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SHORT REPORT

The long-term effect of group living homes versus regular nursing homes for people with dementia on psychological distress of informal caregivers

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Objective: In this follow-up study, the long-term influence of group living homes (GLHs) on informal caregiver distress was compared with modern yet regular nursing homes (NHs).

Method: Informal caregivers of GLH (N = 37) and NH residents (N = 49) were studied at the time of admission, 6 months thereafter, and approximately 24 months after admission. Repeated measures of ANOVA were performed to study group-by-time effects on psychopathology, role overload, and feelings of competence.

Result: All outcomes of psychological distress in GLH caregivers showed significantly greater decline compared with NH caregivers during the first six months after admission. The course of psychological distress stabilized in both caregiver groups after six months.

Conclusion: GLHs may have played a role in reducing caregiver burden during the first six months after the nursing home admission of the care recipient. The stabilization of caregivers’ psychological distress between T1 and T2 may indicate that there is no further room for improvement in the GLH and NH groups after six months. The implication would be that both GLHs and NHs succeeded in keeping caregivers’ distress relatively low over the long term. More knowledge is needed on whether and how caregivers’ psychological distress after institutionalization of the care recipient can be reduced to a greater extent.

Keywords: nursing home care; Alzheimer’s; family caregivers; psychological health; well-being

Introduction

Providing care to a person with dementia places a burden on informal caregivers and may have serious consequences for their mental health (Pinquart & Sörensen, 2003; Schulz & Martire, 2004). About 22% of the informal caregivers, for people with dementia, have a major depressive disorder (Cuijpers, 2005). Caregiver distress can persist after nursing home admission of the care recipient (Lieberman & Fisher, 2001; Pot, Deeg, & Van Dyck, 1997; Schulz et al., 2004), when new stressors related to nursing home (NH) placement may develop despite the alleviation of primary care tasks. Examples of such stressors are worries about the quality of care that is provided, and feelings of guilt or loneliness (Gaugler, 2005; Gaugler, Pot, & Zarit, 2007; Skaff, Pearlin, & Mullan, 1996).

The course of caregivers’ psychological distress after NH placement varies between individuals (Gaugler et al., 2007). Caregiver distress can be predicted not only by caregiver and resident characteristics (such as gender, behavioral problems of the person with dementia, and the type of relationship between the caregiver and care recipient), but also by adaptation to the NH setting by both the resident and the informal caregiver (Whitlatch, Schur, Noelker, Ejaz, & Looman, 2001). Adaptation to the NH setting is related in its turn to the communication and relationship with the nursing facility staff, and family involvement in the daily life of the resident (Chen, Sabir, Zimmerman, Suitor, & Pillemer, 2007; Gaugler, Anderson, Zarit, & Pearlin, 2004; Whitlatch et al., 2001).

Adaptation might be stimulated by small-scale care as provided in group living homes (GLHs) for people with dementia (Kihlgren, Bråne, Kuremyr, Leissner, & Norberg, 1992). GLHs are assumed to be better suited to the residential requirements and complex needs of persons with dementia, because they offer a more familiar, homelike, and safe environment than traditional NHs do (Day, Carreon, & Stump, 2000; Hammer, 1999). GLHs often serve as an intermediate between home care and the NH, but in the Netherlands, they are a substitute for regular NH care. Residents live together in small groups, usually consisting of six to eight people, and their daily lives are kept as “normal” as possible. Family members stay more involved in the daily life of the resident, being encouraged to visit their relative and to have dinner with the residents. In addition, they are more involved...
in decision making with regard to the care (Verbeek, Van Rossum, Zwakhalen, Kempen, & Hamers, 2008).

A previous study has shown GLHs to have moderately positive effects on residents’ quality of life compared with regular NHs (Te Boekhorst, Depla, De Lange, Pot, & Eefsting, 2009). GLHs might be more beneficial to informal caregivers as well, because the informal caregiver retains more influence on the daily life of the relative with dementia. In addition, it can be assumed that they adapt better to the new living situation of their family member.

The effect of GLHs on the psychological distress of informal caregivers was studied by Elmstahl, Ingvad, and Annerstedt (1998). This study was focused on GLHs in Sweden, where they serve as intermediates between the home and NH situations. Elmstahl et al. (1998) found a decrease in caregiver burden 12 months after the admission of the relative with dementia, but there was no control group. Colvez, Joël, Ponton-Sanchez, and Royer (2002) compared the burden of informal caregivers involved in five types of dementia care in Belgium, Denmark, France, Germany, Spain, and Sweden and found that informal caregivers of persons with dementia in GLHs were the least burdened, compared with those whose relatives used home social services, day centers, expert centers, and respite hospitalization. This finding applied to all countries investigated. Unfortunately, this study had a cross-sectional design, and the actual effect of GLHs on caregiver distress after admission was not investigated.

In 2004, we started to study the effect of Dutch GLHs on caregivers’ psychological distress as compared with regular NH facilities. Informal caregivers were studied at the time of the admission of the relative with dementia and six months thereafter, when the caregiver distress of informal caregivers of persons in both GLHs and NHs was found to have decreased enormously in this short period of time. The differences between the distress in the two groups at six months were not statistically significant, however, and we assumed that this lack of significance should be ascribed to an overall sense of relief immediately after admission (Te Boekhorst et al., 2008). We also assumed that the differences between both groups might become significant after a longer period of time, which led us to investigate the longer term effects of GLHs.

This study is focused on the following research question: Compared with regular modern NH care, what is the effect of GLHs on the decrease in psychological distress of informal caregivers approximately two years after their relatives’ admission with dementia?

Our hypothesis was that informal caregivers of people with dementia in GLHs would show a greater decrease in psychological distress in the long term than informal caregivers of people with dementia in regular NHs.

Methods

Sample

In the first two years of the study period, all informal caregivers of newly admitted residents in 19 participating GLHs and 7 NHs were asked to participate in this study. Only “archetypal” GLHs were included, meaning that they had a maximum of six residents per ward, a maximum of six wards per facility, and were located at least 200 meters from their mother facility. To ensure, the effect of GLHs was studied and not the effect of newer versus older facilities, only NHs built according to the Dutch 1997 Building Regulations for Nursing Homes were included. This regulation requires new facilities to offer single bedrooms to each resident, as is done in GLHs. These newer facilities also have a less hospital-like interior than traditional NHs, but the organization of care resembles that of traditional NHs: care is offered on larger wards and there are central housekeeping services such as meal delivery, laundry, and cleaning. All GLHs and NHs participating in this study were non-private facilities and had equal financial inputs per resident regulated by the Dutch government. The decision on placement in GLHs, modern NHs, or traditional NHs is not based on socio-economic or disease-related grounds.

Initial response rates from informal caregivers regarding participation were 85% in GLHs and 68% in NHs. Measurements were taken at the time of the admission of the relative with dementia (T0), six months thereafter (T1), and two years on average after admission of the relative with dementia (T2); 79 GLH informal caregivers and 131 NH informal caregivers completed the T0 questionnaire. It was possible to approach 41 informal caregivers of GLH residents and 64 informal caregivers of NH residents from this sample for the T2 data collection. Attrition was mainly due to the death of the relative with dementia (N = 84) and loss to follow-up (N = 10). Furthermore, although Dutch GLHs are intended to be complete substitutes for regular NHs where residents can stay until death, 11 relatives of GLH caregivers appeared to have been transferred to regular NHs, because their problems were perceived as too complex for the GLH situation.

The T2 questionnaire was actually completed by 37 caregivers of GLH residents and 49 caregivers of NH residents (response rate 90.2% and 76.6%). The 86 caregivers that were examined were compared to those who were unable to participate at T2 on gender, educational level, marital status, relationship with the resident, and the three outcomes of psychological distress assessed at baseline. The participants were significantly younger than non-participants, with a mean age of 54.8 years versus 58.0 years (p = 0.026), but no other variables were significant.

Measures

The demographics, gender, age, relationship to the resident, education, and marital status were assessed.
Psychological distress was measured with three instruments. First of all, the 12-item version of the General Health questionnaire (GHQ; Goldberg & Williams, 1998) was used as an indicator of psychopathology. It was ranked according to the alternative scaling for chronic psychopathology. Secondly, we used the Self-Perceived Pressure from Informal Care (SPPIC) questionnaire as an indicator of role overload resulting from the caregiving situation (Pot, Deeg, Van Dyck, & Jonker, 1998). The total SPPIC score was dichotomized on the median, because it was highly skewed to the left (Te Boekhorst et al., 2008). Lastly, caregivers’ feelings of competence were measured by the Caregiving Competence Scale (Pearlin, Mullan, Semple, & Skaff, 1990).

Since the T0 measurements were linked to times of new resident admissions and the T2 measurements all took place around March 2007, residents’ length of stay in the care facilities at T2 ranged from 11.6 to 34.9 months ($M = 23.97, SD = 6.44$). We adjusted all analyses for this variable.

**Data analysis**

Data for the respondents who participated at all three measurement points were investigated ($N = 86$). Mean scores for the outcome variables at T0, T1, and T2 were computed and repeated measures of ANOVA were done to examine the differences of change in psychological distress among the two caregiver groups over time (group-by-time interaction). The assumption of sphericity was met (Mauchly’s W $> 0.05$). We adjusted for the resident’s length of stay in the care facility, gender, relationship with the resident, and education, if these characteristics proved to be confounders.

**Results**

**Caregiver characteristics**

In the GLH sample, 81.1% was female, whereas it was 63.3% in the NH group. Education level was higher among GLH caregivers: 51.5% had a high education level compared with 34.7% of caregivers of NH residents. Mean age of GLH caregivers was lower (53.54 vs. 55.78 years). These differences in gender, education level, and age were not significant, but there was a significant difference between GLH and NH residents where the average length of stay was concerned (25.85 and 22.07 months, respectively, $p = 0.007$).

**Psychological distress**

At T0, caregivers of GLH residents scored significantly higher than caregivers of NH residents on the GHQ for chronic psychopathology ($p = 0.025$) and the SPPIC scale ($p = 0.019$), and lower on the Competence Scale ($p = 0.048$). The percentage of people with high scores ($\geq 2$) on the GHQ-12 was 86.5% for the GLH group and 87.5% for the NH group (see Table 1 for the mean scores on all outcome variables).

Repeated measures analysis showed a significant group-by-time interaction on role overload and feelings of competence, due to a relatively greater decline in psychological distress among GLH caregivers over time (SPPIC: $F(2, 162) = 4.84, p = 0.009$; Competence Scale: $F(2, 160) = 3.44, p = 0.034$). A trend in favor of the GLH caregivers was found for psychopathology (GHQ: $F(2, 164) = 2.94, p = 0.056$). Simple and repeated contrast analysis revealed that there was a significantly greater decline in all outcomes of psychological distress between T0 and T1 for GLH caregivers as compared with NH caregivers. The course of psychological distress between T1 and T2 was comparable for both caregiver groups (GHQ: $F(1, 162) = 0.097, p = 0.756$; SPPIC: $F(1, 116, p = 0.294$); and Competence Scale ($F = 0.851, p = 0.359$), as illustrated in Figure 1.

**Discussion**

In this follow-up study, the longer term effect of GLHs on informal caregiver distress was investigated in...
comparison with regular yet modern NH care. Both groups of caregivers showed a decline in psychological distress during the first six months after the nursing home admission of their relatives. Compared to the NH caregivers, however, the GLH caregivers started at a higher level in terms of psychological distress and showed more improvement. No differences in change in psychological distress were found between the two groups of caregivers from six months to two years after nursing home admission. Both groups remained relatively low in terms of psychological distress during this period as compared to their distress at admission.

The stabilization of caregivers’ psychological distress between T1 and T2 may indicate that there is no further room for improvement in the GLH and NH groups after six months. The implication would be that both GLHs and NHs succeeded in keeping caregivers’ distress relatively low over the long term.

GLHs may actually have played a role in reducing caregiver burden, but there are various reasons why we cannot draw the conclusion that the greater decrease in the psychological distress of GLH caregivers as compared with NH caregivers was an effect of the GLHs. First of all, this finding might be a result of selection at baseline. GLH caregivers suffered from higher psychological distress at baseline, which might indicate more emotional involvement or other differences in caregiver characteristics – such as personality aspects – that were not measured (Te Boekhorst et al., 2008). Furthermore, just 86 of the initial 210 informal caregivers were able to participate at all three measurement points. In most cases, the attrition was due to the death of the care recipient. It is possible that these remaining informal caregivers form a specific group that influenced our study findings (Gaugler et al., 2007), although post hoc analysis did not show differences in psychological distress at T0 between those who were and were not able to participate at T2.

It may be possible that in this study, the effect of GLHs was underestimated. Apart from loss to follow-up, there were lower response rates at both T1 and T2 in the NH group, which might have been related to more psychological distress or dissatisfaction with care among the caregivers. On the other hand, the effect of GLHs may have been overestimated, because 11 GLH residents were transferred to regular NHs during our study period because of complex care needs, which might have led to less psychological distress among the remaining GLH caregivers at follow-up, because deterioration of the relative with dementia is associated with caregiver distress (Burns, 2000). The lack of equivalency of treatment and control groups is an ongoing problem in services research (Zarit, Femia, & Stephens, 2003).

In this study, GLHs were compared with modern yet regular NHs. A more positive effect of GLHs might have been found when GLHs were compared with facilities built previous to the Dutch 1997 Building Regulations for Nursing Homes, still the most common care facilities for people with dementia in the Netherlands. The decision to include only modern NHs was made to ensure that potential effects were not caused by older facilities versus newer ones, when comparing GLHs with NHs. Furthermore, since many traditional NHs are modernizing, investigating traditional NHs would have been more or less obsolete.

The failure to find a greater effect for GLHs as compared to regular modern NHs may also be explained by the development that elements of GLH care are increasingly being integrated into regular NHs. At the start of this study, the participating GLHs and NHs differed significantly on several characteristics of GLH care (such as the nursing staff not wearing uniforms, or the absence of toileting rounds), but many changes may have been made during the next two years. The absence of a strict medical NH regime is becoming a common practice in all long-term dementia care settings in the Netherlands and the same applies to increasing family involvement. This may mean that the comparison of two apparently different care settings might have been too simplistic. In further research, we should focus more on the daily integration of characteristics of GLH care in different small-scale and large-scale settings. This recommendation is addressed not only to the field of informal caregiver burden, but also to research on job satisfaction and burn-out among nursing staff and on resident well-being.

It is important to note that, despite the decrease in caregivers’ psychological distress during the first six months after admission, approximately 70% was still suffering from high levels of psychological distress two years after the nursing home admission of their relative. More knowledge is needed, therefore, on whether it is possible to reduce caregivers’ psychological distress to a greater extent after institutionalization of the care recipient, and how this can be done. Where the continuing high level of psychological distress after admission is concerned, informal caregivers deserve the
full attention of health care professionals after NH placement of the care recipient.

References


