

Research Article

Physical and Psychosocial Outcomes of People with Dementia in Shared Housing Arrangements – A Cluster-Randomized Study on Long-Term Progression

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Abstract

Background: Shared-housing arrangements (SHA) are a specific German kind of small-scale living facilities for care-dependent persons with dementia. SHA are disconnected from residential facilities and served by community care services.

Purpose: The aim of the study was to evaluate the long-term progression of physical and psychosocial outcomes of people with dementia living in SHA in Berlin/Germany and to investigate if a setting-specific quality development shows a positive impact.

Methods: In a longitudinal cluster-randomised study (2010-2012) 104 residents of 34 shared-housing arrangements were surveyed for one year, the intervention group took part in a setting-specific quality development process. Primary outcome measures are functional ability and non-cognitive symptoms of dementia. Outcome measures were obtained by trained study nurses blinded to group assignment.

Results: During the one year follow-up, analyses show a decrease in residents' physical and mental abilities, the prevalence of neuropsychiatric symptoms remained stable. No statistically significant differences could be proved regarding a setting-specific quality development process.

Conclusions: Results of this study do not clarify finally whether a setting-specific quality development process in SHA is generally advantageous for the care of older people suffering from dementia. Further research as well as longer study intervals are essential.

Keywords: Dementia; Functional Ability; Quality of Care; Neuropsychiatric Symptoms; Shared-Housing Arrangements; Small Scale Living

Abbreviations

AN(C)OVA: Analysis of (co-)variance;

CMAI: Cohen-Mansfield Agitation Inventory;

EBI: Extended Barthel Index;

GDS: Global Deterioration Scale;

MDS: Minimum Data Set;

NPI: Neuropsychiatric Inventory;

PwD: Person with dementia;

QI: Quality Indicator;

RN: Registered nurse;

SD: Standard deviation;

SHA: Shared-housing arrangement

Introduction

Since the number of people with dementia (PwD) is rapidly increasing all over the world [1] great efforts are made to improve care in general as well as to design and evaluate special care settings for PwD. The design of living environments has an impact on behavioural problems of PwD [2]. But in general, there is no consensus on the supremacy of one special care setting in terms of beneficial aspects (e. g. challenging behaviour, quality of life ...) for PwD [3-7].

In line with the international trend of small-scale, homelike living facilities for PwD German shared-housing arrangements (SHA) evolved from the late 1990's as an alternative care arrangement to traditional care facilities and are now widespread over Germany [3,8]. SHA are mostly located in urban settings being completely disconnected from residential care. Community care services provide care and support in these settings which typically accommodate six to eight residents. Main objectives of SHA are the maintenance of self-determination despite of high needs in care and providing a life as "normal" as possible in family-like structures, the involvement of family members in daily living, the connection to neighborhood, ensured access to care and well-being, and obtaining self-esteem and autonomy [8,9].

Although within the last decade, the number of SHA in Germany for care-dependent PwD showed a tenfold increase from 143 SHA in 2003 to more than 1,500 SHA with ca. 11,000 residents in 2012 [8] detailed research on health outcomes of residents is still missing, especially regarding long-term progression. Gräske et al. [9] published a systematic literature review concerning research in German SHA concluding that the current state of research is insufficient especially regarding quality of care and support. For newly admitted residents of SHA long-term results concerning health outcomes and quality of life compared to residents of special care units for PwD were evaluated by Wolf-Ostermann et al [4]. No significant beneficial effects of settings in terms of health outcomes and quality of life were found. Wolf-Ostermann et al [3] evaluated setting-specific quality indicators (QI) for SHA regarding long-term effects of a guided quality development process on resident's quality of life. They proved positive trends regarding quality related outcomes in the intervention group but no statistically significant differences regarding quality of life. Long-term results concerning

resident's functional abilities and psychosocial outcomes in small-scale living arrangements for PwD are still missing.

Materials and Methods

Aims

The aim of the present publication is to assess physical and psychosocial outcomes of PwD living in SHA for one year to describe a long-term progression and to evaluate if sex, age or stage of dementia/ cognitive status are associated with physical and psychosocial outcomes. Another aim is to investigate if a setting specific quality development process results in better physical and psychosocial outcomes of PwD.

Design

A prospective longitudinal cluster-randomized design with two measurements was applied. The measurements took place in SHA in Berlin/Germany at the beginning of the study (t1) and 12 months (t2) later. In a sequential two-step recruiting process first care services in SHA were recruited and afterwards residents of these SHA. We evaluated one group of SHA which was undergoing an externally guided quality development process focusing on care aspects of PwD, which tried to improve cognitive and functional capacity or to reduce neuropsychiatric symptoms, a second group proceeded without this, allocation to groups was randomized. For a detailed description of the quality development process see Wolf-Ostermann et al [3].

Setting

The study was conducted in SHA in Berlin, Germany from 2010-2012. All 132 community care providers in Berlin/Germany offering services in about 400 SHA were invited to participate in the study, 11 care service providers and 34 SHA participated in the study. Shortage of resources and lack of interest were mentioned as the main reasons for not participating in the study.

Sample

The study sample was composed of residents living in the 34 participating SHA. 104 out of 261 residents (39.8%) participated in the study, 68 of them (65.4%) completed the follow up. Inclusion criterion was that participants or their legal representatives signed the informed consent. No additional exclusion criteria beyond fulfilling inclusion criteria were formulated. Main reason for drop-out was the death of mostly older and more cognitively impaired persons.

Outcome Measures

Functional ability and non-cognitive symptoms of dementia are the primary outcome measures of this study. Additionally we evaluated demographical factors, severity of dementia and cognitive impairment. Outcome measures were obtained by trained study nurses (registered Nurses, RN) using general documentation, nursing records and face-to-face interviews blinded to group assignment. Proxy-ratings were

performed by asking the staff.

Functional ability

Functional ability was assessed using the Extended Barthel Index [EBI, 10], which shows sufficient validity and reliability. Activities of daily living and cognitive abilities are measured by sixteen variables which are summed up to a total score ranging from 0 (completely dependent) to 64 (independent).

Non-cognitive symptoms of dementia (neuropsychiatric symptoms and challenging behaviours)

Following the recommendations of the European Interdem Group [11] neuropsychiatric symptoms were assessed by the Neuropsychiatric Inventory tool [NPI-NH, 12]. Frequency and severity of behavioural disturbances in persons with dementia are determined by a trained nurse familiar with the residents behaviour and summed up to a total score ranging from 0 (no behavioural disturbances) to 144 (severe behavioural disturbances). According to Wood et al. [13] behavioural disturbances are considered to be clinically significant if the product of frequency and severity on each subscale is greater or equal to 4 (1-4 for frequency \times 1-3 for severity). The presence of physical aggressive behaviour, physical non-aggressive behaviour and verbally agitated behaviour were measured using the Cohen-Mansfield agitation inventory (CMAI), [14].

Cognitive impairment

Cognitive impairment was assessed using the internationally validated Mini Mental State Examination (MMSE), [15]. The MMSE consists of 19 items yielding a score with a total range from 0-30 points, greater values indicating better cognitive abilities. The Global Deterioration Scale (GDS), [16] was applied to assess the severity of dementia, resulting in stages 1 (objectively normal person) to 7 (severe dementia).

Quality of care and support

The achieved level of quality of care and support per SHA was measured by a summative score (0-100) counting the percentage of a set of 39 quality indicators (QIs) being fulfilled. The included QIs partly refer to the setting SHA as a whole and partly in detail to all residents per SHA. The QIs were especially developed for SHA and include relevant aspects of structures, processes and outcomes involving all relevant stakeholders in SHA (nursing staff, medical practitioners, therapists, family caregivers, volunteers and landlords). For a detailed description compare Wolf-Ostermann et al [3].

Statistical Analysis

We used descriptive statistics to describe basic characteristics of all study participants. We examined correlations between the metric/ordinal variables by Pearson's and Spearman's correlations. Analyses of the data were performed by using Chi-square tests, Fisher's exact tests, and t-tests. For

the longitudinal analyses, we only used measurements of participants with complete follow-up data for each instrument (t1 and t2). We used fixed-effects models of analysis of co-variance (ANCOVA) to analyze longitudinal effects for our main outcome parameters. All ANCOVA models were adjusted for confounding factors as sex, age, length of stay in SHA, stage of dementia (GDS) and cognitive functioning (MMSE). We also included the QI total score at t2 into the model. We did not include the change in QI total scores over time since this was highly positively correlated with the QI total score at t2. Interactions between confounding variables were not modeled because of the small number of study participants. Before conducting analyses we carefully examined statistical model assumptions (e.g. normal distribution, multicollinearity). Significance was set at $p \leq 0.05$. We considered values of $p \leq 0.10$ as pointing towards significance. All statistical analyses were carried out using SPSS® (v22.0).

Ethical Approval

The study was approved by the Ethics Committee of the German Society of Nursing Science (declaration of consent 28th of May 2010).

Results

Participants

The inclusion criteria were met by a sample of 104 residents, 68 of them completed the follow-up after one year. Table 1 shows the socio-demographic characteristics of the study sample. Our sample consists mostly of female residents (73.1 %), with a mean age of 79.0 years. We did not find differences between intervention and control group at baseline except in trend for length of stay (t-test, $p = 0.052$), residents in the intervention group having a slightly longer period of stay already. 69.2% of the participants show at least one challenging behavior (CMAI).

Quality Indicators

The intervention group reached a QI total score of 58.7 (6.3) at t1 and 57.4 (4.9) at t2, remaining almost unchanged. For the control group, values decreased from 60.3 (7.4) at t1 to 56.7 (8.8) at t2, however in this group a few QIs were not measured. The decreased QI total score in the control group was statistically significant (paired t-test, $p = 0.008$).

Functional Status

The study population on average exhibited limitations in their functional abilities. The mean EBI for all participants ($n = 104$) at baseline was 32.9 (intervention group: 33.9, control group: 37.8, see table 1), so the population is obviously limited in their functional abilities. No significant differences between the two groups could be established. Persons with less cognitive abilities (lower MMSE score) also showed fewer abilities of daily living ($r = 0.761$, $p < 0.001$). The mean EBI-score decreased significantly during the one year follow-up ($n = 68$, see table 1) in both the intervention and the control group (all paired t-tests; both groups -6.4.

		Total Sample (n = 104)	Population with complete follow-up (n = 68)					
		Baseline t1	Baseline t1		One-year follow-up t2			
			intervention group (n = 31)	control group (n = 37)	p	intervention group (n = 31)	control group (n = 37)	p
sex in % (n)	female	73.1 (76)	74.2 (23)	78.4 (29)	n. s. ^b			
	male	26.9 (28)	25.8 (8)	21.6 (8)				
age in years M (SD)		79.0 (9.5)	77.5 (9.1)	77.8 (10.9)	n. s. ^b			
length of stay in years M (SD)		2.8 (1.9)	3.3 (2.2)	2.4 (1.8)	0.052 ^b			
care level* in % (n)	none	1.0 (1)	0.0 (0)	2.7 (1)	n. s. ^c			n. s. ^c
	I	16.3 (17)	19.4 (6)	18.9 (7)		6.5 (2)	0.0 (0)	
	II	54.8 (57)	51.6 (16)	62.2 (23)		32.3 (10)	21.6 (8)	
	III	25.0 (25)	19.4 (6)	16.2 (6)		48.4 (15)	59.5 (22)	
MMSE M (SD) (0-30)		11.5 (9.5)	11.3 (9.9)	12.7 (9.8)	n.s. ^b	12.0 (10.0)	10.6 (9.2)	n.s. ^b
GDS in % (n)	≤5	10.6 (11)	12.9 (4)	10.8 (4)	n.s. ^c	25.8 (8)	13.5 (5)	n.s. ^c
	6	50.0 (52)	51.6 (16)	54.1 (20)		45.2 (14)	54.1 (20)	
	7	39.4 (41)	35.5 (11)	35.1 (13)		29.0 (9)	32.4 (12)	
Ext. Barthel Index M (SD) (0-64)		32.9 (17.7)	33.9 (18.2)	37.8 (15.8)	n. s. ^b	29.0 (17.3)	30.6 (14.2)	n. s. ^b
NPI-NH	total score M (SD) (0-144)	15.2 (11.3)	15.2 (11.5)	13.5 (10.8)	n.s. ^b	12.1 (14.4)	10.6 (12.0)	n.s. ^b
	simultaneous symptoms, mean (min; max)	3.3 (1; 8)	3.2 (1; 6)	3.5 (1; 8)	n.s. ^b	2.5 (0; 9)	2.8 (0; 8)	n.s. ^b
	frequent symptoms, mean (min; max)	1.5 (0; 6)	1.3 (0; 5)	1.5 (0; 6)	n.s. ^b	1.8 (0; 8)	1.3 (0; 7)	n.s. ^b
CMAI in % (n)	physical non-aggressive	48.1 (50)	38.7 (12)	62.2 (23)	0.046 ^a	38.7 (12)	43.2 (16)	n.s. ^a
	verbal agitation	44.2 (46)	38.7 (12)	43.2 (16)	n.s. ^a	35.5 (11)	43.2 (16)	n.s. ^a
	physical aggressive	26.9 (28)	16.1 (5)	24.3 (9)	n.s. ^a	22.6 (7)	24.3 (9)	n.s. ^a

^a Fisher's exact test, ^b t-Test, ^c Chi-square test, n. s. = non-significant, M = arithmetic mean, SD = standard deviation, * care level determined by the German long-term care insurance level of care I, II and III requires at least 90 minutes, 3 hours and 5 hours of care per day, ** Frequency x severity ≥ 4, underlined score is most favourable score

Table 1. Characteristics of Total (n = 104) and Follow-up Sample (n = 68) at Baseline (t1) and after One-year Follow-up (t2).

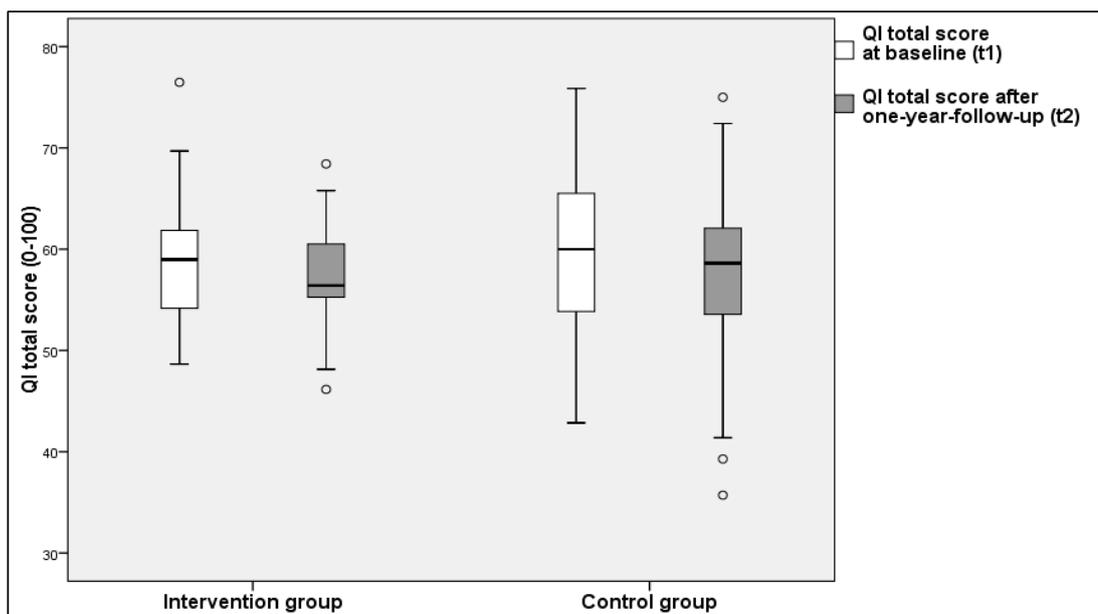


Figure 1. QI Total Score at Baseline (t1) and after One-year-Follow-up (t2) for the Follow-up Sample (n = 68).

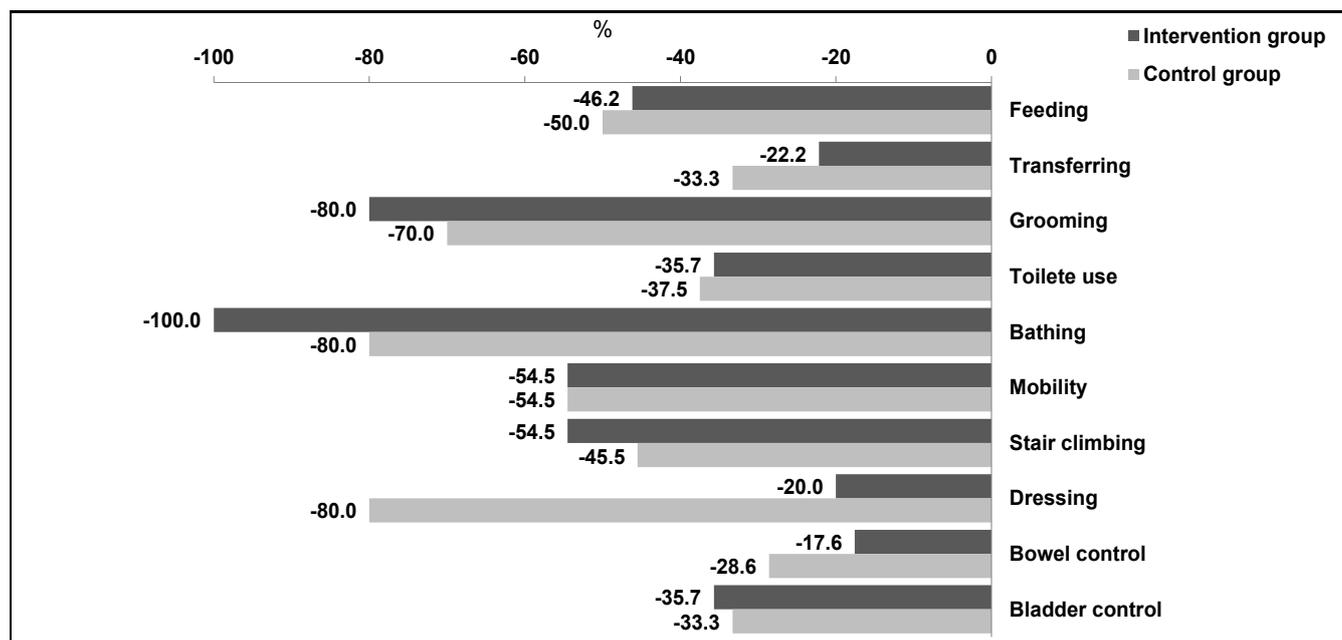


Figure 2. Decline in Proportion of Residents with Full Functionality within the One-year Study Period (t2-t1) in Percentage.

dependent variable	p-value (model)	R ² -coefficient of determination	significant independent variables	p-value partial Eta ² -coefficient
Extended Barthel-score (EBI) at t2 non-significant independent variables: a, b, c, d, f, h (see underline)	p<0.001	0.752	Extended Barthel-score (EBI) at t1 GDS at t2	p<0.001, Eta ² =0.435 p=0.002, Eta ² =0.232
MMSE at t2 non-significant independent variables: a, b, c, d, e, g, h (see underline)	p<0.001	0.549	MMSE at t1	p<0.001, Eta ² =0.325
NPI-NH total score at t2 non-significant independent variables: a, b, c, d, e, f, g, h (see underline)	p=0.700	0.154		

Independent variables: a = intervention / control group, b = sex, c = age, d = length of stay, e = stage of dementia (GDS) at t2, f = at least one challenging behaviour at t2, g = dependent variable at t1, h = QI total score, c.f. section "Methods"

Table 2. Results of ANCOVA-models Analysing One-year Follow-up (n = 68).

$p < 0.001$; intervention group -4.1 . $p = 0.009$; control group: -7.2 $p = 0.001$). Including differences in sex, age, length of stay, stage of dementia (GDS), challenging behaviour and QI total score into the analyses, no significant group differences over time could be shown (see table 2). The EBI-score at t2 was correlated with the EBI-score at baseline and the stage of dementia (GDS). Persons with a high EBI-score at t1 and a less severe stage of dementia also had a high EBI-score at t2. The functional decline over time was about 10 % (EBI at t2 - EBI at t1: -6.4). No significant difference between intervention and control group and according to sex (both t-test $p > 0.005$) could be observed. Significant differences were found for stage of dementia at t1 (GDS). While for a very severe dementia (GDS 7) the functional abilities stayed almost unchanged over time on a low level, we observed a decline in functional abilities for people with severe (GDS 6: -9.7) and less severe stages of dementia (GDS ≤ 5 : -11.8) (ANOVA $p < 0.001$). No correlations were found for age and cognitive function (MMSE) at t1 (both Pearson's r , $p > 0.05$). The highest proportion of residents with functional decline was observed for bathing and grooming (see figure 2).

Cognitive Impairment

All participants at baseline ($n = 104$) showed obvious cognitive impairments (mean MMSE (t1) 11.5; intervention group 11.3. control group: 12.7, see table 1). Over one year the mean MMSE-score in the control group significantly decreased but remained almost unchanged in the intervention group (all paired t-tests; both groups -2.4 . $p = 0.030$ ($n = 68$); intervention group -0.4 . $p = 0.834$. control group: -4.0 . $p = 0.006$.) Including differences in sex, age, length of stay, stage of dementia (GDS), challenging behaviour and QI total score into the analyses, no significant group differences over time could be shown (see table 2). The MMSE score at t2 was closely determined by the MMSE score at baseline. Persons with a high MMSE score at t1 also had a high MMSE score at t2.

Neuropsychiatric Symptoms

Physical non-aggressive behaviour (48.1 %, $n = 104$) and verbal agitation (44.2 %, $n = 104$) were the most frequent challenging behaviours observed in our study at baseline (c.f. table 1). For study participants with a complete follow-up for one year ($n = 68$, see table 1) analyses showed a higher percentage of physical non-aggressive residents in the control group at t1. Figure 3 shows the ratio of residents with agitation as well as the ratio of residents being verbally or physically aggressive compared to all residents in the intervention and control group over time ($n = 68$). No statistically significant improvements over time can be shown.

The mean NPI-NH total score of all participants ($n = 104$) at baseline was 15.2 (intervention group: 15.2. control group: 13.5, see table 1). On average the study group showed 3.3 neuropsychiatric symptoms. High prevalence rates were observed for agitation/aggression (43.3%), irritability (41.3%), depression (34.6%) and apathy/indifference (34.6%) but no significant group differences could be shown (all Fisher's exact test, $p > 0.05$). The only significant group

difference noted was for behaviour during the night, which was more frequent in the control group compared with the intervention group (Fisher's exact test; both groups 17.3%; intervention group 16.3%. control group: 20.0%. $p = 0.028$).

For study participants with a complete follow-up for one year ($n = 68$, see table 1) analyses showed a minimal and not significant decrease of the mean NPI-NH total score in both groups (both groups -0.9 . $p = 0.742$; intervention group -0.2 . $p = 0.966$. control group: -1.3 . $p = 0.714$). No significant differences were found between groups and sex (both t-test, $p > 0.05$) or severity of dementia (GDS, ANOVA $p > 0.05$). Furthermore, no correlations with age and MMSE at baseline were found (Pearson's r , $p > 0.05$). Prevalence rates of most neuropsychiatric symptoms decreased slightly in the whole sample except for hallucinations, anxiety, elation/euphoria and behaviour during the night. Including differences in intervention/control group, sex, age, length of stay, stage of dementia (GDS), challenging behaviour and QI total score into the analyses no significant group differences over time could be shown (see table 2).

Discussion

Concurrent to the rising number of PwD the number of SHA has increased steadily in Germany during the last years being now a regular service in the nursing setting [17]. Our study aimed to examine the long-term development of physical and psychosocial health outcomes of residents with dementia in SHA and to shed light on the question if a guided quality development in SHA can contribute to better health outcomes in residents. Our study is the first quantitatively based study in the setting of SHA in Germany to assess these health outcomes of residents in a one-year follow-up and provide a relationship to quality of care and support.

Wolf-Ostermann et al. [3] proved positive trends regarding quality related outcomes for setting-specific quality indicators (QI) for SHA. Their results especially emphasized the importance of quality developments concerning the use of physical restraints, avoiding malnutrition and falls as well as an increased utilization of routine primary and specialist care in SHAs. Also Vasse et al. [18] stressed the importance of valid QIs for psychosocial interventions in dementia care. According to Vickrey et al. [19] and Reuben et al. [20] the use of evidence-based Qis can substantially help to improve quality of care.

Regarding socio-demographic characteristics of the present study participants at baseline show a typical distribution of male (18.7%) and female (81.3%) residents that mirrors current trends of age distribution in older adults. The results are comparable to those of [4] obtained in SHA as well as those of residents in German nursing homes [21] or results in the Netherlands [5, 6]. The mean age of the participants was 77.8 years at baseline which is similar to findings in German SHA [4, 22] as well as to findings in comparable studies in Germany [23] and in the Netherlands [5, 6]. Also the mean length of stay at baseline (2.8 years) is comparable to similar studies in SHA [22].

The length of stay at baseline was 2.8 years on average which is comparable to similar studies in SHA in Germany [24]. The mortality of participants during the one-year study period (34.6%) is lower than results of a one-year follow-up for newly admitted PwD in SHA in Germany [4] but still high due to age and severe (multi-)morbidity of the residents. Looking at results reported by van Dijk et al. [25] for a two-year mortality of PwD in ambulatory care our results are comparable.

The mean MMSE-score at baseline was 11.5, which corresponds to results in German SHA [4] or in group living homes in Sweden [26] and the Netherlands [5,6]. During the one-year follow-up a significant decline in both groups was found, but no significant differences between the groups. The decline in cognitive functioning reflects findings from similar studies [6,23,27].

The mean NPI-NH total score of all participants at baseline was 15.2, which is lower than the results for PwD living in SHA for one year [4], who found a mean NPI-NH total score of 23.2. The minimal but not significant decrease during follow-up in both groups is in accordance with results of a study by Wolf-Ostermann et al. [4], who reported a decline in the NPI-NH total score for newly admitted PwD in SHA during follow-up. Comparing these results to results reported by Verbeek et al. [5] in small-scale living facilities in the Netherlands, results are very similar. No group differences were found after a one-year study period so at this point of time it must be concluded that quality development processes according to the underlying set of QIs do not seem to influence the occurrence of neuropsychiatric symptoms beyond the influence of “regular” care and support in view of progressing dementia.

No significant changes in the occurrence of challenging behaviours were found between the two groups. Verbeek et al. [5] report similar results for agitation scores in small-scale living facilities remaining stable over time. For the ratio of residents with verbal agitation compared to the total number of residents included into the study a small (not statistically significant) decline in the intervention group was seen for which at this point of time it could be only speculated that this may be the beginning of a positive effect of the quality development process.

In the present study a significant decline in functional abilities during the one-year study period was found. A statistically significant difference between the two groups could not be proven although the loss of functioning was on average slightly higher in the control group. Besides, the extended Barthel-score at t2 is solely depending on the stage of dementia at t2 which is in accordance with results of Sauvaet et al. [28] identifying cognitive impairments as a risk-factor and predictor for a loss of ADL-functioning. Compared to the results of Wolf-Ostermann et al. [4] obtained for a one-year follow-up for newly admitted residents of SHA similar results for ADL-functioning were achieved.

Several limitations should be considered. First we only have a relatively small number of participants. Second, the study

sample was restricted to the city of Berlin. Third, we may have an unintended selection bias concerning SHA being interested to participate in the study which could have resulted in SHA with residents having better physical and psychosocial health outcomes. And fourth, the period of time of one year for implementing and evaluating effects of a quality development processes might be too short to prove possible effects. Therefore, the generalizability of the study results might be limited.

Conclusion

The results of this study imply that even high-quality care is unable to cope with effects of progressing age and progressing illness resulting in declining functional and mental abilities which is not an unexpected result. But, challenging behaviour and neuropsychiatric symptoms can be kept stable over a long time despite losses in the above mentioned abilities. The present study does not suggest at the first sight clear advantages of implementing a setting-specific quality development process. Results of this study do not clarify finally whether a setting-specific quality development process in SHA is generally advantageous for the care of older people suffering from dementia since score-values indicating quality of care were quite high in both groups indicating that we have already reached a high level which cannot be improved easily to a greater extent. Further research therefore should focus on evaluating psychosocial health outcomes as well as the development of functional status in a real random sample of SHA exceeding a follow-up of 12 months.

Competing Interests

All authors state to have no conflict of interest.

Authors Contribution

According to ICMJE guidelines, all authors 1) have made substantial contributions to conception and design, or acquisition of data, or analysis and interpretation of data; 2) have been involved in drafting the manuscript or revising it critically for important intellectual content; 3) have given final approval of the version to be published; and 4) agree to be accountable for all aspects of the work in ensuring that questions related to the accuracy or integrity of any part of the work are appropriately investigated and resolved.

KWO: Study design, data analysis, manuscript preparation

SM: Data collection, manuscript preparation

AW: Data collection, data analysis, manuscript preparation

JG: Study design, data analysis, manuscript preparation

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