

ORIGINAL RESEARCH

Person-centredness and its association with resident well-being in dementia care units

Karin Sjögren, Marie Lindkvist, Per-Olof Sandman, Karin Zingmark & David Edvardsson

Accepted for publication 15 December 2012

Correspondence to K. Sjögren:
e-mail: karin.sjogren@nurs.umu.se

Karin Sjögren MSc RNT
PhD Student
Department of Nursing, Umeå University,
Sweden

Marie Lindkvist PhD
Senior lecture
Department of Statistics, Umeå School of
Business and Economics, Umeå University,
Sweden
and Epidemiology and Global Health,
Department of Public Health and Clinical
Medicine, Umeå University, Sweden

Per-Olof Sandman PhD RNT
Professor
Division of Nursing, Department of
Neurobiology, Care Sciences, and Society
(NVS), Karolinska Institutet, Stockholm,
Sweden

Karin Zingmark PhD RNT
Associate Professor
Research Department, County Council of
Norrbotten, Sweden

David Edvardsson PhD RN
Associate Professor
Department of Nursing, Umeå University,
Sweden
and School of Nursing and Midwifery, La
Trobe University, Melbourne, Australia

SJÖGREN K., LINDKVIST M., SANDMAN P.-O., ZINGMARK K. & EDVARDSSON D. (2013) Person-centredness and its association with resident well-being in dementia care units. *Journal of Advanced Nursing* 00(0), 000–000. doi: 10.1111/jan.12085

Abstract

Aim. To report a study of the relationship between person-centred care and ability to perform activities of daily living, quality of life, levels of pain, depressive symptoms, and agitated behaviours among residents with dementia in residential care facilities.

Background. Standardized measurements of person-centred care have not previously been used to investigate the relationship between person-centred care and well-being for residents with dementia in residential aged care units.

Design. This study had a cross-sectional design.

Method. Staff and resident surveys were used in a sample of 1261 residents with dementia and 1169 staff from 151 residential care units throughout Sweden. Valid and reliable scales were used to measure person-centredness and ability to perform activities of daily living, quality of life, levels of pain, depressive symptoms, and agitated behaviours in residents. All data were collected in May 2010.

Findings. Person-centred care was correlated with residents' ability to perform activities of daily living. Furthermore, residents in units with higher levels of person-centred care were rated as having higher quality of life and better ability to perform activities of daily living compared with residents in units with lower levels of person-centred care.

Conclusions. There seems to be a relationship between person-centredness, residents' ability to perform activities of daily living, and residents' quality of life. Further studies are needed to explain the variation of person-centredness between units and the extent and ways this might impact on the quality of life and well-being of frail older residents with cognitive impairments in clinical practice.

Keywords: activities of daily living, agitated behaviours, dementia care, depressive symptoms, nursing, pain, person-centred care, quality of life

Introduction

Person-centred care (PCC) is promoted as a preferred model of care for people with dementia by national authorities in several countries; for example in Sweden and the UK (Department of Health 2009, Swedish National Board of Health & Welfare 2010). The concept has received widespread attention in care for people with dementia and is often regarded as synonymous with high-quality care (Brooker 2004). Previous publications have indicated a need for studies that investigate the explicit empirical association between PCC and well-being for older people and people with dementia (McCormack 2004, Edvardsson *et al.* 2008), as studies that have used validated measures of person-centredness to explore these matters are few. As scales for valid and reliable staff ratings of person-centredness have recently emerged, we were interested in exploring the extent to which staff ratings of person-centredness had a statistical relationship to various indicators of well-being for residents with dementia in residential aged care units.

Background

The concept of PCC is described as a value base and an approach for care that puts the person with dementia in the centre of consideration (Brooker 2004, Slater 2006). The aim was to create a positive psychosocial environment where relationship and communication is prioritized and to support maintained personhood in spite of declining cognitive ability (Kitwood 1997). Some interventions, activities and intentions such as collecting and using the life story of the resident to individualize both care and environment, share decision-making, individualize daily activities, family members' involvement in care, and striving to understand behaviours and symptoms from the person's own perspective, have been described as dimensions of providing PCC (Epp 2003, Brooker 2004, McCormack 2004, McCormack & McCance 2006, Edvardsson *et al.* 2008).

Some evidence suggests that when implementing various aspects of a PCC approach in dementia care, postintervention outcomes such as increased well-being (Sloane *et al.* 2004, Bone *et al.* 2010, McKeown *et al.* 2010, Teitelman *et al.* 2010), lowered agitation (Moniz Cook *et al.* 2003, Sloane *et al.* 2004, Fossey *et al.* 2006, Chenoweth *et al.* 2009, Teitelman *et al.* 2010), improved skin condition related to showering (Sloane *et al.* 2004), and increased engagement in daily activities (Teitelman *et al.* 2010) have been described. However, most of these intervention studies lack direct estimates of perceived person-centredness of the care or setting, which makes it difficult to make conclusions

about the empirical relationship between PCC and such outcomes.

The concept of PCC has been operationalized in several measurement scales, grounded in practice, research, and theory. Most of them have recently been developed and have been said to need further testing (Edvardsson & Innes 2010). Dementia Care Mapping tool (DCM, Brooker & Surr 2006) has been available the longest and used extensively to guide interventions and to evaluate PCC. DCM includes both evaluation of the quality of care and residents' well-being. However, its usefulness for research has been questioned as DCM is considered time-consuming and requires special training (Sloane *et al.* 2007, Chenoweth *et al.* 2009), which limits its applicability in larger cross-sectional studies (Brooker & Surr 2006). We identified additionally five PCC tools in literature, which could be included in this study: the Person-Directed Care measurement tool (PDC, White *et al.* 2008), the Individualized Care Inventory (ICI, Chappell *et al.* 2007), the Person-centred Care Assessment Tool (P-CAT, Edvardsson *et al.* 2010), the Tool for Understanding Residents' Needs as Individual Persons (Edvardsson *et al.* 2011) and the Person-centred Climate Questionnaire-staff version (PCQ, Edvardsson *et al.* 2009). As the P-CAT showed satisfactory psychometric properties (Sjögren *et al.* 2012), was short, applicable for the context of this study and could give a unit level aggregate measure of person-centredness, we chose that tool in this study to give a general measure of the extent to which staff perceived the care and the organization to be person-centred.

When studying resident outcomes in dementia care, recent articles indicate that studies could benefit from including measures of resident mood, quality of life, activity of daily living, behavioural and psychological symptoms, and pain (Moniz-Cook *et al.* 2008, Wylie & Nebauer 2011). Thus, several of these tools that captures the prevalence and severity of these common clinical challenges were included in this study.

The study

Aim

The study aimed to explore the relationship between PCC and ability to perform activities of daily living, quality of life, levels of pain, depressive symptoms, and agitated behaviours among residents with dementia in residential care facilities.

Design

This study had a cross-sectional design.

Sampling

A Swedish nation-wide network for municipality-based dementia care nurses was used to recruit a geographically varied sample of residential aged care facilities. These dementia care nurses were provided information about the study and an invitation to participate and they sought approval from the municipality chief executive officer who suggested residential aged care facilities for inclusion in the study. This generated a sample of large and small facilities, a variation of urban (74%) and rural (26%) location, and also a variation according to type of facilities, for example, traditional nursing homes (30%) and special care units (70%). The number of residents in each care unit ranged from 4–26 and the number of staff working on a permanent basis ranged from 4–20. A total of 87 residential care facilities participated, amounting to 156 participating care units as facilities could include several autonomous units.

Data collection

Staff data were collected through a study survey consisting of demographic variables and measures of perceived levels of person-centredness of the units. A total of 1482 staff surveys were distributed and 1237 were returned (83%). Resident data were collected through a study survey consisting of demographic variables and valid and reliable scales measuring different aspects of resident well-being. Proxy ratings were used for resident data collection, which meant that the staff member who knew the resident best was instructed to perform the ratings. A total of 1655 resident surveys were distributed and 1471 were returned (89%). All data were collected in May 2010.

Instrumentation

Person-centredness was investigated with the P-CAT (Edvardsson *et al.* 2010, Sjögren *et al.* 2012), a scale that measures the extent to which staff perceive the care provided as being person-centred. The P-CAT consists of 13 items formulated as statements about the content in care, the environment, and organization. A total score is calculated and higher values indicate a higher degree of person-centredness in a possible range of 13–65. The Swedish version includes two subscales: 1 – Extent of personalizing care and 2 – Amount of organizational and environmental support.

Quality of life was investigated with the Quality of Life in Late Stage Dementia (QUALID, Weiner *et al.* 2000, Falk *et al.* 2007), containing 11 items based on concrete,

observable behaviours and emotions and low values indicate higher quality of life in a possible range of 11–55. Pain was investigated with the Pain Assessment In Advanced Dementia (PAINAD, Warden *et al.* 2003), containing five items about breathing, vocalization, facial expression, body language and consolability and higher scores indicate greater pain in a possible range of 0–10. Depressive symptoms were investigated with the Cornell Scale of Depression in Dementia (CSDD, Alexopoulos *et al.* 1988). The scale consists of 19 items relating to mood, behavioural disturbances, physical signs, cyclic functions, and ideational disturbances and higher scores indicate more depressive symptoms in a possible range of 0–38. Agitated behaviours were measured by the Cohen-Mansfield Agitation Inventory (CMAI, Cohen-Mansfield *et al.* 1989). The scale consists of 29 items and evaluates agitation including physically aggressive behaviours, physically non-aggressive behaviours, and verbally agitated behaviours. Higher scores indicate higher frequency of agitated behaviours in a possible range of 29–103. To investigate ADL ability the Multi-Dimensional Dementia Assessment Scale (MDDAS, Sandman *et al.* 1988) was used. Higher scores indicate higher ADL ability in a possible range of 4–24. The prevalence of cognitive impairment was investigated with the Geriatric Rating Scale (GRS, Gottfries *et al.* 1969), consisting of 27 items concerning the person's ability to orientate. Higher scores indicate a higher ability to orientate in a possible range of 0–27 and scores <24 indicate a cognitive impairment equivalent to dementia (Sandman *et al.* 1988).

Ethical considerations

Ethics approval for the study was obtained from the Regional Ethical Review Board in Umeå (Dnr 2010-135-32).

Data analyses

The PASW statistics version 18 was used to analyse data. The analysis procedure was performed in several steps. First, sample characteristics were explored using descriptive and comparative statistics. Second, explorative analyses of scale distribution and normality were performed through measures of skewness, the Kolmogorov–Smirnov test of normality and visual examination of histogram and Q–Q plots. Third, an aggregate unit score of person-centredness was correlated to resident ADL ability, quality of life, levels of pain, depressive symptoms, and agitated behaviours, using the Spearman rank order correlation coefficient. Fourth, differences in resident characteristics and resident

outcomes, such as ADL ability, quality of life, levels of pain, depressive symptoms, and agitated behaviours, between units with higher and lower levels of person-centredness were explored using independent samples *t*-test, chi-squared test, and effect sizes as calculated through Eta squared. Last, reliability of all included measures was explored using Cronbach's alpha.

All analyses of person-centredness were based on an aggregated unit level score (mean value for the unit), while all resident variables were based on individual scores. Quartiles of the distribution were used as cut-off for high and low person-centredness. Care units in the highest quartile ($n = 38$, PCC scores ≥ 52.9), were compared with care units in the lowest quartile ($n = 37$, PCC scores ≤ 46.3). Recommended cut-off scores were used when available for ADL ability (Lövheim *et al.* 2011), pain (Leong *et al.* 2006), depressive symptoms (Alexopoulos 2010), and agitated behaviours (Testad *et al.* 2007). The sample median value of quality of life scores was used as a cut-off for higher ≤ 20 and lower >20 quality of life.

For inclusion on care unit level, there had to be at least three independent ratings of person-centredness available, together with data from both residents and staff. Only residents with cognitive impairment were included in the study. When $>10\%$ of the items were not completed in a scale, the whole scale was excluded for that individual. This resulted in a final sample of 1261 residents and 1169 staff in 151 care units. In addition, if $<10\%$ of the items were not completed in a scale, these missing values were replaced with the individual mean (Shrive *et al.* 2006); $P \leq 0.05$ were regarded as statistically significant.

Validity and reliability

It has previously been found that the P-CAT has satisfactory estimates of reliability (Cronbach's $\alpha = 0.75$) and construct validity (Sjögren *et al.* 2012) and also that the QUALID has satisfactory estimates of reliability (Cronbach's $\alpha = 0.74$), criterion validity and inter-rater reliability (Falk *et al.* 2007). The PAINAD has shown good criterion validity (Leong *et al.* 2006), but internal consistency for the scale has been found moderate ($\alpha = 0.5-0.65$, Warden *et al.* 2003). The CSDD has been found to have good validity and reliability (Alexopoulos *et al.* 1988, Kørner *et al.* 2006), which also is true for the CMAI (Cronbach's $\alpha > 0.70$, Finkel *et al.* 1992, Choy *et al.* 2001, Rabinowitz *et al.* 2005). The MDDAS has shown satisfactory intra- and inter-rater reliability (Sandman *et al.* 1988). Criterion validity for the GRS has been established against the Mini-Mental State Examination (Sandman *et al.* 1988).

Results

As shown in Table 1, participating staff were most often female (95%), Enrolled Nurses (80%), with a mean age of 46 years (SD 11, range 19–67 years) and with about 16 years of work experience in aged care (SD 10). A slight majority (56%) had a continuing education in dementia care and most staff did not receive supervision on a regular basis (79%). Almost all staff were the primary contact person for a resident (92%).

As shown in Table 2, participating residents were most often women (70%) with a mean age of 85 years (SD 8, range 48–102 years). They had been in the facility for an average of 2.6 years (SD 3). A majority of residents (62%) walked normally and 10% were totally bed-bound. Five per cent could manage their personal hygiene independently, 49% could eat and drink independently, and 10% could dress independently.

The person-centred scores were normally distributed, whereas scores for resident quality of life, pain, depressive symptoms, and agitated behaviours were skewed towards

Table 1 Characteristics of the sample (staff).

| | n^{\dagger} (%) | Mean (SD) |
|---------------------------------------|-------------------|-------------|
| Gender | | |
| Men | 56 (4.8) | |
| Women | 1105 (95.2) | |
| Age, years | | 45.8 (11.2) |
| Years of experience in aged care | | 15.9 (10.4) |
| Qualifications | | |
| Registered Nurses | 35 (3.1) | |
| Enrolled Nurses | 910 (80.1) | |
| Nurses' assistants | 120 (10.6) | |
| No formal qualifications | 42 (3.7) | |
| Other education | 29 (2.6) | |
| Regular supervision | 234 (20.9) | |
| Continuing education in dementia care | 598 (56.0) | |
| Primary responsible | 1160 (92.1) | |
| Type of employment | | |
| Part-time ($\leq 75\%$) | 386 (33.3) | |
| Full-time ($\geq 76\%$) | 772 (66.7) | |
| Day/night staff | | |
| Day shift | 1035 (91.8) | |
| Night shift | 10 (0.9) | |
| Day and night shift | 82 (7.3) | |
| Form of employment | | |
| Permanent | 1143 (99.0) | |
| Casual | 11 (1.0) | |

$^{\dagger}n$ does not always add up to 1169 in all variables due to missing items.

Table 2 Characteristics of the sample (residents).

| | <i>n</i> [†] (%) | Mean (SD) |
|--|---------------------------|------------|
| Gender | | |
| Men | 375 (30.1) | |
| Women | 870 (69.9) | |
| Age, years | | 85.0 (7.5) |
| Time in facility, years | | 2.6 (2.5) |
| Normal ability to talk | 890 (72.0) | |
| Normal ability to walk | 743 (61.6) | |
| Totally bound to the bed | 99 (10.4) | |
| Normal ability to dress on own initiative | 123 (9.8) | |
| Accomplishes personal hygiene on own initiative | 63 (5.0) | |
| Eats and drinks independently | 611 (48.9) | |
| Can go to the lavatory on own initiative (urine) | 314 (26.7) | |
| Can control the bowel and evacuate on toilet without aid | 635 (51.7) | |

[†]*n* does not always add up to 1261 in all variables due to missing items.

high levels of quality of life, low levels of pain, low levels of depressive symptoms, and low levels of agitated behaviours. There were no significant correlations between PCC and resident quality of life ($\rho = -0.05$, $P = 0.07$), pain ($\rho = -0.03$, $P = 0.29$), depressive symptoms ($\rho = -0.03$, $P = 0.59$), or agitated behaviours ($r = -0.003$, $P = 0.93$). There was a significant correlation between PCC and ADL ability ($\rho = 0.06$, $P = 0.04$). When the subscales of the P-CAT were used as units of analyses, we found significant correlations between 'Amount of organizational and environmental support' and quality of life ($\rho = -0.06$, $P = 0.05$) and between 'Amount of organizational and environmental support' and ADL ability ($\rho = 0.1$, $P = 0.001$). No correlations were found between 'Extent of personalizing care' and outcome variables.

As shown in Table 3, residents in units with higher levels of PCC were rated as having higher quality of life compared with residents in units with lower levels of PCC (mean difference = 1.3, $P = 0.04$, $\eta^2 = 0.01$). It was also found that residents in facilities with higher levels of PCC were rated as having higher ADL ability compared with residents in units with lower PCC levels (mean difference = 0.9, $P = 0.05$, $\eta^2 = 0.01$). No significant mean differences were found in relation to levels of pain, depressive symptoms, or agitated behaviours between units rated as having higher and lower person-centredness.

No significant differences were found in resident quality of life, levels of pain, depressive symptoms, or agitated behaviours, when these measures were used as categorical

variables with suggested cut-offs, between units rated as having higher and lower person-centredness. However, a significantly higher proportion of residents (33%) could manage ADL independently in units with higher levels of person-centredness compared with units with lower PCC scores (23%; $P = 0.04$). More specifically, a higher proportion of residents could eat and drink independently ($P = 0.01$), could control the bowel and evacuate on toilet without aid ($P = 0.05$) and could go to the lavatory on own initiative ($P = 0.01$) in units with higher levels of person-centredness as compared with units with lower levels of PCC (Table 4).

The reliability of all included scales was found satisfactory, as the Cronbach's alpha values exceeded, or were very near as for the PAINAD, the suggested cut-off of 0.7 [QUALID $\alpha = 0.73$, PAINAD $\alpha = 0.69$, CMAI $\alpha = 0.89$, CSDD $\alpha = 0.86$, MDDAS (ADL) $\alpha = 0.89$, GRS $\alpha = 0.95$, P-CAT $\alpha = 0.76$].

Discussion

The aim of this study was to explore the relationship between PCC and ability to perform activities of daily living, quality of life, levels of pain, depressive symptoms and agitated behaviours among residents with dementia in residential care facilities. Findings indicated that residents in more person-centred facilities had higher ADL ability in aspects such as eating, drinking, and toileting. One interpretation of these findings is that in settings with higher levels of person-centredness, staff, to a greater extent, know the ability, preferences and needs of the residents and they might use this knowledge to support the residents in completing the activities of daily living as independently as possible. Hence, residents would be able to keep these abilities longer. In that sense, accomplishing these activities independently can be interpreted as a fundamental part and a positive impact of PCC (Nazarko 2009) and previous work has indicated that person-centred interventions increased residents' participation in ADL activities (Sidani *et al.* 2009, O'Connor *et al.* 2011) and maintained ADL functioning (Arbesman & Lieberman 2011).

Another interpretation of these findings is that in units where residents are, to a greater extent able to complete activities of daily living more independently, staff workload is reduced. If so, staff might have greater possibilities to get to know residents, introduce activities, and discuss how to give a person-centred care. As the data in this study are cross-sectional, we cannot establish the causal direction of these findings. Further studies with other designs are needed to clarify these issues.

Table 3 Comparison of person-centred care (PCC) scores, resident ADL ability, quality of life, levels of pain, depressive symptoms, and agitated behaviours in all care units and in care units with lower and higher levels of PCC.

| | All care units (<i>n</i> = 151) Mean (SD) | Care units with lower levels of PCC (<i>n</i> = 37) Mean (SD) | Care units with higher levels of PCC (<i>n</i> = 37) Mean (SD) | <i>P</i> value* |
|---------------------|--|--|---|-----------------|
| PCC score | 49.3 (4.6) | 43.7 (2.2) | 54.8 (2.0) | <0.001* |
| ADL ability | 1.4 (5.6) | 12.7 (5.7) | 13.6 (6.0) | 0.05 |
| Quality of life | 21.6 (7.2) | 22.8 (7.8) | 21.5 (7.3) | 0.04 |
| Pain | 2.1 (2.1) | 2.3 (2.3) | 2.1 (2.0) | 0.12 |
| Depressive symptoms | 7.6 (5.6) | 8.1 (6.1) | 7.5 (5.7) | 0.48 |
| Agitated behaviour | 49.1 (19.2) | 50.6 (21.1) | 49.6 (19.2) | 0.54 |

*Independent sample *t*-test, comparing care units with lower and higher levels of PCC.

Table 4 Comparison of resident characteristics and ADL ability in care units with lower and higher levels of person-centred care (PCC).

| | Care units with lower level of PCC, <i>n</i> (%) | Care units with higher level of PCC, <i>n</i> (%) | <i>P</i> value* |
|--|---|--|-----------------|
| Gender | | | |
| Men | 87 (26.9) | 84 (30.1) | |
| Women | 237 (73.1) | 195 (69.9) | 0.49 |
| Age, years | | | |
| Mean (SD) | 85.1 (7.5) | 85.4 (7.6) | 0.65 |
| Time in facility, years | | | |
| Mean (SD) | 2.7 (2.5) | 2.6 (2.4) | 0.43 |
| Can manage ADL independently | 72 (23) | 90 (33) | 0.04 |
| Normal ability to dress on own initiative | 27 (8.3) | 30 (10.7) | 0.58 |
| Accomplishes personal hygiene on own initiative | 15 (4.6) | 16 (5.7) | 0.93 |
| Eats and drinks independently | 132 (40.6) | 140 (50.2) | 0.01 |
| Can go to the lavatory on own initiative (urine) | 63 (20.2) | 71 (37.7) | 0.01 |
| Can control the bowel and evacuate on toilet without aid | 148 (45.8) | 155 (55.6) | 0.05 |

*Chi-squared test.

The results also indicated that residents in units with higher levels of PCC had higher quality of life compared with those in units with lower levels of PCC. This finding is supported by previous papers arguing that person-centredness is linked to the extent to which residents can experience well-being and 'the good life' (Sloane *et al.* 2004, Bone *et al.* 2010, McKeown *et al.* 2010, Teitelman *et al.* 2010). On the other hand, when Zimmerman and colleagues

(Zimmerman *et al.* 2005) investigated relationship between PCC attitudes among staff and quality of life of residents with dementia, they only found a positive relationship when residents' quality of life was reported by staff, not when reported by residents themselves, or reported by outside observers. Similar findings have also been reported by others (Lintern *et al.* 2000a,b, Winzelberg *et al.* 2005). Thus, the relationship between PCC, quality of life, and well-being seems to be complex. Further studies are needed.

Although a statistical significant correlation between PCC and ADL capacity was found in this study, the size of the correlation coefficient was 0.06, very small according to widely used statistical guidelines (cf. Cohen 1992). In addition, the mean differences in quality of life and ADL capacity between units with high and low person-centredness in this study were 1.3 and 0.9, respectively, and the corresponding effect sizes were 0.01. The possible range is 44 and 20 points for quality of life and ADL capacity, respectively, and the question of the clinical significance of these differences arises. Previous studies using the QUALID in similar contexts have reported differences between 1.4 and 7.0 in relation to physical and depressive disorders (Barca *et al.* 2011), differences between 1.5 and 4.5 in relation to functional abilities (Weiner *et al.* 2007, Garre-Olmo *et al.* 2010, Barca *et al.* 2011), and differences between 1.5 and 4.1 in relation to levels of cognitive impairment (Weiner *et al.* 2007, León-Salas *et al.* 2011). A few previous studies using the MDDAS have reported differences in ADL scores between 0.7 and 2.1 in relation to differences in cognitive impairment, psychological and behavioural symptoms and gender (Lövheim *et al.* 2008, 2009, 2011). Thus, the differences found in this study are in line with previous research, even though the clinical significance of these findings requires more study. Future studies using these scales in conjunction with clinical observations could

What is already known about this topic

- Person-centred care is recurrently described as synonymous with good care and is promoted as the gold-standard dementia care in several countries.
- Person-centred interventions report outcomes such as increased well-being, lowered agitation, improved skin conditions, and increased engagement in daily activities.
- Few studies have linked valid measures of person-centredness to resident outcomes.

What this paper adds

- This article reports a nation-wide study using validated measures of person-centredness to explore relationships between person-centredness and various indicators of health for residents with dementia in residential aged care units.
- This article demonstrates a relationship between person-centred care and residents' ability to perform activities of daily living and quality of life.
- Residents in units with higher levels of person-centred care were rated as having better preserved ability to perform activities of daily living and higher quality of life compared with residents in units with lower levels of person-centred care.

Implications for practice and/or policy

- Findings indicate that person-centred care can improve some resident outcomes and these warrant consideration in relation to issues of practice development and care delivery.
- Residential care units can use these findings to increase the person-centredness of their care and with that resident ability to perform activities of daily living and quality of life.
- Validated measures of person-centredness can be helpful for management and staff, when developing person-centred care in units for people with dementia.

generate valuable knowledge to guide the interpretation of the extent to which statistical differences in scores are connected to clinical significance and relevance to practice.

No correlations were found between PCC and levels of pain, depressive symptoms, and agitated behaviour and no significant differences were found in levels of pain, depressive symptoms, or agitated behaviours between facilities with higher and lower person-centredness. It needs

to be noted that a unit level aggregate measure of person-centredness was used and that this procedure will lower the variability and consequently the potential co-variability in scores. This might be one explanation of the lack of significant correlations between person-centredness and resident outcomes. Another interpretation of the lack of significant correlations is the degree to which it is reasonable to expect that a concept of care as measured by a 13-item scale can be related to less pain, depression, and agitation, as these are symptoms known to be highly prevalent in this population. We hypothesized that symptoms of pain, depression, and agitation perhaps would be detected and managed to a higher degree in more person-centred settings and hence the expected correlation between higher levels of person-centredness and less prevalence of symptoms. However, this study was unable to give empirical support for these anticipated relationships.

We know from previous studies that the prevalence rates of pain (45–83%, Fisher *et al.* 2002), depression (14–82%, Seitz *et al.* 2010), and agitation (75–82%, Schreiner 2001, Testad *et al.* 2007) in this population constitute a considerable clinical challenge. Thus, there would be many other factors in addition to the person-centredness of care that can influence levels of pain, depression, and agitation. Such factors include staff knowledge of symptom presentation, the extent to which valid and reliable assessments are carried out (Huffman & Kunik 2000, Husebo *et al.* 2009, McAuliffe *et al.* 2009), and the availability of medical consultations and individualized treatment (Visser *et al.* 2008). Thus, individualized medical assessments and treatments are arguably essential tenets for a PCC in clinical settings.

Limitations

The shortness of the scale measuring person-centredness needs to be considered. Is it possible to capture all aspects of the multidimensional and complex concept in 13 items? It has previously been concluded that the P-CAT is a reliable scale, covering most common aspects of PCC as described in theory (Edvardsson *et al.* 2010, Sjögren *et al.* 2012) although further studies are needed to evaluate the content validity of the scale. Another consideration is the proxy-based resident data for this study. The residential care system in Sweden has staff primarily responsible for residents. These primarily responsible staff were asked to conduct the ratings of residents for whom they were contact person. This would indicate that even though the ratings were proxy-based, they were based on extensive personal knowledge of the residents. However, it needs to be acknowledged that proxy-based ratings are less than ideal

due to questionable agreement between proxy and self-ratings (Logsdon *et al.* 2002), but it may well be the only way research can avoid systematically excluding residents based on their cognitive function.

Staff ratings of person-centredness were based on self-report and this also has its limitations. The concept of PCC is in Sweden and elsewhere a preferable approach to care as expressed through national policies (Swedish National Board of Health & Welfare 2010) and this might have influenced the ratings. We do not know if staff ratings are based on the real or the ideal, as critics might argue that an element of politically correct positioning on behalf of staff may have been influencing their ratings. We do not know to what extent this is the case. Further studies where self-report ratings of PCC are linked to observations of what actually happens and how this is perceived by various stakeholders would be valuable, to achieve a deeper understanding of what these ratings actually mean. The self-selection recruitment strategy is also a limitation of this study. This may have resulted in those willing to participate being more progressive units. Needless to say, a non-randomized sampling strategy carries the risk of generating a sample with unknown representation. A random sampling of care units would of course have increased the representativeness and generalizability of the results and an extension of this study is planned using a randomized nationally representative sample.

Conclusions

This study showed that PCC is related to ADL ability and quality of life, as residents in more person-centred units were rated as having higher ADL ability and higher quality of life. No relationships were found between person-centredness and levels of pain, depressive symptoms, and agitated behaviours. Further studies are needed to understand and explain the variation of person-centredness between units, the factors that influence this variation, and the extent and ways person-centredness can impact on aspects of well-being for frail older residents with cognitive impairments in clinical practice.

Acknowledgement

We acknowledge the dementia care nurses for their assistance in recruitment.

Funding

This study was funded by the Swedish Brain Power and Umeå University, Sweden.

Conflict of interest

No conflict of interest has been declared by the authors.

Author contributions

All authors have agreed on the final version and meet at least one of the following criteria [recommended by the ICMJE (http://www.icmje.org/ethical_1author.html)]:

- substantial contributions to conception and design, acquisition of data, or analysis, and interpretation of data;
- drafting the article or revising it critically for important intellectual content.

References

- Alexopoulos G.S. (2010) *The Cornell Scale for Depression in Dementia. Administration and Scoring Guidelines*. Cornell Institute of Geriatric Psychiatry. Retrieved from <http://www.scalesandmeasures.net> on December 2010.
- Alexopoulos G.S., Abrams R.C., Young R.C. & Shamoian C.A. (1988) Cornell scale for depression in dementia. *Biological Psychiatry* 23, 271–284.
- Arbesman M. & Lieberman D. (2011) Methodology for the systematic reviews on occupational therapy for adults with Alzheimer's disease and related dementias. *The American Journal of Occupational Therapy* 65, 490–496.
- Barca M.L., Engedal K., Laks J. & Selbaek G. (2011) Quality of life among elderly patients with dementia in institutions. *Dementia and Geriatric Cognitive Disorders* 31, 435–442.
- Bone C., Cheung G. & Wade B. (2010) Evaluating person centred care and Dementia Care Mapping in a psychogeriatric hospital in New Zealand: a pilot study. *New Zealand Journal of Occupational Therapy* 57, 35–40.
- Brooker D. (2004) What is person-centred care in dementia?. *Reviews in Clinical Gerontology* 13, 215–222.
- Brooker D.J. & Surr C. (2006) Dementia Care Mapping (DCM): initial validation of DCM 8 in UK field trials. *International Journal of Geriatric Psychiatry* 21, 1018–1025.
- Chappell N.L., Reid R.C. & Gish J.A. (2007) Staff-based measures of individualized care for persons with dementia in long-term care facilities. *Dementia* 6, 527–547.
- Chenoweth L., King M.T., Jeon Y.H., Brodaty H., Stein-Parbury J., Norman R., Haas M. & 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. *Lancet Neurology* 8, 317–325.
- Choy C.N.P., Lam L.C.W., Chan W.C., Li S.W. & Chiu H.F.K. (2001) Agitation in Chinese elderly: validation of the Chinese version of the Cohen-Mansfield Agitation Inventory. *International Psychogeriatrics* 13, 325–335.
- Cohen J. (1992) A power primer. *Psychological Bulletin* 112, 155–159.
- Cohen-Mansfield J., Marx M.S. & Rosenthal A.S. (1989) A description of agitation in a nursing home. *Journal of Gerontology* 44, 77–84.

- Department of Health, UK (2009) *Living Well With Dementia: A National Dementia Strategy*. Retrieved from http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_094058 on January 2013
- Edvardsson D. & Innes A. (2010) Measuring person-centered care: a critical comparative review of published tools. *The Gerontologist* 50, 834–846.
- Edvardsson D., Winblad B. & Sandman P.O. (2008) Person-centred care of people with severe Alzheimer's disease: current status and ways forward. *Lancet Neurology* 7, 362–367.
- Edvardsson D., Sandman P.O. & Rasmussen B. (2009) Construction and psychometric evaluation of the Swedish language Person-centred Climate Questionnaire – staff version. *Journal of Nursing Management* 17, 790–795.
- Edvardsson D., Fetherstonhaugh D., Nay R. & Gibson S. (2010) Development and initial testing of the Person-centered Care Assessment Tool (P-CAT). *International Psychogeriatrics* 22, 101–108.
- Edvardsson D., Fetherstonhaugh D. & Nay R. (2011) The Tool for Understanding Residents' Needs as Individual Persons (TURNIP): construction and initial testing. *Journal of Clinical Nursing* 20, 2890–2896.
- Epp T.D. (2003) Person-centred dementia care: a vision to be refined. *The Canadian Alzheimer Disease Review* 5, 14–19.
- Falk H., Persson L.O. & Wijk H. (2007) A psychometric evaluation of a Swedish version of the Quality of Life in Late-Stage Dementia (QUALID) scale. *International Psychogeriatrics* 19, 1040–1050.
- Finkel S.I., Lyons J.S. & Anderson R.L. (1992) Reliability and validity of the Cohen–Mansfield agitation inventory in institutionalized elderly. *International Journal of Geriatric Psychiatry* 7, 487–490.
- Fisher S.E., Burgio L.D., Thorn B.E., Allen-Burge R., Gerstle J., Roth D.L. & Allen S.J. (2002) Pain assessment and management in cognitively impaired nursing home residents: association of certified nursing assistant pain report, Minimum Data Set pain report and analgesic medication use. *Journal of the American Geriatrics Society* 50, 152–156.
- 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. *The British Medical Journal* 332, 756–761.
- Garre-Olmo J., Planas-Pujol X., López-Pousa S., Weiner M.F., Turon-Estrada A., Juvinyà D., Ballester D. & Vilata-Franch J. (2010) Cross-cultural adaptation and psychometric validation of a Spanish version of the Quality of Life in Late-Stage Dementia Scale. *Quality of Life Research* 19, 445–453.
- Gottfries C., Gottfries I. & Roos B. (1969) The investigation of homovanillic acid in the human brain and its correlation to senile dementia. *The British Journal of Psychiatry* 115, 563–574.
- Huffman J.C. & Kunik M.E. (2000) Assessment and understanding of pain in patients with dementia. *The Gerontologist* 40, 574.
- Husebo B.S., Strand L.L., Moe-Nilssen R., Husebo S.B. & Ljunggren A.E. (2009) Pain behaviour and pain intensity in older persons with severe dementia: reliability of the MOBID Pain Scale by video uptake. *Scandinavian Journal of Caring Sciences* 23, 180–189.
- Kitwood T.M. (1997) *Dementia Reconsidered: The Person Comes First*. Open University Press, Buckingham.
- Körner A., Lauritsen L., Abelskov K., Gulmann N., Brodersen A.M., Wedervang-Jensen T. & Kjeldgaard K.M. (2006) The Geriatric Depression Scale and the Cornell Scale for depression in dementia: a validity study. *Nordic Journal of Psychiatry* 60, 360–364.
- Leong I.Y.O., Chong M.S. & Gibson S.J. (2006) The use of a self-reported pain measure, a nurse-reported pain measure and the PAINAD in nursing home residents with moderate and severe dementia: a validation study. *Age and Ageing* 35, 252.
- León-Salas B., Logsdon R.G., Olazarán J., Martínez-Martin P. & The MSU-ADRU (2011) Psychometric properties of the Spanish QoL-AD with institutionalized dementia patients and their family caregivers in Spain. *Aging & Mental Health* 15, 775–783.
- Lintern T., Woods R. & Phair L. (2000a) Before and after training: a case study of intervention. *Journal of Dementia Care* 8(1), 15–17.
- Lintern T., Woods B. & Phair L. (2000b) Training is not enough to change care practice. *Journal of Dementia Care* 8(2), 15–17.
- Logsdon R.G., Gibbons L.E., McCurry S.M. & Teri L. (2002) Assessing quality of life in older adults with cognitive impairment. *Psychosomatic Medicine* 64, 510–519.
- Lövheim H., Sandman P.O., Kallin K., Karlsson S. & Gustafsson Y. (2008) Symptoms of mental health and psychotropic drug use among old people in geriatric care, changes between 1982 and 2000. *International Journal of Geriatric Psychiatry* 23, 289–294.
- Lövheim H., Sandman P.O., Karlsson S. & Gustafsson Y. (2009) Sex differences in the prevalence of behavioral and psychological symptoms of dementia. *International Psychogeriatrics* 21, 469–475.
- Lövheim H., Gustafsson Y., Karlsson S. & Sandman P.O. (2011) Comparison of behavioral and psychological symptoms of dementia and psychotropic drug treatments among old people in geriatric care in 2000 and 2007. *International Psychogeriatrics* 23, 1616–1622.
- McAuliffe L., Nay R., O'Donnell M. & Fetherstonhaugh D. (2009) Pain assessment in older people with dementia: literature review. *Journal of Advanced Nursing* 65, 2–10.
- McCormack B. (2004) Person-centredness in gerontological nursing: an overview of the literature. *Journal of Clinical Nursing* 13, 31–38.
- McCormack B. & McCance T.V. (2006) Development of a framework for person-centred nursing. *Journal of Advanced Nursing* 56, 472–479.
- McKeown J., Clarke A., Ingleton C., Ryan T. & Repper J. (2010) The use of life story work with people with dementia to enhance person-centred care. *International Journal of Older People Nursing* 5, 148–158.
- Moniz Cook E., Stokes G. & Agar S. (2003) Difficult behaviour and dementia in nursing homes: five cases of psychosocial intervention. *Clinical Psychology & Psychotherapy* 10, 197–208.
- Moniz-Cook E., Vernooij-Dassen M., Woods R., Verhey F., Chattat R., DeVugt M., Mountain G., O'Connell M., Harrison J., Vasse E., Drees R.M. & Orrell M. (2008) A European consensus on outcome measures for psychosocial intervention research in dementia care. *Aging & Mental Health* 12, 14–29.

- Nazarko L. (2009) Providing high quality dementia care in nursing homes. *Nursing and Residential Care* 11, 296–300.
- O'Connor C., Smith R., Nott M., Lorang C. & Mathews R. (2011) Using Video Simulated Presence to reduce resistance to care and increase participation of adults with dementia. *American Journal of Alzheimer's Disease and Other Dementias* 26, 317–325.
- Rabinowitz J., Davidson M., De Deyn P.P., Katz I., Brodaty H. & Cohen-Mansfield J. (2005) Factor analysis of the Cohen-Mansfield Agitation Inventory in three large samples of nursing home patients with dementia and behavioral disturbance. *American Journal of Geriatric Psychiatry* 13, 991.
- Sandman P., Adolfsson R., Norberg A., Nyström L. & Winblad B. (1988) Long-term care of the elderly. A descriptive study of 3600 institutionalized patients in the county of Vasterbotten, Sweden. *Comprehensive Gerontology – Section A, Clinical and Laboratory Sciences* 2, 120–133.
- Schreiner A.S. (2001) Aggressive behaviors among demented nursing home residents in Japan. *International Journal of Geriatric Psychiatry* 16, 209–215.
- Seitz D., Purandare N. & Conn D. (2010) Prevalence of psychiatric disorders among older adults in long-term care homes: a systematic review. *International Psychogeriatrics* 22, 1025–1039.
- Shrive F., Stuart H., Quan H. & Ghali W. (2006) Dealing with missing data in a multi-question depression scale: a comparison of imputation methods. *BioMedical Central, Medical Research Methodology* 6, 57. doi:10.1186/1471-2288-6-57.
- Sidani S., LeClerc C. & Streiner D. (2009) Implementation of the abilities-focused approach to morning care of people with dementia by nursing staff. *International Journal of Older People Nursing* 4, 48–56.
- Sjögren K., Lindkvist M., Sandman P., Zingmark K. & Edvardsson D. (2012) Psychometric evaluation of the Swedish version of the Person-Centered Care Assessment Tool (P-CAT). *International Psychogeriatrics* 24, 406–415.
- Slater L. (2006) Person-centredness: a concept analysis. *Contemporary Nurse* 23, 135–144.
- Sloane P.D., Hoeffler B., Mitchell C.M., McKenzie D.A., Barrick A.L., Rader J., Stewart B.J., Talerico K.A., Rasin J.H., Zink R.C. & Koch G.G. (2004) Effect of person-centered showering and the towel bath on bathing-associated aggression, agitation and discomfort in nursing home residents with dementia: a randomized, controlled trial. *Journal of the American Geriatrics Society* 52, 1795–1804.
- Sloane P.D., Brooker D., Cohen L., Douglass C., Edelman P., Fulton B.R., Jarrott S., Kasayka R., Kuhn D. & Preisser J.S. (2007) Dementia care mapping as a research tool. *International Journal of Geriatric Psychiatry* 22, 580–589.
- Swedish National Board of Health and Welfare (2010) *Nationella riktlinjer för vård och omsorg vid demenssjukdom 2010: stöd för styrning och ledning*. Socialstyrelsen, Stockholm.
- Teitelman J., Raber C. & Watts J. (2010) The power of the social environment in motivating persons with dementia to engage in occupation: qualitative findings. *Physical & Occupational Therapy in Geriatrics* 28, 321–333.
- Testad I., Aasland A. & Aarsland D. (2007) Prevalence and correlates of disruptive behavior in patients in Norwegian nursing homes. *International Journal of Geriatric Psychiatry* 22, 916–921.
- Visser S., McCabe M., Hudgson C., Buchanan G., Davison T. & George K. (2008) Managing behavioural symptoms of dementia: effectiveness of staff education and peer support. *Aging and Mental Health* 12, 47–55.
- Warden V., Hurley A.C. & Volicer L. (2003) Development and psychometric evaluation of the Pain Assessment in Advanced Dementia (PAINAD) scale. *Journal of the American Medical Directors Association* 4, 9–15.
- Weiner M.F., Martin-Cook K., Svetlik D.A., Saine K., Foster B. & Fontaine C. (2000) The quality of life in late-stage dementia (QUALID) scale. *Journal of the American Medical Directors Association* 1, 114–116.
- Weiner M.F., Davis B., Martin-Cook K., Hynan L.S., Saine K.C. & Cullum C.M. (2007) A direct functional measure to help ascertain optimal level of residential care. *American Journal of Alzheimer's Disease and Other Dementias* 22, 355–359.
- White D.L., Newton-Curtis L. & Lyons K.S. (2008) Development and initial testing of a measure of person-directed care. *The Gerontologist* 48(Spec No. 1), 114–123.
- Winkelberg G.S., Williams C.S., Preisser J.S., Zimmerman S. & Sloane P.D. (2005) Factors associated with nursing assistant quality-of-life ratings for residents with dementia in long-term care facilities. *The Gerontologist* 45, 106–114.
- Wylie K. & Nebauer M. (2011) The fragmented story of pain: a saga of economic discourse, confusion and lack of holistic assessment in the residential care of older people. *Collegian: Journal of the Royal College of Nursing Australia* 18, 11–18.
- Zimmerman S., Sloane P.D., Williams C.S., Reed P.S., Preisser J.S., Eckert J.K., Boustani M. & Dobbs D. (2005) Dementia care and quality of life in assisted living and nursing homes. *The Gerontologist* 45, 133–146.

The *Journal of Advanced Nursing (JAN)* is an international, peer-reviewed, scientific journal. *JAN* contributes to the advancement of evidence-based nursing, midwifery and health care by disseminating high quality research and scholarship of contemporary relevance and with potential to advance knowledge for practice, education, management or policy. *JAN* publishes research reviews, original research reports and methodological and theoretical papers.

For further information, please visit *JAN* on the Wiley Online Library website: www.wileyonlinelibrary.com/journal/jan

Reasons to publish your work in *JAN*:

- **High-impact forum:** the world's most cited nursing journal, with an Impact Factor of 1.477 – ranked 11th of 95 in the 2011 ISI Journal Citation Reports (Social Science – Nursing).
- **Most read nursing journal in the world:** over 3 million articles downloaded online per year and accessible in over 10,000 libraries worldwide (including over 3,500 in developing countries with free or low cost access).
- **Fast and easy online submission:** online submission at <http://mc.manuscriptcentral.com/jan>.
- **Positive publishing experience:** rapid double-blind peer review with constructive feedback.
- **Rapid online publication in five weeks:** average time from final manuscript arriving in production to online publication.
- **Online Open:** the option to pay to make your article freely and openly accessible to non-subscribers upon publication on Wiley Online Library, as well as the option to deposit the article in your own or your funding agency's preferred archive (e.g. PubMed).