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Person-centered care and quality of life of patients with dementia in long-term care facilities

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ABSTRACT

Good quality of life (QOL) is an important goal of dementia care. However, there have been few studies on the relationship of care characteristics to QOL of dementia patients in long-term care facilities. We developed a questionnaire evaluating person-centered care and used it to assess person-centered care and QOL of elderly patients with dementia in both geriatric health service facilities (GHSF) and hospitals. In GHSF, person-centered care scores were not correlated with cognitive or activities of daily living (ADL) functions, but were significantly correlated with four subscale scores on a quality of life questionnaire for dementia (QOL-D) after controlling the effect of age, cognitive function, and ADL scores. In contrast, in hospitals, person-centered care scores were significantly correlated with cognitive and ADL function. We found quite different patterns in the relationship of person-centered care scores to clinical characteristics. Dementia care characteristics and QOL of dementia patients are significantly interrelated, especially in GHSF. Improvement of dementia care standards might affect the QOL of dementia patients. We should pay more attention to the quality of dementia care and QOL of dementia patients.

1. Introduction

Dementia is a syndrome characterized by a progressive decline in memory and cognitive functioning, and it is recognized as a major health problem in the elderly. The cognitive decline leads to increasing functional impairment and the eventual death of those affected (Murray and Boyd, 2009). The proportion of the elderly population is rapidly expanding in Japan, and individuals with dementia will become an increasingly important subgroup (Terada et al., 2002).

Providing a good quality of life (QOL) has been recognized as the main goal of currently available dementia care, and recently, much research on QOL of dementia patients has been performed. However, QOL is essentially subjective, and QOL ratings by patients with severe dementia are not necessarily reliable (Logsdon et al., 2002; Kurz et al., 2003). Therefore, many studies on the QOL of dementia patients were performed using QOL scales rated by caregivers.

Many factors affecting the QOL of dementia patients have been reported. Irritability, abulia, and troublesome behavior, as well as depression, in dementia patients were correlated with QOL when rated by caregivers (Hoe et al., 2006, 2007; Hurt et al., 2008), and dependency at the daily living and functional level was significantly negatively correlated with QOL as rated by caregivers (Snow et al., 2005; Hoe et al., 2006, 2007).

The relationship between the condition of caregivers and the QOL of dementia patients was also evaluated. Depression and mental health of caregivers are reported to be correlated with the QOL of dementia patients as rated by caregivers (Snow et al., 2005; Schiffczyk et al., 2010). A good relationship between patients and caregivers is also related to a better QOL of dementia patients (Zimmerman et al., 2005b). However, there are only a few empirical studies relating components of long-term care to the QOL of residents with dementia (Zimmerman et al., 2005a).

Recently, person-centered care has become valued in the field of dementia care (Murray and Boyd, 2009). The philosophy of person-centered care for persons with cognitive loss was first proposed by Kitwood (1997), and it reconceptualized dementia as a process dependent on not only the pathological process but also the social psychology of the person affected (Kitwood, 1993; Murray and Boyd, 2009). Although there is no universal consensus on the definition of the concept, some common aspects of

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person-centered care are: striving to maintain personhood in spite of declining cognitive ability (Normann et al., 1999); collecting and using personal experiences of life and relationships to individualize care and the environment (Post, 2000; Normann et al., 1999; Ettema et al., 2007); prioritizing relationships as much as care tasks (Sjögren et al., 2011); and involving family members in care and offering shared decision making (Sabat, 2005; Hughes et al., 2011; Van der Steen et al., 2011; Sjögren et al., 2011). Person-centered care is now thought to be very important in dementia care (Murray and Boyd, 2009). However, the relationship of person-centered care to QOL of dementia patients has not been clarified. In this study, we tried to elucidate the relationship of long-term care to QOL among dementia patients.

2. Methods

2.1. *Questionnaire evaluating person-centered care*

Using information obtained from caregiver interviews, expert opinion, and a comprehensive review of the literature (Dewing, 1999; Pritchard, 1999), questionnaire items evaluating the quality of person-centered care for patients with dementia were collected. To identify which items collected in the generation phase were the most useful for assessing person-centered care of the elderly with dementia, we conducted a preliminary survey. The item-generation phase produced 20 items.

2.2. *Preliminary survey*

The details of the preliminary survey have already been reported elsewhere (Terada et al., 2001). This preliminary survey consisted of two parts.

The first section of the questionnaire, including all items collected in the generation phase, was completed by members of the nursing staff who were well acquainted with the patients being rated. Six-hundred and one participants with dementia were rated. The questionnaire included 20 items and used a multi-response scale having 3-point options (the highest score was 2 and the lowest score was 0). The items with a graded scale of answers for one choice ($>70\%$ select one choice, $n=5$) or showing a high rate of no answers ($>10\%$, $n=3$) were excluded. In addition, the wording of some questionnaire items was revised so that they were more easily understood.

In the second section, caregivers were asked to rate the importance of each item for person-centered care using a 4-point scale (the maximum score was 3.0, and the minimum was 0). One-hundred forty-two answers were collected. Items with a mean score of less than 2.0 were removed ($n=4$). Thus, eight items were retained.

2.3. *Main field survey—Patient selection*

Representative facilities from each of the two major types of institutions caring for elderly people with dementia in Okayama Prefecture were asked to participate in the study. In total, three wards for dementia in geriatric hospitals and three geriatric health service facilities (GHSF) agreed to take part. All patients in these facilities with a diagnosis of dementia, except for bedridden persons, were included in this study.

Wards for dementia in geriatric hospitals were medical care wards to treat patients with behavioral and psychiatric symptoms of dementia. Geriatric health services facilities (“kaigo roujin hoken shisetsu” in Japanese) were created to provide nursing care and rehabilitation services to enable elderly persons who do not need to be hospitalized to return home. In both facilities, most persons are not bed-ridden and intensive care is supplied. In this study, these two types of facilities were selected and compared.

2.4. *Items evaluating person-centered care*

The eight items were: (1) Can the patient decide his/her daily schedule? (2) Can the patient choose the clothes he/she wears? (3) Can the patient consume nonessential grocery items (such as a little alcohol, tea, or coffee) whenever he/she wishes? (4) Can patient privacy be maintained during excretion? (5) Can the patient talk with his/her family when he/she wishes? (6) Does the patient talk to anyone? (7) Does the patient have many familiar personal items in his/her room? (8) Does the patient eat meals in a homey atmosphere?

The eight items evaluating person-centered care were rated using a four-point multi-response scale ranging from “not considered” (1) to “sufficiently considered” (4). The answer was determined as: “not considered,” not considered or almost always no; “slightly considered,” slightly considered or sometimes yes (less than 50%); “moderately considered,” moderately considered or usually yes (more than 50%); “sufficiently considered,” sufficiently considered or almost always yes. The total score for person-centered care was defined as the sum of the 8-item score divided by eight (therefore, the total score ranged from 1 to 4).

2.5. *Questionnaire table*

The profiles of the patients with dementia and the respondents to the questionnaires were investigated. The questionnaire items were the age, sex, living environment, and diagnosis of the patient with dementia, scores of the Nishimura Mental state scale (NM scale), Nishimura ADL scale (N-ADL scale), and QOL questionnaire for dementia (QOL-D) of the patients with dementia (Nishimura et al., 1993; Terada et al., 2002), and the age, sex, and occupation of the respondents.

The patients with Alzheimer’s disease (AD) met the American Psychiatric Association’s revised DSM-IV criteria for primary degenerative dementia of the Alzheimer type (APA, 1994) as well as the NINCDS-ADRDA criteria for probable or possible Alzheimer’s disease with cerebrovascular events (McKhann et al., 1984). The patients with vascular dementia (VaD) met the NINDS-AIREN criteria for probable vascular dementia (Román et al., 1993).

Cognitive impairment in dementia patients was assessed using the NM scale, which is a popular bedside screening measure of the cognitive components of mental status in Japan. The activities of daily living (ADL) were evaluated using the N-ADL scale, which is one of the most utilized scales for the evaluation of ADL in Japan (Nishimura et al., 1993). On both scales, the maximum score is 50, and the lowest possible score is zero. The NM scores are: normal, 48–50; borderline, 43–47; mild dementia, 31–42; moderate dementia, 17–30; and severe dementia, 0–16. On the N-ADL scale, five items are evaluated: walking/sitting, range of activities, dressing/bathing, eating, and excretion. Each item is given 0 to 10 points, and the total is regarded as the N-ADL scale score. The reliability of both scales when completed by nurses or nursing staffs has been reported to be good (Nishimura et al., 1993).

The QOL-D consists of 31 items grouped into six response sets, each with its own scale. Each item is rated using a four-point multi-response scale ranging from “none” (1 point) to “frequent” (4 points). The six domains are: (1) positive affect, (2) ability to communicate, (3) negative affect and actions, (4) spontaneity and activity, (5) restlessness, and (6) attachment to others. In four domains of the QOL-D (positive affect, ability to communicate, spontaneity and activity, and attachment to others), a high score means a higher QOL, whereas in two domains of the QOL-D (negative affect and actions and restlessness), a high score means a lower QOL. The reliability is good to excellent, and the validity is, to some extent, established (Terada et al., 2002).

2.6. *Respondents*

Questionnaires were completed for all subjects by members of the nursing staff who were well acquainted with and chiefly in charge of the participants being rated. All the raters had daily contact with the individuals being studied. No attempt was made to select raters, and no training beyond the instructions provided with the scale was given. In some cases, the physician in charge administered the instruments. Upon completion of the questions, the forms were returned by mail for scoring and item analysis.

2.7. *Reliability*

Internal consistency reliability within the eight items evaluating person-centered care was assessed using Cronbach’s coefficient alpha. Values >0.70 are conventionally considered acceptable (Cronbach and Meehl, 1955; Brod et al., 1999). In addition to the main field survey, 18 dementia patients were rated by four different evaluators. Moreover, test–retest reliability was evaluated by administering the questionnaire to another 18 dementia patients twice with a 4-wk interval. Interrater reliability and test–retest reliability were assessed by intraclass correlation coefficients (ICC).

2.8. *Statistical analysis*

Statistical analyses were performed using SPSS (Statistical Package for Social Science) software 18.0J. Correlations of care scores to age, NM scale scores, N-ADL scale scores, and six subscale scores of QOL-D were calculated using Pearson’s correlation coefficient. The partial correlation coefficient of care scores to six QOL-D subscale scores was calculated controlling for the effect of age, NM scale scores, and N-ADL scale scores. A p level of <0.05 was considered significant.