



Quality of Care and Its Impact on Quality of Life for Care-Dependent Persons With Dementia in Shared-Housing Arrangements: Results of the Berlin WGQual-Study

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ABSTRACT

Aim: The aim of study was to evaluate setting-specific quality indicators (QIs) for shared-housing arrangements (SHA) regarding effects of a guided quality development process on resident's quality of life (QoL).

Background: 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.

Method: In a longitudinal cluster-randomised design 104 residents of 34 SHA were surveyed for 1 year; the intervention group took part in a quality development process. QIs, physical and psychological health outcomes including QoL were surveyed.

Results: During the 1 year follow-up, analyses show a positive trend regarding QI-outcomes in the intervention group, but no statistically significant differences could be proved regarding QoL.

Conclusions: Setting-sensitive QIs are absolutely essential to measure quality of care in multi-professional settings like SHA. Further research as well as longer study intervals is essential.

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Introduction

The number of people with dementia (PwD) is rapidly increasing all over the world (Wimo & Prince, 2010). Results of Marquardt and Schmiege (2009) show that the design of the living environment has an impact on QoL and on behavioural problems of PwD. In general, there is no consensus on the supremacy of one special care setting in terms of beneficial aspects (e. g. QoL, challenging behaviour, ...) for PwD (Kane, Lum, Cutler, Degenholtz, & Yu, 2007; te Boekhorst, Depla, de Lange, Pot, & Eefsting, 2009, Verbeek et al. (2010), Wolf-Ostermann, Worch, Fischer, Wulff, & Gräske (2012)).

German SHA were developed in line with the international trend of of small-scale, homelike living facilities being an alternative care arrangement to traditional care facilities (Wolf-Ostermann, et al., 2012). Typically, six to eight residents share one large apartment in a mostly urban setting (Wolf-Ostermann, et al., 2012, Gräske et al., 2013). SHA are completely disconnected from residential care, being served by community care service providers (Wolf-Ostermann & Fischer, 2010). SHA are characterised by different groups of relevant stakeholders: residents, relatives, volunteers, care provider, physicians, therapists and landlords. 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 (Wolf-Ostermann, et al., 2012, Gräske et al., 2013). 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 (Wolf-Ostermann, Worch, Meyer, & Gräske, 2013). In contrast to residential care no special legal guidelines for SHA in Germany concerning quality of care and support exist besides general legal quality requirements for care provider. SHA are judged as private domesticities although PwD are considered to be a vulnerable group of people who have to be especially protected.

Since different settings have different requirements in terms of providing high quality care for PwD, quality development needs to be tailored to given structural (e. g. number and qualification of staff) and procedural (e. g. nursing interventions) conditions. For long-term care in nursing homes, Nakrem, Vinsnes, Harkless, Paulsen, & Seim (2009) give an overview of nursing sensitive quality indicators (QIs). In the case of dementia care QIs "mainly focus on diagnostics, screening, and pharmacological interventions" (Vasse et al., 2012). For small-scale living facilities like the German SHA, particular criteria for assessing and appraising the quality of care beyond the well-established indicators such as falls, pressure ulcer, nutrition etc., are widely lacking. Based on a systematic literature review, a set of 39 QIs was developed, taking into account the multi-professional network of care providers in SHA and focusing on different aspects of structures,

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procedures and outcomes (see [table 1](#)) (Worch, Gräske, Dierich, & Wolf-Ostermann, 2011). The concept behind is to establish QIs which are easy to measure but are nevertheless evidence-based and not solely on expert opinion. A set of QIs meeting these requirements can be used routinely by care providers to enhance their quality of services as well as by PwD and their informal caregivers to compare SHA by means of quality aspects.

The aim of the present publication is to evaluate a set of previously developed QIs tailored to SHA in order to ascertain if a guided quality development process by means of these QIs leads to better health outcomes and better quality of life (QoL) for the residents.

Methods

Design

A cluster-randomised longitudinal design with measurements before intervention (t1) and twelve months (t2) later was used to evaluate a set of QIs for measuring quality of care and support in SHA and outcomes of residents in SHA in Berlin, Germany. In a sequential two-step recruiting process first care services in SHA were recruited and afterwards residents of these SHA. The intervention group consisted of SHA which were undergoing an externally guided quality development process; the control group proceeded without this.

Ethical approval

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

Setting

In 2010, existing community care provider in Berlin/Germany providing services in SHA were informed about the purpose of the study and invited to participate; 11 out of 132 care service providers and 37 out of 400 SHA expressed interest in participating in the study. Main reasons for not participating in the study were shortage of resources and lack of interest.

Sample

All 261 potential study participants were informed about the aims of our study in April 2010. The total sample at baseline consisted of 34 SHA and 104 participants (39.8% of all residents, see [Fig. 1](#)). All participants or their legal representatives signed the informed consent to be included into the study. During follow-up, 36 (34.6%) mostly older and more cognitively impaired persons dropped out of the study. A total of 68 persons participated in all measurements during 1-year follow-up period. A power calculation (G-Power v.3.0.10) for a repeated measurements ANCOVA for our main outcome parameter QoL (QUALIDEM, 10 subscales) with two groups, a Bonferroni-corrected $\alpha = 0.005$ and power $(1-\beta) = 0.95$ yielded a total sample size $n = 44$. We assumed a medium effect size ($d = 0.36$), which corresponds to a difference in five points on the QUALIDEM scales (0–100).

Outcome measures

A set of 39 evidence-based QIs was previously developed especially for SHA (Worch, et al., 2011) and was evaluated. Residents' QoL as well as ADL-functioning, cognitive impairment, need-driven behaviour and demographical factors were surveyed. The main outcome measure was QoL (QUALIDEM). Study nurses (registered nurses (RN)) were trained in conducting research interviews and assessed the QIs as well as residents' outcomes. Information was obtained using general documentation, nursing records and face-to-

face interviews blinded to group assignment. Proxy-ratings were performed by asking the staff.

Quality indicators

Quality requirements concerning all service providers in SHA are not wide spread. These are necessary for a sufficient care for the residents, which are predominantly with dementia. To identify care aspects of these people, which improve cognitive and functional capacity, quality of life or neuropsychiatric symptoms, we conducted a systematic literature research in databases CareLit[®], CINAHL[®], GeroLit[®] and PubMed[®] (Worch et al. (2011)) including 567 publications. Based on this, we developed a set of QIs for measurement and improvement of quality. The QIs include relevant aspects of structures, processes, outcomes (see [table 1](#)) and involve all service providers in SHA (nursing staff, medical practitioners, therapists, family caregivers, volunteers and landlords). Every QI - except the ratio of residents per staff persons in SHA - is expressed as the percentage of the available total number. The QIs partly refer to the setting SHA as a whole and partly in detail to all residents per SHA. Some QIs, focusing on service provision of health care providers, were only evaluated in the intervention group (see [table 1](#)) in order not to initiate quality development processes based on the QIs in the control group. A summative score for each resident was calculated counting the percentage of QIs being fulfilled. This QI-total-score is standardized from 0–100; all QIs were equally weighted. In order to measure the overall quality we recoded all available QI into dichotomous variables, with a value of one indicating a quality above average and a value of zero indicating a quality below average. The relative QI total score (0–100) was calculated by summing up the recoded variables and dividing the sum by the number of contributing QIs.

Cognitive impairment

The internationally validated performance-based instrument mini mental state examination (MMSE) was used to screen cognitive status (Folstein, Folstein, & McHugh, 1975). The MMSE contains 30 questions with a total range from 0–30 points, greater values indicating better cognitive abilities. To assess the severity of dementia, the Global Deterioration Scale (Reisberg, Ferris, de Leon, & Crook, 1982) was applied to grading residents into stages 1 (objectively normal person) to 7 (severe dementia). Higher values indicate an increasing stage of dementia. The instrument is both valid and reliable.

Neuropsychiatric symptoms

The presence of physical aggressive behaviour, physical non-aggressive behaviour and verbally agitated behaviour were measured using the Cohen–Mansfield agitation inventory (CMAI, Cohen-Mansfield, Marx, & Rosenthal, 1989), with proved validity and reliability.

Activities of daily living

Activities of daily living were measured by the Extended Barthel Index (EBI, Prosiegel et al., 1996), which shows sufficient validity and reliability. Sixteen variables describing activities of daily living and cognitive abilities are summed up to a total score ranging from 0 (completely dependent) to 64 (independent).

Quality of life

To evaluate QoL, the QUALIDEM was used (Ettema, Dröes, Lange, Mellenbergh, & Ribbe, 2007), which is especially applicable in SHA. Currently, the QUALIDEM is the best available instrument to assess (in terms of acceptance, reliability and validity) residents' QoL in SHA (Gräske, et al., 2013). The QUALIDEM is a proxy-rating instrument,

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