


# Assessing Quality for People Living With Dementia in Residential Long-Term Care: Trends and Challenges

Gerontology & Geriatric Medicine  
Volume 5: 1–7  
© The Author(s) 2019  
Article reuse guidelines:  
sagepub.com/journals-permissions  
DOI: 10.1177/2333721419861198  
journals.sagepub.com/home/ggm  


Eleanor S. McConnell, PhD, RN<sup>1,2</sup>   
and Julienne Meyer, CBE, PhD, RN, RNT<sup>3</sup>

## Abstract

The global prevalence of dementia is growing rapidly, driving an increased use of residential long-term care (LTC) services. Performance indicators for residential LTC should support targeting of limited resources to promote person-centered care, health, and well-being for both patients and caregivers (formal and informal), yet many performance indicators remain focused on structure, process, or outcome measures that are only assumed to support personally relevant outcomes for those with dementia, without direct evidence of meaningfulness for these individuals. In this article, two complementary approaches to assessing quality in residential LTC serve as a lens for examining a series of tensions related to assessment in this setting. These include measurement-focused approaches using generic psychometrically valid instruments, often used to monitor quality of services, and meaning-focused approaches using individual subjective assessment of personally relevant outcomes, often used to monitor care planning. Examples from the European and U.S. literature suggest an opportunity to strengthen an emphasis on personally meaning-focused outcomes in quality assessment.

## Keywords

person-centered care, outcomes, performance indicators, Alzheimer's/dementia, long-term care

**Manuscript received:** February 12, 2019; **final revision received:** April 25, 2019; **accepted:** June 3, 2019.

## Introduction

The prevalence of dementia and its associated costs are increasing, internationally, as the global population ages (World Health Organization, 2017). Care of these incurable, progressive disorders should focus on outcomes that matter to people living with dementia and their families (Bunn et al., 2017; Jennings et al., 2017). However, in Western countries, where 50% to 70% of long-term care (LTC) residents have dementia (Alzheimer's Society, 2018; Bjork et al., 2016; Lithgow, Jackson, & Browne, 2012), addressing personally meaningful outcomes in care is challenged by performance indicators that emphasize service standards over personally meaningful outcomes (Kane & Cutler, 2015; Miller & Barrie, 2016). Although attempts to redesign care and systems to foster person-centered and relationship-centered care have emerged (Chisholm et al., 2018; Nolan, Davies, Brown, Keady, & Nolan, 2004; Owen, 2006), the alignment of performance indicators with personally relevant goals has been uneven (Shier, Khodyakov, Cohen, Zimmerman, & Saliba, 2014).

The purpose of this article is to highlight a series of tensions that impede the development and use of performance indicators that are focused on personally meaningful outcomes for people living with dementia in residential LTC. We propose that resolving these tensions will require clinicians, policy makers, and consumers to engage collectively in three overarching activities: (a) taking a more balanced approach to formulating goals of care, by integrating personally meaningful goals with what is clinically advised, (b) attending to the relationship-centered nature of care that is crucial to support well-being among people living with dementia, and (c) considering more carefully how what we measure influences what we accomplish.

<sup>1</sup>Duke University School of Nursing, Durham, NC, USA

<sup>2</sup>Geriatric Research Education and Clinical Center, Durham Veterans Affairs Healthcare System, NC, USA

<sup>3</sup>City, University of London, UK

## Corresponding Author:

Eleanor S. McConnell, Associate Professor, Duke University School of Nursing, Box 3322 DUMC, Durham, NC 27710, USA.  
Email: eleanor.mcconnell@duke.edu



## Background: Challenges and Trends in Outcome Assessment in Dementia in Residential LTC

Quality measurement approaches are often organized using Donabedian's "Structure-Process-Outcome" (SPO) framework (Ayanian & Markel, 2016; Donabedian, 1988). This framework was developed to measure quality in acute care and therefore has focused on outcomes such as recovery from surgery and mortality. Although the SPO framework also can be useful for the development of performance indicators in chronic illness care, dementia presents particular challenges. First, the diseases that underlie dementia are diverse, causing considerable heterogeneity in presentation, trajectories of symptoms, and progression. This heterogeneity makes it difficult to predict when symptoms may occur and when function will be lost. Second, the lack of effective disease-modifying therapies for the various causes of chronic dementia means that maintaining function is not a reliable outcome throughout the course of illness. Indeed, goals of care and related outcomes will differ as dementia progresses within and between individuals. Third, self-reported outcomes can be difficult to obtain due to the multiple cognitive domains impaired in dementia (Strikwerda-Brown, Grilli, Andrews-Hanna & Irish, 2019). Although one can rely more on self-report in the earlier stages of dementia (Kane et al., 2003), later stages may require use of proxies, who may or may not be able to represent the perspectives of the person living with dementia (Schmidt, Lingler, & Schultz, 2009). Despite these challenges, the SPO framework contributes value in dementia care. People living with dementia often experience coexisting illness, owing to the long trajectory of dementia, which averages 10 years in Alzheimer's disease. Poorly controlled coexisting chronic illness can worsen dementia symptoms and adversely affect quality of life, and so the SPO framework helps to address those threats in dementia. However, current trends in health care underscore the importance of emphasizing person-centered care approaches over clinician or service-driven approaches to care (Institute of Medicine, 2001; Lithgow et al., 2012). This trend is particularly appropriate for assessing outcomes and organizational performance in dementia and residential LTC.

Person-centered care (PCC) has been defined as

An approach to the planning and delivery of care across settings and time that is centered around collaborative partnerships among individuals, their defined family, and providers of care. It supports health and well-being by being consistent with, respectful of, and responsive to an individual's priorities, goals, needs, and values. (U.S. National Quality Forum, 2014, p. 9)

PCC outcomes include experience of care, health-related quality of life, burden of illness, shared decision making, effective navigation, and self-management.

Balancing clinically desirable goals with personal preference is championed by reform-minded organizations such as the Pioneer Movement in the United States, which has advocated for culture change within residential LTC to promote care processes that improve quality of life while maintaining necessary care quality (Koren, 2010). Likewise, in the United Kingdom, researchers have explored tensions between *meaning* in outcomes, which entails the need for detailed, contextualized information on individual experience to inform individual planning and service improvement, and *measurement* that would satisfy the need to aggregate information on personal outcomes to inform decision making at organizational and national levels (Miller & Barrie, 2016). This Meaningful and Measurable project brought together three academic organizations, eight practice partners, and four national stakeholder organizations with a shared interest in adopting a focus on personal outcomes in health, social care, and other human services. Both of these efforts highlighted the importance of balancing good care with personal preference. For example, in the United States, as noted by Calkins, Schoenman, Brush, and Mayer (2018), regulatory guidance can seem conflicting because care homes are required to accommodate resident preferences, including their right to decline treatments such as a therapeutic diet, whereas the home is still held accountable for the resident's care and safety, including the outcomes of those decisions. In these circumstances, the Pioneer Network recommends engaging with residents, and surrogates whether decision-making capacity is impaired, to modify therapeutic diets to maximize the resident's preferences. This approach is very consistent with the approach taken by the Meaningful and Measureable project, which emphasized active listening to the individual receiving care and integrating the clinicians approach to formulating problems with concerns identified by the individual (Joint Improvement Team, 2012).

## Relationship-Centered Care as a Vehicle to Achieve PCC in Dementia

The idea that human relationships serve as the vehicle through which PCC is achieved in residential LTC for people living with dementia is an important but often overlooked aspect of PCC (Koren, 2010; Nolan et al., 2004). Only when residents, relatives, and staff are in positive relationship with each other can care be delivered in an authentic person-centered way. This focus on relationships, sometimes referred to as relationship-centered care, requires us to think additionally about the needs of relatives and staff (Nolan et al., 2004). More creative approaches (e.g., use of metaphor and interpretation, visual images, and augmented communication) may also be required to understand and assess the subjective experience of quality of life and

well-being for people with dementia (Kindell, Keady, Sage, & Wilkinson, 2017).

A relationship-centered approach highlights the need for all parties (residents, relatives, and staff) to fulfill six senses to ensure well-being and good relationship with each other: (a) security—feeling safe, (b) belonging—feeling part of things, (c) continuity—making connections, (d) purpose—having goals, (e) achievement—progressing toward goals, and (f) significance—mattering as a person (Nolan et al., 2004). These relationship-focused outcomes, identified in an ethnographic study conducted in the United Kingdom, align well with other models designed to promote well-being developed for residential LTC in the United States, such as those developed by the Eden Alternative (Wilby, Stryker, Hyde, & Ransom, 2016). Focusing on relationships highlights the importance of engaging with people with dementia *and* with their proxies, including paid and unpaid caregivers. Thus, outcome assessment and performance indicators should be part of a care planning process that focuses on the real and particular needs of individuals (personal outcomes) and also the needs of those who care for them, both paid and unpaid (relationship-centered outcomes). The routine assessment of relationship-centered outcomes appears a long way off. Although the needs of residents are always prioritized, the needs of carers, both paid and unpaid, are often ignored. There is a growing recognition of the importance of valuing more direct care workers (Dill, Chuang, & Morgan, 2014; Scales, Bailey, Middleton, & Schneider, 2017). A personal outcomes approach recognizes the need to engage with carers about what is achievable in relation to the resident's desired outcomes and thus aligns more to relationship-centered outcomes and relationship-centered care.

A key challenge to making care standards more resident-centered is a commonly held belief that professionals know what is best for the resident (Calkins et al., 2018). Although professional inputs are important, collective living in LTC requires thinking beyond the individual. Care needs to be negotiated and considered within the context of multiple residents, restricted resources, existing regulations, and the business case for quality.

### **Personal Outcomes Approach: A Strategy for Operationalizing PCC Performance Indicators**

A personal outcomes approach, developed in the United Kingdom (Miller & Barrie, 2016) and being evaluated for adoption in the United States (Karhoff, Borer, & McConnell, 2018), is underpinned by three core elements: *engagement* with individuals using services and their caregivers, *recording* of information on outcomes of personal importance, and *using information* on desired outcomes for decision making. *Engagement*

with individuals using services and their caregivers focuses on ascertaining what they want to achieve in life, the assets/strengths they and others bring to achieve this, and the extent to which outcomes are achieved, and what helps and hinders. *Recording* of information on outcomes specifically focuses on recording qualitative data in language meaningful to the person that may also be summarized in tick boxes or standardized assessment forms. *Using information* for decision making includes individual care and support, service delivery and improvement, and planning and commissioning.

*Identifying personal outcomes* involves addressing issues that are important to people in their lives and ensuring that services work in partnership with the public toward effective use of resources in achieving well-being. This is a central plank of national policy in several countries. For instance, in Scotland, work to support the development and implementation of a personal outcomes approach began in 2007 and led to the establishment of the Personal Outcomes Network (<https://personaloutcomescollaboration.org/>), a national cross-sector group, seeking to develop a wider and more consistent understanding of personal outcomes across diverse service settings including long-term residential care. They suggest that adopting a personal outcomes approach requires a shift in culture to rebalance the powerbase of relationships between the person and those individuals working with them.

The personal outcomes approach takes account of the person's own abilities, achievement, and assets, including people, places, community, as well as ensuring effective use of resources. A personal outcomes approach is underpinned by the principle of enabling people to participate in making decisions, which impacts on their human rights. Reflecting on this work, Miller (2010) suggests outcomes-based working requires more honest communication about what matters to people, what is feasible in any given circumstance, and a focus on maximizing the potential of each individual, rather than responding to more superficial and generic consumerist demand and a tendency to do things *to*, rather than *with*, people. A personal outcomes approach requires the wider system to realign around the individual and to place much more focus on the importance of enabling relationships to help coordinate and deliver PCC.

### *Commissioning and Regulatory Processes Influence Performance Indicators*

Although systems for commissioning and regulating residential LTC quality differ among Western countries, all countries use some form of performance indicators to ensure that provider organizations can demonstrate their ability to deliver good quality residential and/or nursing care. Although the regulators and commissioners use a variety of inspection processes and rating systems to register and monitor care homes or facilities, health and

social care organizations use a range of alternative methods to monitor quality, with no consistent way of benchmarking across the entire system. Currently in the United States, information about staffing, performance on routine inspections, and performance on resident-specific quality indicators derived from the Nursing Home Minimum Data Set system predominate in the rating (Centers for Medicare and Medicaid Services, 2019). Some have argued that a quality system that is overly focused on inspections causes management to focus on satisfying minimum standard requirements, rather than on a “nuanced consideration of the meaning of resident-centered quality and best practice” (Tolson, Dewar, & Jackson, 2014). Importantly, the Centers for Medicare and Medicaid Services (CMS) star-rating system also has been criticized because it does not adequately capture perspectives of the person living in residential LTC, nor the perspectives of their family members (A. Williams, Straker, & Applebaum, 2016), and we argue that omitting staff perspectives is also problematic.

### Tensions in Using Performance Indicators

The challenges and trends in measurement of quality and performance described above suggest a set of tensions that require further exploration if we are to arrive at a satisfactory set of person-centered performance indicators for residential LTC of those living with dementia.

#### *Metrics Versus Meaning*

First, trade-offs exist between taking a more targeted and objective approach to performance indicators, which maximizes efficiency of measurement, and taking a holistic approach, which emphasizes the individuality of the person receiving care and the meaning that person derives from a particular outcome. Examples of these differences can be seen in the approach to measurement of dementia care quality taken by the U.S. CMS, compared with the approach advocated by the Scottish Joint Improvement Team. The United States-based CMS uses a lengthy list of quality indicators, such as immunization rates, use of antipsychotic medication, and falls as key performance indicators. Although these targeted indicators capture clinical services and related outcomes that are important to many, these do not necessarily represent personally meaningful goals to an individual, nor are all equally important for a specific person. Although assuring safety and freedom from complications of chronic disease is important in dementia, given the life-limiting nature of dementia, equal attention to personally relevant goals, as is routinely the focus in palliative care, warrants more careful attention. Kane and Cutler (2015) have specifically noted that an overemphasis on safety in residential LTC may interfere with quality of life.

Note how in a more holistic approach taken by the Scottish Joint Improvement Team, outcomes are identified after the service provider engages in a conversation with the person receiving care and their family carers “to identify what is important to them in life and what they need to change” and then

Recording the outcomes in a support plan which is shared by everyone involved . . . [so that] later on, the person, their family and staff can get together to check whether the outcomes have been achieved or if the plan needs to change. The outcomes can be measured for the person—“did we achieve what we hoped.” By looking at lots of support plans and reviews, outcomes can be measured for the service—“what is working well in our service and what needs to change.” (Cook & Miller, 2012, p. 2)

Rather than focusing too narrowly on a problem list (e.g., pain, reduced range of motion, reduced mobility, mental deficiency, and inadequate care), using a personal outcomes approach focuses on personally meaningful outcomes, for example,

[1] get to her daughter’s for Christmas, [2] not feel distressed that the carers were having to rush, and [3] wanting to be involved in decisions [4] getting to the lunch club to alleviate loneliness, [5] have an opportunity to talk about family [6] not be in pain. (Joint Improvement Team, 2012, p. 21)

Goal attainment scaling is an approach that has been used in dementia care to help quantify person-centered outcomes (Jennings et al., 2017).

A second tension relates to the tendency to focus on either health care outcomes or social care outcomes. This tension is driven largely by how most countries organize services for older adults, which typically administers social care and health care separately. A growing recognition of the importance of social determinants of health effects on health outcomes could drive service organizations to collaborate around evaluation of outcomes. However, as funding of these services often is provided under the auspices of different organizations and service standards are developed separately, performance assessment may focus too narrowly on one or the other service sector, rather than focusing on personally meaningful outcomes. People living and dying in care homes with co-morbidity, high levels of dependency, and complex needs require an interplay of both health and social care, regardless of whether they are in a residential setting for postacute rehabilitation, or in a setting designed for chronic care. The false dichotomy between health and social services is particularly problematic for people living with dementia and their caregivers as the nature of the impairments associated with dementia are such that both physical and social functioning are affected, and therefore integration of health care and social services is particularly important in residential LTC.

A third tension concerns subtle but important distinctions between three interrelated concepts that are key to ensuring outcomes in residential LTC: quality of life, quality of care, and quality of leadership and management. Although failing to attend to basic human needs to prevent adverse outcomes such as pressure ulcers or malnutrition can impact quality of life, quality of care does not equate to quality of life and vice versa. As noted by Bamford and Bruce (2001), "Quality of life outcomes center on having access to normal activities and patterns of life in ways that maximize feelings of choice and control and encompass social, physical and emotional needs" (p. 561). For instance, routines designed to ensure that basic needs are met, such as turning schedules to prevent pressure ulcers or strict dietary rules, could interfere with access to social contacts or maintaining a sense of personal identity and can lead to quality of life being compromised. The quality of leadership within a LTC home holds potential to manage these challenges (Corazzini et al., 2015), yet historically leadership characteristics have not been considered in performance management systems.

A fourth tension arises from attempts to operationalize PCC and relationship-centered care, which some may view as competing rather than complementary perspectives. There is a risk, when considering approaches to optimizing an individual's personal experience, that those concerned with quality focus too narrowly on the individual and overlook the importance of the many relationships that form the fabric of day-to-day life in residential LTC. Attention to nurturing and strengthening these relationships through approaches such as consistently assigning the same caregiver is an important start, but as performance indicators shift to focus on outcomes that matter to people living in residential LTC, it will be important to note how conflicts among individual preferences and needs of others in the relationship are managed over time. Recognizing that even those residents who live with moderately severe dementia can engage in positive relationships with other residents, relatives, and staff, and then equipping staff with effective communication tools to help manage conflict and support relationships is a cornerstone of delivering effective PCC. The relationship between PCC and relationship-centered care deserves more attention, if we are to avoid the trap of PCC being equated with customer-service models. This became particularly apparent in an European Union (EU)-funded study to identify quality indicators in care homes (Hoffman & Leichsenring, 2011). Using existing quality management guidelines and frameworks from the countries represented in the project, as well as the Nursing Home Minimum Data Set from the United States, the project team collected an initial list of performance indicators and found that they tended to focus on quality of care rather than

quality of life, observable measurement rather than subjective opinion, and the needs of residents rather than relatives and staff. New indicators were added to address a broader perspective and their usefulness assessed through a Delphi study involving multiple stakeholders, including residents, relatives, providers (or their representatives), commissioners, regulators, and academics in each of the partnering countries. All the new indicators were accepted, with the exception of those for staff. Although researchers showed a narrow perspective at the start of the study, the multiple stakeholders demonstrated a more inclusive approach. However, both researchers and multiple stakeholders internationally struggled to recognize the importance of the well-being of staff to delivering quality of life in care homes for older people. Attending to the call to amend the so-called triple aim of health care improvement (reducing costs, improving patient experience, and improving population health) by adding improvements to the workforce's well-being (Bodenheimer & Sinsky, 2014) is an important next step.

A fifth tension relates to the purpose of assessing care quality and outcomes. Performance indicators that are effective for monitoring (e.g., infection rates or complications of care) typically differ from metrics that foster performance improvement (e.g., measuring the extent and impact of residents' family involvement in care planning). The latter may require more qualitative assessment and, in the early phases of establishing new processes to support this desired end, may require a tolerance for performing poorly as staff work through "what it takes" to create a process that actually works. Aspirational indicators can be helpful in stimulating improvements in care, in addition to using outcome metrics to ensure a minimum standard of care (Stange et al., 2014). The Dementia Friendly Communities movement may be a good source of aspirational metrics as they seek to improve well-being for people living with dementia (Handley, Bunn, & Goodman, 2017).

A sixth, and particularly challenging tension is the importance of distinguishing the advantages of collective outcome tools compared with personal outcome tools. As residential LTC attracts additional attention by the research community, a variety of new instruments focused on thriving (Edvardsson et al., 2017) and well-being (Wilby et al., 2016) are increasingly available to measure performance. Although such instruments are a welcome advance in LTC quality assessment, it is not safe to assume that the specific indicators in each of these measures (e.g., "being able to be outdoors as much as I wish") will apply equally well to all individuals who reside in LTC (White et al., 2012), especially internationally. Therefore, it is likely that any quantitative instrument will need to be supplemented by data from a more qualitative approach to ensure that the various metrics used to assess achieve-

ment of outcomes are grounded in the specific resident's way of making meaning.

## Conclusion

The shift toward a more person-centered approach to assessing outcomes in health care generally is a welcome trend that holds great potential for improving the quality of life of people who live, die, visit, and work in residential LTC. Before that promise can be realized, leaders in the field should consider carefully strategies to address the tensions that exist when trying to personalize the assessment of outcomes, particularly among those living with dementia. Before any international consensus on measurement can be reached, there needs to be debate about the tensions that exist in the literature, specifically (a) metrics versus meaning, (b) health versus social care outcomes, (c) quality of life versus quality of care versus quality of management/leadership, (d) person-centered versus relationship-centered care, (e) quality monitoring versus quality improvement, and (f) collective outcome tools versus personal outcomes tools. This review has attempted to move the discussion beyond an "either-or" approach to managing the tensions, by suggesting some approaches that may integrate the seemingly divergent poles of each issue. We believe the use of performance indicators for those seeking to enhance outcomes for people living with dementia in residential LTC should embrace a "mixed-methods" approach to identifying and monitoring outcomes that balance and integrate the best of existing structures (periodic, systematic assessment) with newer approaches to capturing narratives of the personal experience, and use those combined methods to create innovative approaches to performance improvement within residential LTC.

## Authors' Note

The content is solely the responsibility of the authors and does not necessarily represent the official views of the NIH.

## Declaration of Conflicting Interests

The author(s) declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

## Funding

The author(s) disclosed receipt of the following financial support for the research, authorship, and/or publication of this article: The authors were supported with resources provided through a Population Health Pilot Project (McConnell and Corazzini MPIs) awarded by the Center for Nursing Research and the National Center for Advancing Translational Sciences (NCATS), National Institutes of Health, through Grant Award Number UL1TR002553.

## ORCID iD

Eleanor S. McConnell  <https://orcid.org/0000-0002-2896-8596>

## References

- Alzheimer's Society. (2018). *Dementia—The true cost: Fixing the care crisis*. Retrieved from <https://www.alzheimers.org.uk/our-campaigns/fix-dementia-care>
- Ayanian, J. Z., & Markel, H. (2016). Donabedian's lasting framework for health care quality. *The New England Journal of Medicine*, *375*, 205-207. doi:10.1056/NEJMp1605101
- Bamford, C., & Bruce, E. (2001). Defining the outcomes of community care: The perspectives of older people with dementia and their carers. *Aging & Society*, *20*, 543-570.
- Bjork, S., Juthberg, C., Lindkvist, M., Wimo, A., Sandman, P. O., Winblad, B., & Edvardsson, D. (2016). Exploring the prevalence and variance of cognitive impairment, pain, neuropsychiatric symptoms and ADL dependency among persons living in nursing homes; a cross-sectional study. *BMC Geriatrics*, *16*, Article 154. doi:10.1186/s12877-016-0328-9
- Bodenheimer, T., & Sinsky, C. (2014). From triple to quadruple aim: Care of the patient requires care of the provider. *The Annals of Family Medicine*, *12*, 573-576. doi:10.1370/afm.1713
- Bunn, F., Burn, A., Robinson, L., Poole, M., Rait, G., Brayne, C., . . . Goodman, C. (2017). Healthcare organization and delivery for people with dementia and comorbidity: A qualitative study exploring the views of patients, carers and professionals. *BMJ Open*, *7*, e013067.
- Calkins, M., Schoenman, K., Brush, J., & Mayer, R. (2018). *Honoring preferences when the choice involves risk: A process for shared decision making and care planning*. Pioneer Network. Retrieved from <https://www.pioneer-network.net/wp-content/uploads/2018/10/Honoring-preferences-when-the-choice-involves-risk.pdf>
- Centers for Medicare and Medicaid Services. (2019). *Five star quality rating system*. Retrieved from <https://www.cms.gov/medicare/provider-enrollment-and-certification/certificationandcompliance/fsqrs.html>
- Chisholm, L., Zhang, N. J., Hyer, K., Pradhan, R., Unruh, L., & Lin, F. C. (2018). Culture change in nursing homes: What is the role of nursing home resources? *Inquiry*. Jan-Dec; *55*. doi: 10.1177/0046958018787043.
- Cook, A. and Miller, E. (2012). Talking Points Personal Outcomes Approach: A Practical Guide. Joint Improvement Team. Scotland. Retrieved from <https://personaloutcomes.files.wordpress.com/2014/03/talking-points-summary-briefing-21-june-2012.pdf>
- Corazzini, K., Twersky, J., White, H. K., Buhr, G. T., McConnell, E. S., Weiner, M., & Colon-Emeric, C. S. (2015). Implementing culture change in nursing homes: An adaptive leadership framework. *The Gerontologist*, *55*, 616-627. doi:10.1093/geront/gnt170
- Dill, J. S., Chuang, E., & Morgan, J. C. (2014). Healthcare organization-education partnerships and career ladder programs for health care workers. *Social Science & Medicine*, *122*, 63-71. doi:10.1016/j.socscimed.2014.10.021
- Donabedian, A. (1988). The quality of care: How can it be assessed? *The Journal of the American Medical Association*, *260*, 1743-1748. doi:10.1001/jama.1988.03410120089033
- Edvardsson, D., Sjögren, K., Lood, Q., Bergland, Å., Kirkevold, M., & Sandman, P.-O. (2017). A person-centred and thriving-promoting intervention in nursing homes—Study protocol for the U-age nursing home multi-centre, non-equivalent controlled group before-

- after trial. *BMC Geriatrics*, 17, Article 22. doi:10.1186/s12877-016-0404-1
- Handley, M., Bunn, F., & Goodman, C. (2017). Dementia-friendly interventions to improve the care of people living with dementia admitted to hospitals: A realist review. *BMJ Open*, 7(7), e015257. doi:10.1136/bmjopen-2016-015257
- Hoffmann, F. & Leichsenring, K. (2011). *Quality management by result-oriented indicators: Towards benchmarking in residential care for older people*. Policy Brief 6.1/2011. Vienna: European Centre.
- Institute of Medicine. (2001). *Crossing the quality chasm: A new health system for the 21st century*. Washington, DC: The National Academies Press. doi:10.17226/10027
- Jennings, L. A., Palimaru, A., Corona, M. G., Cagigas, X. E., Ramirez, K. D., Zhao, T., . . . Reuben, D. B. (2017). Patient and caregiver goals for dementia care. *Quality of Life Research*, 26, 685-693.
- Joint Improvement Team. (2012). *Talking points: A practical guide*. Retrieved from <http://www.jitscotland.org.uk/wp-content/uploads/2014/01/Talking-Points-Practical-Guide-21-June-2012.pdf>
- Kane, R. A., & Cutler, L. J. (2015). Re-imagining long-term services and supports: Towards livable environments, service capacity, and enhanced community integration, choice, and quality of life for seniors. *The Gerontologist*, 55, 286-295. doi:10.1093/geront/gnv016
- Kane, R. A., Kling, K. C., Bershadsky, B., Kane, R. L., Giles, K., Degenholtz, H. B., . . . Cutler, L. J. (2003). Quality of life measures for nursing home residents. *Journals of Gerontology—Series A Biological Sciences and Medical Sciences*, 58, 240-248.
- Karhoff, C., Borer, A., & McConnell, E. S. (2018). *Adapting the Personal Outcomes Approach (POA) to promote well-being among people living with dementia*. Proposal summary posted on Duke University Clinical Translational Research Institute website. Retrieved from <https://www.ctsi.duke.edu/news/2018-ctsi-population-health-improvement-award-recipients-announced>
- Kindell, J., Keady, J., Sage, K., & Wilkinson, R. (2017). Everyday conversation in dementia: A review of the literature to inform research and practice. *International Journal of Language & Communication Disorders*, 52, 392-406. doi:10.1111/1460-6984.12298
- Koren, M. J. (2010). Person-centered care for nursing home residents: The culture-change movement. *Health Affairs*, 29, 312-317. doi:10.1377/hlthaff.2009.0966
- Lithgow, S., Jackson, G. A., & Browne, D. (2012). Estimating the prevalence of dementia: Cognitive screening in Glasgow nursing homes. *International Journal of Geriatric Psychiatry*, 27, 785-791. doi:10.1002/gps.2784
- Miller, E. (2010). Can the shift from needs-led to outcomes-focused assessment in health and social care deliver on policy priorities? *Research, Policy and Planning*, 28, 115-127.
- Miller, E., & Barrie, K. (2016). *Learning from the meaningful and measurable project: Strengthening links between identity, action and decision-making healthcare improvement Scotland*. Retrieved from <https://ihub.scot/media/2126/po-learning.pdf>
- National Quality Forum. (2014). *Priority setting for health-care performance measurement: Addressing performance measure gaps in person-centered care and outcomes*. Retrieved from [http://www.qualityforum.org/Publications/2014/08/Priority\\_Setting\\_for\\_Healthcare\\_Performance\\_Measurement\\_Addressing\\_Performance\\_Measure\\_Gaps\\_in\\_Person-Centered\\_Care\\_and\\_Outcomes.aspx](http://www.qualityforum.org/Publications/2014/08/Priority_Setting_for_Healthcare_Performance_Measurement_Addressing_Performance_Measure_Gaps_in_Person-Centered_Care_and_Outcomes.aspx)
- Nolan, M. R., Davies, S., Brown, J., Keady, J., & Nolan, J. (2004). Beyond person-centred care: A new vision for gerontological nursing. *Journal of Clinical Nursing*, 13, 45-53.
- Owen, T. (2006). A new vision for care homes in the 21st century: My Home Life. *British Journal of Community Nursing*, 11, 524-526. doi:10.12968/bjcn.2006.11.12.22421
- Scales, K., Bailey, S., Middleton, J., & Schneider, J. (2017). Power, empowerment, and person-centred care: Using ethnography to examine the everyday practice of unregistered dementia care staff. *Sociology of Health and Illness*, 39, 227-243. doi:10.1111/1467-9566.12524
- Schmidt, K. L., Lingler, J. H., & Schultz, R. (2009). Verbal communication among Alzheimer's disease patients, their caregivers and primary care physicians during primary care office visits. *Patient Education and Counseling*, 77, 197-201.
- Shier, V., Khodyakov, D., Cohen, L. W., Zimmerman, S., & Saliba, D. (2014). What does the evidence really say about culture change in nursing homes? *The Gerontologist*, 54(Suppl 1), S6-S16. doi:10.1093/geront/gnt147
- Stange, K. C., Etz, R. S., Gullett, H., Sweeney, S. A., Miller, W. L., Jaen, C. R., . . . Glasgow, R. E. (2014). Metrics for assessing improvements in primary health care. *Annual Review of Public Health*, 35, 423-442. doi:10.1146/annurev-publhealth-032013-182438
- Strikwerda-Brown C., Grilli M. D., Andrews-Hanna J., Irish M. (2019). "All is not lost"—Rethinking the nature of memory and the self in dementia. *Ageing Res Rev*. 54:100932. doi: 10.1016/j.arr.2019.100932
- Tolson, D., Dewar, B., & Jackson, G. (2013). Quality of life and care in the nursing home. *The Journal of the American Medical Association*, 14, 154-157.
- White, H. K., Corazzini, K., Twersky, J., Buhr, G., McConnell, E., Weiner, M., & Colon-Emeric, C. S. (2012). Prioritizing culture change in nursing homes: Perspectives of residents, staff, and family members. *Journal of the American Geriatrics Society*, 60, 525-531. doi:10.1111/j.1532-5415.2011.03840.x
- Wilby, F., Stryker, C. D., Hyde, D., & Ransom, S. (2016). Plotting the course of well-being: The Eden alternative well-being assessment tool. *SAGE Open*. doi:10.1177/2158244016646147
- Williams, A., Straker, J. K., & Applebaum, R. (2016). The nursing home five star rating: How does it compare to resident and family views of care? *The Gerontologist*, 56, 234-242. doi:10.1093/geront/gnu043
- World Health Organization. (2017). *Global dementia observatory*. Retrieved from <http://apps.who.int/gho/data/node.dementia?lang=en>