Social participation in home-living patients with mild Alzheimer’s disease

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Abstract

The purpose of this study was to investigate social participation in home-living patients with mild Alzheimer’s disease (AD) and to identify predictors for low social participation. The study was based on baseline data from 330 home-living patients with mild AD who participated in The Danish Alzheimer Intervention Study (DAISK). Proxy-obtained information from primary caregiver assessed patients’ social participation. The result showed that low social participation was present in mild AD. Significant independent predictors of low social participation were impairment in activities of daily living (ADL) and neuropsychiatric symptoms. The findings from this study add to the literature that social impairment is present even in the mild stage of AD. The findings underscore the importance of assessing social participation in mild AD as soon as few ADL skills are lost.

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1. Introduction

A fast growing number of population-based studies have recognized the benefits of social ties and relations on health outcome and mortality (Berkman and Syme, 1979; House et al.,...
This is particularly so among elderly people (Seeman, 2000; Avlund et al., 2002, 2004), and benefits seemingly extend to their well being (Farquhar, 1995), and abilities to cope with chronic disease (Kruse and Lehr, 1989). One pathway by which social relations may influence health status is social participation (SP) (Berkman et al., 2000). By definition, AD is associated with progressing impairment in social behavior and functioning, although the concept of social impairment is not clearly defined in the clinical diagnostic criteria for dementia and AD (McKhann et al., 1984; WHO, 1993; APA, 2000). One pathway by which social relations may influence the health status is by SP and social engagement (Berkman et al., 2000). Social disengagement, social isolation, and infrequent participation in social activities may be risk factors for cognitive decline in aging (Bassuk et al., 1999; Zunzunegui et al., 2003; Barnes et al., 2004). Engagement in stimulating social activities, an extensive social network, and a socially integrated lifestyle may reduce the risk of dementia (Fabrigoule et al., 1995; Fratiglioni et al., 2000, 2004; Wang et al., 2002).

Although little is known about the nature of social relations in the mild phase of the disease, AD is associated with impaired intellectual capacity, communication deficits, and functional impairment which may influence social relations. Further, AD patients may be exposed to social distancing as the disease progresses (Werner, 2005). Consequently, reduced social relations may expose AD patients to accelerated cognitive decline, and additional health risks.

The assessment of social impairment is challenging, social roles may be influenced by many factors other than health, and social norms vary between cultures; additionally, there is a lack of conceptual consensus in the literature. In this study we used the conceptual framework with social relations as the main concept and structure and function of social relations as sub-concepts (Fig. 1), as originally described by Due et al. (1999). In this framework the structure of social relations is defined as the nature and presence of individuals with whom one has a formal or informal relation (social network). Formal relationships, defined as social relations arising from one’s position and role in society, include various professionals (e.g., homecare assistants, dentists, lawyers). Informal relationships are defined as the social network, i.e., individuals and linkages between individuals, with whom one has a close family relation or friendship. SP, a measure of informal relations (social network), is assessed in three parts: (a) receiving visitors at home, (b) visiting others, and (c) participating in social activities outside home (Avlund et al., 1999, 2002, 2004; Sørensen et al., 2002). The function of social relations covers the qualitative and behavioral aspects of the social relations and comprises social support, relational strain and social anchorage (Fig. 1).
In the WHO International Classification of Functioning, Disability and Health (ICF), participation is a central element defined as involvement in a life situation from both an individual and a societal perspective (WHO, 2001).

Little knowledge exists about SP and possible determinants of low SP in patients with mild AD. We aimed to investigate SP in patients with mild AD and to identify predictors of low SP.

2. Methods

2.1. Study population

In this study we used baseline data from an ongoing longitudinal multi-center study, the DAISY (Waldemar et al., 2006b), which investigates the efficacy of an intensive structured intervention program with counseling and support to home-living patients with mild AD and their primary caregivers. To define AD as mild Mini Mental State Examination (MMSE) ≥20 point (range 0–30 points, high score means better cognitive function) (Folstein et al., 1975), was used.

2.2. Study design

DAISY was designed as a multi-center single-blind randomized controlled trial, with randomization to the intensive program or to usual care and 1 year follow-up, performed in 5 Danish regions: 3 rural regions, 1 urban and 1 mixed. Included were 330 home-living patients with a recent clinical diagnosis (<12 months) of probable AD, mixed AD (WHO, 1993; APA, 2000), or dementia with Lewy bodies (DLB) (McKeith et al., 1996) established or confirmed by the local specialist referral unit (memory clinic), age ≥50, and MMSE ≥20 point (range 0–30 point) (Folstein et al., 1975), and informed consent to participate in the study. Further, patients should have at least weekly contact with a primary caregiver willing to participate in the study, and informed consent. Excluded were patients with severe somatic or psychiatric co-morbidity, including impaired hearing or vision, which would significantly impair cooperation in the program, and those participating in other intervention studies at inclusion or during the study. Patients were recruited from local memory clinics; local specialists in psychiatry, neurology, and geriatrics; and GP’s. Announcements were mailed to relevant physicians and clinics in each area. All patients were outpatients, and if referred from private practice specialists or GP’s the diagnosis was confirmed by the local memory clinic. Referring physicians had an attempt to check in- and exclusion criterions prior to referral but the patients did not represent a consecutive series of patients. At baseline all patients and their primary caregiver were interviewed using separate, structured questionnaires. The interviews were performed by the local project-coordinator in each of the five centers. The caregivers’ interview included the AD Cooperative Study (ADCS-ADL) Inventory (Galasko et al., 1997): the ADCS-ADL scale, range 0–78 points with 78 points indicating high ADL function. Their interview also included the Neuropsychiatric Inventory Questionnaire (NPI-Q) (Kauf er et al., 2000), which has two scores: a score for severity and a score for distress. In this study we used the
score for severity (range 0–36) with 0 point indicating no neuropsychiatric symptoms. An MMSE was performed on all patients.

2.3. SP

The patients’ SP was assessed in the caregiver questionnaire and measured by three questions concerning the last months: (a) how often did he/she receive visitors at home? (b) How often did he/she visit others? And (c) how often did he/she participate in social activities outside home? The Pearson correlation coefficient between (a) and (b) is 0.567 \( (p = 0.0001) \), between (a) and (c) 0.223 \( (p = 0.0001) \) and between (b) and (c) 0.143 \( (p = 0.0018) \) (Avlund et al., 1999). The possible answers were: “once a week or more” (score 1), “less than once a week or never” (score 0) and “don’t know” (no score). Each patient was assigned a score of either 0 or 1 for each of the three questions. Thus the total composite score ranged from 0 to 3. If the information was not available for one or more of the three questions patients were excluded from the analyses. The remaining patients were dichotomized into two groups with low SP (total score 0–1 points) and high SP (total score 2–3 points), respectively and in accordance with earlier publications (Avlund et al., 1999, 2002, 2004; Sørensen et al., 2002).

2.4. Statistical analyses

Due to cluster effect between the five centers, probabilities and corresponding 95% confidence intervals were estimated using a Generalized Estimating Equation regression model. A multivariate model with backwards elimination was applied with a 5% significance level in order to identify predictors of low SP. According to previous papers (Avlund et al., 1999, 2002, 2004; Sørensen et al., 2002) we dichotomized patients into two groups with low SP (total score 0–1 points) and high SP (total score 2–3 points), respectively. If the information was not available for one or more of the three questions patients were excluded from the analyses.

Pearson’s chi-square was used to evaluate goodness of fit for the reduced model. A deviance approximately equal to its degrees of freedom was used as indicator of a good model fit. The following variables were included in the model: age, sex, living alone, caregiver status (spouse/not spouse) short vocational education, MMSE, ADCS-ADL, and NPI-Q severity scores. Short vocational education was defined as less than 3 years duration. In the multivariate analysis the ADCS-ADL score was categorized into three groups: severe ADL impairment = 0–50 points, moderate ADL impairment = 51–70 points, and minor ADL impairment = 71–78 points. The NPI-Q score for severity was dichotomized into: mild neuropsychiatric symptoms = score 0–9 points, and moderate to severe neuropsychiatric symptoms = score 10–36 points. All statistical analyses were performed using SAS, version 9.1, proc Gee (SAS Institute Inc., Cary, NC).

2.5. Ethics

The DAISY project was approved by the Danish Data Protection Agency (j. nr. 2003-41-3178). The local Scientific Ethical Committee has evaluated the project protocol (j. nr.
(KF) 02-005/04) and the project was registered in the Clinical Trial Database, ISRCTN74848736. All patients and caregivers gave informed consent to study participation.

3. Results

The socio-demographic data for patients and caregivers are given in Table 1. The mean age of the patients ± S.D. was 76.2 ± 7.2, ranging 54–92 years. In total 30.9% lived alone and 37.9% had more than 3 years’ vocational education. The mean age of caregivers was 66.0 ± 12.7, 33% were males. The majority of caregivers were spouses (65.2%), 27.9% were children, and 6.9% were others (e.g. friends and neighbors). Of all caregivers, 76.0% had daily contact, 18.5% had contact more than once a week, and 5.5% had contact once a week with the patient. Most patients (96%) received treatment with an acetylcholinesterase inhibitor (AChEI) (not in table).

Table 2 shows the distribution of scores for the three individual questions to assess SP. Most of the patients received visitors at home once a week or more (66.6%), while 39.9% visited others once a week or more, and 36.4% participated in social activities outside home once a week or more.

The cumulated score for SP could be calculated for 308 patients (93.3%), of whom 54.2% had low SP (score 0–1) and 45.8% had high SP (score 2–3) (Table 3).

The mean ADCS-ADL score for patients with low SP was 59.3 (95% CI = 57.7–61.1) and for those with high SP, 64.1 (95% CI = 62.4–65.8). The mean NPI-Q score for patients with low SP was 4.6 (95% CI = 4.0–5.2) and for those with high SP, 3.2 (95% CI = 2.6–

Table 1
Socio-demographic characteristics of patients and caregivers (N = 330)

<table>
<thead>
<tr>
<th></th>
<th>Patients</th>
<th>Caregivers</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age, mean ± S.D.</td>
<td>76.2 ± 7.2</td>
<td>66.0 ± 12.7</td>
</tr>
<tr>
<td>Male/female, N/N</td>
<td>151/179</td>
<td>110/220</td>
</tr>
<tr>
<td>Diagnosis: probable AD/mixed AD/Lewy body, N/N/N</td>
<td>239/82/9</td>
<td></td>
</tr>
<tr>
<td>Live alone/live with partner, N/N</td>
<td>102/228</td>
<td>38/292</td>
</tr>
<tr>
<td>Relation to patient</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Spouse, N (%)</td>
<td>–</td>
<td>215 (65.2)</td>
</tr>
<tr>
<td>Child, N (%)</td>
<td>–</td>
<td>92 (27.9)</td>
</tr>
<tr>
<td>Other relation, N (%)</td>
<td>–</td>
<td>23 (6.9)</td>
</tr>
<tr>
<td>Vocational education</td>
<td></td>
<td></td>
</tr>
<tr>
<td>None, N (%)</td>
<td>117 (35.5)</td>
<td>79 (23.9)</td>
</tr>
<tr>
<td>&lt;3 years, N (%)</td>
<td>74 (22.4)</td>
<td>95 (28.8)</td>
</tr>
<tr>
<td>≥3 years, N (%)</td>
<td>125 (37.9)</td>
<td>142 (43.0)</td>
</tr>
<tr>
<td>Unknown, N (%)</td>
<td>14 (4.2)</td>
<td>14 (4.2)</td>
</tr>
<tr>
<td>Contact frequency to patient</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Daily, N (%)</td>
<td></td>
<td>251 (76.0)</td>
</tr>
<tr>
<td>&gt;Once a week, N (%)</td>
<td></td>
<td>61 (18.5)</td>
</tr>
<tr>
<td>Once a week, N (%)</td>
<td></td>
<td>18 (5.5)</td>
</tr>
</tbody>
</table>
3.7). In the multivariate analysis (Table 4) with backwards elimination, significant predictors of low SP were ADCS-ADL \( \leq 50 \) (OR = 3.1, 95% CI = 1.8–6.9), ADCS-ADL 51–70 (OR = 1.5, 95% CI = 1.1–1.9), and NPI-Q total 10–36 (OR = 2.2, 95% CI = 1.1–4.3) while sex, age, living alone, spouse/not spouse and MMSE were not independent determinants. Model fit by Pearson’s chi-square = 1.0.

### 4. Discussion

Deterioration and impairment of social function and behavior is an integrated part of the AD syndrome, although none of the clinical diagnostic criteria include specific criteria for...
the level of social impairment (McKhann et al., 1984; WHO, 1993; APA, 2000). To our knowledge this paper is the first to quantitatively address SP in mild AD defined as the frequency of receiving visitors at home, visiting others, and participation in social activities outside home. This study on home-living patients with mild AD found that 54.2% had low SP. Impaired ADL and neuropsychiatric symptoms were significant independent predictors of low SP.

Social relations are recognized as having powerful effects on physical and mental health. In the literature, the term social relation is a comprehensive concept, and there are several sets of theories that form the foundation for the empirical investigation of social relations and their influence on health. As a consequence, conceptualization still lacks a strong consensus, and many terms are used loosely and interchangeably (Berkman et al., 2000). In this study we chose the conceptual framework with social relations as the main concept and the structure and the function of social relations as sub-concepts chosen (Due et al., 1999) (Fig. 1).

4.1. Predictors of SP

4.1.1. ADL

ADL impairment was found to be a significant, independent predictor of low SP. ADL impairment is an important pre-requisite for the clinical AD diagnosis, but the ADCS-ADL that was used as an instrument to assess ADL in this study does not include any items covering social relations. Before including ADCS-ADL into the multivariate analysis the variable was categorized into three levels to reflect minor, moderate and severe ADL-impairment, respectively. The progressive ADL impairment AD patients are exposed to demands a continuous strategy of adaptation. Nygård (2004) examined how patients and caregivers adapt to this challenge in mild to moderate stages of dementia. In an aggregated analysis of seven completed empirical studies Nygård (2004) found that patients used a rich variety of response strategies in everyday life. One of the strategies occurred when responsibility of ADL was allocated to someone in the social environment; then elements of passive accommodation were seen in the patient. This could be one of the causal elements in the close association between low SP and ADL impairment found in this study. The association between low SP and ADL is undoubtedly complex and other elements predicting low SP should be considered in future studies.

4.1.2. Neuropsychiatric symptoms

In this study neuropsychiatric symptoms were also a significant, independent predictor for low SP. Even in mild AD when only few neuropsychiatric symptoms are present, they may influence SP negatively. In a study (Shin et al., 2005) of 62 patients with mild and moderate AD it was found that patients’ and caregivers’ quality of life was affected negatively by neuropsychiatric symptoms. This is in line with findings in a prospective study (de Vugt et al., 2005), which indicate that caregivers’ emotional reaction to patients’ behavior is more important than problem behaviors per se in the decision to institutionalize patients. Senanarong et al. (2004) examined a non-pharmacological intervention for caregivers of home-living patients with dementia. They found that patients’ neuropsychiatric symptoms were reduced in the intervention group. Another intervention study
(Nobili et al., 2004) suggests that caregiver stress may be relieved by a structured intervention for them. Further research in non-pharmacological interventions to patients with neuropsychiatric symptoms and their caregivers are needed to get more knowledge about which elements are the most effective in the intervention.

4.2. SP

We chose to focus on SP for several reasons. In the WHO’s, ICF, participation is one of the core concepts. In that framework SP is defined as involvement in a life situation denoting aspects of functioning from a societal perspective (WHO, 2001). Social isolation has repeatedly been shown to prospectively predict mortality and serious morbidity in both general population samples (House et al., 1982, 1988; Berkman et al., 2000) and the elderly (Seeman, 2000; Avlund et al., 2002, 2004). Longitudinal population studies have shown independent associations between SP and survival (House et al., 1982; Lee, 2000). The method for assessment of SP was chosen because it is well validated (Avlund et al., 1999, 2002, 2004; Sørensen et al., 2002). The measure has good face validity, as it is a simple measure of core dimensions of the structure of social relations, it contains core elements of social life at home and outside home in the Danish culture, and it is based on three questions that must be answered in an unambiguous way.

4.2.1. Social participation in elderly populations

In a community based Danish population study it was found that 70% of 748 elderly individuals had low SP at age 75 years in 1989 and 49% of the 442 elderly individuals remaining in the study had low SP at age 80 years in 1994 (Sørensen et al., 2002). In our AD population 54.2% had low SP. Thus it seems that the AD patients had a relatively high SP compared to the general population. However, a direct comparison to our results presents difficulties, because the age interval of the patients in this study was broader (54–92 years old), they were required to have a primary caregiver with contact at least once a week, and thus by definition a higher SP, and they had a higher education (38% with education >3 years) as compared to the general population of persons <50 years old (15% with education >3 years) (Danish National Institute of Public Health, 2000). Finally the population data were obtained 17 and 12 years ago (Sørensen et al., 2002).

Results from a follow-up study among elderly Taiwanese persons found that participation in social activities outside the family may have greater impact in maintaining cognitive function than social contacts with family or non-relatives (Glei et al., 2005). In our study patients’ participation in social activities outside home was lower than social contacts with friends and family in both patients with high and low SP. In an on-going follow-up study the possible association between social activities outside the home and the cognitive decline in this patient sample will be examined.

4.2.2. SP and social isolation

In a 3-year follow-up study of 60 patients with mild to severe dementia Orrell et al. (2000) found that social isolation may be associated with reduced survival in persons with dementia, whereas social support and participation were associated with improved survival. Accordingly, SP in patients with AD should be studied in longitudinal design.
4.3. Patient population

The patients in this study belonged to a resourceful part of the AD population, as their diagnosis was disclosed in the mild phase of the disease. They were willing to participate in a comprehensive social research and intervention program, and all had a primary caregiver. Another resource was that 96% of the patients were on treatment with AChEI. In contrast, it was estimated that only 27% of all patients with AD (all stages) in Denmark are treated with anti-AD drugs (Waldemar et al., 2006a). Finally the patients’ vocational education was somewhat higher than in the general population (Danish National Institute of Public Health, 2000). The special attributes of this study population indicate that a selection bias must be taken into account when the results are compared to other population studies and in attempts to generalize the results. The results do not include the socially less privileged and isolated undiagnosed patients’ situation, which is a limitation of this study. Because the studied population is privileged with close contact to relatives we assume that low SP is even more present in a less privileged population. Further research is needed to clarify that.

5. Implications

Social impairment is present in mild AD and this study has shown that at this stage even a minor loss of ADL activities and mild neuropsychiatric symptoms are significant independent predictors of low SP. In addition, other studies (Bassuk et al., 1999; Zunzunegui et al., 2003; Barnes et al., 2004) have shown that in elderly people without dementia SP has a protective effect against cognitive decline. Consequently, the cognitive status of patients with AD may be threatened by both the progress of the disease and low SP. The low SP could be the first step towards social isolation, which is widely recognized as deleterious for health. The exact pathways between health and social relations are unknown.

This study could be helpful in the care planning for patients with AD, as it presents arguments for considering the patients’ SP as soon as minor losses of ADL activities and neuropsychiatric symptoms occur.

Prospective follow-up studies will be necessary to determine if a decline in ADL function and/or worsening of neuropsychiatric symptoms is related to decline in SP. In the multivariate analysis the cognitive level measured by MMSE did not turn out to predict low SP. The reason could be the high level of MMSE in the patients.

Further studies to examine which interventions are suitable and effective for prevention of low SP are needed. Prospective follow-up studies will be necessary to determine if an increased decline in ADL and/or worsening of neuropsychiatric symptoms is related to decline in SP.

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