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Title: Australian long-term care personnel's knowledge and attitudes regarding palliative care for people with advanced dementia

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Declaration of Conflicting Interests

The Author(s) declare(s) that there is no conflict of interest

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Abstract

The current study aimed to describe Australian long-term care (LTC) personnel's knowledge and attitudes concerning palliative care for residents with advanced dementia, and explore relationships with LTC facility/personnel characteristics.

An analysis was undertaken of baseline data from a cluster randomised controlled trial (RCT) of facilitated family case conferencing for improving palliative care of LTC residents with advanced dementia (the 'IDEAL Study'). Participants included any LTC personnel directly involved in residents' care. Knowledge and attitudes concerning palliative care for people with advanced dementia were measured using the questionnaire on Palliative care for Advanced Dementia (qPAD) (Long et al., 2012). Univariate and multivariate analyses explored relationships between personnel knowledge/attitudes and facility/personnel characteristics.

Of 307 personnel in the IDEAL Study, 290 (94.5%) from 19/20 LTCFs provided sufficient data for inclusion. Participants included nine (2.8%) nurse managers, 59 (20.5%) registered nurses, 25 (8.7%) enrolled nurses, 187 (64.9%) assistants in nursing/personal care assistants and nine (3.1%) care service employees. In multivariate analyses, a facility policy not to rotate personnel through dementia units was the only variable associated with more favorable overall personnel knowledge and attitudes. Other variables associated with favorable knowledge were a designation of nursing manager or registered or enrolled nurse, and having a preferred language of English. Other variables associated with favorable attitudes were tertiary level of education and greater experience in dementia care.

Like previous international research, this study found Australian LTC personnel knowledge and attitudes regarding palliative care for people with advanced dementia to be associated with both facility and personnel characteristics. Future longitudinal research is needed to better understand the relationships between knowledge and attitudes, as well as between these attributes and quality of care.

Keywords

Dementia, long-term care, palliative care, knowledge, attitudes, surveys and questionnaires

Background

It is essential that care for people with advanced dementia is driven by a palliative approach focused on comfort and quality of life (QOL) embedded within evidence-based frameworks (van der Steen et al., 2014). However, care in long-term care (LTC) is often suboptimal because nurses and other direct care personnel ('personnel') lack awareness of care needs associated with advanced dementia and how to manage these within the context of cognitive and communication impairments (Birch & Draper, 2008). In particular, LTC personnel have been found to lack knowledge regarding pain assessment and treatment in people with advanced dementia (Brazil, Kaasalainen, McAiney, Brink, & Kelly, 2012; Michelle Burns & Sonja McIlfatrick, 2015; Zwakhalen, Hamers, Peijnenburg, & Berger, 2007), and to be reluctant to discuss end of life care with families or engage in advance care planning (Beck, McIlfatrick, Hasson, & Leavey, 2017; Dowding & Homer, 2000; Livingston et al., 2012). In LTC, pain in people with advanced dementia often goes under-treated, while lifesustaining care and hospital admissions are sometimes inappropriately initiated, with little improvement to survival and detrimental effects on QOL (Engel, Kiely, & Mitchell, 2006; Givens et al., 2010; McAuliffe, Nay, O'Donnell, & Featherstonehaugh, 2009; Mitchell, Kiely, & Hamel, 2004).

In Australia, the *National Palliative Care Strategy 2018* provides an overarching vision "that people affected by life-limiting illnesses get the care they need to live well" (Australian Department of Health, 2018) (p.5). The Strategy defines high quality palliative care as person-centered and evidence-based, and identifies people with dementia in LTC as a population and setting requiring special attention to improve access.

Recognition of suboptimal dementia palliative care in LTC has led to research aimed at understanding gaps in the knowledge and attitudes of LTC personnel, and educational interventions to help them better assess and manage the needs of this resident population (M Burns & S McIlfatrick, 2015b; Chang et al., 2005; Evripidou, Charalambous, Middleton, & Papastavrou, 2018; Karacsony, Chang, Johnson, Good, & Edenborough, 2015). A range of LTC facility (LTCF) and personnel characteristics have been found to correlate with personnel's better knowledge and more positive attitudes in relation to a palliative approach for people with dementia in LTC, including LTCF policies on end-of-life care and personnel education, training and experience (M Burns & S McIlfatrick, 2015a; Chen et al., 2018; Nakanishi & Miyamoto, 2016; Nakanishi, Miyamoto, Long, & Arcand, 2015; Zwakhalen et al., 2007). To date, however, no such studies have been conducted in Australia.

The current study aimed to describe the knowledge and attitudes of Australian LTC personnel concerning palliative care for residents with advanced dementia, and explore relationships with LTCF and personnel characteristics. The research question was, "what LTCF and personnel characteristics are associated with favorable knowledge and attitudes towards palliative care for LTC residents with advanced dementia?".

Methods

A secondary analysis was undertaken of data from a cluster randomized controlled trial (RCT) of facilitated family case conferencing for residents with advanced dementia living in 20 Australian LTCFs (the 'IDEAL Study') (Agar et al., 2015; Agar et al., 2017). The current analysis focused on baseline data collected prior to the intervention being implemented. The IDEAL study took place from 2013 to 2014 with ethical approval from the University of New South Wales Human Research Ethics Committee (approval number HC12455).

Sample

LTCFs were eligible to participate in the IDEAL Study if they were located in the greater metropolitan areas of Sydney or Brisbane and met the following criteria: 1) ≥100 high care beds and 2) ≥50% residents with dementia (or equivalent number of residents with dementia achieved by a higher proportion or residents with dementia but lower number of beds). To minimize selection bias, eligible LTCFs were identified via the Aged Care Australia website (since superseded by 'My Aged Care') and approached in random order until the target sample size of 20 was achieved.

LTC personnel were eligible to participate if they had ongoing contracts (either full- or part-time), and delivered direct care to residents. Administrative and service staff (e.g. kitchen staff, cleaners) were excluded. All personnel gave written informed consent to take part.

Data collection

Personnel knowledge and attitudes concerning palliative care for people with advanced dementia were measured using the questionnaire on Palliative care for Advanced Dementia (qPAD) (Long, Sowell, Hess, & Alonzo, 2012). This questionnaire was selected because while other instruments measure knowledge and attitudes concerning either palliative care (Karacsony, Chang, Johnson, Good, & Edenborough, 2018; Thompson, Bott, Boyle, Gajewski, & Tilden, 2011) or dementia (Annear et al., 2015; Robinson et al., 2014), the qPAD is the only one that focuses on palliative care in dementia (Karacsony et al., 2015).

The 35-item self-complete qPAD has a 23-item *Knowledge Test* component and a 12-item *Attitude Scale* component. Initial testing of the qPAD's psychometric properties was undertaken in a convenience sample of 85 personnel from four LTCFs in the USA, around half of whom (48%) were described as certified nursing assistants or 'caregiver' staff (Long et al., 2012). Internal consistency was moderately strong for both the *Knowledge Test* (Cronbach's alpha = 0.81) and *Attitude Scale* (Cronbach's alpha =0.83). The qPAD has demonstrated convergent validity and responsiveness in further US and Japanese studies (Long, 2017; Nakanishi & Miyamoto, 2016; Nakanishi et al., 2015). A total *Knowledge Test* summary score (possible range 0 to 23) is calculated by summing the number of correct responses to the 23 knowledge questions, and the *Attitude Scale* summary score (ranging from 12 to 60) by summation of responses to the 12 attitude items (rated from 1 - strongly disagree, to 5 - strongly agree), such that a higher score indicates a more favorable attitude. Additionally, the qPAD has three knowledge factors (*Anticipating Needs, Preventing Negative Outcomes*, and *Insight and Intuition*) and three attitude factors (*Job Satisfaction, Perceptions and Beliefs*, and *Work Setting Support of Families*).

In the current study, personnel were administered the qPAD alongside demographic questions on their: date of birth; country of birth; preferred language; designation within the LTCF (nursing manager, registered nurse [RN], enrolled nurse [EN], assistant in nursing [AIN], personal care assistant [PCA], other care service employee); full- or part-time employment status; highest level of education; length of employment in the current LTCF and LTC more generally; experience in dementia care; and receipt of aged and dementia care training. In Australia, qualification as an RN has required a university degree since the mid 1980s, whereas ENs and AINs are qualified at an institute for Technical And Further Education (TAFE) by means of a diploma and certificate III respectively. Both ENs and AINs work under the delegation of registered nurses. ENs have a role in nursing care (e.g. wound dressing), whereas AINs focus largely on personal care, mobilizing and feeding.

LTCF variables were collected from facility records and via manager report. These variables were concerned with the three months prior to data collection and related to: i) personnel hours to beds ratio; ii) proportion of residents with dementia; iii) proportion of residents with advanced dementia; and iv) proportion of residents requiring complex care, as defined by the Aged Care Funding Instrument, a tool used to allocate government funds to LTCFs in Australia. Policy-related data items were concerned with whether: the LTCF had a: i) philosophy or policy of providing palliative care and/or person centered care; ii) admissions based on the level of dementia; iii) personnel

participated in the development of care plans; iv) personnel were selectively recruited for dementia units; v) personnel were rotated through units within the LTCF.

<u>Analysis</u>

The relationship between the *Knowledge Test* and *Attitude Scale* scores was explored using a Pearson's correlation coefficient. Univariate associations between each qPAD scale and summary scores and LTCF / personnel characteristics were explored using independent samples t-tests. Personnel age was dichotomized into 18 to 44 years versus 45 years and older; personnel designation into EN/RN/managers versus AIN/PCA/care service employee; education into none/school versus tertiary; LTC training into none or Certificate 3/4/Leisure and Health versus Diploma/Bachelor/Postgraduate; experience in LTC into <7 years versus 7 years or more and experience in dementia care into <6 years versus 6 years or more (each based on a median split). Interactions between LTCF policies and personnel time spent within the LTCF (by stratification into <12 months versus 1 year or more) were also analyzed to explore whether there might be an enculturation effect.

Variables found to be significantly associated with qPAD *Knowledge Test* and *Attitudes Scale* summary scores on univariate association with a p value <0.2 were included in a linear regression models to examine adjusted relationships. In these models, age was included as a continuous variable. Tests of collinearity were conducted.

Scores on qPAD scales were extrapolated if missing data amounted to <20%. The p value of significance was set at 0.05, and all analyses were conducted using SPSS version 24 (IBM).

Results

Sample characteristics

Of 307 personnel enrolled in the IDEAL Study, 290 (94.5%) in 19 of the 20 LTCFs provided sufficient questionnaire data at baseline for inclusion in analysis. The 20th LTCF did not submit staff data to be included in the analysis. Study participants had a median age of 45 years (inter-quartile range [IQR] 20), and had worked in their current LTCF for a median of 60.0 months (inter-quartile range [IQR] 95), LTC a median of 84.0 months (IQR 125), and dementia care a median of 72.0 months (IQR 114). See Table 1 for other personnel characteristics.

Table 1 about here

The mean number of permanent residents in each LTCF was 109 (standard deviation [SD] 28.1), with the median prevalence at each LTCF of dementia being 60% (IQR 20), advanced dementia, 26.3% (IQR 22), and complex care needs, 65% (IQR 68). Most LTCF's admission criteria made reference to severity of dementia (n=16, 84.2%). Personnel were recruited selectively for dementia units in approximately two-thirds of the LTCFs (n=12, 63.2%) and rotated through dementia units in just under half (n=7/15 responding, 46.7%). The majority of LTCFs had a philosophy or policy of providing palliative care (n=17/18 responding, 94.4%) and just over half a philosophy or policy of providing person centered care (n=11, 57.9%). The ratio of personnel hours to beds was 20.2 (SD 5.7).

qPAD scores and associated factors

A summary of qPAD scores (means and standard deviations) is presented in Table 2. While scores on the *Knowledge Test* and the *Attitudes Scale* were significantly correlated, the size of this effect was small to medium (r = 0.23, p < 0.001, n = 288).

Table 2 about here

<u>Univariate analyses</u>

Univariate analyses identified a number of LTCF and personnel characteristics as associated with qPAD scores (Tables 3 and 4).

Tables 3 and 4 about here

Analysis of LTCF characteristics identified that personnel in LTCFs with a philosophy or policy of person-centered care had significantly higher scores on the *Attitudes Scale* summary and the three factor scores, and on the *Insight and intuition* knowledge factor score (see Table 4). For LTCFs where personnel rotated through units within the LTCFs, the *Knowledge Test* score and two of the factor scores were significantly lower/poorer (p<0.05). Knowledge and attitude scores as a function of philosophy or policy of providing palliative care and admissions criteria for residents were not analysed because of the markedly unequal distribution in each case. Specifically, only one facility did not have a philosophy or policy of providing palliative care, and only three did not base admission on severity of dementia. Analyses of interactions between LTCF characteristics and personnel time spent in the LTCF found no consistent patterns.

Older personnel had significantly higher scores on the *Knowledge Test* summary (p<0.05) and *Anticipating needs* factor (p<0.01; see Table 3). Those personnel whose preferred language was

English had significantly higher scores on the *Knowledge Test* summary the *Preventing Negative Outcomes* factor score (p< 0.01); there was no significant difference between preference for English between personnel of differing designation. However, personnel designation was associated with differences in qPAD scores, with AIN/PCAs having lower scores than managers/RNs/ENs across all *Knowledge Test* summary and factors as well as the *Attitudes Scale* summary and *Perception and Beliefs* factor (p<0.01). Education level had a greater influence on attitudes than knowledge, with tertiary educated personnel demonstrating higher scores on the *Knowledge Test* summary and *Perception and Beliefs* factor (p<0.01). The influences of LTC and dementia care training was more pervasive, with both being associated with having higher *Knowledge Test* (p<0.01) and *Attitudes Scale* (p<0.05) summary scores. Similarly, general experience in LTC was less influential than experience specific to dementia care, with the latter associated with higher summary scores on both the *Knowledge Test* and *Attitudes Scale*, but the former only higher *Attitudes Scale* (p<0.01).

Multivariate analyses

In multivariate analyses, a LTCF policy to not rotate personnel through dementia units was the only variable associated with more favorable personnel *Knowledge Test* (p<0.05) and *Attitudes Scale* (p<0.05) scores (Tables 5 and 6). Other variables associated with a more favorable *Knowledge Test* score were having a preferred language of English (p<0.01) and a designation of registered or enrolled nurse or nursing manager (p<0.01). Other variables associated with a more favorable *Attitudes Scale* score were tertiary level of education (p<0.05) and greater experience in dementia care (p<0.01). The model for personnel knowledge (F(9,189) = 6.64, p<0.001) predicted 20.4% of variance, while the model for personnel attitudes (F(9,190) = 4.41, p<0.001) predicted 13.4% of variance. Neither model violated criteria for collinearity amongst predictor variables.

Tables 5 and 6 about here

Discussion

This is the first published report of qPAD data on Australian LTCF personnel knowledge and attitudes about palliative care for people with advanced dementia. An LTCF policy not to rotate personnel through dementia units was the only LTCF or personnel variable found to correlate with more favorable knowledge and attitudes after controlling for other variables. In the absence of evidence to explain this finding, we speculate that not rotating personnel might enable them to deepen their understanding of residents' differing histories and needs and so be less likely to generalise on the basis of dementia status alone, and also to become more involved in care decisions and family communication, contributing to job satisfaction (Greenwood, 2018). However, evidence in favor of consistently assigning the same LTC personnel to a given group of residents is mixed (Roberts, Nolet, & Bowers, 2015), perhaps because poor quality care can become entrenched as readily as good. If so, the implication for policy might be that consistent staffing alone is insufficient, unless it is accompanied by measures aimed at promoting a 'virtuous cycle'.

Evidence in favour of retaining experienced personnel at the LTC level is more consistent, with substantial research showing a significant association between personnel turnover and poor resident outcomes regardless of dementia status (Bostick, Rantz, Flesner, & Riggs, 2006). This is consistent with our finding that longer experience in dementia care was associated with more favourable personnel attitudes, and previous research that found relationships between qPAD attitudes and time spent as a care worker (Nakanishi & Miyamoto, 2016) and working in LTC (Chen et al., 2018). These findings are especially encouraging given concern that personnel who provide palliative care may be at risk of 'compassion fatigue' that negatively impacts their approach to care (Melvin, 2012). The implication for policy is to invest in LTC personnel to improve retention.

Conversely, the current findings differ from Japanese qPAD studies by Nakanishi and Miyamoto (Nakanishi & Miyamoto, 2016; Nakanishi et al., 2015) in finding nurses to have better knowledge than less qualified care workers. This inconsistency may relate to between-country differences in the qualification and role of nurses vis-à-vis other care workers. In Australia, substantial advocacy has focused on the unique role of registered personnel in LTC and their inadequate representation within the LTC workforce (Australian College of Nursing, 2016). Data from the National Aged Care Workforce Census and Survey suggests that RNs may make up only 14.6% of the LTC direct care workforce (Mavromaras et al., 2017), compared with 30% that modelling suggest may be "the minimum care requirement and skills mix to ensure safe residential and restorative care" (Willis et

al., 2016) p.9. Results from the current study are consistent with the need to advocate for more RNs in Australian LTC.

Interestingly, multivariate analyses identified separate associations between personnel knowledge and designation on the one hand, and attitudes and tertiary education on the other, despite the fact that nurses require tertiary level qualification for registration in Australia. In contrast, Nakanishi and Miyamoto (2016) found general education to correlate with qPAD knowledge but not attitudes (Nakanishi & Miyamoto, 2016), while a Norwegian study was closer to our own in finding personnel's education level to correlate with favorable attitudes toward advanced dementia, based on a hypothetical vignette (Normann, Asplund, & Norberg, 1999).

On the other hand, relationships between favorable attitudes/knowledge and training in LTC and dementia care identified in univariate analyses in our study became non-significant when controlling for other variables. This finding differs from the Taiwanese qPAD study, which found training in dementia and palliative care be independently related to attitudes and knowledge respectively (Chen et al., 2018). The inconsistency of our results with international studies raises concerns about the quality of training available in Australia, where LTCFs are expected to offer personnel regular inservice training but such programs are poorly regulated and not required to be evidence-based.

Future longitudinal research is needed to elucidate the relationships between the attributes of knowledge and attitudes, as well as the relationships of each to personnel behaviours and quality of care. The divergent relationships between LTCF / personnel characteristics and knowledge versus attitudes identified by research to date suggest they may not develop hand in hand. As well as the surprisingly divergent relationships between designation/knowledge and education/attitudes, we followed previous qPAD research in finding LTCF policies to be generally more associated with attitudes than knowledge, at least in univariate analyses (Nakanishi & Miyamoto, 2016). Developing a better understanding of how interactions between knowledge and attitudes might be optimally leveraged is the logical next step in refining policies and education aimed at improving palliative care for people with advanced dementia living in LTC.

Limitations

The cross-sectional nature of our study limits inference regarding causal relationships between LTCF/personnel characteristics and knowledge/attitudes, or between knowledge and attitudes themselves. Knowledge and attitudes scores differed in their relationships with many LTCF/personnel characteristics. Reviews have found these attributes to both be amenable to

intervention (Chang et al., 2005; Evripidou et al., 2018), but further longitudinal studies are needed to better understand how efforts to improve them might be optimally designed and sequenced to capitalize on relationships between them.

The secondary nature of our analysis meant that the LTCF and personnel characteristics at our disposal were limited and did not consistently enable comparison with previous research. Using baseline data from an RCT of intervention aimed at improving palliative care may also have led to sampling bias in that LTCFs choosing to participate in this type of research might be more proactive than the industry average. Selection bias may also have occurred due to reliance on volunteers to participate. Knowledge and attitudes in this Australian sample were somewhat more positive than those in the Japanese and Taiwanese samples, but comparable with knowledge in the US dataset where descriptive data were reported (Chen et al., 2018; Long, 2017; Nakanishi & Miyamoto, 2016; Nakanishi et al., 2015); job satisfaction, appeared to be especially high in this Australian sample. The likelihood of selection bias means that our findings likely overestimate knowledge and attitudes among personnel compared to Australian LTC more generally. Data on policies did not include assessment of whether these were implemented in routine practice in the way intended.

Finally, we assessed knowledge and attitudes but not skills or confidence, which have been measured as separate constructs in other studies (Evripidou et al., 2018; Karacsony et al., 2015; Leung, Trevena, & Waters, 2014). Moreover, we did not measure personnel behaviours, which are likely to have a more direct influence on the quality of care, but which cannot necessarily be predicted by knowledge and attitudes (Ajzen & Fishbein, 2005; Evripidou et al., 2018). That said, the qPAD measures knowledge and attitudes that have high face validity vis-à-vis guidelines for palliative dementia care (van der Steen et al., 2014), including understanding of signs and symptoms, and confidence in discussing care with families.

Conclusion

Results from the current study reinforce the need for targeted LTC initiatives that increase the capacity of providers to deliver palliative dementia care, as well as to ensure that education programs in this setting are evidence-based. Our findings are also consistent with a LTCF policy of not rotating staff through dementia units and calls to increase the number of registered and enrolled nurses, especially given the growing number of LTC residents with advanced dementia and complex care needs.

References

- Agar, M., Beattie, E., Luckett, T., Phillips, J., Luscombe, G., Goodall, S., . . . Chenoweth, L. (2015). Pragmatic cluster randomised controlled trial of facilitated family case conferencing compared with usual care for improving end of life care and outcomes in nursing home residents with advanced dementia and their families: the IDEAL study protocol. *BMC Palliative Care*, 14(1), 63. doi:http://dx.doi.org/10.1186/s12904-015-0061-8
- Agar, M., Luckett, T., Luscombe, G., Phillips, J., Beattie, E., Pond, D., . . . Chenoweth, L. (2017). Effects of facilitated family case conferencing for advanced dementia: A cluster randomised clinical trial. *PLoS ONE [Electronic Resource]*, *12*(8), e0181020. doi:10.1371/journal.pone.0181020
- Ajzen, I., & Fishbein, M. (2005). The influence of attitudes on behavior. *The handbook of attitudes,* 173(221), 31.
- Annear, M. J., Toye, C. M., Eccleston, C. E., McInerney, F. J., Elliott, K. E., Tranter, B. K., . . . Robinson, A. L. (2015). Dementia Knowledge Assessment Scale: Development and Preliminary Psychometric Properties. *Journal of the American Geriatrics Society, 63*(11), 2375-2381. doi:10.1111/jgs.13707
- Australian College of Nursing. (2016). *The role of registered nurses in residential aged care facilities:*Position statement. Retrieved from Parramatta, New South Wales:
- Australian Department of Health. (2018). *National palliative care strategy 2018*. Retrieved from Canberra:
- Beck, E. R., McIlfatrick, S., Hasson, F., & Leavey, G. (2017). Nursing home manager's knowledge, attitudes and beliefs about advance care planning for people with dementia in long-term care settings: a cross-sectional survey. *Journal of Clinical Nursing*, 26(17-18), 2633-2645.
- Birch, D., & Draper, J. (2008). A critical literature review exploring the challenges of delivering effective palliative care to older people with dementia. *Journal of Clinical Nursing*, *17*(9), 1144-1163.
- Bostick, J. E., Rantz, M. J., Flesner, M. K., & Riggs, C. J. (2006). Systematic review of studies of staffing and quality in nursing homes. *Journal of the American Medical Directors Association*, 7(6), 366-376.
- Brazil, K., Kaasalainen, S., McAiney, C., Brink, P., & Kelly, M. L. (2012). Knowledge and perceived competence among nurses caring for the dying in long-term care homes. *International Journal of Palliative Nursing*, 18(2), 77-83.
- Burns, M., & McIlfatrick, S. (2015a). Nurses' knowledge and attitudes towards pain assessment for people with dementia in a nursing home setting. *International Journal of Palliative Nursing*, 21(10), 479-487. doi:https://dx.doi.org/10.12968/ijpn.2015.21.10.479
- Burns, M., & McIlfatrick, S. (2015). Palliative care in dementia: literature review of nurses' knowledge and attitudes towards pain assessment. *International Journal of Palliative Nursing*, *21*(8), 400-407.
- Burns, M., & McIlfatrick, S. (2015b). Palliative care in dementia: literature review of nurses' knowledge and attitudes towards pain assessment. *International Journal of Palliative Nursing*, *21*(8), 400-407. doi:https://dx.doi.org/10.12968/ijpn.2015.21.8.400
- Chang, E., Hancock, K., Harrison, K., Daly, J., Johnson, A., Easterbrook, S., . . . Davidson, P. M. (2005). Palliative care for end-stage dementia: a discussion of the implications for education of health care professionals. *Nurse Education Today*, *25*(4), 326-332. doi:10.1016/j.nedt.2005.02.003
- Chen, I. H., Lin, K. Y., Hu, S. H., Chuang, Y. H., Long, C. O., Chang, C. C., & Liu, M. F. (2018). Palliative care for advanced dementia: Knowledge and attitudes of long-term care staff. *Journal of Clinical Nursing*, *27*(3-4), 848-858.
- Dowding, C., & Homer, P. (2000). Teaching palliative care principles to UK nursing home care assistants. *International Journal of Nursing Practice*, *6*(3), 160-163.
- Engel, S. E., Kiely, D. K., & Mitchell, S. L. (2006). Satisfaction with End-of-Life Care for Nursing Home Residents with Advanced Dementia. *Journal of the American Geriatrics Society*, *54*(10), 1567-1572.

- Evripidou, M., Charalambous, A., Middleton, N., & Papastavrou, E. (2018). Nurses' knowledge and attitudes about dementia care: Systematic literature review. *Perspect Psychiatr Care*. doi:10.1111/ppc.12291
- Givens, J. L., Jones, R. N., Shaffer, M. L., Kiely, D. K., Mitchell, S. L., Givens, J. L., . . . Mitchell, S. L. (2010). Survival and comfort after treatment of pneumonia in advanced dementia. *Archives of Internal Medicine*, *170*(13), 1102-1107.
- Greenwood, D. (2018). Consistent staffing models: sharing the learning. *Dementia Care*, 7, https://journalofdementiacare.com/consistent-staffing-models-sharing-the-learning/.
- Karacsony, S., Chang, E., Johnson, A., Good, A., & Edenborough, M. (2015). Measuring nursing assistants' knowledge, skills and attitudes in a palliative approach: A literature review. *Nurse Education Today*, *35*(12), 1232-1239. doi:10.1016/j.nedt.2015.05.008
- Karacsony, S., Chang, E., Johnson, A., Good, A., & Edenborough, M. (2018). Assessing nursing assistants' competency in palliative care: An evaluation tool. *Nurse Education in Practice*, *33*, 70-76. doi:https://doi.org/10.1016/j.nepr.2018.09.001
- Leung, K., Trevena, L., & Waters, D. (2014). Systematic review of instruments for measuring nurses' knowledge, skills and attitudes for evidence-based practice. *Journal of Advanced Nursing*, 70(10), 2181-2195. doi:https://dx.doi.org/10.1111/jan.12454
- Livingston, G., Pitfield, C., Morris, J., Manela, M., Lewis-Holmes, E., & Jacobs, H. (2012). Care at the end of life for people with dementia living in a care home: a qualitative study of staff experience and attitudes. *International Journal of Geriatric Psychiatry*, 27(6), 643-650.
- Long, C. (2017). Palliative Care for Advanced Dementia: Nursing Home Staff Knowledge and Attitudes (S714). *Journal of Pain and Symptom Management*, *53*(2), 417. doi:10.1016/j.jpainsymman.2016.12.224
- Long, C., Sowell, E., Hess, R., & Alonzo, T. (2012). Development of the questionnaire on palliative care for advanced dementia (qPAD). *American Journal of Alzheimer's Disease & Other Dementias*, 27(7), 537-543. doi:http://dx.doi.org/10.1177/1533317512459793
- Mavromaras, K., Knight, G., Isherwood, L., Crettenden, A., Flavel, J., Karmel, T., . . . Wei, Z. (2017). The aged care workforce, 2016. Retrieved from Canberra, Australian Capital Territory:
- McAuliffe, L., Nay, R., O'Donnell, M., & Featherstonehaugh, D. (2009). Pain Assessment in Older People with Dementia: Literature Review. *Journal of Advanced Nursing*, 65(1), 2-10.
- Melvin, C. S. (2012). Professional compassion fatigue: what is the true cost of nurses caring for the dying? *International Journal of Palliative Nursing*, *18*(12), 606-611. doi:10.12968/ijpn.2012.18.12.606
- Mitchell, S. L., Kiely, D. K., & Hamel, M. B. (2004). Dying with advanced dementia in the nursing home. *Archives of Internal Medicine*, *164*(3), 321-326.
- Nakanishi, M., & Miyamoto, Y. (2016). Palliative care for advanced dementia in Japan: knowledge and attitudes. *British Journal of Nursing*, *25*(3), 146-155. doi:10.12968/bjon.2016.25.3.146
- Nakanishi, M., Miyamoto, Y., Long, C. O., & Arcand, M. (2015). A Japanese booklet about palliative care for advanced dementia in nursing homes. *International Journal of Palliative Nursing*, 21(8), 385-391. doi:https://dx.doi.org/10.12968/ijpn.2015.21.8.385
- Normann, H. K., Asplund, K., & Norberg, A. (1999). Attitudes of registered nurses towards patients with severe dementia. *Journal of Clinical Nursing*, 8(4), 353-359. doi:10.1046/j.1365-2702.1999.00261.x
- Roberts, T., Nolet, K., & Bowers, B. (2015). Consistent assignment of nursing staff to residents in nursing homes: a critical review of conceptual and methodological issues. *The Gerontologist*, 55(3), 434-447. doi:10.1093/geront/gnt101
- Robinson, A., Eccleston, C., Annear, M., Elliott, K. E., Andrews, S., Stirling, C., . . . McInerney, F. (2014). Who knows, who cares? Dementia knowledge among nurses, care workers, and family members of people living with dementia. *Journal of Palliative Care*, 30(3), 158-165.

- Thompson, S., Bott, M., Boyle, D., Gajewski, B., & Tilden, V. P. (2011). A Measure of Palliative Care in Nursing Homes. *Journal of Pain and Symptom Management, 41*(1), 57-67. doi:10.1016/j.jpainsymman.2010.03.016
- van der Steen, J. T., Radbruch, L., Hertogh, C. M., de Boer, M. E., Hughes, J. C., Larkin, P., . . . on behalf of the European Association for Palliative Care (EAPC). (2014). White paper defining optimal palliative care in older people with dementia: A Delphi study and recommendations from the European Association for Palliative Care. *Palliative Medicine*, 28(3), 197-209.
- Willis, E., Price, K., Bonner, R., Henderson, J., Gibson, T., Hurley, J., . . . Currie, T. (2016). *Meeting residents' care needs: A study of the requirement for nursing and personal care staff.* . Retrieved from Adelaide, South Australia:
- Zwakhalen, S. M., Hamers, J. P., Peijnenburg, R. H., & Berger, M. P. (2007). Nursing staff knowledge and beliefs about pain in elderly nursing home residents with dementia. *Pain Research and Management*, 12(3), 177-184.

Table 1: Characteristics of personnel working at 19 long-term care facilities

Characteristic (N for each analysis, excluding missing data)	n (%)				
Gender (n=287) - Female	254 (88.5)				
Country of birth (n=280) - Australia	101 (36.1)				
Preferred language (n=290) - English	215 (74.1)				
Employment status (n=284) - Full-time	129 (45.4)				
Health care provider category (n=285)					
Nurse Manager	8 (2.8)				
Registered Nurse	59 (20.5)				
Enrolled Nurse	25 (8.7)				
Assistant in Nursing/Personal Care Assistant	187 (64.9)				
Care Service Employee	9 (3.1)				
Education (N=286)					
School/no formal education	126 (44.1)				
Diploma	68 (23.8)				
Bachelor degree	68 (23.8)				
Postgraduate degree	24 (8.4)				
Formal LTC training (N=276)					
Certificate III Aged Care	105 (38.0)				
Certificate IV Aged Care or similar	79 (28.6)				
Lifestyle Certificate	12 (4.3)				
Diploma in Aged Care or similar	18 (6.5)				
Bachelor degree in Aged Care or similar field	27 (9.8)				
Postgraduate degree in Aged Care	9 (3.3)				
Other	9 (3.3)				
Dementia Care Training (N=282) - Any	251 (89.0)				

Table 2: Summary of scores for the questionnaire on Palliative care for Advanced Dementia (qPAD) (Long et al., 2012) from 290 personnel working at 19 Australian long-term care facilities

qPAD scale (observed score range)	Mean (SD)			
Knowledge Test summary (5-22)	15.2 (2.8)			
Anticipating Needs (0-8)	4.0 (1.6)			
Preventing Negative Outcomes (1-11)	8.6 (1.7)			
Insight and Intuition (0-4)	2.6 (1.1)			
Attitudes Scale summary (18-60)	47.7 (5.9)			
Job Satisfaction (7-35)	28.8 (3.7)			
Perception and Beliefs (3-15)	10.7 (2.7)			
Work Setting Support of Families (2-10)	8.2 (1.4)			

SD = standard deviation

Table 3: Univariate relationships between personnel knowledge and attitudes regarding palliative care for people with dementia (as measured by the questionnaire on Palliative care for Advanced Dementia [qPAD] (Long et al., 2012)) and characteristics of 19 long-term care facilities

					qPAD question	naire sub-sc	ales (possible	e score ranges					
	-				Knowledge Test					Attitudes Scale			
	LTCF	Personnel	Summary	Anticipating	Preventing	Insight	Summary	Job	Perception	Work			
		n	score	Needs	Negative	and	score	Satisfaction	and Beliefs	Setting			
	n				Outcomes	Intuition				Support of			
										Families			
			(0-23)	(0-8)	(0-11)	(0-4)	(12-60)	(7-35)	(3-15)	(2-10)			
Philosophy/policy of			(0-23)	(0-8)	(0-11)	(0-4)	(12-60)	(7-55)	(3-13)	(2-10)			
person centered care													
•	4.4	172	45.2	4.4	0.4	2.0	40.6	20.2	11.0	0.2			
Yes	11	173	15.3	4.1	8.4	2.8	48.6	29.3	11.0	8.3			
No	8	117	15.1	4.0	8.7	2.4‡	46.4‡	28.2†	10.2†	8.0†			
Personnel rotate													
through dementia													
units*													
Yes	7	97	14.7	3.7	8.2	2.8	47.4	28.6	10.8	8.0			
No	8	134	15.7†	4.3†	8.7†	2.7	48.7	29.4	10.9	8.4†			
Personnel recruited													
selectively for the													
dementia unit													
Yes	12	187	15.2	4.1	8.6	2.5	47.8	28.8	10.7	8.3			
No	7	103	15.1	3.9	8.5	2.7	47.5	28.9	10.6	8.0			

^{*} n = 4 not answered; † p < 0.05; ‡ p < 0.01; LTCF = long-term care facility

Table 4: Univariate associations between personnel knowledge and attitudes regarding palliative care for people with dementia (as measured by the questionnaire on Palliative care for Advanced Dementia [qPAD] (Long et al., 2012)) and personnel characteristics at 19 long-term care facilities

			qPAD questionnaire sub-scales (possible score ranges)								
		Knowledge Test					Attit	udes Scale			
Personnel characteristic		Summary score	Anticipating Needs	Preventing Negative Outcomes	Insight and Intuition	Summary score	Job Satisfaction	Perception and Beliefs	Work Setting Support of Families		
		(0-23)	(0-8)	(0-11)	(0-4)	(12-60)	(7-35)	(3-15)	(2-10)		
Age											
18-44 years	132	14.7	3.7	8.5	2.5	48.3	29	11.0	8.3		
45 years or more	143	15.5†	4.3‡	8.5	2.7	47.4	28.8	10.4	8.1		
Preferred language											
English	215	15.6	4.3	8.8	2.5	47.7	28.7	10.8	8.3		
Other	75	14.0‡	3.3‡	7.9‡	2.8	47.7	29.2	10.5	8		
Education level											
School	126	14.9	4.0	8.3	2.6	46.6	28.7	9.8	8.1		
Tertiary	160	15.4	4.1	8.7†	2.6	48.6‡	28.9	11.5‡	8.2		
Staff designation											
AIN/PCA/care service	196	14.5	3.7	8.2	2.6	47.0	28.9	10.0	8.2		
EN/RN/nursing manager	92	16.8‡	4.8‡	9.3‡	2.6	49.3‡	28.7	12.3‡	8.3		
LTC training											
Nil/Certificate	218	14.8	3.8	8.4	2.6	47.3	29.0	10.1	8.2		
Diploma/Bachelor/Postgrad	58	16.3‡	4.7‡	9.0‡	2.6	49.2†	28.4	12.5‡	8.2		
Dementia Care training											
No	31	13.4	3.2	7.6	2.6	45.2	27.8	9.5	7.8		
Yes	251	15.4‡	4.1‡	8.6†	2.6	48.0†	28.9	10.8†	8.2		
Experience in LTC											
<7years	127	14.6	3.7	8.4	2.5	47.2	28.6	10.4	8.2		
7 years or more	145	16.0‡	4.5‡	8.8†	2.7	48.4	29.1	11.1†	8.2		
Experience in dementia care											
<6 years	128	14.7	3.6	8.6	2.5	46.2	28.0	10.2	8.0		

6 v	ears or more	138	16.0‡	4.5‡	8.7	2.8†	49.3‡	29.6‡	11.3‡	8.4†

Higher attitudes scores indicate greater job satisfaction, better perceptions/beliefs and attitudes towards support of families with in the work setting. $\dagger p < 0.05$; $\dagger p < 0.01$; AIN = assistant in nursing; EN = enrolled nurse; LTCF = long-term care facility; PCA = personal care assistant; RN = registered nurse

Table 5. Results from multivariate analysis of adjusted relationships between personnel knowledge regarding palliative care for people with dementia (as measured by the *Knowledge Test* summary score of the questionnaire on Palliative care for Advanced Dementia [qPAD] (Long et al., 2012)) and characteristics of long-term care facilities and personnel

			Standardized				
	Unstandardiz	zed Coefficients	Coefficients			Collinearity Statistic	
Independent variable	В	Std. Error	Beta	t	Sig.	Tolerance	VIF
LTCF characteristic							
No staff rotation through units	.847	.351	.160	2.413	.017	.919	1.088
Personnel characteristic							
Age	.007	.018	.034	.419	.676	.620	1.613
Preferred language not English	-1.315	.409	209	-3.213	.002	.949	1.054
Tertiary education	.250	.402	.047	.621	.535	.696	1.438
AIN/PCA/care service employee	-1.840	.536	316	-3.429	.001	.473	2.116
Any LTC education	328	.549	052	597	.551	.535	1.868
Any dementia care education	473	.666	049	711	.478	.848	1.179
Experience in LTC	.865	.558	.164	1.550	.123	.358	2.797
Experience in dementia care	145	.530	028	274	.785	.396	2.524

AIN = assistant in nursing; LTCF = long-term care facility; PCA = personal care assistant

Table 6. Results from multivariate analysis of adjusted relationships between personnel attitudes regarding palliative care for people with dementia (as measured by the *Attitudes Scale* summary score of the questionnaire on Palliative care for Advanced Dementia [qPAD] [Longet al. 2012]) and characteristics of long-term care facilities and personnel

			Standardized				
	Unstandardiz	ed Coefficients	Coefficients			Collinearity Statistic	
Independent variable	В	Std. Error	Beta	t	Sig.	Tolerance	VIF
LTCF characteristic							
Policy of person-centered care	657	.853	053	771	.442	.930	1.075
No staff rotation through units	1.680	.755	.153	2.226	.027	.917	1.090
Personnel characteristic							
Age	010	.038	023	269	.788	.621	1.609
Tertiary education	1.734	.860	.159	2.016	.045	.703	1.423
AIN/PCA/care service employee	-1.485	1.152	123	-1.289	.199	.475	2.107
Any LTC education	962	1.184	073	813	.417	.534	1.872
Any dementia care education	-2.305	1.430	115	-1.611	.109	.853	1.172
Experience in LTC	-1.206	1.207	111	999	.319	.353	2.833
Experience in dementia care	3.644	1.148	.335	3.175	.002	.391	2.560

AIN = assistant in nursing; LTCF = long-term care facility; PCA = personal care assistant