018). Sexuality and cognitive status: A U.S. nationally representative study of home-dwelling older adults. <i>Journal of the American Geriatrics Society</i>, 66(10), 1902-1910. https://doi.org/10.1093/pm/pny180 ↗</p> <p>46. Odzakovic, E., Hellström, I., Ward, R., & Kullberg, A. (2018). ‘Overjoyed that I can go outside’: Using walking interviews to learn about the lived experience and meaning of neighborhood for people living with dementia. <i>Dementia</i>. [Epub ahead of print] https://doi.org/10.1177/1471301218817453 ↗</p>

Behavioral Symptoms

1. Terracciano, A., Islam, M., Mazumder, M., Schwabe-Warf, D., Stephan, Y., & Sutin, A. (2018). Personality changes with dementia from the informant perspective: New data and meta-analysis. *Innovation in Aging*, 2(suppl_1), 973-973. [Epub ahead of print] <https://doi.org/10.1016/j.jamda.2018.11.004> ↗

Abstract

Objective: To examine changes in personality in individuals with mild cognitive impairment (MCI) or dementia as observed by family members using both new data and a meta-analysis with the published literature. Design: Current and retrospective personality assessments of individuals with dementia by family informants. PubMed was searched for studies with a similar design and a forward citation tracking was conducted using Google Scholar in June 2018. Results from a new sample and from published studies were combined in a random effect meta-analysis. Setting And Participants: Family members of older adults with MCI or dementia. Measures: The 5 major dimensions (neuroticism, extraversion, openness, agreeableness, and conscientiousness) and facets of personality were assessed with NEO Personality Inventory questionnaires. Results: The new sample (n = 50) and meta-analysis (18 samples; n = 542) found consistent shifts in personality from the premorbid to current state in patients with cognitive impairment. The largest changes (>1 standard deviation) were declines in conscientiousness (particularly for the facets of self-discipline and competence) and extraversion (decreased energy and assertiveness), as well as increases in neuroticism (increased vulnerability to stress). The new sample suggested that personality


changes were larger in individuals taking cognition-enhancing medications (cholinesterase inhibitors or memantine). More recent studies and those that examined individuals with MCI found smaller effects. Conclusions And Implications: Consistent with the clinical criteria for the diagnosis of dementia, the new study and meta-analysis found replicable evidence for large changes in personality among individuals with dementia. Future research should examine whether there are different patterns of personality changes across etiologies of dementia to inform differential diagnosis and treatments. Prospective, repeated assessments of personality using both self- and informant-reports are essential to clarify the temporal evolution of personality change across the preclinical, prodromal, and clinical phases of dementia. © 2018 AMDA – The Society for Post-Acute and Long-Term Care Medicine.

2. Vernon, E., Cooley, B., Rozum, W., Rattinger, G., Behrens, S., Matyi, J., et al. (2018). Caregiver-care recipient relationship closeness is associated with neuropsychiatric symptoms in dementia. *The American Journal of Geriatric Psychiatry*. [Epub ahead of print] <https://doi.org/10.1016/j.jagp.2018.11.010> ↗

Abstract


Objective: Closer caregiver-care recipient (CG-CR) relationships are associated with better cognitive and functional abilities, activities of daily living (in persons with dementia), and lower informal care costs. Methods: Due to the difficulty in treating neuropsychiatric symptoms (NPSs) and their detrimental effects on caregivers and care recipients, we examined whether closeness of CG-CR relationships was associated with overall NPS severity or with specific NPS symptom domains in care recipients. In a longitudinal population-based study in Cache County, Utah, the 12-item Neuropsychiatric Inventory (NPI-12) was assessed in 300 CG-CR dyads. Caregivers reported current relationship closeness using the Whitlatch Relationship Closeness Scale. Linear mixed models examined associations between CG-CR closeness and NPI-12 total score or selected symptom domains over time (observation period: 2002-2012). Results: In unadjusted linear mixed models, higher closeness scores were associated with a five-point lower NPI-12 score and a one-point lesser increase in NPI-12 per year. NPI scores also showed lower affective cluster scores (two points) and lesser increase in psychosis cluster (approximately 0.5 points per year) and agitation/aggression (0.16 points per year) for each unit increase in closeness. When controlling for NPI caregiver distress, associations between closeness and NPSs diminished to a 0.5-point lesser increase in total NPI-12 score per year. Adjusted models for NPI domains/clusters showed -0.32 points per year for the psychosis cluster, -0.11 points per year for agitation/aggression, and -0.67 overall for the affective cluster. Conclusion: Higher CG-CR closeness, a potentially modifiable factor, is associated with lower NPS severity and may provide a target for intervention. © 2018 Elsevier Ltd.

Care Approaches and Interventions

3. Bosco, A., Schneider, J., Coleston-Shields, D., & Orrell, M. (2019). Dementia care model: Promoting personhood through co-production. *Archives of Gerontology and Geriatrics*, 81, 59-73. <https://doi.org/10.1016/j.archger.2018.11.003> 

Abstract


Background: Despite robust evidence on its effectiveness, current approaches that aspire to person-centered care (PCC) frequently locate people with dementia as passive recipients rather than as active agents in the care process. We define active involvement in care as ‘co-production’. In order to investigate co-production, we set out to review the evidence concerning personhood and dignity in dementia care. Method: We adopted a meta-ethnographic approach to synthesize the predominantly- qualitative literature on personhood and dignity in dementia care using EMBASE, PsycINFO, and ASSIA databases. We also included relevant policy documents. Members of Patient and Public Involvement (PPI) group were consulted throughout. Results: A total of 14 empirical studies were subjected to content analysis. Three themes were identified: dignity and personhood, coping with dementia, and barriers to dignity in care. The findings suggest that positive strategies and coping mechanisms are associated with superior outcomes in relation to: sense of self, dignity and quality of care. The 22 policy documents yielded six themes pertaining to co-production: the part played by the person with dementia, family, environment, behavior, governance and law, and health care partnership. Conclusion: Personhood in dementia care is enhanced through co-production, by actively participating in social, civic and political life. This is promoted through behavioral changes at the micro and macro levels of society, including providers of care being trained in co-producing care and policy makers creating opportunities with, rather than for people with dementia. © 2018 Elsevier B.V.

4. Holle, C., Turnquist, M., & Rudolph, J. (2018). Safeguarding older adults with dementia, depression, and delirium in a temporary disaster shelter. *Nursing Forum*. [Epub ahead of print] <https://doi.org/10.1111/nuf.12309> 

Abstract


Natural disasters impact people of every age in the communities where they occur, with older adults being a vulnerable subset of the population. Most disaster shelter volunteer nurses are experienced in addressing common health needs of older adult clients such as diabetes, hypertension, and pulmonary disease. These nurses also have the requisite training to respond to more acute medical events, including the symptoms of a heart attack or stroke. They provide care and comfort to those suffering from the distress, anxiety, and fear caused by disasters. However, they may be less adept at triaging and caring for older adults with mental health conditions such as delirium, depression, or dementia. The trauma associated with a disaster and relocation will challenge cognitive abilities in those with dementia, may exacerbate existing depression, or lead to the onset of delirium, which is a medical

emergency. Older adults experiencing these conditions are at risk for harm and deterioration with serious short and long-term consequences. Since disaster shelter volunteer health care staff may not be well-versed in distinguishing between dementia, depression, or delirium, behavior observation, and safety considerations are critical determinants of whether it is possible to support the older adult in the shelter environment or it is necessary to transition to a higher level of care. © 2018 Wiley Periodicals, Inc.

5. King J., Jones K., Goldberg E., et al. (2019). Increased functional connectivity after listening to favored music in adults with Alzheimer dementia. *Journal of Prevention of Alzheimer's Disease*, 6(1), 56-62. <https://doi.org/10.14283/jpad.2018.19> 

Abstract


Background: Personalized music programs have been proposed as an adjunct therapy for patients with Alzheimer disease related dementia, and multicenter trials have now demonstrated improvements in agitation, anxiety, and behavioral symptoms. Underlying neurophysiological mechanisms for these effects remain unclear. Methods: We examined 17 individuals with a clinical diagnosis of Alzheimer disease related dementia using functional MRI following a training period in a personalized music listening program. Results: We find that participants listening to preferred music show specific activation of the supplementary motor area, a region that has been associated with memory for familiar music that is typically spared in early Alzheimer disease. We also find widespread increases in functional connectivity in corticocortical and corticocerebellar networks following presentation of preferred musical stimuli, suggesting a transient effect on brain function. Conclusions: Findings support a mechanism whereby attentional network activation in the brain's salience network may lead to improvements in brain network synchronization.

6. Leggett, A., Kales, H., & Gitlin, L. (2019). Finding fault: Criticism as a care management strategy and its impact on outcomes for dementia caregivers. *International Journal of Geriatric Psychiatry*. [Epub ahead of print] <https://doi.org/10.1002/gps.5052> 

Abstract


Background: Despite a large literature on the stress process, little attention has focused on how caregivers for persons living with dementia (PLWDs) provide care and how this may impact care outcomes. Criticism is a management strategy caregivers may use to respond to behavioral symptoms. We consider whether criticism is associated with caregivers' mental health and service utilization. Methods: Data are drawn from the Advancing Caregiver Training intervention study including 256 informal caregivers living with a PLWD. In multiple linear regressions controlling for caregivers' demographics and PLWDs' clinical factors, we consider criticism (criticism subscale of the Dementia Management Strategies Scale) as a predictor of caregiver burden, depressive symptoms, desire to institutionalize the PLWD, level of frustration with care, and the number of home-based, social, and health services utilized. Results: On average, 15% of the sample sometimes reported using criticism

as a management strategy to manage the challenges of care. Greater use of criticism was associated with significantly more caregiver burden ($\beta = 0.26, P < 0.001$) and frustration with caregiving ($\beta = 0.66, P < 0.001$), but not depressive symptoms or a desire to institutionalize the PLWD. Criticism was also associated with significantly greater utilization of home-based ($\beta = 0.14, P < 0.05$) and social services ($\beta = 0.15, P < 0.05$), but not health care services. Conclusion: Criticism appears to be used by more burdened and frustrated caregivers. The association of criticism with social and home-based services potentially reflects a need for greater support among this group of caregivers. Behavioral interventions that can help caregivers manage behavioral symptoms with positive, empirically validated strategies may be helpful. © 2018 John Wiley & Sons, Ltd.

7. Leng, M., Liu, P., Zhang, P., Hu, M., Zhou, H., Li, G., et al. (2019). Pet robot intervention for people with dementia: A systematic review and meta-analysis of randomized controlled trials. *Psychiatry Research*, 271, 516-525. <https://doi.org/10.1016/j.psychres.2018.12.032> 

Abstract

This study aims to systematically evaluate the efficacy of Pet robot intervention (PRI) for people with dementia. Two waves of electronic searches of the PubMed, EMBASE, Web of Science, Cochrane library, IEEE Digital Library and PsycINFO databases were conducted. In total, eight articles from six randomized controlled trials (RCTs) met the eligibility criteria and were included in this systematic review. The results of the meta-analysis showed a statistically significant decrease in behavioral and psychological symptoms of dementia (BPSD), especially agitation and depression, in people with dementia who were treated with PRI. Both individual and group format PRI significantly ameliorated BPSD. However, there were no significant improvements in cognitive function or quality of life. The results of the meta-analysis suggest that PRI may be suitable as a treatment option for BPSD in people with dementia and should be considered as a useful tool in clinical practice. © 2018. Published by Elsevier B.V.

8. Meyer, C., Hill, K., Hill, S., & Dow, B. (2019). Falls prevention for people with dementia: a knowledge translation intervention. *Dementia*, <https://doi.org/10.1177/1471301218819651>  [Epub ahead print]

Abstract

Purpose: Strong evidence exists for falls prevention, yet uptake of strategies can be by changes in memory and planning. This paper describes the findings of a knowledge translation intervention for adoption of falls prevention strategies for people with dementia. Methods: Twenty-five dyads (people with dementia and their caregivers) participated in this mixed method intervention. The Knowledge to Action framework guided: collation of existing evidence into a useable format; identification of individual issues; understanding context; and evaluation of change over time. Demographic details, functional status, dementia severity, activity level, self-efficacy, falls risk and readiness to change behaviour

were collected at baseline, 6 and 12 months. Goal setting and action planning using a discussion tool drove implementation. Results: Falls rates were 5.4 falls per 1000 days for the 12-month period, with no significant change in functional capacity or self-efficacy. There was a non-significant trend towards reduced falls risk. Readiness to change behaviour for falls risk increased from 84% to 96% by 6 months, with most moving from contemplation into action (n = 16), or preparation into action (n = 36), with adoption of strategies high (82%). Conclusion: Engagement with the person with dementia and their caregiver, through identification of their needs and preferences, and enabling choice resulted in high adoption of falls prevention strategies.

9. Teri, L., Logsdon, R., McCurry, S., Pike, K., & McGough, E. (2018). Translating an evidence-based multicomponent intervention for older adults with dementia and caregivers. *The Gerontologist*. [Epub ahead of print] <https://doi.org/10.1093/geront/gny122>

Abstract

Background and Objectives: Effective community-based programs to maintain health and well-being of adults with dementia are needed. This article describes the translation, implementation, and effectiveness of a multicomponent exercise plus behavioral/psychosocial intervention (Reducing Disability in Alzheimer's Disease-NorthWest [RDAD-NW]) conducted by staff in regional Area Agencies on Aging (AAAs). **Research Design and Methods:** Staggered multiple baseline design was used; 10 AAAs, 20 case managers, and 255 community-residing persons with dementia (PWDs), and family caregivers were enrolled. RDAD-NW was conducted in-home over 6 weeks with aerobic/endurance, strength, and balance/flexibility exercises, dementia education, training to increase pleasant events, and activator-behavior-consequence problem-solving approach. **Outcomes included case manager treatment fidelity, and caregiver/PWD physical activity, restricted activity days, physical functioning, quality of life, and affect. Results:** RDAD-NW was successfully translated and implemented by AAA agency staff through their usual service provision mechanisms. Staff responded positively and delivered the program with a high degree of fidelity. Caregiver/PWD dyads also responded favorably engaging in both exercise and behavioral/psychosocial portions of the program. A total of 207 dyads (81%) completed the intervention and 140 (55%) completed the 13-month follow-up. PWD physical activity increased significantly pre- to posttreatment ($p < .001$, $ES = .54$), and 13 months ($p < .01$, $ES = .21$). Quality of life of PWD increased significantly pre- to posttreatment ($p < .001$, $ES = .29$); caregiver depression improved pre- to posttreatment ($p = .01$, $ES = -.18$). **Discussion and Implications:** RDAD-NW was successfully translated and implemented by AAA case managers and resulted in increased physical activity and improved behavioral and emotional outcomes of caregiver/PWDs. Results support continued dissemination and implementation of RDAD-NW.

10. Weise, L., Jakob, E., Töpfer, N., & Wilz, G. (2018). Study protocol: Individualized music for people with dementia - improvement of quality of life and social participation for people with

dementia in institutional care. *BMC Geriatrics*, 18(1). <https://doi.org/10.1186/s12877-018-1000-3> (free)

Abstract

Background: People with dementia (PwD) experience a range of negative behavioral and psychological symptoms which can lower their quality of life. Because of the increasing prevalence of dementia, interventions that maintain and enhance the quality of life for PwD are needed. Listening to individualized music constitutes a promising non-pharmacological intervention for PwD. However, despite some preliminary results, evidence regarding the effectiveness of such interventions has been mixed and previous studies have shown a number of methodological limitations. In a randomized controlled trial, we address the limitations of previous research and assess the feasibility, efficacy, and acceptability of an individualized music intervention for PwD living in a nursing home. **Methods:** Residents with dementia from four to five nursing homes in Germany will be randomly assigned to either an intervention or control group. The intervention group will listen to personally-relevant music for 20 min every other day for six weeks. Nursing staff will assess participants' quality of life and problem behavior at the six-week baseline, pretest, posttest, and at the six-week follow-up. Additionally, the participants' behavior will be observed during the intervention period by project staff. The implementation, acceptance, and applicability of the intervention will also be evaluated. **Discussion:** The study results will show whether an individualized music intervention can improve the quality of life for PwD living in a nursing home. Additionally, it will provide valuable insight into the acceptability and implementation of an individualized music intervention in the institutional care setting. If the individualized music intervention proves to be effective and widely applicable, it could be implemented on a large scale in institutional care as an easy-to-administer intervention.

11. Zucchella, C., Sinforiani, E., Tamburin, S., Federico, A., Mantovani, E., Bernini, S., et al. (2018). The multidisciplinary approach to Alzheimer's Disease and dementia. A narrative review of non-pharmacological treatment. *Frontiers in Neurology*, 9. [Epub ahead of print] <https://doi.org/10.3389/fneur.2018.01058> (free)

Abstract

Background: Alzheimer's disease (AD) and dementia are chronic diseases with progressive deterioration of cognition, function, and behavior leading to severe disability and death. The prevalence of AD and dementia is constantly increasing because of the progressive aging of the population. These conditions represent a considerable challenge to patients, their family and caregivers, and the health system, because of the considerable need for resources allocation. There is no disease modifying intervention for AD and dementia, and the symptomatic pharmacological treatments has limited efficacy and considerable side effects. Non-pharmacological treatment (NPT), which includes a wide range of approaches and techniques, may play a role in the treatment of AD and dementia. **Aim:** To review, with a narrative approach, current evidence on main NPTs for AD and dementia. **Methods:** PubMed

and the Cochrane database of systematic reviews were searched for studies written in English and published from 2000 to 2018. The bibliography of the main articles was checked to detect other relevant papers. Results: The role of NPT has been largely explored in AD and dementia. The main NPT types, which were reviewed here, include exercise and motor rehabilitation, cognitive rehabilitation, NPT for behavioral and psychological symptoms of dementia, occupational therapy, psychological therapy, complementary and alternative medicine, and new technologies, including information and communication technologies, assistive technology and domotics, virtual reality, gaming, and telemedicine. We also summarized the role of NPT to address caregivers' burden. Conclusions: Although NPT is often applied in the multidisciplinary approach to AD and dementia, supporting evidence for their use is still preliminary. Some studies showed statistically significant effect of NPT on some outcomes, but their clinical significance is uncertain. Well-designed randomized controlled trials with innovative designs are needed to explore the efficacy of NPT in AD and dementia. Further studies are required to offer robust neurobiological grounds for the effect of NPT, and to examine its cost-efficacy profile in patients with dementia.


Care Transitions

12. Burton, J., Guthrie, B., Hapca, S., Cvorov, V., Donnan, P., & Reynish, E. (2018). Living at home after emergency hospital admission: prospective cohort study in older adults with and without cognitive spectrum disorder. *BMC Medicine*, *16*(1), 231.
<https://doi.org/10.1186/s12916-018-1199-z> (free)

Abstract


Background: Cognitive spectrum disorders (CSDs) are common in hospitalized older adults and associated with adverse outcomes. Their association with the maintenance of independent living has not been established. The aim was to establish the role of CSDs on the likelihood of living at home 30 days after discharge or being newly admitted to a care home. **Methods:** A prospective cohort study with routine data linkage was conducted based on admissions data from the acute medical unit of a district general hospital in Scotland. 5570 people aged ≥ 65 years admitted from a private residence who survived to discharge and received the Older Persons Routine Acute Assessment (OPRAA) during an incident emergency medical admission were included. The outcome measures were living at home, defined as a private residential address, 30 days after discharge and new care home admission at hospital discharge. Outcomes were ascertained through linkage to routine data sources. **Results:** Of the 5570 individuals admitted from a private residence who survived to discharge, those without a CSD were more likely to be living at home at 30 days than those with a CSD (93.4% versus 81.7%; difference 11.7%, 95%CI 9.7-13.8%). New discharge to a care home affected 236 (4.2%) of the cohort, 181 (76.7%) of whom had a CSD. Logistic regression modelling identified that all four CSD categories were associated with a reduced

likelihood of living at home and an increased likelihood of discharge to a care home. Those with delirium superimposed on dementia were the least likely to be living at home (OR 0.25), followed by those with dementia (OR 0.43), then unspecified cognitive impairment (OR 0.55) and finally delirium (OR 0.57). Conclusions: Individuals with a CSD are at significantly increased risk of not returning home after hospitalization, and those with CSDs account for the majority of new admissions to care homes on discharge. Individuals with delirium superimposed on dementia are the most affected. We need to understand how to configure and deliver healthcare services to enable older people to remain as independent as possible for as long as possible and to ensure transitions of care are managed supportively.

13. Cottrell, L., Duggleby, W., Ploeg, J., McAiney, C., Peacock, S., Ghosh, S., et al. (2018). Using focus groups to explore caregiver transitions and needs after placement of family members living with dementia in 24-hour care homes. *Aging & Mental Health*. [Epub ahead of print] <https://doi.org/10.1080/13607863.2018.1531369> 

Abstract

Objectives: Family caregivers (defined broadly as family and friends) of persons with dementia are challenged to cope with myriad stressors and changes that occur along the dementia trajectory. The purpose of this study was to explore the transitions experienced by caregivers of persons with dementia after their relative relocated to a 24-hour care home. **Method:** Qualitative thematic and conversational analysis were used: themes were co-created and modes of speech and syntactical patterns analyzed to expose discourses related to caregiving after placement in 24-hour care homes. **Results:** Four main themes were co-constructed from the data analysis: living with loss, relinquishing, redefining the caregiving role, and rediscovering and recreating a new self. **Discussion:** Caregiving continues after placement of family members with dementia in 24-hour care homes. Caregivers are at-risk group and require ongoing support throughout the caregiving journey. Study participants reported that navigation skills such as relationship building, communication, and advocacy were particularly salient to the post-placement period, when navigating the complex health care environment was a significant obstacle. Ultimately, findings from these focus groups will be used to inform an online intervention to support caregivers of a family member with dementia residing in a 24-hour care home.

14. Jacobsohn, G., Hollander, M., Beck, A., Gilmore-Bykovskyi, A., Werner, N., & Shah, M. (2019). Factors influencing emergency care by persons with dementia: Stakeholder perceptions and unmet needs. *Journal of The American Geriatrics Society*. [Epub ahead of print] <https://doi.org/10.1111/jgs.15737> 

Abstract

Background/Objectives: People with dementia (PwD) frequently use emergency care services. To mitigate the disproportionately high rate of emergency care use by PwD, an understanding of contributing factors driving reliance on emergency care services and


identification of feasible alternatives are needed. This study aimed to identify clinician, caregiver, and service providers' views and experiences of unmet needs leading to emergency care use among community-dwelling PwD and alternative ways of addressing these needs. Design: Qualitative, employing semi-structured interviews with clinicians, informal caregivers, and aging service providers. Setting: Wisconsin, United States. Participants: Informal caregivers of PwD (n = 4), emergency medicine physicians (n = 4), primary care physicians (n = 5), geriatric healthcare providers (n = 5), aging service providers (n = 6), and community paramedics (n = 3). Measurements: Demographic characteristics of participants and data from semistructured interviews. Findings: Four major themes were identified from interviews: (1) system fragmentation influences emergency care use by PwD, (2) informational, decision-making, and social support needs influence emergency care use by PwD, (3) emergency departments (EDs) are not designed to optimally address PwD and caregiver needs, and (4) options to prevent and address emergency care needs of PwD. Conclusion: Participants identified numerous system and individual-level unmet needs and offered many recommendations to prevent or improve ED use by PwD. These novel findings, aggregating the perspectives of multiple dementia-care stakeholder groups, serve as the first step to developing interventions that prevent the need for emergency care or deliver tailored emergency care services to this vulnerable population through new approaches. © 2019 The American Geriatrics Society.

15. Jensen, A., Pedersen, B., Olsen, R., Wilson, R., & Hounsgaard, L. (2018). "If only they could understand me!" Acute hospital care experiences of patients with Alzheimer's disease. *Dementia*. [Epub ahead of print] <https://doi.org/10.1177/1471301218820483>

Abstract

Patients with dementia as co-morbidity find hospital stays challenging, because the focus is primarily on the somatic cause for the admission, with less emphasis on the needs pertaining to dementia-related support and care. This results in poorer holistic outcomes, compared to patients without dementia, and an increased cost for the healthcare sector and, society as a whole. The quest is to make hospitals a dementia-friendly context, because this is likely to lead to better patient outcomes for people with dementia generally; however, further research is required to understand where gains may be made in this regard. This study conducted participant observation research strategies to follow patient journeys with Alzheimer's disease admitted to orthopedic wards, to learn about their experiences as patients. Longitudinal data were gathered by following patients on both day and evening shifts within a specialist orthopedic hospital ward, commencing at patient admission and concluding at time of discharge. The data were interpreted from a phenomenological-hermeneutic perspective, inspired by Ricoeur's interpretation theory. The study revealed a communication style among nurses who failed to take into account the comprehensive needs of patients with dementia, in terms of timely information exchange and clinical relevance. Patients expressed the desire to be more fully engaged in the care decision-making, together with indicating

their appreciation of the work of the health professionals who cared for them. The data revealed that the process of getting to know the patient at the beginning of every shift left little room to alleviate patients' experienced distress, caused by being in hospital. This resulted in patients who were less involved in the caring situation, or, if a patient took the initiative to act, intentions ended up being misinterpreted as disruptive behavior. The findings have relevance for staff and ward management who are interested to strive to enhance the patient journey as a dementia-friendly hospital.

16. Lethin, C., Giertz, L., Vingare, E., & Hallberg, I. (2018). Dementia care and service systems – a mapping system tested in nine Swedish municipalities. *BMC Health Services Research*, 18(1). <https://doi.org/10.1186/s12913-018-3592-x> 

Abstract

Background: In dementia care, it is crucial that the chain of care is adapted to the needs of people with dementia and their informal caregivers throughout the course of the disease. Assessing the existing dementia care system with regard to facilities, availability and utilization may provide useful information for ensuring that the professional dementia care and service system meets the needs of patients and their families from disease onset to end of life. **Methods:** The aim of this study was to further develop and test a mapping system, and adapt it to a local context. In addition, the aim was to assess availability and utilization of care activities as well as professional providers' educational level in nine municipalities under the categories of Screening, the diagnostic procedures, and treatment; Outpatient care facilities; Institutional care and Palliative care. This cross-sectional study was conducted in April through May 2015. Data was derived from the health care and social service systems in nine rural and urban municipalities in two counties in Sweden. The mapping system covered seven categories with altogether 56 types of health care and social service activities. **Results:** The mapping system was found to be reliable with minor adaptations to the context mainly in terms of activities. Availability of care activities was common with low utilization regarding Screening, the diagnostic procedures, and treatment; Outpatient care facilities; Institutional care and Palliative care and dementia trained staff was rare. Availability and utilization of care activities and professionals' educational level was higher concerning screening, the diagnostic procedures and treatment compared with outpatient care facilities, institutional care and palliative care. **Conclusions:** The mapping system enables policy makers and professionals to assess and develop health care and social service systems, to be offered proactively and on equal terms to people with dementia and their informal caregivers throughout the course of the disease. The educational level of professionals providing care and services may reveal where, in the chain of care, dementia-specific education for professionals, needs to be developed.

Cognitive Screening, Diagnosis, and Assessment Scale

17. Budgett, J., Brown, A., Daley, S., Page, T., Banerjee, S., Livingston, G., & Sommerlad, A. (2019). The social functioning in dementia scale (SF-DEM): Exploratory factor analysis and psychometric properties in mild, moderate, and severe dementia. *Alzheimer's & Dementia: Diagnosis, Assessment & Disease Monitoring*, 11, 45-52. <https://doi.org/10.1016/j.dadm.2018.11.001> (free)

Abstract


Introduction: The psychometric properties of the social functioning in dementia scale over different dementia severities are unknown. **Methods:** We interviewed 299 family carers of people with mild, moderate, or severe dementia from two UK research sites; examined acceptability (completion rates); conducted exploratory factor analysis; and tested each factor's internal consistency and construct validity. **Results:** Of 299, 285 (95.3%) carers completed questionnaires. Factor analysis indicated three distinct factors with acceptable internal consistency: spending time with other people, correlating with overall social function ($r = 0.56$, $P < .001$) and activities of daily living ($r = -0.48$, $P < .001$); communicating with other people correlating with activities of daily living ($r = -0.66$, $P < .001$); and sensitivity to other people correlating with quality of life ($r = 0.35$, $P < .001$) and inversely with neuropsychiatric symptoms ($r = -0.45$, $P < .001$). The three factors' correlations with other domains were similar across all dementia severities. **Discussion:** The social functioning in dementia scale carer version measures three social functioning domains and has satisfactory psychometric properties in all severities of dementia.

18. Koo, B., & Vizer, L. (2019). Mobile technology for cognitive assessment of older adults: A scoping review. *Innovation in Aging*, 3(1), igy038. <https://doi.org/10.1093/geroni/igy038> (free)

Abstract

Background and Objectives: The number of people diagnosed with dementia is rising appreciably as the population ages. In an effort to improve outcomes, many have called for facilitating early detection of cognitive decline. Increased use of mobile technology by older adults provides the opportunity to deliver convenient, cost-effective assessments for earlier detection of cognitive impairment. This article presents a review of the literature on how mobile platforms-smartphones and tablets-are being used for cognitive assessment of older adults along with benefits and opportunities associated with using mobile platforms for cognitive assessment. **Research Design and Methods:** We searched MEDLINE, Web of Science, PsycInfo, CINAHL, EMBASE, and Cochrane Central Register of Controlled Trials in October 2018. This search returned 7,024 articles. After removing 1,464 duplicates, we screened titles and abstracts then screened full-text for those articles meeting inclusion and exclusion criteria. **Results:** Twenty-nine articles met our inclusion criteria and were categorized into 3 groups as follows: (a) mobile versions of existing article or computerized

neuropsychological tests; (b) new cognitive tests developed specifically for mobile platforms; and (c) the use of new types of data for cognitive assessment. This scoping review confirms the considerable potential of mobile assessment. Discussion and Implications: Mobile technologies facilitate repeated and continuous assessment and support unobtrusive collection of auxiliary behavioral markers of cognitive impairment, thus allowing users to view trends and detect acute changes that have traditionally been difficult to identify. Opportunities include using new mobile sensors and wearable devices, improving reliability and validity of mobile assessments, determining appropriate clinical use of mobile assessment information, and incorporating person-centered assessment principles and digital phenotyping.

19. Umeda-Kameyama, Y., Mori, T., Wada-Isoe, K., Kikuchi, T., Kojima, S., Kagimura, T., et al. (2018). Development of a novel convenient Alzheimer's disease assessment scale, the ABC Dementia Scale, using item response theory. *Geriatrics & Gerontology International*, 19(1), 18-23. <https://doi.org/10.1111/ggi.13552> 

Abstract

Aim: The present study aimed to assess the interrater reliability and construct the validity of a novel, convenient informant-based Alzheimer's disease assessment scale to prepare its final version. Methods: For the assessment, site investigators, co-medicals and, if available, medical staff other than doctors or co-medicals interviewed study informants to assess individuals using this scale. We then analyzed the interrater reliability and construct validity using factor analysis and item response characteristics. Results: In this study, 427 eligible participants were enrolled. We first examined the interrater reliability and found that the lower limit of the confidence interval of each item was never <0.4 (except for the item "delusion of theft"). After deleting this item, the 14 items of this scale were organized into three domains (activities of daily living, behavioral and psychological symptoms of dementia, and cognitive function) through factor analysis. After discussion of the similarity of two items and their integration into one item, we confirmed that the final version of the 13-item scale showed almost the same degree of interrater reliability and construct validity as the former version of this scale. Conclusions: The final version of this novel Alzheimer's disease assessment scale had high interrater reliability and construct validity. We named it the ABC (activities of daily living, behavioral and psychological symptoms of dementia, and cognitive function) Dementia Scale. Further studies on its validation are required. © 2018 The Authors.

Dementia and Diverse Populations

20. Lau, B., Lou, V., & Cheung, K. (2018). Exemplary care among Chinese dementia familial caregivers. *Healthcare*, 6(4), 141. <https://doi.org/10.3390/healthcare6040141>  (free)

Abstract

Objective: This study investigates the feasibility of using the Exemplary Care Scale (ECS) among Chinese dementia familial caregivers and reports its psychometric properties.

Method: Back translation was used to develop the Chinese version of ECS (C-ECS). Three hundred and ninety-seven dyads of caregivers and their relatives with dementia responded to an assessment battery which included questions on care recipients' cognition, behavioral and psychological symptoms, daily activities assistance, social support, and caregiver well-being.

Results: Results of an exploratory principal component analysis revealed two subscales in the 11-item C-ECS: considerate caregiving and preserving esteem. C-ECS and its subscales demonstrated sufficient reliability, as well as criteria-related validity through its association with care recipient's cognition and health, and caregivers' well-being and social support.

Discussion: Our findings provide preliminary support to C-ECS as a reliable and valid measure of exemplary caregiving among Hong Kong Chinese familial dementia caregivers. In the light of the increasing importance of familial care in dementia care planning, we recommend the use of this brief scale in regular caregiver assessment in research and service delivery.

21. Milani, S., Marsiske, M., Cottler, L., Chen, X., & Striley, C. (2018). Optimal cutoffs for the Montreal Cognitive Assessment vary by race and ethnicity. *Alzheimer's & Dementia: Diagnosis, Assessment & Disease Monitoring*, 10, 773-781.
<https://doi.org/10.1016/j.dadm.2018.09.003> (free)

Abstract

Introduction: The Montreal Cognitive Assessment (MoCA), scored from 0 to 30, is used as a screening tool for mild cognitive impairment (MCI). The current cutoff (26) may not be optimal among minorities. **Methods:** Data from the National Alzheimer's Coordinating Center Uniform Data Set March 2018 data freeze was used to calculate optimal cutoffs for detection of MCI and dementia by race/ethnic group and education. **Results:** Of the 3895 individuals included, 80.7% were non-Hispanic White, 15.0% were non-Hispanic Black, and 4.2% were Hispanic. Optimal cutoffs for detection of MCI were 25 among non-Hispanic Whites, 24 among Hispanics, and 23 among non-Hispanic Blacks. Optimal cutoffs for detection of dementia were 19 among non-Hispanic Whites and 16 for both non-Hispanic Blacks and Hispanics. Lower educational attainment produced lower optimal cutoffs. **Discussion:** Our findings suggest cutoffs may need to be stratified by race/ethnicity and education to ensure detecting MCI from normal and MCI from dementia.

22. Parveen, S., Barker, S., Kaur, R., Kerry, F., Mitchell, W., Happs, A., et al. (2018). Involving minority ethnic communities and diverse experts by experience in dementia research: The Caregiving HOPE Study. *Dementia*, 17(8), 990-1000.
<https://doi.org/10.1177/1471301218789558>

Abstract

Patient and public involvement is imperative to ensure relevance of research. There is a growing literature on the theoretical underpinning on patient and public involvement including level and processes of involvement. The aim of this paper is to describe a person-centered and culturally sensitive approach to working with minority ethnic communities, involving carers, people living with dementia, members of the public and carer support workers, as used in the Caregiving HOPE study; and the influence of the approach on the study's research processes and outcomes. Patient and public involvement members were considered experts by experience and involved with study conception, design, conduct and dissemination. The perspective of the experts by experience is also presented in this article. The level and nature of involvement was influenced by each individual's needs and desires which changed over the course of the study. The approach had a significant impact on study outcomes as evidenced by successful recruitment and engagement at a national level but was not without challenges with greater flexibility required and fuller consideration of financial and time costs required. Benefits of the approach included strong engagement, improved outcomes (successful recruitment of seldom heard groups) and meaningful relationships between researchers and experts by experience. A person-centred and culturally sensitive approach is required with patient and public involvement to ensure involvement is not detrimental to those involved, is meaningful and enjoyable and has a positive impact on the research.


23. Sagbakken, M., Spilker, R., & Nielsen, T. (2018). Dementia and immigrant groups: A qualitative study of challenges related to identifying, assessing, and diagnosing dementia. *BMC Health Services Research*, 18(1), 910. <https://doi.org/10.1186/s12913-018-3720-7> (free)

Abstract

Background: Along with the ageing of the general population, Europe's migrant populations are also ageing, thus posing new challenges for dementia care services, particularly if the services are to be adjusted to persons with different linguistic and cultural backgrounds. From the perspective of health professionals, this study aims to explore challenges involved in identifying, assessing and diagnosing people with cognitive impairment/dementia who have different linguistic and cultural backgrounds. **Methods:** Research on health professionals experiences regarding the management of dementia among immigrants is scarce and qualitative methods was used to address the objective of the study. Using qualitative in-depth interviews and focus-group discussions, we sought to gather participants' experiences regarding the diagnostic process for immigrants with dementia. The material was analyzed and interpreted based on Kvale and Brinkmann's descriptions of three different contexts of interpretation: self-understanding, critical common-sense understanding, and theoretical understanding. **Results:** Health professionals described how families could attribute symptoms of dementia to processes of normal ageing, while others saw the

symptoms as something shameful; both instances delayed or hindered help-seeking. Many clinicians had limited experience with older immigrants suffering from dementia, and general practitioners (GPs) in particular experienced difficulties assessing dementia due to language barriers and difficulties related to the involvement of the family or an interpreter. The findings illustrate challenges in assessment, such as unfamiliarity with test situations among those being assessed and lack of knowledge regarding appropriate diagnostic tools among health professionals. Lack of continuity and poor information exchange in the chain of care seem to reinforce many of these challenges. Conclusions: Detection, treatment and care may be improved if primary care professionals strengthen their cross-cultural competences. Training in communication skills and in the use of cross-cultural assessment tools may help build competence and confidence when assessing and caring for people with different cultural and linguistic backgrounds. Closer collaboration among families, nurses in home-based services, dementia teams, and GPs may facilitate close monitoring of a patient over time. Such collaboration requires sufficient information exchange during transitions in the chain of care, continuity among health professionals, and a shared understanding of the goals for treatment and care.

Dementia with Lewy Bodies, Frontotemporal Dementia, Korsakoff's Syndrome, and Young-onset Dementia

24. Ducharme, S., Pearl-Dowler, L., Gossink, F., McCarthy, J., Lai, J., Dickerson, B., et al. (2019). The Frontotemporal Dementia versus Primary Psychiatric Disorder (FTD versus PPD) Checklist: A bedside clinical tool to identify behavioral variant FTD in patients with late-onset behavioral changes. *Journal of Alzheimer's Disease*, 67(1), 113-124. <https://doi.org/10.3233/JAD-180839> 

Abstract

Background: Differentiating early behavioral variant frontotemporal dementia (bvFTD) and primary psychiatric disorders (PPD) is complex and biomarkers have limited accuracy, leading to inaccurate diagnoses. Objectives: Develop a simple bedside clinical tool to differentiate bvFTD from PPD. Methods: A checklist of clinical features differentiating bvFTD from PPD was developed based on literature and clinical experience. The checklist was filled prospectively for 29 consecutive patients (Montreal Neurological Hospital) with late-onset (\geq age 40) behavioral changes suggestive of bvFTD. The checklist was subsequently retrospectively completed on the baseline visit (N=137) of the Late-Onset Frontal Lobe study (Amsterdam). In both cohorts, patients were followed 2 years to establish a final best clinical diagnosis, categorizing patients into Probable FTD (N=46), Possible FTD (N=8), Other Cognitive Disorder (N=36), Other Neurological Disorder (N=10), or PPD (N=66). Results: All items distinguished the two groups except "duration more than 5 years", which was removed to create a final 17-item version. Mean checklist scores were


significantly different across all groups (Oneway ANOVA $F(4,161)=27.462$, $p<0.001$). The PPD group had lower scores than all other dementia categories, with the largest difference between Probable FTD ($\bar{X}=12.04$) and PPD ($\bar{X}=7.48$). A score ≥ 11 was found to be strongly indicative of bvFTD (specificity 93.9%, sensitivity 71.1%, PPV 89.2%). Scores ≤ 8 were strongly indicative of a PPD (specificity 91.3%, sensitivity 77.3%, PPV 92.7%). Patient with scores of 9-10 are considered indeterminate. Conclusions: Although further prospective validation is required, the “FTD vs PPD Checklist” could provide a simple tool to improve diagnostic accuracy, particularly in non-specialized settings.

25. Heirene, R., John, B., & Roderique-Davies, G. (2018). Identification and evaluation of neuropsychological tools used in the assessment of alcohol-related cognitive impairment: A systematic review. *Frontiers in Psychology*, 9. [Epub ahead of print]
<https://doi.org/10.3389/fpsyg.2018.02618> (free)

Abstract


Background: Neuropsychological assessment is central to identifying and determining the extent of Alcohol-Related Cognitive Impairment (ARCI). The present systematic review aimed to synthesize and discuss the evidence appraising the neuropsychological tests used to assess ARCI in order to support clinicians and researchers in selecting appropriate tests for use with this population. Methods: We searched for studies investigating the psychometric, diagnostic and practical values of tools used in the screening, diagnosis, and assessment of Korsakoff's Syndrome (KS), Alcohol-Related Dementia (ARD), and those with a specific diagnosis of Alcohol-Related Brain Damage (ARBD). The following databases were searched in March 2016 and again in August 2018: MEDLINE, EMBASE, Psych-INFO, ProQuest Psychology, and Science Direct. Study quality was assessed using a checklist designed by the authors to evaluate the specific factors contributing to robust and clearly reported studies in this area. A total of 43 studies were included following the screening of 3646 studies by title and abstract and 360 at full-text. Meta-analysis was not appropriate due to heterogeneity in the tests and ARCI samples investigated in the studies reviewed. Instead, review findings were narratively synthesized and divided according to five domains of assessment: cognitive screening, memory, executive function, intelligence and test batteries, and premorbid ability. Effect sizes (d) were calculated to supplement findings. Results: Overall, several measures demonstrated sensitivity to the cognitive deficits associated with chronic alcoholism and an ability to differentiate between gradations of impairment. However, findings relating to the other psychometric qualities of the tests, including those important for the accurate assessment and monitoring of ARCI (e.g., test-retest reliability), were entirely absent or limited. Additionally, the synthesis of neuropsychological outcomes presented here supports the recent impetus for a move away from discrete diagnoses (e.g., KS, ARD) and the distinctions between them toward more broad and inclusive diagnostic conceptualizations of ARCI, thereby recognizing the heterogeneity in presentation. Conclusions: Based on the evidence reviewed, provisional recommendations for appropriate

tests in each domain of assessment are presented, though further validation of most tests is warranted. Review findings can support efficient and evidenced-based test-selection and guide future research in this area.

26. Kobiske, K., Bekhet, A., Garnier-Villarreal, M., & Frenn, M. (2018). Predeath grief, resourcefulness, and perceived stress among caregivers of partners with young-onset dementia. *Western Journal of Nursing Research*. [Epub ahead of print]
<https://doi.org/10.1177/0193945918806689> 

Abstract


More than 200,000 Americans are currently diagnosed with young-onset dementia (YOD). YOD is dementia diagnosed prior to the age of 65. Most persons of YOD are cared for by their partners. Using the theoretical framework of Resilience Theory, this cross-sectional, correlational study examined the moderating effects of personal and social resourcefulness on the relationship between predeath grief and perceived stress among 104 YOD caregiving partners (life partners/spouses) using an online survey platform. Results indicated a large positive correlation between predeath grief and caregiver perceived stress ($r = .65$; $p < .001$). Together predeath grief, personal resourcefulness and social resourcefulness explained 51.5% of the variance in perceived stress. Personal resourcefulness did not moderate the relationship. Social resourcefulness did positively moderate this relationship between predeath grief and perceived stress. These findings allow for a better understanding of the caregiving experience for a partner with YOD and creates opportunities for future research studies.

27. Moheb, N., Charuworn, K., Ashla, M., Desarant, R., Chavez, D., & Mendez, M. (2018). Repetitive behaviors in frontotemporal dementia: Compulsions or impulses?. *The Journal of Neuropsychiatry and Clinical Neurosciences*. [Epub ahead of print]
<https://doi.org/10.1176/appi.neuropsych.18060148> 

Abstract


Objective: The presence of repetitive behaviors is one of the core criteria for behavioral variant frontotemporal dementia (bvFTD). Patients with bvFTD often have perseverative, stereotyped, or compulsive-ritualistic behavior as an early aspect of their disorder. It is unclear whether such behaviors are related to compulsions, as in obsessive-compulsive disorder (OCD), or are part of the impulse disorder spectrum. Methods: The authors investigated early (within 3 years) repetitive behaviors among 93 well-characterized patients who met International Consensus Criteria for clinically probable bvFTD and compared the results with the literature on OCD. The most common repetitive behaviors among 59 (63.4%) bvFTD patients were stereotypies of speech (35.5%), simple repetitive movements (15.2%-18.6%), hoarding and collecting (16.9%), and excessive or unnecessary trips to the bathroom (13.5%). Results: Only hoarding and collecting was significantly common in both bvFTD and OCD; otherwise, the bvFTD patients had very low frequencies of the common OCD

behaviors of checking, cleaning, counting, and ordering. The repetitive behaviors in bvFTD were not associated with verbalized anxiety, obsessional ideation, or reports of relief after completing the act. In contrast, these behaviors were often triggered by environmental stimuli and could be temporarily prevented from completion without undue distress. Finally, among the bvFTD patients, the repetitive behaviors were always associated with impulsive or disinhibited behaviors, such as inappropriate verbal or physical behavior. Conclusions: These findings suggest that the repetitive behaviors in bvFTD are repetitive impulses, possibly from specific involvement of frontostriatal-anterior temporal pathology.

28. Mueller, C., Soysal, P., Rongve, A., Isik, A., Thompson, T., Maggi, S., et al. (2019). Survival time and differences between dementia with Lewy bodies and Alzheimer's disease following diagnosis: A meta-analysis of longitudinal studies. *Ageing Research Reviews*. [Epub ahead of print] <https://doi.org/10.1016/j.arr.2019.01.005> 

Abstract

Objective: To synthesize the evidence across longitudinal studies comparing survival in dementia with Lewy bodies (DLB) and Alzheimer's disease (AD). Methods: We conducted a systematic review and meta-analysis of studies comparing survival in clinically diagnosed DLB to AD. Longitudinal cohort studies were identified through a systematic search of major electronic databases from inception to May 2018. A random effects meta-analysis was performed to calculate survival time and relative risk of death. Results: Overall, 11 studies were identified including 22,952 patients with dementia: 2,029 with DLB (mean diagnosis age 76.3; 47% female) compared with 20,923 with AD (mean diagnosis age 77.2; 65.1% female). Average survival time in DLB from diagnosis was 4.11 years (SD \pm 4.10) and in AD 5.66 (SD \pm 5.32) years, equating to a 1.60 (95% CI: -2.44 to -0.77) years shorter in DLB ($p < 0.01$). Relative risk of death was increased by 1.35 (95%CI: 1.17-1.55) in DLB compared to AD ($p < 0.01$). Differences in survival were not explained by follow-up time, age at diagnosis, gender, or cognitive score. Conclusions: There is consistent evidence for higher and earlier mortality in DLB compared to AD. This is important for all stakeholders and underlines the importance of expanding research into DLB. © 2019. Published by Elsevier B.V.

29. Slot, R., Sikkens, S., Berkhof, J., Brodaty, H., Buckley, R., Cavedo, E., et al. (2018). Subjective cognitive decline and rates of incident Alzheimer's disease and non-Alzheimer's disease dementia. *Alzheimer's & Dementia*. [Epub ahead of print] <https://doi.org/10.1016/j.jalz.2018.10.003> 

Abstract

Introduction: In this multicenter study on subjective cognitive decline (SCD) in community-based and memory clinic settings, we assessed the (1) incidence of Alzheimer's disease (AD) and non-AD dementia and (2) determinants of progression to dementia. Methods: Eleven cohorts provided 2978 participants with SCD and 1391 controls. We estimated dementia

incidence and identified risk factors using Cox proportional hazards models. Results: In SCD, incidence of dementia was 17.7 (95% Poisson confidence interval 15.2-20.3)/1000 person-years (AD: 11.5 [9.6-13.7], non-AD: 6.1 [4.7-7.7]), compared with 14.2 (11.3-17.6) in controls (AD: 10.1 [7.7-13.0], non-AD: 4.1 [2.6-6.0]). The risk of dementia was strongly increased in SCD in a memory clinic setting but less so in a community-based setting. In addition, higher age (hazard ratio 1.1 [95% confidence interval 1.1-1.1]), lower Mini-Mental State Examination (0.7 [0.66-0.8]), and apolipoprotein E ϵ 4 (1.8 [1.3-2.5]) increased the risk of dementia. Discussion: SCD can precede both AD and non-AD dementia. Despite their younger age, individuals with SCD in a memory clinic setting have a higher risk of dementia than those in community-based cohorts. © 2018 The Authors.

Family and Informal Caregiving

30. Donnellan, W., Bennett, K., & Soulsby, L. (2018). How does carer resilience change over time and care status? A qualitative longitudinal study. *Aging & Mental Health*, 1-7. [Epub ahead of print] <https://doi.org/10.1080/13607863.2018.1503998>

Abstract

Objectives: Little research examines trajectories of carer resilience or the factors that facilitate or hinder resilience over time. We use qualitative longitudinal methods to examine trajectories of resilience and which assets and resources are associated with resilience and care status transitions in spousal dementia carers. **Method:** Based on an original sample of 23 spousal dementia carers (Donnellan, Bennett, & Soulsby, 2015), we conducted 13 follow-up interviews, including: 5 continuing home carers, 3 former carers (institutionalized), and 5 former carers (widowed). **Results:** Five participants remained resilient (stable resilient), three remained non-resilient (stable non-resilient) and four participants became resilient (non-resilient to resilient). Only one participant became non-resilient (resilient to non-resilient). Stable resilience was characterized by continuing individual assets and community resources. Carers who became resilient returned to previous resources or gained new resources. **Conclusion:** Institutionalization and widowhood are not always barriers to resilience; spousal dementia carers can remain or even become resilient over time despite deteriorating health, institutionalization, or death of the care recipient.

31. Jütten, L., Mark, R., & Sitskoorn, M. (2018). Predicting self-esteem in informal caregivers of people with dementia: Modifiable and non-modifiable factors. *Aging & Mental Health*. [Epub ahead of print] <https://doi.org/10.1080/13607863.2018.1531374>

Abstract

While informal caregivers often feel burdened by the care for a person with dementia, they can also experience positive consequences due to caregiving; caregiver gains. One of these, relatively overlooked, caregiver gains is heightened self-esteem. We assessed the predictive

ability of non-modifiable (caregiver sociodemographic- and dementia related-) and modifiable (psychological-) factors for caregiver self-esteem). A cross-sectional study in which 201 caregivers, who spent at least eight hours a week on caring for a community-residing person with dementia, completed a semi-structured interview and five questionnaires. One two-block (1: non-modifiable-; 2: modifiable variables) hierarchic multiple regression analysis was used to assess which variables predicted self-esteem. None of the non-modifiable variables significantly predicted self-esteem. Regarding the modifiable variables, depression and relationship quality with the person with dementia significantly predicted self-esteem (adjusted $R^2 = .460$, $\beta = -.207$, $p = .015$ and $\beta = .632$, $p < .001$ respectively). Caregivers who experience a better relationship quality with the person with dementia, and fewer depression symptoms, experience a higher level of self-esteem. Interventions focused on heightening self-esteem should strive to optimize these factors to enhance the lives of informal dementia caregivers.

32. Lee, J., Barlas, J., Thompson, C., & Dong, Y. (2018). Caregivers' experience of decision-making regarding diagnostic assessment following cognitive screening of older adults. *Journal of Aging Research*, 2018. [Epub ahead of print]
<https://doi.org/10.1155/2018/8352816> (free)

Abstract


Targeted screening for dementia among older adults in primary healthcare has potential benefits such as better clinical outcomes and the opportunity to access services. Cognitive screening can be followed up by further diagnostic assessment to determine a diagnosis of dementia. Unfortunately, the rates of accepting further diagnostic assessment following cognitive screening are low. The objective of this study was to explore the caregivers' decision-making process regarding uptake of diagnostic assessment following positive screening results. A qualitative design was employed, and interpretative phenomenological analysis was used to analyze the data. Three major themes in caregiver decision-making were identified: gathering information, protecting the patient, and balancing obligation and convenience in caregiving. These findings suggest that the decision-making process involved effort to process information through observations of the patient and that caregivers emphasized quality of life.

33. Meichsner, F., Töpfer, N., Reder, M., Soellner, R., & Wilz, G. (2019). Telephone-based cognitive behavioral intervention improves dementia caregivers' quality of life. *American Journal of Alzheimer's Disease & Other Dementias*[®]. [Epub ahead of print]
<https://doi.org/10.1177/1533317518822100>

Abstract


The present study examined the effects of a telephone-based cognitive behavioral intervention on dementia caregivers' quality of life (QoL). A total of 273 caregivers were randomly assigned to an intervention or control group. The intervention comprised 12

telephone sessions of individual cognitive behavioral therapy (CBT) over 6 months. At baseline, postintervention, and 6-month follow-up, QoL was assessed with the World Health Organization QoL-BREF, which measures perceived QoL for the domains physical health, psychological health, social relationships, and environment as well as overall QoL and satisfaction with general health. Intention-to-treat analyses using latent change models were performed. At postintervention, intervention group participants reported better overall QoL and satisfaction with general health as well as better physical and psychological health compared to control group participants. Together with existing evidence, the results suggest that the telephone CBT intervention does not only reduce impairments but also fosters improvements in health-related QoL.

34. Miller, V., Killian, M., & Fields, N. (2018). Caregiver identity theory and predictors of burden and depression: Findings from the REACH II study. *Aging & Mental Health*. [Epub ahead of print] <https://doi.org/10.1080/13607863.2018.1533522> 

Abstract

Objective: To examine the relationship between care recipient (person with Alzheimer’s disease) ability to perform daily tasks and caregivers’ (CG) perceived burden and depression, guided by the caregiver identity theory. We also examine the mediating effect of CG abilities to meet their basic needs. **Methods:** This study utilizes the baseline data of the REACH II study. Spearman’s rho (ρ) was used to test for relationships between burden, reported depression, and each ADLs and IADLs. To further explore the relationship between burden and each ADLs and IADLs, structural equation modeling was conducted using Mplus 8.0. **Results:** Reported CG total scores indicated increased perceived CG burden with greater number of assisted daily activities. CG depression scores were significantly predicted by reported burden scores and caregiver’s ability to pay for basic needs. Importantly, 34.6% of variation in CG reported depression scores were explained by reported burden scores. A multivariate regression model with reported burden scores, controlling for caregiver’s ability to pay for basic needs, explained 36.6% of the variance in CG depression scores. Burden scores and CG ability to pay for basic needs significantly predicted depression scores. Results from the three models indicated that CG burden fully mediated the relationship between daily living skill scores and CG depression. **Conclusion:** Our study findings suggest the need to more closely examine the link between AD caregiving, financial instability, and mental health and bolster support for policies and programs that offer tangible supports and services to offset the costs of informal AD CG.

35. Quinn, C., & Toms, G. (2018). Influence of positive aspects of dementia caregiving on caregivers’ well-being: A systematic review. *The Gerontologist*. [Epub ahead of print] <https://doi.org/10.1093/geront/gny168> 

Abstract


Background and Objectives: There is a growing evidence base that informal caregivers can identify positive aspects of providing care and that this may have a beneficial influence on their well-being. The aim of this systematic review was to explore how positive aspects of caregiving (PAC) affects the well-being of caregivers of people with dementia. **Research Design and Methods:** We searched electronic databases for quantitative studies exploring the association between PAC and caregiver well-being. Studies were included if they involved informal (unpaid) caregivers of people with dementia, at least 75% of whom had to be residing in the community. A narrative synthesis was used to explore patterns within the data. **Results:** Fifty-three studies were included in the narrative synthesis. Most studies utilized a cross-sectional design. The majority of samples consisted primarily of spouses and female caregivers. Twenty different PAC measures were employed, and studies referred to a variety of constructs, such as satisfactions, gains, meaning, and rewards. PAC was associated with lower depressive symptoms and burden. Conversely, PAC was associated with better mental health, quality of life, satisfaction with life, and competence/self-efficacy. PAC was not associated with self-rated health or personal strain/stress. **Discussion and Implications:** The findings suggest that identifying PAC is associated with better caregiver well-being, although further longitudinal studies are required to explore how this relationship changes over time. Interventions that enable caregivers to gain a more positive experience of caregiving could be beneficial for their well-being.

36. Sakka, M., Goto, J., Kita, S., Sato, I., Soejima, T., & Kamibeppu, K. (2018). Associations among behavioral and psychological symptoms of dementia, care burden, and family-to-work conflict of employed family caregivers. *Geriatrics & Gerontology International*. [Epub ahead of print] <https://doi.org/10.1111/ggi.13556>

Abstract

Aim: The present study aimed to examine the associations among behavioral and psychological symptoms of dementia (BPSD) of persons with dementia (PWD), care burden and family-to-work conflict (FWC) of employed family caregivers. **Method:** A cross-sectional study was carried out with employed adult daughter or son (or in-law) caregivers for PWD from two rural cities in Japan. FWC, care burden and the degree of BPSD were evaluated by the Survey Work-Home Interaction-NijmeGen, Zarit Burden Scale-Short Version and Dementia Behavior Disturbance Scale, respectively. Of the 200 questionnaires distributed, 130 were returned. A total of 53 respondents were not employed, and seven questionnaires had missing data for demographic variables, Survey Work-Home Interaction-NijmeGen, Zarit Burden Scale-Short Version or Dementia Behavior Disturbance Scale. Thus, complete data from 70 respondents were analyzed through structural equation modeling. **Results:** The mean age of employed family caregivers was 56 years, and 34 (48.5%) were men. The mean age of PWD was 84 years, and there were 68 (68.6%) men. The path model with a good fit was shown (root mean square error of approximation 0.136,

comparative fit index 0.960 and goodness of fit index 0.965). The path model showed that BPSD affected FWC, and that the association was partially mediated by care burden. Conclusions: The results show that a decrease in not only care burden, but also BPSD, of PWD is important for employed family caregivers to reduce their FWC and maintain their work-life balance. © 2018 Japan Geriatrics Society.

37. Stall, N., Kim, S., Hardacre, K., Shah, P., Straus, S., Bronskill, S., et al. (2018). Association of informal caregiver distress with health outcomes of community-dwelling dementia care recipients: A systematic review. *Journal of The American Geriatrics Society*. [Epub ahead of print] <https://doi.org/10.1111/jgs.15690> 

Abstract

Background: Most dementia care occurs in the community with support from informal caregivers who are often distressed. Dementia caregiver distress is known to be hazardous to the caregiver's health, but the impact on the dementia care recipient is not well known. Methods: We searched the Medline, Embase, PsycINFO, CINAHL, and Cochrane databases from inception until June 2017 for studies investigating the association of informal caregiver distress with health outcomes of community-dwelling dementia care recipients. The search results were screened and then data abstracted, and the risk of bias was appraised independently by pairs of reviewers. Results: We included 81 original investigations (n = 43 761 caregivers and dementia care recipients). Sixty-six studies (81.5%) were observational or cross-sectional in design, and 47 studies (58%) had a low risk of bias. There was considerable clinical and methodological heterogeneity precluding quantitative synthesis. Dementia care recipients (n = 21 881) had a mean age of 78.2 years (SD ± 3.8 y), half (50.0%) were women, and two-thirds (66.1%) had Alzheimer's disease. The dementia caregivers (n = 21 880) had a mean age of 62.5 years (SD ± 23.3), three-quarters (74.1%) were women, and one-half (50.5%) were spouses of the dementia care recipient. Twenty-two unique dementia care recipient outcomes were studied including cognition, mood, quality of life, function, healthcare utilization, and costs. Overall, informal caregiver distress is commonly associated with the institutionalization of the dementia care recipient, worsening behavioral and psychological symptoms of dementia, and experiencing elder abuse. Conclusion: Informal caregiving is a cornerstone of dementia care, and distress related to this role is associated with worsening of several dementia care recipient health outcomes. It is important that clinicians and researchers worldwide consider the broader consequences of caregiver distress. © 2018 The American Geriatrics Society.

Intellectual Disabilities/Down Syndrome and Dementia

38. Ali, A., Brown, E., Spector, A., Aguirre, E., & Hassiotis, A. (2018). Individual cognitive stimulation therapy for people with intellectual disability and dementia: protocol of a

feasibility randomised controlled trial. *BMJ Open*, 8(12), e022136.
<https://doi.org/10.1136/bmjopen-2018-022136> (free)

Abstract

Introduction: Cognitive stimulation therapy (CST) is a psychosocial intervention for dementia. Group CST is effective in reducing cognitive decline and improving quality of life in patients with dementia. There is some evidence that individual CST (iCST) may be beneficial in reducing cognitive decline. People with intellectual disability (ID) have an increased risk of dementia. However, there are no published studies of CST in people with ID and dementia. This protocol describes the feasibility and acceptability of a randomized controlled trial of iCST delivered by carers to people with ID and dementia, compared with treatment as usual (TAU). The results of this study will inform the design of a future definitive randomized controlled trial. **Methods And Analysis:** The iCST intervention has been adapted for this trial. Forty dyads (individuals with ID and their carer) will be randomized to either iCST or TAU. The manualized intervention comprises 40 iCST sessions delivered by a carer for 30 min, twice a week, over 20 weeks. The primary outcome will be process measures assessing the feasibility and acceptability of the intervention and trial procedures. The secondary outcome will be changes in the scores of outcome measures (cognition, functional ability and quality of life in individuals with ID, and caregiver burden, competence in managing dementia, and anxiety and depression in carers). Data will be collected at baseline, 11 weeks and at 21 weeks. A process evaluation will examine adherence to iCST and will include qualitative interviews with participants to identify aspects of the intervention that were or were not successful. **Ethics And Dissemination:** The study has received ethical approval. The results of the study will be presented at conferences and submitted to a peer reviewed journal. © Author(s) (or their employer(s)) 2018.

39. Hithersay, R., Startin, C., Hamburg, S., Mok, K., Hardy, J., Fisher, E., et al. (2018). Association of dementia with mortality among adults with Down syndrome older than 35 years. *JAMA Neurology*. [Epub ahead of print]
<https://doi.org/10.1001/jamaneurol.2018.3616>

Abstract

Importance: This work quantifies the fatal burden of dementia associated with Alzheimer disease in individuals with Down syndrome (DS). **Objective:** To explore the association of dementia associated with Alzheimer disease with mortality and examine factors associated with dementia in adults with DS. **Design, Settings and Participants:** Prospective longitudinal study in a community setting in England. Data collection began March 29, 2012. Cases were censored on December 13, 2017. The potential sample consisted of all adults 36 years and older from the London Down Syndrome Consortium cohort with 2 data times and dementia status recorded (N = 300); 6 withdrew from study, 28 were lost to follow-up, and 55 had a single data collection point at time of analysis. The final sample consisted of 211 participants, with 503.92 person-years' follow-up. **Exposures:** Dementia status, age, sex,

APOE genotype, level of intellectual disability, health variables, and living situation. Main Outcomes and Measures: Crude mortality rates, time to death, and time to dementia diagnosis with proportional hazards of predictors. Results: Of the 211 participants, 96 were women (45.5%) and 66 (31.3%) had a clinical dementia diagnosis. Twenty-seven participants (11 female; mean age at death, 56.74 years) died during the study period. Seventy percent had dementia. Crude mortality rates for individuals with dementia (1191.85 deaths per 10 000 person-years; 95% CI, 1168.49-1215.21) were 5 times higher than for those without (232.22 deaths per 10 000 person-years; 95% CI, 227.67-236.77). For those with dementia, APOE ϵ 4 carriers had a 7-fold increased risk of death (hazard ratio [HR], 6.91; 95% CI, 1.756-27.195). For those without dementia, epilepsy with onset after age 36 years was associated with mortality (HR, 9.66; 95% CI, 1.59-58.56). APOE ϵ 4 carriers (HR, 4.91; 95% CI, 2.53-9.56), adults with early-onset epilepsy (HR, 3.61; 95% CI, 1.12-11.60), multiple health comorbidities (HR, 1.956; 95% CI, 1.087-3.519), and those living with family (HR, 2.14; 95% CI, 1.08-4.20) received significantly earlier dementia diagnoses. Conclusions and Relevance: Dementia was associated with mortality in 70% of older adults with DS. APOE ϵ 4 carriers and/or people with multiple comorbid health conditions were at increased risk of dementia and death, highlighting the need for good health care. For those who died without a dementia diagnosis, late-onset epilepsy was the only significant factor associated with death, raising questions about potentially undiagnosed dementia cases in this group.

40. Schaap, F., Fokkens, A., Dijkstra, G., Reijneveld, S., & Finnema, E. (2018). Dementia care mapping to support staff in the care of people with intellectual disability and dementia: a feasibility study. *Journal of Applied Research in Intellectual Disabilities*, 31(6), 1071-1082. <https://doi.org/10.1111/jar.12464>

Abstract

Background: The number of people with intellectual disability and dementia increases; this combination causes behavioral changes. Dementia Care Mapping (DCM) supports staff in dementia care in nursing homes and may be useful in intellectual disability-care. This qualitative study examines the feasibility of DCM for older people with intellectual disability and dementia. **Methods:** The present authors obtained data in focus groups and interviews with professional users and analyzed using a framework for feasibility studies. With experts in dementia and intellectual disability researches, the present authors determined the overall feasibility. **Results:** DCM was found to be feasible in intellectual disability-care, regarding five domains of feasibility. Staff reported DCM to be useful and valuable and addresses to their demand for skills and knowledge. All professional users found DCM feasible in intellectual disability-care, which was confirmed by experts. **Conclusions** DCM is feasible in intellectual disability-care. When fully tailored to intellectual disability-care, DCM is useful and provides opportunities to assess its effectiveness. © 2018 The Authors.

41. Strydom, A., Coppus, A., Blesa, R., Danek, A., Fortea, J., Hardy, J., et al. (2018). Alzheimer's disease in Down syndrome: An overlooked population for prevention trials.

Alzheimer's & Dementia: Translational Research & Clinical Interventions, 4, 703-713.
<https://doi.org/10.1016/j.trci.2018.10.006> ↗

Abstract


The discovery that adults with Down syndrome (DS) have neuropathological features identical to individuals with sporadic Alzheimer's disease (AD) played a key role in the identification of the amyloid precursor protein gene on chromosome 21 and resulted in the amyloid cascade hypothesis. Individuals with DS have a lifetime risk for dementia in excess of 90%, and DS is now acknowledged to be a genetic form of AD similar to rare autosomal-dominant causes. Just as DS put the spotlight on amyloid precursor protein mutations, it is also likely to inform us of the impact of manipulating the amyloid pathway on treatment outcomes in AD. Ironically, however, individuals with DS are usually excluded from AD trials. This review will discuss primary and secondary prevention trials for AD in DS and the potential barriers and solutions to such trials and describe the Europe-wide Horizon21 Consortium to establish a DS-AD prevention clinical trials network.

Living Alone with Dementia

42. Bloch, F., Lundy, J., & Rigaud, A. (2017). Profile differences of purchasers, non-purchasers, and users and non-users of Personal Emergency Response Systems: Results of a prospective cohort study. *Disability and Health Journal*, 10(4), 607-610.
<https://doi.org/10.1016/j.dhjo.2017.01.008> ↗

Abstract


Background: 'Personal Emergency Response Systems' (PERS) can provide a solution for raising the alert after a fall but no criteria are available to enable us to estimate whether a population which is set to benefit from a PERS will be able to use the device. **Objective:** To describe the profile differences of purchasers and non-purchasers of a PERS and to explore the population of users and non-users of these devices. **METHODS:** The study was part of an observational cohort survey of elderly fallers which took place in the emergency department of our University urban hospital. **Results:** 413 patients were included. 115 of them were purchasers of a PERS, presented a lower index of independence in daily activities, greater fall history and a tendency to live alone. Only 18 purchasers used their PERS to alert and they were significantly more likely to live alone, showed a trend to be younger and less demented. This subgroup spent less time on the ground and with a lower 6-months mortality. **Conclusions:** The subjects who had and had not purchased a PERS presented no significant differences in terms of time on the ground or consequences. However, it was more relevant to focus on the users and non-users of those PERS to isolate a frailer population. Indeed, the consequences of falls were more devastating in the group of purchasers who had not used their device to alert. This group may benefit the most from new generations of PERS which do not require control by the subject. © 2017 Elsevier Inc.

43. Johannessen, A., Engedal, K., Haugen, P., Dourado, M., & Thorsen, K. (2018). "To be, or not to be": experiencing deterioration among people with young-onset dementia living alone. *International Journal of Qualitative Studies on Health and Well-Being*, 13(1), 1490620. <https://doi.org/10.1080/17482631.2018.1490620> 

Abstract

Having dementia before the age of 65 (YOD) represents a radical break from an age-normative and expected life course. The disease afflicts the person's identity, threatens the self-image and self-confidence, and erodes the person's plans. The aim of the study was to examine how people living alone with YOD perceive the course of dementia, their needs, and coping strategies, with a focus on narrating everyday life experiences. A longitudinal study using a qualitative approach was used. Five interviews, each with 10 informants, took place every 6 months from 2014 to 2017. The main theme is the person's experiences of changes of identity over time. The most significant aspects of their experiences of the dementia affecting them and their reactions are these: the initial signs, coping efforts, concealing the diagnosis, social retraction, existential anxiety, revival of the self, worse and worse, and health personnel as background. The study concluded that people with dementia are able to describe their experiences and needs for a long time during the progression of dementia. Their voices should be listened to for planning of services. Personalized care should be used to support them in order to preserve their identity in a normalized everyday life as far as possible.

Living with Dementia

44. Bosco, A., Schneider, J., Coleston-Shields, D., Jawahar, K., Higgs, P., & Orrell, M. (2018). Agency in dementia care: systematic review and meta-ethnography. *International Psychogeriatrics*. [Epub ahead of print] <https://doi.org/10.1017/S1041610218001801> 

Abstract

Objectives: Dementia often limits the agency of the person to such an extent that there is need for external support in making daily life decisions. This support is usually provided by family members who are sometimes legally empowered to engage in decision-making on behalf of the person for whom they care. However, such family carers receive little or no information on how to best provide support when there is a lack of capacity. This may have an impact on the agency of the person with dementia. This review explores the experience of agency in people living with dementia. **Design:** A systematic search was conducted on IBSS, MedLine, PsychINFO, EMBASE, and CINAHL. Two independent researchers screened the studies and conducted the quality appraisal. We used meta-ethnography for data analysis. As part of the synthesis, we identified behavioral mechanisms underlying the process of decision-making and looked at how the support of carers comes into play in making deliberate choices. **Results:** The meta-ethnography involved 20 studies. Three levels of third-

order constructs were identified, each describing a decision-making pathway and reflecting the degree of autonomy of the person with dementia: autonomous decision-making, shared decision-making, and pseudo decision-making. Findings highlight those inter-relational processes that promote or negatively impact on the agency of people with dementia. Conclusions: Our review will provide health and social care personnel with an understanding of the role of the carer in the decision-making process, and therefore which mechanisms need to be promoted or discouraged through training.

45. Lindau, S., Dale, W., Feldmeth, G., Gavrilova, N., Langa, K., Makelarski, J., & Wroblewski, K. (2018). Sexuality and cognitive status: A U.S. nationally representative study of home-dwelling older adults. *Journal of the American Geriatrics Society*, 66(10), 1902-1910. <https://doi.org/10.1093/pm/pny180> ↗

Abstract

Objectives: To determine patterns and prevalence of sexual behavior, problems, and attitudes in individuals with different cognitive status. **DESIGN:** We used data from the National Social Life, Health, and Aging Project to describe the relationship between sexual behavior, function, and cognitive status (normal, mild cognitive impairment, dementia), classified using an adapted Montreal Cognitive Assessment (MoCA) (0-30 points). **Setting:** U.S. home-dwelling older adults. **Participants:** Nationally representative probability sample of 3,196 adults (1,682 women, 1,514 men) aged 62 to 91 (mean 72). **Measurements:** Cognitive status and sexual activity, problems, and attitudes. **RESULTS:** The weighted response rate was 74%. Mean MoCA score was 22.7. Of partnered people with dementia, 59% of men and 51% of women were sexually active, including 41% of those aged 80 to 91; 46% of all men (95% confidence interval (CI)=37.8-53.2%) and 18% of all women (95% CI=13.6-21.5%) with dementia were sexually active. The rate of sexual function problems was high across gender and cognitive groups (77%). Having sex primarily out of obligation was similar across cognitive groups for women (12%) and higher in men with dementia (17%) than other men (2-5%; $P < .001$). The majority of people were having sex less often than they would like. Few men (17%) or women (1%) with dementia talked with a doctor about sex. **Conclusions:** Many home-dwelling men and women with dementia are sexually active. Although the rate of sexual function problems was uniformly high, people with lower cognitive function infrequently discussed sex with a physician. © 2018, Author.

46. Odzakovic, E., Hellström, I., Ward, R., & Kullberg, A. (2018). 'Overjoyed that I can go outside': Using walking interviews to learn about the lived experience and meaning of neighborhood for people living with dementia. *Dementia*. [Epub ahead of print] <https://doi.org/10.1177/1471301218817453> ↗

Abstract

This study explores the relationships between people living with dementia and their neighborhood as they venture out from home on a regular and often routine basis. Here, we

report findings from the Swedish field site of an international 5-year project: *Neighborhoods: our people, our places*. The aims of this study were to investigate the lived experience of the neighborhood for people with dementia and through this to better understand the meaning that neighborhood held for the participants. In this study, we focus on the walking interviews which were conducted with 14 community-dwelling people with dementia (11 men and 3 women) and were analyzed using an interpretative phenomenological method. Four themes were revealed from these interviews: life narratives embedded within neighborhood; the support of selfhood and wellbeing through movement; the neighborhood as an immediate social context; and restorative connections to nature. These themes were distilled into the ‘essence’ of what neighborhood meant for the people we interviewed: A walkable area of subjective significance and social opportunity in which to move freely and feel rejuvenated. We have found that the neighborhood for community-dwelling people with dementia holds a sense of attachment and offers the potential for freedom of movement. Our research indicates that a dementia diagnosis doesn’t necessarily reduce this freedom of movement. The implications for practice and policy are considered: future research should explore and pay closer attention to the diverse living conditions of people living with dementia, and not least the particular challenges faced by people living alone with dementia.