

Everyday activities for people with dementia in residential aged care: associations with person-centredness and quality of life

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Background. Providing everyday activities is central to high quality residential aged care, but further research is needed on the association between activity participation, person-centred care and quality of life.

Aims and objectives. To explore the point-prevalence of participation in everyday activities for residents with dementia within a national sample of Swedish residential aged care units and to explore if residents participating in everyday activities lived in more person-centred units and/or had higher quality of life as compared to residents not participating in everyday activities.

Design and methods. A cross-sectional design was used to collect valid and reliable questionnaire data on activity participation, unit person-centredness and quality of life in a sample of residents in residential aged care ($n = 1266$).

Results. Only 18% of residents participated in everyday activities such as making coffee, setting or clearing the table, cleaning or watering plants, 62% participated in outdoor walks, 27% participated in parlour games, and 14% and 13% participated in excursions and church visits, respectively. Those residents who had participated in everyday activities lived in more person-centred units, had significantly higher quality of life and higher cognitive scores as compared to those residents who had not participated in everyday activities.

Conclusions. Even though the prevalence of resident participation in everyday activities was low, resident participation was significantly associated with unit person-centredness and resident quality of life. It seems that everyday activities that are routine and commonplace to residential aged care can be potent nursing interventions for promoting resident quality of life.

Implications for practice. The study indicates that residents can benefit from participation in everyday activities that are commonly occurring in aged care practice. It seems that such everyday tasks and procedures can provide fruitful ways to make person-centred care happen in clinical practice, and ways to increasingly involve residents with cognitive impairment need to be further developed.

Key words: housing for older people, leisure activities, long-term care, nursing homes, nursing, quality of life

Introduction

The conceptual emergence of person-centred care as initiated in dementia contexts by Kitwood (1997), and further developed across other care contexts by contemporary nursing theory and research, is essentially arguing for a shift from the medical model of care to a more holistic life-world approach to care. This life-world approach builds on biographical knowledge of the person and family participation to enable shared decision-making, includes subjective experiences of illness and everyday life and strives to promote a continuation of self and normality in spite of illness, institutionalisation or dependence on care (McCormack & McCance, 2006; Brooker, 2007; Edvardsson *et al.*, 2010a). The meaning and role of person-centred care have been debated, whether or not it represents a glossy buzz word for contemporary care policy, is a humanistic care philosophy, the extent to which it is possible to operationalise in practice (Nolan *et al.*, 2004). Up until recently, a large amount of publications into person-centred care have been focused on identifying the content, philosophical underpinnings and/or policy implications of the concept (McCormack & McCance, 2006; Edvardsson *et al.*, 2008; Morgan & Yoder, 2012). However, a number of international journal articles have recently emerged that provide suggestions of how to actually realise person-centredness in practice.

Based on studies across a variety of care settings, such recent publications have pointedly illuminated how the concrete doings of everyday, direct care delivery can assist in developing person-centred conversations and relationships (McCormack *et al.*, 2010; Edvardsson *et al.*, 2011; Lindqvist *et al.*, 2012). These articles have contributed a timely and necessary shift of focus around the discussion of person-centred care, from the philosophical realm of policy and practice rhetoric towards how to actually achieve person-centred care in everyday

nursing practice. By describing that everyday doings of nursing practice can open up the realisation of frontline person-centred care and that many everyday and routine nursing tasks and interventions can provide the 'way in' to make this happen, these articles provide concrete and helpful guidance in how to establish person-centred care. Providing bodily care, for example, can open up a window of opportunity for getting to know the person and connect to his/her life-world through conversing on everyday topics, events or happenings that are meaningful to the patient as person and not only disease-related matters that are meaningful to the patient as patient. Such conversations – sometimes condescendingly referred to as 'small talk' in clinical practice – have been highlighted as essential to bedside implementation of person-centred care (Lindqvist *et al.*, 2012). Other examples include involving patients in everyday tasks that can represent forms of normality for them, such as setting the table, watering plants, folding serviettes (Edvardsson *et al.*, 2011). However, it is critical that staff conceptualise the potential of such routine care tasks as ways to develop person-centred care and for transformation of the ordinary into the extraordinary (McCormack *et al.*, 2010; Edvardsson *et al.*, 2011; Lindqvist *et al.*, 2012).

Within residential aged care, an abundance of routine tasks and procedures are daily occurring that could be used to assist in developing person-centred relationships and activities, and thereby maintaining connections to residents' life-worlds. Such tasks can be used to involve residents in non-medicalised everyday activities, and as forms of sharing space and moment with residents/patients which can facilitate a climate of 'at-homeness' and well-being in dementia care (Edvardsson *et al.*, 2011). Furthermore, the meaning and role of everyday activities in aged care can have an existential dimension. Davis *et al.* (2009) argued that participation in everyday activities represents and defines

us as persons and functions to support a sense of self. Consequently, collecting valid data on which roles and activities are important to residents and also offering such activities in daily care practice could be central in reaffirming a sense of self for residents in the light of the dissolving life roles and diminished activity participation that can be associated with residential care (Davis *et al.*, 2009). Such existential interpretations of the meaning of everyday activities for older people have been further supported in an interview study illuminating that everyday activities were experienced to provide a meaningful content to the day, reaffirm residents as capable and valuable persons and promote a continuation of self and normality for residents (Edvardsson *et al.*, 2010a,b). Other studies have also outlined that everyday activities, as core features of person-centred aged care, can facilitate experiences of at-homeness (Zingmark *et al.*, 2002; McKeown *et al.*, 2010).

Studies into the quality of life of older people in residential aged care also advocate for the use of care tasks and everyday activities as avenues to promote resident well-being. For example, the quality of life of residents in long-term aged care has been associated with having access to a garden (Raske, 2010), being connected to others and to meaningful activities (Zimmerman *et al.*, 2005; Murphy *et al.*, 2007; Cooney *et al.*, 2009), being engaged in various hobbies or interests (Drageset *et al.*, 2009) and participating in housekeeping activities such as cooking and doing laundry (Funaki *et al.*, 2005). However, a recent systematic review of the effectiveness of non-pharmacological interventions to improve quality of life of people with dementia indicated that further research is needed on the association between non-pharmacological activities and quality of life for people with dementia (Cooper *et al.*, 2012).

In the light of the above studies and the contemporary argument to increasingly transform nursing tasks into meaningful everyday activities for residents, this study aimed to explore the point-prevalence of participation in everyday activities for residents with dementia within a national sample of Swedish residential aged care units and to explore if residents who participated in everyday activities lived in more person-centred units and/or had higher quality of life as compared to residents not participating in everyday activities.

Methods

Design

Analyses were based on data from a cross-sectional survey into the characteristics of residential aged care in relation to resident health status in Sweden. Staff in 159 residential aged

care units throughout Sweden were invited to participate by providing self-report data on the person-centredness of their unit and data relating to their work situation, as well as ratings of resident health status.

Sampling and procedure

A nationwide sample of residential aged care units was invited to participate, representing various locations (rural/urban) and a variation of traditional residential care facilities, nursing homes and special care units for people with dementia. Recruitment of units was conducted through a national network of community-based dementia care nurses, who delivered information to municipalities across Sweden. These nurses informed interested municipalities to contact the researchers for participation in the study. The sampling was based on voluntary participation, and the recruitment strategy represented a form of self-selected participation from the municipalities for which the dementia care nurses were responsible. The sampling procedure resulted in a geographically representative sample of residential aged care units across Sweden. All data were collected between April and June 2010. In total, 1655 resident questionnaires were distributed and 1471 were returned, amounting to a response rate of 89%. For analyses purposes, we only included data from residents classified as being cognitively impaired using the established cut-off of <24 points on the Geriatric Rating Scale (Gottfries *et al.*, 1982). The final sample consisted of 1266 residents from 156 residential aged care units.

Data collection

The *Quality of life in Late-stage Dementia Scale* (QUALID, Weiner *et al.*, 2000) was used to measure resident quality of life through 11 items. The Swedish version of QUALID with reported satisfactory psychometric estimates (Falk *et al.*, 2007) was used, and higher scores indicate lower quality of life. The *Multi-dimensional Dementia Assessment Scale* (MDDAS, Sandman *et al.*, 1988) was used to collect data on the reported prevalence of resident participation in everyday activities, which type of activity they had been engaged in and data on resident ADL capacity, functional ability, and prevalence of behavioural and psychiatric symptoms. The MDDAS has been shown to have good intra- and inter-rater reliability (Sandman *et al.*, 1988). The Geriatric Rating Scale (Gottfries *et al.*, 1982) was used to assess cognitive status in residents. The scale uses 27 items relating to cognitive status and <24 points indicates a cognitive impairment, which correlates with a sensitivity of 90% and a specificity of 91% (Sandman *et al.*, 1988) to the cut-off 24/30 commonly used for the Mini Mental State

Examination (Folstein *et al.*, 1975). The Person-centred Care Assessment Tool (P-CAT, Edvardsson *et al.*, 2010b) was used to measure unit person-centredness. The P-CAT contains 13 items that provide an aggregate measure of unit person-centredness. A total score was calculated with higher values indicating a higher degree of person-centredness within a possible range of 13–65, and a mean value of person-centredness was calculated for each unit. The Swedish version with reported satisfactory psychometric properties was used (Sjögren *et al.*, 2012).

Statistical analyses

Descriptive statistics were used to illuminate the point-prevalence of resident participation in everyday activities, and independent samples *t*-tests were used to explore sample differences, together with differences in unit person-centredness, quality of life and cognition between residents who had participated in everyday activities and those who had not. A cut-off level of <0.05 was considered appropriate for establishing statistical significance. All analyses were performed with PASW Statistics 18.

Ethics

Ethics approval was obtained from the regional Human Research Ethics Committee (Dnr 2010-135-32).

Results

A total cross-sectional sample of 1266 residents was included in the analyses. As shown in Table 1, the majority of participating residents were female (70%), with an average age of 86 years (SD \pm 7.5) and a mean length of stay in the residential aged care facility of nearly 3 years (SD \pm 2.4). Female residents in the sample were significantly older and had stayed significantly longer in their facilities. In relation to activities of daily living, most participating residents were unable to dress independently and unable to manage hygiene independently. Roughly, half of the participants were able to eat and drink without assistance, and significantly, more male than female residents were able to eat and drink without assistance. Most participants could not manage toileting (urine) independently, whereas a small majority of participating residents could manage toileting (faeces) independently.

As described in Table 2, 18% of residents participated daily or weekly in everyday activities such as making coffee, setting or clearing the table, cleaning or watering plants and 82% of residents 'never' or 'almost never' participated in such activities.

Table 1 Sample characteristics

Residents (<i>n</i> = 1266)*	Men 377	Women 872	<i>P</i> -value
ADL-items			
Dressing independently			
Yes	42 (11)	81 (9)	0.333
No	329 (89)	787 (91)	
Managing hygiene independently			
Yes	17 (5)	46 (5)	0.658
No	359 (95)	820 (95)	
Eats/drinks without assistance			
Yes	200 (54)	408 (47)	0.041
No	173 (46)	458 (53)	
Toileting (urine) independently			
Yes	98 (26)	218 (25)	0.264
No	233 (63)	615 (71)	
Toileting (faeces) independently			
Yes	202 (55)	430 (51)	0.188
No	166 (45)	420 (49)	
Age, years			
Mean (SD)	83.1 (7.9)	85.8 (7.2)	0.000
Time in facility, years			
Mean (SD)	2.3 (2.4)	2.8 (2.5)	0.011

**n* does not add up to 1266 in all variables due to missing data.

Table 2 Proportion of residents who participated in housing-activities within the unit

	<i>n</i> *	%
Yes, daily	71	5.6
Yes, one or a few times a week	156	12.4
No, almost never	248	19.7
No, never	782	62.2
	1257	100

**n* does not add up to 1266 in all variables due to missing data.

However, as shown in Table 3, a slight majority of residents had been on outdoor walks (62%); some had participated in parlour games (27%); or had been out on excursions outside the residential care facility (14%); and a minority of residents had been taken to church (13%) during the last week. Thus, outdoor walks were the only activity that more than 27% of residents reportedly participated in on a weekly basis. No significant differences were found in activity participation between male and female residents.

As described in Table 4, those residents who had participated in outdoor walks, parlour games and church visits lived in units with significantly higher person-centredness scores as compared to those who had not. In addition, those residents who had participated in everyday activities were also assessed as having significantly higher quality of life and higher cognitive scores as compared to those residents who had not. These significant differences were found across all

Table 3 Proportion of residents participating in everyday activities during the last week

	Outdoor walks		Excursions		Parlour games		Church visits	
	<i>n</i> *	%	<i>n</i> *	%	<i>n</i> *	%	<i>n</i> *	%
Yes	744	62	139	14	277	27	131	13
No	448	38	852	86	754	73	872	87
Total	1192	100	991	100	1031	100	1003	100

**n* does not add up to 1266 in all variables due to missing data.

Table 4 Mean differences in resident QUALID, unit P-CAT scores and GRS (cognition) between residents participating and not participating in everyday activities

	QUALID (Mean)	<i>P</i> -value	P-CAT (Mean)	<i>P</i> -value	GRS (Mean)	<i>P</i> -value
Outdoor walks		<0.001		<0.001		<0.001
Yes	20.9		49.5		11.2	
No	22.8		48.3		9.2	
Excursions		<0.01		0.236		<0.001
Yes	20.1		49.5		12.8	
No	22.2		49.0		10.1	
Parlour games		<0.001		0.016		<0.001
Yes	19.7		49.6		13.4	
No	22.4		48.9		9.7	
Church visits		<0.01		0.021		<0.001
Yes	19.7		49.8		12.8	
No	22.4		48.0		10.2	
Housing-activities		<0.001		0.078		<0.001
Yes*	19.6		49.5		13.8	
No†	22.0		48.9		9.9	

*‘Yes, daily’ or ‘Yes, one or a few times a week’.

†‘No, almost never’ or ‘Never’.

the explored activities, indicating that those residents who had been given the possibility to participate in outdoor walks, excursions, parlour games, church visits and housing-related activities were assessed as having significantly higher quality of life and cognitive capacity as compared to those residents who had not participated in such activities.

Discussion

This study aimed to explore the point-prevalence of participation in everyday activities for residents with dementia within a national sample of Swedish residential aged care units and to explore if residents participating in everyday activities lived in more person-centred units and/or had higher quality of life as compared to residents not participating in everyday activities. It was found that a minority of residents (18%) participated in housing-activities such as making coffee, setting or clearing the table, cleaning or watering plants and that only a slight majority of residents (62%) had been on outdoor walks during the week prior to data collection. It was further reported that a small percentage of residents had participated in parlour games

(27%), excursions (14%) or church visits (13%). The results also showed that those residents who had participated in everyday activities lived in more person-centred units had significantly higher quality of life and higher cognitive scores as compared to those residents who had not been participating in any such activities.

Even though this study highlights what appears to be a surprisingly low point-prevalence of resident participation in everyday activities, the findings support previous data indicating that resident quality of life may be improved by participation in everyday activities (Funaki *et al.*, 2005; Zimmerman *et al.*, 2005; Murphy *et al.*, 2007; Cooney *et al.*, 2009; Drageset *et al.*, 2009). The findings contribute to the literature by indicating that even though resident quality of life seems to be supported by participation in everyday activities, the reported prevalence of residents partaking in such activities is low, at least in the Swedish residential aged care units studied. This is a somewhat disconcerting finding given that, for a number of years, high quality aged care has been described in terms of providing a variety of meaningful activities and interactions that build

upon resident life history and interests (Zingmark *et al.*, 2002; Sandman *et al.*, 2006).

Even though the reason for the low prevalence of activity participation in the sample remains unknown, it seems reasonable that this is influenced by previously described factors such as task orientation, a high prevalence of cognitive impairment and perceived high workloads among staff, together with an organisational inflexibility in considering routine everyday activities as not being part of nursing care (Magaziner *et al.*, 2000; Cohen-Mansfield & Bester, 2006). It seems that organisations, individual staff members and ultimately the residents could benefit from a reconceptualisation of what nursing care in residential aged care facilities involves. Hence, if the everyday housing-activities that are constantly recurring in the daily life of residential aged care are purposefully used as therapeutic opportunities, plenty of avenues for meaningful occupation of residents suddenly emerge that may contribute to counter the boredom commonly connected with life in residential aged care. However, a diminished cognitive capacity also seems to play a part in the low participation in everyday activities, as lower cognitive capacity was related to less activity participation. Involving cognitively impaired residents in activities can be a significant challenge for staff, but the household activities in this study seem manageable for cognitively impaired residents. It could be the case that staff attitudes, communication skills and biographical resident knowledge, together with a creative, reflective and individualised practice might facilitate the participation of residents with severe cognitive impairment in meaningful activities. Further research and best practice exemplars would be valuable in providing successful strategies to move aged care practice forward towards increased involvement of residents in meaningful activities.

The centrality of providing everyday activities surfaced as a fundamental part of providing person-centred care in this study, and everyday activities also constitute a part of contemporary measurements of person-centred care. For example, the person-centred care assessment tool (Edvardsson *et al.*, 2010b) includes resident participation in individualised everyday activities, and the person-directed care measurement scale (White *et al.*, 2008) measures residents' activity participation through several items of the scale. Thus, evidence suggests that one element of person-centred residential aged care is to facilitate everyday activity participation, which aligns with previous empirical findings between everyday activities and resident quality of life (Funaki *et al.*, 2005; Zimmerman *et al.*, 2005; Murphy *et al.*, 2007; Cooney *et al.*, 2009; Drageset *et al.*, 2009). However, the findings do not necessarily suggest wide-ranging activity programs or replacing nursing staff with activity coordinators. Many of the

activities explored in this study represent such everyday tasks and procedures that are carried out daily by nursing staff in residential aged care, and as such, they can provide excellent 'ways in' to establish person-centred relationships for the operationalisation of person-centred care. Thus, if residents are consciously and carefully involved in the completion of routine everyday tasks and procedures, these can be transformed to become therapeutic and concrete operationalisations of person-centred care (McCormack *et al.*, 2010; Edvardsson *et al.*, 2011; Lindqvist *et al.*, 2012).

Philosophically, arguments that activities are connected to constructing and maintaining personhood and a sense of self as provided by Davis *et al.* (2009), have an appealing logic and fidelity and resonate with constructivist notions of personhood as being socially constructed and bestowed upon us by others (Kitwood, 1997; Harre, 1998). If participating in everyday activities represents a form of construction and presentation of self, providing everyday activities that reflects interests, life roles or everyday life routines for residents may be important parts of identity-promoting interventions that target the very core of person-centredness, supporting personhood in spite of cognitive decline and institutionalisation (McCormack *et al.*, 2010; Edvardsson *et al.*, 2011). This reasoning reinforces the importance of staff conceptualising the everyday tasks and activities that present themselves in residential aged care life as therapeutic person-centred interventions that can facilitate resident quality of life. Thus, a practical implication of these findings is to conceptualise such everyday tasks and procedures as potent nursing interventions and to have ongoing discussions of how resident participation in such everyday activities can be facilitated. It seems imperative to be aware that such everyday tasks and procedures may present one of the few possibilities for residents to participate in everyday activities familiar to them, activities that they can still master and that can promote their quality of life.

Limitations

One limitation of the study is the cross-sectional design, which only allows for detecting differences and not interpretations of causal directions. Other designs are needed to establish causal relationships between everyday activities, person-centred care and quality of life. Additional multivariate analyses are also needed to disentangle the unique contribution of cognition, activities and person-centredness to further explain the variance in resident quality of life. The study is also limited by the procedure of evaluating quality of life in residents through proxy ratings by staff; as such, ratings have been debated (Sloane *et al.*, 2005; Smith *et al.*, 2005). However, issues relating to an expected high sample

prevalence of cognitive impairment in this population (Magaziner *et al.*, 2000), together with reduced abilities to communicate, make self-report studies among residential aged care residents very challenging. Consequently, for a large proportion of this frail population, proxy ratings might present the only avenue for participation. We instructed that ratings were to be made by the staff member who knew the resident best so as to increase the reliability of the proxy ratings. To what extent this was successful, in that staff ratings truly corresponded to residents' experiences, remains unknown. Nevertheless, the study provides an important contribution to the literature by illustrating that everyday activities, person-centred care and resident quality of life are associated and by highlighting a seemingly low point-prevalence of resident participation in everyday activities that can be further used for international comparisons.

Conclusions

This study shows that a minority of residents participated in housing-activities such as making coffee, setting or clearing the table, cleaning or watering plants within the units and that only a slight majority of residents participated in outdoor walks. About one-quarter of residents had participated in parlour games, and roughly, one-tenth of residents had participated in excursions or church visits respectively. The results also show that those residents who had participated in everyday activities lived in more person-centred units had significantly higher quality of life and cognitive ability as compared to those residents who had not participated in such everyday activities.

Implications for practice

The findings seem highly relevant to clinical practice by suggesting that resident participation in everyday activities may need to increase, as residents who participated in everyday activities had significantly higher quality of life as compared to those residents who had not. Most of the everyday activities explored in this study are most likely to be already occurring in practice, and if not, they are highly applicable and achievable: making coffee, setting or clearing the table, cleaning or watering plants, partaking in parlour games and outdoor walks. However, when involving residents in such activities, it is imperative that staff build on things that residents' have enjoyed throughout life, are individualised and tailored to the individual resident's level. There are innovative initiatives available that can be used to facilitate implementation of resident engagement in everyday activities, the TimeSlips initiative for example, which have shown positive outcomes (Fritsch *et al.*, 2009).

Through such implementation, many of the everyday tasks and procedures that are commonplace to residential aged care practice can become manifestations of person-centred care and facilitators of quality of life if they are conceptualised as meaningful activities that build on resident involvement and life history and not just remain as routine tasks that are swiftly completed by staff. By this, the ordinary can become the extraordinary, and the 'doings and beings' of aged care nursing can merge in favour of resident quality of life and person-centred care provision.

Implications for practice

- The prevalence of participation in everyday activities for residents with dementia can increase.
- Everyday activities such as making coffee, setting or clearing the table, cleaning or watering plants are associated with resident quality of life in residential aged care.
- Involving residents in commonly occurring tasks and procedures is a way of providing person-centred care.

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Contributions

Study design: DE, POS; data collection and analysis: KS, LP, ML and manuscript preparation: DE, POS, KS, LP, ML.

Conflict of interest

No conflict of interest has been declared by the authors.

References

- Brooker D. (2007) *Person-Centred Dementia Care: Making Services Better*. Jessica Kingsley, London.
- Cohen-Mansfield J. & Bester A. (2006) Flexibility as a management principle in dementia care: the Adards example. *Gerontologist* **46**, 540–544.
- Cooney A., Murphy K. & O'Shea E. (2009) Resident perspectives of the determinants of quality of life in residential care in Ireland. *Journal of Advanced Nursing* **65**, 1029–1038.
- Cooper C., Mukadam N., Katona C., Lyketsos C.G., Ames D., Rabins P., Engedal K., de Mendonca Lima C., Blazer D., Teri L., Brodaty H. & Livingston G. (2012) Systematic review of the

- effectiveness of non-pharmacological interventions to improve quality of life of people with dementia. *International Psychogeriatrics* 24, 856–870.
- Davis S., Byers S., Nay R. & Koch S. (2009) Guiding design of dementia friendly environments in residential care settings: considering the living experiences. *Dementia* 8, 185–203.
- Drageset J., Natvig G.K., Eide G.E., Bondevik M., Nortvedt M.W. & Nygaard H.A. (2009) Health-related quality of life among old residents of nursing homes in Norway. *International Journal of Nursing Practice* 15, 455–466.
- Edvardsson D., Winblad B. & Sandman P.O. (2008) Person-centred care for people with Alzheimer's disease – current status and ways forward. *The Lancet Neurology* 7, 362–367.
- Edvardsson D., Fetherstonhaugh D. & Nay R. (2010a) Promoting a continuation of self and normality: person-centred care as described by people with dementia, family members and aged care staff. *Journal of Clinical Nursing* 19, 2611–2618.
- Edvardsson D., Fetherstonhaugh D., Gibson S. & Nay R. (2010b) Development and initial testing of the Person-centred Care Assessment Tool (P-CAT). *International Psychogeriatrics* 22, 101–108.
- Edvardsson D., Sandman P.O. & Rasmussen B.H. (2011) Forecasting the ward climate: a study from a dementia care unit. *Journal of Clinical Nursing* 21, 1136–1144.
- 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.
- Folstein M.F., Folstein S.E. & McHugh P.R. (1975) "Mini-mental state". A practical method for grading the cognitive state of patients for the clinician. *Journal of Psychiatry Research* 12, 189–198.
- Fritsch T., Kwak J., Grant S., Lang J., Montgomery R.R. & Basting A.D. (2009) Impact of TimeSlips, a creative expression intervention program, on nursing home residents with dementia and their caregivers. *The Gerontologist* 49, 117–127.
- Funaki Y., Kaneko F. & Okamura H. (2005) Study on factors associated with changes in quality of life of demented elderly persons in group homes. *Scandinavian Journal of Occupational Therapy* 12, 4–9.
- Gottfries C.G., Bråne G., Gullberg B. & Steen G. (1982) A new rating scale for dementia syndromes. *Archives of Gerontology and Geriatrics* 1, 311–321.
- Harre R. (1998) *The Singular Self: an Introduction to the Psychology of Personhood*. Sage, London.
- Kitwood T.M. (1997) *Dementia Reconsidered: the Person Comes First*. Open University Press, Buckingham.
- Lindqvist O., Tishelman C., Lundh Hagelin C., Clark J.B., Daud M.L., Dickman A., Domeisen Benedetti F., Galushko M., Lunder U., Lundquist G., Miccinesi G., Sauter S.B., Furst C.J. & Rasmussen B.H. (2012) Complexity in non-pharmacological caregiving activities at the end of life: an international qualitative study. *PLoS Medicine* 9, e1001173.
- Magaziner J., German P., Zimmerman S.I., Hebel J.R., Burton L., Gruber-Baldini A.L., May C. & Kittner S. (2000) The prevalence of dementia in a statewide sample of new nursing home admissions aged 65 and older: diagnosis by expert panel. *Gerontologist* 40, 663–672.
- McCormack B. & McCance T.V. (2006) The Person-Centred Nursing conceptual framework. *Journal of Clinical Nursing* 56, 1–8.
- McCormack B., Karlsson B., Dewing J. & Lerdal A. (2010) Exploring person-centredness: a qualitative meta-synthesis of four studies. *Scandinavian Journal of Caring Sciences* 24, 620–634.
- 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.
- Morgan S. & Yoder L.H. (2012) A concept analysis of person-centered care. *Journal of Holistic Nursing* 30, 6–15.
- Murphy K., O'Shea E. & Cooney A. (2007) Quality of life for older people living in long-stay settings in Ireland. *Journal of Clinical Nursing* 16, 2167–2177.
- Nolan M., Davies S., Brown J., Keady J. & Nolan J. (2004) Beyond 'person-centred' care: a new vision for gerontological nursing. *International Journal of Older People Nursing* 13, 45–53.
- Raske M. (2010) Nursing home quality of life: study of an enabling garden. *Journal of Gerontological Social Work* 53, 336–351.
- Sandman P.O., Adolfsson R., Norberg A., Nystrom 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, 120–132.
- Sandman P.O., Edvardsson D. & Winblad B. (2006) Care of patients in the severe stage of dementia. In *Clinical Diagnosis and Management of Alzheimer's Disease*, 3rd edn. (Gauthier S. ed). Taylor & Francis, London, pp. 233–246.
- Sjögren K., Sandman P.O., Zingmark K. & Edvardsson D. (2012) Psychometric evaluation of the Swedish version Person-centred Care Assessment Tool (P-CAT). *International Psychogeriatrics* 24, 406–415.
- Sloane P.D., Zimmerman S., Williams C.S., Reed P.S., Gill K.S. & Preisser J.S. (2005) Evaluating the quality of life of long-term care residents with dementia. *The Gerontologist* 45, 37–49.
- Smith S.C., Murray J., Banerjee S., Foley B., Cook J.C., Lamping D.L. & Mann A. (2005) What constitutes health-related quality of life in dementia? Development of a conceptual framework for people with dementia and their carers. *International Journal of Geriatric Psychiatry* 20, 889–895.
- Weiner M.F., Martin-Cook K., Svetlik D.A., Saine K., Foster B. & Fontaine C.S. (2000) The quality of life in late-stage dementia (QUALID) scale. *Journal of the American Medical Directors Association* 1, 114–116.
- White D.L., Newton-Curtis L. & Lyons K.S. (2008) Development and initial testing of a measure of person-directed care. *The Gerontologist* 48, 114–123.
- 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.
- Zingmark K., Sandman P.O. & Norberg A. (2002) Promoting a good life among people with Alzheimer's disease. *Journal of Advanced Nursing* 38, 50–58.