

University of Nebraska - Lincoln

DigitalCommons@University of Nebraska - Lincoln

Honors Theses, University of Nebraska-Lincoln

Honors Program

3-15-2021

A Person-Centered Care Model's Effectiveness for Older Adults with Dementia: A Systematic Review and Meta-Analysis

Karen Goeschel

University of Nebraska - Lincoln

Follow this and additional works at: <https://digitalcommons.unl.edu/honorsthesis>



Part of the [Gerontology Commons](#), [Geropsychology Commons](#), and the [Medicine and Health Commons](#)

Goeschel, Karen, "A Person-Centered Care Model's Effectiveness for Older Adults with Dementia: A Systematic Review and Meta-Analysis" (2021). *Honors Theses, University of Nebraska-Lincoln*. 319. <https://digitalcommons.unl.edu/honorsthesis/319>

This Thesis is brought to you for free and open access by the Honors Program at DigitalCommons@University of Nebraska - Lincoln. It has been accepted for inclusion in Honors Theses, University of Nebraska-Lincoln by an authorized administrator of DigitalCommons@University of Nebraska - Lincoln.

A Person-Centered Care Model's Effectiveness for Older Adults with Dementia: A Systematic
Review and Meta-Analysis

An Undergraduate Honors Thesis
Submitted in Partial Fulfillment of
University Honors Program Requirements
University of Nebraska Lincoln

by
Karen J. Goeschel, BS
Biochemistry
College of Arts and Sciences

March 15, 2021

Faculty Mentor:
Bede Bolin, MS, MA, Gerontology

Abstract

I evaluated the effectiveness of person-centered care interventions for older adults with dementia. Quality of life and agitation levels were used as primary outcomes for the effectiveness of the intervention. Electronic databases were searched for studies which satisfied the inclusion principles and did not satisfy exclusion principles. Cluster-randomized trials and non-randomized control trials which compared person-centered care approaches to usual care were included. I performed two random-effects meta-analyses. Six studies with 1,384 patients were included. For older adults with dementia, person-centered care had no significant impact on quality-of-life improvement (SMD = -0.116, $p = 0.206$) or agitation reduction (SMD = 6.673, $p = 0.124$). No absolute conclusion about the correlation between person-centered care intervention and the studied outcomes could be made.

Keywords: person-centered care, dementia, older adults, meta-analysis, quality of life, agitation

1. Introduction

As the world population becomes increasingly older, more and more individuals will be diagnosed with dementia. It was estimated that in 2010, 35.6 million people lived with dementia, and this number is expected to nearly double every 20 years (Prince et al., 2013). This means that by 2030, it is expected that 65.7 million people worldwide will have dementia, and by 2050, there will be 115.4 million individuals diagnosed. With this outlook, there is a need to ensure that older adults with dementia (OAWDs) can receive the best care possible.

Many OAWDs reside in assisted living facilities, nursing homes, and/or receive care in acute settings (Kolanowski et al., 2018), especially those with severe dementia. Many of those facilities operate in a task-focused manner that is either unhelpful or counter-productive to providing the appropriate care to OAWDs. In hectic acute-care settings, a task-focused environment can incite behaviors in OAWDs that can challenge or complicate treatment (McGillick & Murphy-White, 2013). Disregarding the personal and psychosocial needs of these individuals can prompt need-driven dementia-compromised behaviors or isolation that can accelerate an individual's decline (Brooker et al., 2007). These unintended adverse effects are an example of cascade iatrogenesis.

A major neuropsychiatric symptom in OAWDs is agitated behavior, and it is persistent throughout the course of the disease (Wetzels et al., 2010). In busy task-focused facilities, psychotropic drugs are often used to treat agitation and other neuropsychiatric symptoms, even though there is evidence that this approach is not the most effective and could cause severe side effects (Ballard & Corbett, 2010). Practices of physical restraint can also exacerbate need-driven dementia-compromised behaviors. The effects of this include loss of self-care, social engagement, and decision-making (Ballard et al., 2001). Instead, non-pharmacological

treatments are recommended as the primary intervention (Gauthier et al., 2010; Salzman et al., 2008). Psychosocial interventions or other non-pharmacological treatments which are tailored to an individual's background and interests are especially effective modes for treating agitation (Cohen-Mansfield, 2001).

Person- or patient-centered care (PCC) is a care approach which strives to maintain personhood and incorporate a person's individuality into their care plan. There is no universal definition of PCC, but the concept is characterized by striving to individualize care by incorporating the person's life experiences and relationships, maintaining personhood despite cognitive decline, and involving the individual and their family in care decision-making (Godfrey et al., 2018). The main focus is to preserve an OAWD's personhood throughout the course of their dementia disease (Kitwood, 1997). PCC honors an OAWD's choices, values, and strengths (McCance et al., 2011). The care that is provided and the care environment are both important factors in determining an individual's ability to maintain well-being (Kitwood & Bredin, 1992).

Kitwood first proposed the philosophy of PCC for individuals with cognitive loss in 1993 (Kitwood, 1997). Kitwood's philosophy reconceptualized the process of dementia as dependent on the social psychology of the OAWD in addition to their pathological process (Murray & Boyd, 2009). In the last few decades, the field of dementia care has increasingly valued the PCC approach. In the United Kingdom, for example, the National Service Framework for Older People mandates the care for OAWD must incorporate PCC (Watson, 2001). Research supports the effectiveness of adopting PCC programs promoting OAWDs' well-being as the first priority in residential care facilities (Webster, 2011).

The goal of this review and meta-analysis is to determine how effective PCC is as an intervention for OAWDs. This will be done by measuring two variables dependent on the PCC treatment: quality of life (QoL) and agitation levels. QoL is increasingly acknowledged as a crucial measure of effectiveness for interventions in dementia research (Ballard, 2001; Murray & Boyd, 2009). However, despite its importance, the relationship between QoL and PCC has not yet been clarified. This may be because QoL is largely subjective, and ratings are not always reliable. As aforementioned, agitated behavior is one of the major neuropsychiatric symptoms in OAWDs and is exacerbated by nonpersonal, task-focused care. The Social-Psychological Theory of Personhood in Dementia further explains that “agitation can result from negative contextual stimuli that disregard or deny personhood” (Kitwood & Bredin, 1992). Therefore, a reduction in agitation would be an indication that the implemented PCC program has optimal outcomes for the OAWDs, including a preservation of personhood.

2. Methods

2.1. Eligibility Criteria

I included studies which were conducted with older adults (>50 years of age) with dementia. The older adults could have any type of dementia, but they needed to have a formal diagnosis. I included studies which had patients with comorbidities, as long as the study accounted for that information in the data results.

I only included studies which included a patient-centered care treatment group. This included studies which used a direct PCC approach, used a VIPS approach, or a dementia care mapping (DCM) approach. PCC, according to Brooker (2007), is comprised of four elements represented by “VIPS”: valuing people with dementia (V), individualized care (I), understanding

the world from the patient's perspective (P), and providing a social environment that supports the needs of the patient (S). Essentially, PCC and VIPS are synonymous. DCM is an observational tool which was developed to implement PCC into nursing homes (Kitwood, 1992). DCM is based on PCC and is used as an assessment tool which provides feedback for improving patient care by assessing strictly from the patient's perspective (Yasuda & Sakakibara, 2016). I did not include studies which implemented a person-centered environment or those which implemented staff training only.

I included studies which were set in a care facility environment. This included nursing homes, assisted living, and acute care settings. I did not include studies which researched independent living facilities, home-health, or informal caregiving.

The primary effectiveness outcome was either QoL or agitation reduction. I did not include studies which measured ill-being, satisfaction with care, or medication levels. All studies included were primary sources and had data reported as a mean-difference or as outcomes from which a mean-difference could be calculated. This was to ensure the data could be synthesized effectively.

2.2. Search

I conducted an electronic database search in EBSCO Host, National Institutes of Health (NIH), and PubMed on November 30, 2020. I examined reference lists of included studies, other studies, and systematic reviews for more research articles. I did an updated electronic database search on January 6, 2021. I did not search for or include clinical trials or unpublished works.

2.3. Study Selection

I screened all potential studies by title and abstract for eligibility. Of the studies potentially eligible, I screened the full text for inclusion and exclusion criteria. Those which displayed exclusion principles were noted and omitted. Six studies remained.

2.4. Data Collection and Data Items

For each study, I extracted the title, study characteristics, sample characteristics, intervention type, outcome measurement type, and outcome data. I organized this information into a spreadsheet. I extracted outcome data twice (once on January 8, 2021, and a second time on January 16, 2021) to ensure the data collection was correct and consistent. If data was reported to be “not significant,” a p-value of 1 was recorded. This was to err on the side of no relation or causation.

2.5. Data Synthesis

For those studies which did not report data directly as mean difference, the mean difference outcome was calculated using the sample size, before/after raw data scores, and their p-values. This calculation was done using the meta-analysis software. If studies reported more than one treatment outcome, only QoL and/or agitation data were synthesized.

Two separate meta-analyses were conducted: one for QoL outcomes and one for agitation level outcomes. The software used to conduct these analyses was the Open-Meta Analyst program available through Brown University. I expected there to be a large heterogeneity between studies, so I conducted the meta-analyses using a random-effects model. I ran the

analysis using standard mean differences (also known as Cohen's mean difference) because the studies all measured the same outcome but used slightly different methods.

3. Results

3.1. Study Selection

In total, I screened about 50 articles. 24 studies contributed to this review. Six studies were used for analysis. These six studies contributed a total of 1,384 patients for analysis.

3.2. Description of Included Studies

3.2.1. Study Characteristics

The six articles which contributed to the analysis included cluster randomized trials (n=5) and one non-randomized control trial. The studies were conducted worldwide, and none were performed in the United States. The studies were conducted in Japan (n=1), Australia (n=2), United Kingdom (n=1), Norway (n=1), and Singapore (n=1). The care setting also varied between studies. Nursing homes (n=3), residential care settings (n=2), and hospitals (n=1) were included. All studies reported the final result during a follow-up, so the results of this review were focused on long-term effects of the intervention.

3.2.2. Sample and Intervention Characteristics

1,384 OAWDs were included for analysis, and studies included patient numbers ranging from 80 to 349. Ages ranged from 53 to 101 years old. The average age in all six studies was in the mid-80s, and all but two studies reported at least 70% female patients. Only one study reported less than 50% female patients.

More than half of the studies (n=4) treated the OAWDs with a standard PCC approach, including one study that investigated a CAIME (Care for Acute Mentally Infirm Elders) acute hospital dementia unit adopting a PCC approach. The remaining studies (n=2) implemented a PCC & DCM combination program. The DCM aspect helped researchers measure the success of their program.

The majority of the studies measured QoL as the primary outcome (n=5). There were four different scales used to quantify QoL, including Well-ill Being (WIB) (n=1) assessed by DCM practitioners; DemQOL (n=1), a self-report or proxy interview method; Quality of Life in Late-Stage Dementia (QUALID) scale (n=2) which records frequency of behaviors; and EuroQOL (n=1) which assesses three health domains.

Agitation was measured as a primary or secondary outcome in more than half of the studies (n=4). Three studies used the Cohen-Mansfield Agitation Inventory (CMAI). The fourth study used the Brief Agitation Rating Scale (BARS), a subset of the CMAI.

Treatment was conducted in one study for a group of patients (n=620) and in the rest of the studies for individual patients (n=170). Experiments ran between three months long and ten months long.

3.3. Quantitative Analysis

3.3.1. Quality of Life

I conducted a first meta-analysis with five out of six studies which included QoL as a primary outcome measurement. Four of these studies were cluster-randomized trials, and one was a non-randomized control trial. 1,035 total OAWDs were included in this meta-analysis.

About half of the studies reported an increase in QoL while the others reported a decrease in QoL.

The overall outcome from the meta-analysis reported a slight decrease in QoL, SMD = -0.116. (Fig 1). With a p-value of 0.206 (Fig 2), the result is not statistically significant. With a heterogeneity of $I^2 = 22.21$ ($p = 0.273$) (Fig 2), the included studies were determined to be no more than mildly heterogeneous, and no sub-analyses were required. There was no evidence in the forest plot of any publication bias.

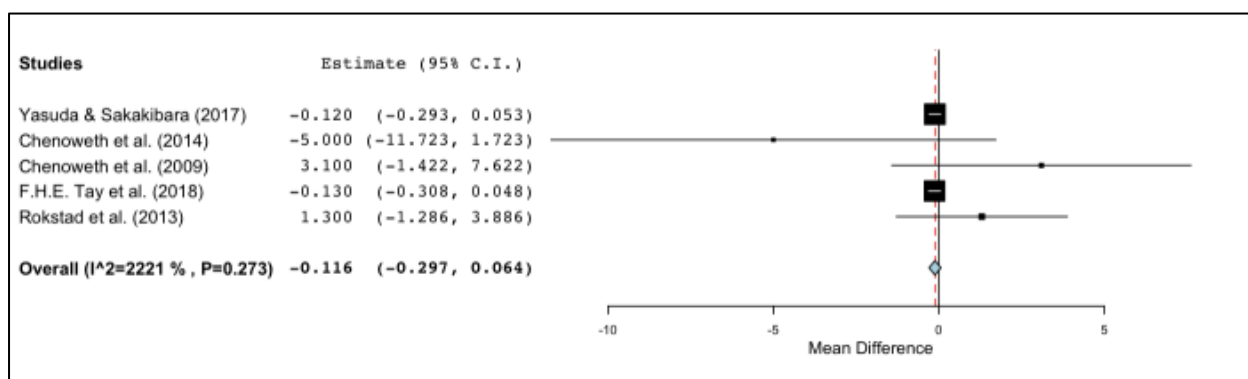


Fig 1. Forest plot for meta-analysis using QoL as a primary outcome measure. Mean differences with 95% confidence intervals are plotted. The diamond represents the overall outcome.

3.3.2 Agitation

I conducted a second meta-analysis with four out of the six studies which included agitation as a primary outcome measurement. All four studies included were cluster-randomized trials. A total of 1,114 OAWDs were included in this meta-analysis. All four of the included studies reported a decrease in agitation levels for the OAWDs.

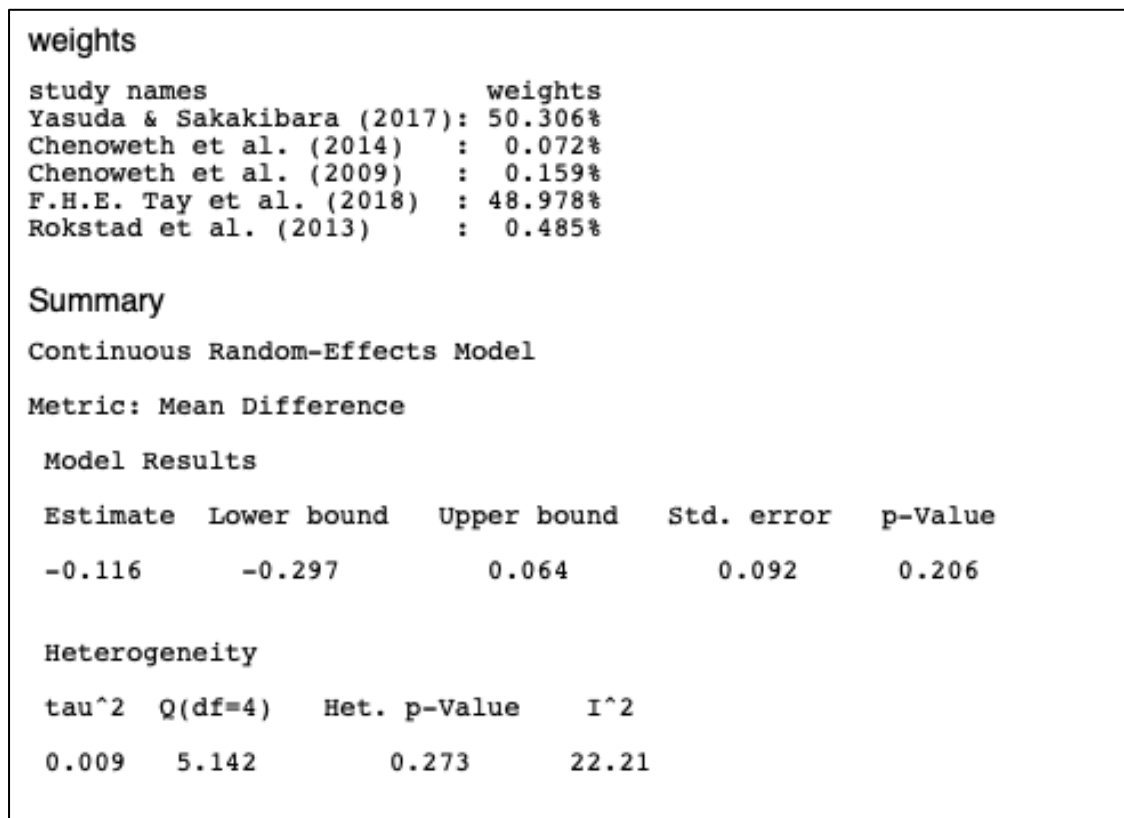


Fig 2. Meta-analysis summary for QoL outcome. Included are the weights for each study in the overall outcome, analysis details, overall outcome result, and heterogeneity outcome for the study.

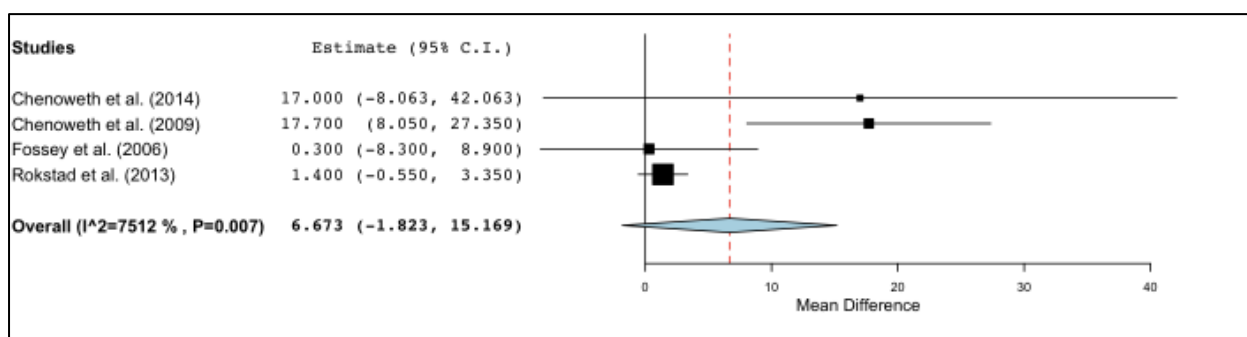


Fig 3. Forest plot for meta-analysis using agitation as a primary outcome measurement. Mean differences for each study with 95% confidence intervals are plotted. The diamond represents the overall outcome.

The overall outcome therefore reported a decrease in agitation levels for OAWDs as a result of PCC (SMD = 6.673) (Fig 3). This result was also not statistically significant, as determined by a p-value of $p = 0.124$ (Fig 4). The studies included showed very serious heterogeneity with a value of $I^2 = 75.115$ ($p = 0.007$) (Fig 4). If more studies were included, sub-analyses would be performed to target the source of heterogeneity.

weights				
study names	weights			
Chenoweth et al. (2014):	8.853%			
Chenoweth et al. (2009):	25.742%			
Fossey et al. (2006)	: 27.631%			
Rokstad et al. (2013)	: 37.775%			
Summary				
Continuous Random-Effects Model				
Metric: Mean Difference				
Model Results				
Estimate	Lower bound	Upper bound	Std. error	p-Value
6.673	-1.823	15.169	4.335	0.124
Heterogeneity				
tau ²	Q(df=3)	Het. p-Value	I ²	
48.758	12.056	0.007	75.115	

Fig 4. Meta-analysis summary for agitation outcome. The summary includes the weights for each study in the overall outcome, analysis details, overall outcome result, and heterogeneity outcome for the study.

4. Discussion

My systematic review and meta-analysis investigated the effectiveness of PCC techniques for older adults with dementia. The effectiveness was measured using QoL and

agitation levels as outcomes. I did not show that PCC interventions had any statistically significant effect on either outcome. These results are correlated to older adults specifically with dementia. Effects were not investigated for older adults with physical ailments or older adults with other psychological disorders. I analyzed the evidence of six studies, totaling 1,384 OAWDs.

4.1. Quality of Life

I found that there was virtually no correlation between PCC intervention and QoL improvement for OAWDs. The included studies reported mixed results on whether it increased QoL or actually decreased QoL. One possible explanation might be the small variances in the programs implemented. Perhaps a more plausible explanation might be the varying scales used to measure results. Only two of the five included studies used the same scale. The meta-analysis includes a comprehensive selection of studies, and the differences in patient care environment, patient characteristics, and study designs all have an effect on the results. For a solid conclusion to be made, more evidence is required.

4.2. Agitation

I found that there was no statistically significant correlation between PCC intervention and reduced agitation in OAWDs. The included studies all showed a correlation to a reduction in agitation, but their results were not significant. Perhaps a systematic review with a larger number of studies would yield significant results. Similar to the previous analysis, one possible explanation for the results of the agitation analysis might be the variance in the programs implemented. One strength of this analysis is that all of the studies included were cluster-

randomized trials. Unfortunately, more evidence would be needed to make a reliable conclusion on this correlation.

4.3. Methodological Evaluation

My systematic review falls short of addressing the topic comprehensively. It does address the effects of PCC interventions on OAWDs. It does so by measuring two outcomes, which offers a variety in the outcome effects. Due to the limited number of sources screened for articles, it is extremely unlikely that the number of included studies approaches the number of existing articles. Articles from several databases and unpublished works were not included in this review. When performing the meta-analysis, I did follow methodological standards in accordance with current guidelines (Higgins et al., 2021). The final results of the included studies were measured during a follow-up, so the results of the meta-analysis would have been applicable to long-term effects of PCC interventions had they been statistically significant. There were no conflicts of interest identified.

4.4. Quality of Evidence

I was unable to make a conclusion about the methodological quality of any of the studies. However, due to the cluster-randomized trials, I predicted there was little bias present in the studies. Bias still might be present due to inadequate blinding or any undocumented conflicts of interest. The heterogeneity of the studies determined by the meta-analysis was expected due to the variety in study designs. The methods for each study were significantly different, and multiple care environments were studied. In addition, QoL was measured using different scales for almost all included studies. The results were not precise.

4.5. Future Research

The number of included studies in this review was too few, so the first change I would make in a future review would be to include more studies. Additionally, a more diverse group of studies should be included. Numerous databases should be screened for potential studies. Unpublished studies and dissertations should also be included. Based on the results from this analysis, the variety in study methodology caused a large heterogeneity between studies. A future analysis should be performed using studies which were done in more similar care environments and which were measured using the same or more similar scales. Based on the analysis results, the environment which had the greatest QoL improvement was residential care facilities. Perhaps a future study could focus on this care environment specifically. Future research could also investigate PCC effectiveness for other older adult populations.

5. Conclusion

This study found no significant correlation between PCC interventions and increased QoL or decreased agitation levels for OAWDs. The effectiveness of this intervention for this population should be further investigated, as individual studies did site significant outcomes. This review was too narrow in its inclusion of studies, and further research should include a greater number of articles in the review and analysis. Further research should also focus on specific types of care facilities and address PCC as a potential intervention for other older adult populations.

References

- Ballard, C., & Corbett, A. (2010). Management of Neuropsychiatric Symptoms in People with Dementia. *CNS Drugs*, *24*, 729–739. <https://doi.org/10.2165/11319240-000000000-00000>
- Ballard, C., O'Brien, J., James, I., Mynt, P., Lana, M., Potkins, D., ... Fossey, J. (2001). Quality of Life for People With Dementia Living in Residential and Nursing Home Care: The Impact of Performance on Activities of Daily Living, Behavioral and Psychological Symptoms, Language Skills, and Psychotropic Drugs. *International Psychogeriatrics*, *13*(1), 93–106. <https://doi.org/10.1017/s1041610201007499>
- Brooker, D. J., Woolley, R. J., & Lee, D. (2007). Enriching opportunities for people living with dementia in nursing homes: An evaluation of a multi-level activity-based model of care. *Aging & Mental Health*, *11*(4), 361–370. <https://doi.org/10.1080/13607860600963679>
- Chenoweth, L., Forbes, I., Fleming, R., King, M. T., Stein-Parbury, J., Luscombe, G., ... Brodaty, H. (2014). PerCEN: a cluster randomized controlled trial of person-centered residential care and environment for people with dementia. *International Psychogeriatrics*, *26*(7), 1147–1160. <https://doi.org/10.1017/s1041610214000398>
- Chenoweth, L., King, M. T., Jeon, Y.-H., Brodaty, H., Stein-Parbury, J., Norman, R., ... Luscombe, G. (2009). Caring for Aged Dementia Care Resident Study (CADRES) of person-centred care, dementia-care mapping, and usual care in dementia: a cluster-randomised trial. *The Lancet Neurology*, *8*(4), 317–325. [https://doi.org/10.1016/s1474-4422\(09\)70045-6](https://doi.org/10.1016/s1474-4422(09)70045-6)
- Cohen-Mansfield, J. (2001). Nonpharmacologic Interventions for Inappropriate Behaviors in Dementia: A Review, Summary, and Critique. *The American Journal of Geriatric Psychiatry*, *9*(4), 361–381. <https://doi.org/10.1097/00019442-200111000-00005>
- Fossey, J., Ballard, C., Juszcak, E., James, I., Alder, N., Jacoby, R., & Howard, R. (2006). Effect of enhanced psychosocial care on antipsychotic use in nursing home residents with severe dementia: cluster randomised trial. *BMJ*, *332*(7544), 756–761. <https://doi.org/10.1136/bmj.38782.575868.7c>
- Gauthier, S., Cummings, J., Ballard, C., Brodaty, H., Grossberg, G., Robert, P., & Lyketsos, C. (2010). Management of behavioral problems in Alzheimer's disease. *International Psychogeriatrics*, *22*(3), 346–372. <https://doi.org/10.1017/s1041610209991505>
- Godfrey, M., Young, J., Shannon, R., Skingley, A., Woolley, R., Arrojo, F., ... Surr, C. (2018). The Person, Interactions and Environment Programme to improve care of people with dementia in hospital: a multisite study. *Health Services and Delivery Research*, *6*(23), 1–154. <https://doi.org/10.3310/hsdr06230>

- Higgins, J. P. T., Thomas, J., Chandler, J., Cumpston, M., Li, T., & Page, M. J. (Eds.). (2021). *Cochrane Handbook for Systematic Reviews of Interventions*. Cochrane Handbook for Systematic Reviews of Interventions | Cochrane Training. <https://training.cochrane.org/handbook/current>.
- Kitwood, T. (1997). The experience of dementia. *Ageing & Mental Health, 1*(1), 13–22. <https://doi.org/10.1080/13607869757344>
- Kitwood, T., & Bredin, K. (1992). Towards a theory of dementia care: personhood and well-being. *Ageing and Society, 12*, 269–287.
- Kolanowski, A., Fortinsky, R. H., Calkins, M., Devanand, D. P., Gould, E., Heller, T., ... Zimmerman, S. (2018). Advancing Research on Care Needs and Supportive Approaches for Persons With Dementia: Recommendations and Rationale. *Journal of the American Medical Directors Association, 19*(12), 1047–1053. <https://doi.org/10.1016/j.jamda.2018.07.005>
- McCance, T., McCormack, B., & Dewing, J. (2011). An exploration of person-centredness in practice. *Online Journal of Issues in Nursing, 16*(1).
- McGillick J, Murphy-White M. (2013). Getting to yes, or how to encourage person-centered dementia care in hospitals. *Generations, 37*(3), 92-96.
- Murray, L. M., & Boyd, S. (2009). Protecting Personhood and Achieving Quality of Life for Older Adults With Dementia in the U.S. Health Care System. *Journal of Aging and Health, 21*(2), 350–373.
- Prince, M., Bryce, R., Albanese, E., Wimo, A., Ribeiro, W., & Ferri, C. P. (2013, September). *The global prevalence of dementia: A systematic review and metaanalysis*. <https://pubmed.ncbi.nlm.nih.gov/23305823/>.
- Rokstad, A. M., Røsvik, J., Kirkevold, Ø., Selbaek, G., Saltyte Benth, J., & Engedal, K. (2013). The Effect of Person-Centred Dementia Care to Prevent Agitation and Other Neuropsychiatric Symptoms and Enhance Quality of Life in Nursing Home Patients: A 10-Month Randomized Controlled Trial. *Dementia and Geriatric Cognitive Disorders, 36*(5-6), 340–353. <https://doi.org/10.1159/000354366>
- Salzman, C., Jeste, D. V., Meyer, R. E., Cohen-Mansfield, J., Cummings, J., Grossberg, G. T., ... Zubenko, G. S. (2008). Elderly Patients With Dementia-Related Symptoms of Severe Agitation and Aggression: consensus statement on treatment options, clinical trials methodology, and policy. *The Journal of Clinical Psychiatry, 69*(6), 889–898. <https://doi.org/10.4088/jcp.v69n0602>

- Tay, F. H. E., Thompson, C., Nieh, C. M., Nieh, C. C., Koh, H. M., Tan, J. J. C., & Yap, P. L. K. (2018). Person-centered care for older people with dementia in the acute hospital. *Alzheimer's & Dementia: Translational Research & Clinical Interventions*, 4, 19–27. <https://doi.org/https://doi.org/10.1016/j.trci.2017.11.003>
- Watson, R. (2001, December 20). *National Service Framework for Older People by Department of Health*. Wiley Online Library. <https://onlinelibrary.wiley.com/doi/full/10.1046/j.1365-2648.2001.1863e.x>.
- Webster J. Improving care for people with dementia in acute hospital: The role of person-centered assessment. *Qual Ageing Old Adults* 2011;12:86–94.
- Wetzels, R. B., Zuidema, S. U., de Jonghe, J. F. M., Verhey, F. R. J., & Koopmans, R. T. C. M. (2010). Course of Neuropsychiatric Symptoms in Residents with Dementia in Nursing Homes Over 2-Year Period. *The American Journal of Geriatric Psychiatry*, 18(12), 1054–1065. <https://doi.org/10.1097/jgp.0b013e3181f60fa1>
- Yasuda, M., & Sakakibara, H. (2016). Care staff training based on person-centered care and dementia care mapping, and its effects on the quality of life of nursing home residents with dementia. *Ageing & Mental Health*, 21(9), 991–996. <https://doi.org/10.1080/13607863.2016.1191056>