Do communication breakdowns impact caregiver burden of informal caregivers of persons with Alzheimer's Dementia?

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Abstract

The present study critically evaluates the literature regarding the impact of communication breakdowns on caregiver (CG) burden of informal caregivers of individuals with Alzheimer's Dementia (AD). The study includes four single-group case studies with qualitative survey research. Results provide a somewhat suggestive relationship between communication breakdowns and informal caregiver burden. Further research is necessary to establish the extent of impact. As the number of individuals with AD increases, there will be an increasing need for clinicians to provide education and training for effective communication strategies to not only reduce CG burden but also improve kinship status and quality of life of persons with AD and their friends and family.

Introduction

Alzheimer's dementia (AD) is the most common form of dementia, accounting for 60-80% of all dementia cases. (Alzheimer's Association and the National Alliance for Caregiving, 2004). One of the major sources of dependency and substantial burden for informal caregivers (CG) of individuals with AD are communication difficulties. (Hendryx-Bedalov, 1999) 61% of CG of persons with AD are categorized as having the heaviest burden of care relative to the activities and time involved in care. (Alzheimer's Association and the National Alliance for Caregiving, 2004). CG burden, as it is termed, is defined as "the perceived impact of care tasks on caregiver's emotions and on their resources." (Savundranayagam et al, 2005).

Research in AD has focused on CG burden being primarily associated with disease-related factors such as problem behaviors and/or communication impairments. Within the context of AD, communication breakdowns can be a result of the neurodegenerative processes or due to "ineffective communication strategies." (Savundranayagam and Orange., 2011). Roberto et al, (1998) reported that compared to normal adults, individuals with AD "exhibit high incidence of circumlocution, use semantic jargon (non-sense words), display word-finding difficulties, and show reduced vocabulary diversity." These changes in the use of language reflect a breakdown in the ability of AD patients to use communication as a tool. As communication is a fundamental basis of all human relationships, impairment of language skills creates physical and emotional barriers that can compromise quality of life of these individuals and their relationships. (Richter et al. 1995)

Objectives

The objective of this paper was to critically review the literature to examine the impact of communication breakdowns on CG burden experienced by informal CGs of persons with Alzheimer's Dementia.

Methods

Search Strategy

Online databases including: PubMed, Medline (Ovid) and Google Scholar were used to locate articles using the following search terms:

1. Caregiver burden AND communication,
2. Communication problems AND caregiver burden, and
3. Alzheimer's AND caregiver burden

The search was limited to articles in English. Reference lists of selected articles were also searched for relevant articles.

Selection Criteria

Articles selected for inclusion were required to have participants that were informal CGs of persons with AD that reported on their experiences with caregiving.

Data Collection

The concentration of search criteria resulted in 4 single-group case studies with qualitative survey research.

Results

Roberto et al., (1998), examined communication patterns and in-home CG stress between individuals with AD and their spouses. A group of 14 CGs and spouses who had been diagnosed with AD within the last 5 years participated in the study. The participants were American born individuals with English as their primary language and no history of stroke and/or head injuries. Two structured discourse tasks were recorded in home settings and analyzed.

Results of this study indicated that couples who displayed the greatest dysfunction in communication strategies also reported the highest levels of CG stress, CG burden and behavioral problems in the individual with AD. Results were presented as sample conversations. No statistical analysis or numerical data was reported.

Due to its limitations, specifically the lack of statistical analyses provided, the study only provides somewhat suggestive evidence that dysfunctional communication increases the stress and burden placed on informal CGs.

Murray et al., (1999) performed a cross-national study to develop a profile of co-resident CGs (spouses) for people with Dementia of the Alzheimer's Type (DAT). The researchers examined: living arrangements, formal and informal support, service support, perceived burden of CGs and psychological wellbeing of CGs. A sample of 20 co-resident spouses caring for people with DAT (diagnosis within the last 2-3 years), completed a semi-structured interview, open-ended qualitative questions about experience of caring, as well as objective measures such as the Caregiver Burden Inventory (CBI) and General Health Questionnaire-12 (GHQ -12).

Results of the study identified language loss alongside behavioral problems as factors contributing to co-resident CG's high levels of burden and mental stress. Researchers acknowledged several notable limitations, including: subjectivity of the measures which were open to bias and recruitment of participants that could not be controlled for each country. Considering these limitations, this study provides suggestive evidence of the association between communication breakdown in individuals with AD and informal CG stress and burden.

Balkanska, Polina (2012) looked at main difficulties families caring for patients with dementia experience. A sample of 178 families from Sofia, Bulgaria participated in the study. Within the participant subset, 43% of care-recipients were individuals with Alzheimer's. Results showed that communication problems due to neurodegenerative processes were one of the 3 major sources of emotional strain and chronic distress.

Results of this study identified communication breakdowns as a factor contributing to CG stress. However, there were significant limitations to Balkanska's research, specifically the lack of information about participant recruitment and selection and nature of relationship between CG and care-recipient. In addition, due to the geographical limitation on the subject population, the results did not carry generalization potential. Therefore, though this paper describes communication breakdown as one of the key factors impacting CG stress and emotional strain, due to its significant limitation, it does not provide suggestive evidence.

Savundranayagam and Orange (2011), investigated the impact of CGs' appraisal of the effectiveness of their own communication strategies on CG burden when caring for individuals with AD. The study consisted of 84 informal CGs (family members) of individuals with AD. Participants answered questionnaires about appraisal of their communication strategies, problem behaviors and levels of the three types of burden: stress, relationship and objective burden. Results indicated that kinship status and effective communication strategies were significant factors and that higher appraisals of effective strategies of communication were linked to lower levels of stress and relationship burden.

Unlike other studies, this study focused on communicative strategies used by CGs as a mean to study the effect of communication impact on CG burden. The study had appropriate participant selection criteria, use of standardized questionnaires and appropriate statistical analyses. As a result, the article provides suggestive evidence that communication breakdowns, or in this case, the strategies used to facilitate communication with individuals with AD does have an impact on levels of CG burden.

Discussion and Conclusion

The present study sought to examine the relationship between burden of informal CGs and communication breakdowns in persons with AD. Taken together, these studies provided a somewhat suggestive relationship between communication breakdowns and its impact on CG burden, but more evidence is necessary to establish the extent of this impact.

Some of the limitations presented across the literature were as followed:

- Alongside communication breakdowns, all the studies also described behavioral problems as a co-occurring factor, confounding the impact of communication breakdown on CG burden.
- Recruitment and selection criteria could not be controlled across studies due to multiple factors such as geographical limitations, years since the diagnosis of persons with AD, as well as severity of the disease.

- Only half of the studies (2 out of 4), used objective measures such as standardized questionnaires (for example: CBI) to measure the effect of CG burden, instead of perceived reports from CGs alone.
- Due to the nature of the qualitative studies, there was also an increase of subjectivity in measures, as well as researcher and participant bias.

Overall, though these studies present a recurring relationship between communication breakdowns and CG burden of informal CG of persons with AD, the aforementioned limitations suggest further research is required to establish the extent of this impact.

Clinical Implications

As the number of individuals with AD increases, there will be an increasing need for clinicians to provide education and training for effective communication strategies to not only reduce CG burden but also improve kinship status and quality of life of persons with AD and their friends and family

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