Critical Review: The outcomes of communication skills training for the familial caregivers of people with dementia of the Alzheimer's type

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The purpose of this critical review is to examine the outcomes of communication skills training for the familial caregivers of people with dementia of the Alzheimer's type (DAT). Using a computerized database search strategy of studies published from 2000 to present, four papers were selected to be included in this review. Study designs include: within-groups repeated measures design, mixed within and between groups design, and randomized clinical trials. Results indicate that the research supports the training of communication strategies for familial caregivers of people with DAT; however, further research is required in order to specify the most effective means of training.

Introduction

Dementia is a syndrome of acquired, progressive, persistent decline in 3 of 5 spheres of mental activity: memory, language and communication, personality, visuospatial skills, and cognition (e.g., abstraction, reasoning, judgment) (Cummings, Benson, & LoVerme, 1980). A loss of language and communication was identified as the number one most difficult aspect to cope with when caring for a family member with Alzheimer's Disease (Murray, Schneider, Banerjee, & Mann, 1999) Approximately 500,000 Canadians have Alzheimer's disease or a related dementia; it is projected that this rate will climb to 1,125,200 by the year 2038 – in just one generation's time. The demand for long-term care will increase ten-fold. Approximately 50% of Canadians with dementia continue to live at home, leaving family members to be the primary caregivers (RISING, 2010). General education for caregivers of individuals with Dementia of the Alzheimer's Type (DAT) is a well-recognized element of care. Over half of these patients are cared for by familial caregivers; however, the empirical study of communication training for caregivers is emergent.

Objectives

After reading work by Orange and Colton-Hudson, 1998, combined with personal exposure to an individual with dementia in the clinical setting, I became very motivated to learn more about effective communication with individuals who have dementia of the Alzheimer's type. The primary objective of this review is to critically evaluate the existing literature regarding the outcomes of communication skills training for the familial caregivers of people with dementia of the Alzheimer's type.

Methods

Search Strategy

Computerized databases, including CINAHL, SCOPUS, and PubMed, were searched using the following search strategy: ((Alzheimer's disease) OR (Alzheimer's dementia)) AND ((communication skills training) OR (communication) OR (communication strategies) OR (communication training)) AND ((caregiver) OR (familial caregiver)). The search was limited to articles written from 2000 to 2010.

Selection Criteria

Studies selected for inclusion in this critical review paper investigated the effect of communication skills training on familial caregivers of a person with DAT. Position papers, conceptual papers, non-systematic literature reviews, incomplete reviews, those that examined the effects on professional (as opposed to familial) caregivers, and papers published before 2000 were excluded.

Data Collection

Results of the literature search yielded the following types of articles congruent with the aforementioned selection criteria: randomized clinical trial (RCT) (2), within-groups repeated measure design (1), and a mixed within and between groups design (1).

Results

Strengths Across All Studies Reviewed:

Originality: Each of the papers examined was an original study, which added to the body of literature in this area. Haberstroh, Neumeyer, Schmitz, Perels, and Pantel, 2006, introduced the "TAnDem Training Program", Done and Thomas 2002 compared caregiver training via workshop vs. an information booklet, Roque, Oritz, Araujo, and Bertolucci, 2009 branched out from the type of communication training provided to carers of persons with aphasia and applied it to Alzeimer's dementia, and Weinrich, Jensen, and Hughes, 2006 looked at differentiating familial from professional caregivers.

Specific inclusion and exclusion criteria: Each of the four studies reviewed clearly stated both inclusion and exclusion criteria required of participants.

Sensible study design: All studies reviewed used a research design method appropriate to the type of

question being asked. All studies used statistical tests to evaluate their results.

Similar recommendations: All studies indicate benefits to training familial caregivers of persons with DAT.

Randomized Control Studies:
RCTs are the most powerful of all study designs and are accepted as providing high levels of evidence because the randomization allows both variables of interest and potentially confounding variables to be equally distributed, allowing for comparison between groups. Also, blinding eliminates researcher bias. Controls being used allow comparisons to similar groups to be made. However, threats to reliability and/or validity may constrain conclusions.

Study # 1:
A 2001 study by Done et al examined whether therapist-led workshops are more effective than a booklet in enhancing knowledge about effective communication strategies; if it reduced the frequency of communication problems experienced by the caregiver back at home; and if it reduced the level of distress that arises specifically from communication problems. There were 45 participants; 30 were assigned to the workshop group and 15 to the booklet group. The research design was a randomized clinical trail using weighted block randomization. Data was taken pre and six weeks post on five measures: Assessment of Awareness about Communication Strategies, Carer Stress, The Thomas Assessment of Communication Inadequacy and a consumer evaluation which contained both Likert scales and a qualitative component. The data was analyzed by an analysis of variance (ANOVA), percentages between groups on the scale, and identifying main themes in the qualitative data. The study concluded that there was greater improvement of knowledge about effective communication in the workshop group compared to the booklet only group, and benefits were more frequently reported in the workshop group. The ability to manage problems at home improved for both groups, and neither group.

Strengths: The authors were clear regarding the outcomes they wanted to measure. The researchers recognized that there were no appropriate tests to capture the desired outcome measures, and thus created their own. This study also has the largest sample size (n=45) of all studies reviewed in this area, making it more able to generalize results. The quantitative results were analyzed according to the original study protocol, and confidence intervals were provided.

Limitations: It is not known if the outcomes of the study are generalizable to 'real-life' conditions, as carers were not observed in interactions with the person with DAT. The authors did not state if they determined whether the groups are comparable or if they adjusted for baseline differences – parametric tests were used in spite of this. Additionally, the qualitative analysis appeared to be an 'add-on'; by standards of rigor for qualitative research it is unsatisfactory and there is not enough detail provided to assess what was done. Insufficient detail was provided to determine if assessment was blind. The assessment tools developed by the researchers have not been validated.

Evaluation: This study provides level 1b evidence (OCEBM), is well designed and provides suggestive to compelling evidence for the effectiveness of caregiver training. The results of this study indicate that training provided via a workshop is preferable to a booklet in terms of increasing knowledge of communicative strategies and carer's preferences. However, small sample size, lack of long-term follow-up, and unclear statistical analysis make it difficult to ascertain the strength of the results.

Study # 2:
In 2006, a study by Haberstroh et al attempted to increase the knowledge of the caregiver to the issues of communication with a person with dementia, to improve the communicative competence of the caregiver when face-to-face with the patient, to decrease the subjective perceived burden of the caregiver in household maintenance and to increase the quality of life of the person with dementia. There were 35 participants. The 13 participants assigned to the waiting group for treatment were used as the control. 22 participants (10 men and 12 women) received the training. The research design used was a randomized clinical trial with a waiting group control. TAnDem training for caregivers was provided once a week for five weeks from 3:00 – 5:30 in the afternoon. An ANOVA was used to examine the knowledge of communication with a person with dementia, the burden of household care/maintenance, and the quality of life of the person with dementia. Additionally, the researchers examined the slope of a regression line in order to determine significance. Results showed that post training there was a significant effect on knowledge of the caregivers and the quality of life of the person with dementia; however, the burden on caregivers was not affected.

Strengths: The authors clearly outlined the four outcomes they wished to examine through their study. References were available to validate tests administered upon request from the authors; however, I was unable to access them to verify as the training manual is soon to be published and the authors are no longer permitted to provide them upon request. Appropriate tests were used to determine significance.

Limitations: This paper is not available in English, which has made this work unknown to many top Canadian researchers. It was unclear specifically how each of the desired outcomes was in fact measured; it appeared to have been paper tests without 'real-life' application. Insufficient detail was provided to determine if assessment was truly blind, nor were participants randomized to their groups, as caregiver preferences to available dates were taken into account. Information regarding the control group was not provided. The sample size was small, and this makes it difficult to generalize results. The authors did not state if they determined whether the groups are comparable or if they adjusted for baseline differences – parametric tests were used in spite of this. As such, this is best viewed as a pilot study. The authors developed their own opinionaire/ questionnaire, but this was not provided and thus was not able to be assessed. Additionally, the format of carer diaries was not provided. Furthermore when no significant differences were found when analyzing three factors, the authors then looked at sub-factors. By splitting data and overanalyzing, one will eventually find statistical significance somewhere. This suggests that the data may not have been analyzed in accordance with the original study protocol. Moreover figures could have been more descriptive; as a result, I was unable to assess if outliers were present, and if so how they were interpreted, nor could p-values be independently determined. Lastly, confidence intervals for the data were not provided.

Evaluation: This study provided level 1b evidence (OCEBM). Given the limitations noted, the overall validity of the study is suggestive; however, the overall clinical importance of the study is compelling. This study is promising in that it presents a new method of training caregivers of people with DAT in communication strategies. There are some major methodological holes in the design; however, there is much potential for further work on this project. This study shows benefits of caregiver training; however, a lack of some specific details makes clinical application difficult.

Within Repeated Measures Design:
In a within subjects repeated measure design, every participant is subject to every treatment including the control. Participants act as their own control, which reduces error that would be present from individual variability between different people.

Study # 3:
In a 2009 paper by Roque et al, the effectiveness of a communication strategies training program for caregivers of patients with moderate Alzheimer's disease was evaluated. Participants included seven female familial caregivers of seniors with moderate Alzheimer's dementia who had been using glutamate receptor antagonists or acetylcholinesterase inhibitors for at least three months and seven individuals with AD. The research design used was a within groups repeated measures design. Specific measures included questionnaires before training and a film recording of an interactive situation between the caregiver and patient; measures were repeated seven to twenty-one days after training. Two evaluators who were blind to whether the film was made before or after intervention analyzed the video. Strategies were divided into two groups: presence or absence of strategies when filming, and frequency of strategy presence. Data were analyzed using a Komogorov-Simirnove statistical test of adherence to determine non-normality of the data. The Wilcoxon paired samples test was used to compare the frequency and effectiveness of the strategies being used before and after intervention. The Spearman Correlation verified the correlation between use and the effectiveness of the strategies by the caregivers. Caregivers reported the training had a positive impact on them. The authors stated that the program was able to promote changes in the communicative behavior of caregivers effectively and increase the use of strategies.

Strengths: This study captured 'real-life' conversational situations by filming interactions between the caregiver and patient during mealtimes and enabled researchers to objectively observe the use of communication strategies as opposed to the perceived outcomes of carers as reported by prior studies. Blinding observers to whether the films were made pre or post training minimized researcher bias. The researchers were clear about the desired outcomes they wanted to measure. Additionally, the authors recognized that their data was not normally distributed and analyzed it using non-parametric statistical tests.

Limitations: There was a small sample size, which makes generalization of findings problematic. There were some aspects of analysis that could have been better rationalized and explained for the reader. For example, although having begun to analyze the data using non-parametric assessments and stated that they would be using a Spearman's Rank Correlation Coefficient (σ - rho), the authors than stated an '*r* value', which is associated with Pearson's correlation coefficient and would be used to analyze parametric data. This is odd as the authors had already used a paired Wilcoxon test as opposed to a *t* test to analyze the data non-parametrically; no explanation was provided for this. It was not possible to independently analyze whether the data had been evaluated according to the original study protocol because the results lacked sufficient detail. This also prevents one from observing if there were any outliers in the data and if so, what adjustments may have been made. Confidence intervals for the data were not provided, and as the raw data was not given, it is not

possible to determine whether the p-values were calculated and interpreted correctly. Despite having found no statistically significant difference before and after carer training, the authors hypothesized several reasons why this might be and then went on to conclude overall that carer training is effective.

Evaluation: This study provided level 2b evidence (OCEBM) and in light of the limitations noted, conclusions from this study should be examined with caution. Therefore, the results are considered to be equivocal. While this study agrees with previous research that carer's perceptions of communicative competence with a person with dementia improve after training, problems with methodology and statistical analysis do not allow for concluding training is effective, as the authors did. Moreover, the specific details of what was trained and how were not provided, making the reproducibility and clinical application of these methods impossible.

Mixed Design:
In a between groups design, participants can be in either the control group or the experimental group; however, they cannot be in both. When this is combined with a pre and post measurement within a group – as in a within groups design – this is referred to as mixed design.

Study # 4:
In 2006, Weinrich et al examined the effectiveness of short-term communication counseling on decreasing daily hassles for caregivers, improving communication between the person with AD and the caregiver, and to increase the caregiver's knowledge of the communication problems that are associated with AD and how to manage them. Participants included 2 groups of caregivers - 13 professional caregivers and 6 familial caregivers of individuals with AD. (For the purposes of this review, the outcomes of the familial caregivers will be examined). The research design used was mixed - both between and within groups. Specific measurements included a caregiving hassles scale, a communication perceptions questionnaire, and a knowledge survey. Participants filled these out pre-counseling and again following two ninety-minute communication counseling sessions. The data were analyzed using paired t tests for pre and post measures. Independent sample t tests were used for all measures to compare between groups. The study concluded that brief communication counseling significantly increases awareness of communication strategies for improving interactions with persons with AD. There were no significant changes in level of hassles and no significant changes in that counseling caregiver's changes their perception of their communicative interaction with the person with AD for family caregivers. The study also found that the satisfaction level of caregivers when communicating with the person with AD changed.

Strengths: This paper presented very specific outcomes and was clear about how they would be measured. Appropriate statistical analysis was conducted.

Limitations: This study evaluated only perceived differences and did not evaluate the caregivers in 'real-life' situations. The authors did not state if they determined whether the groups are comparable or if they adjusted for baseline differences – parametric tests were used in spite of this. Another possible limitation was that the participants weren't necessarily blinded as they were informed before the study that they would do before and after evaluations. A sample size of 6 familial caregivers is too small to generalize data from; however, the authors noted this and determined this to be a pilot study. Not all of the data collected was provided, so it is not possible to determine if the data was analyzed according to the original study protocol, whether any outliers were present in the data, nor any statistical adjustments that may have been made. Confidence intervals were not provided for the data, and as not all data was given, it is not possible to calculate p-values independently and assess their interpretation.

Evaluation: This study provided level 2b evidence (OCEBM). Given the limitations of the study, the validity is suggestive; however, the overall clinical importance of the study is compelling. This study agrees with previous research that the training of communication skills increases awareness of communication strategies to improve interactions with a person with DAT. However, as the study did not examine these strategies in real-life contexts, it cannot be ascertained the effectiveness of them in daily living.

Limitations Across All Studies Reviewed:
Participants: All studies failed to give sufficient information regarding participants and/or their recruitment. Roque et al cited participants as being gathered "from records" without further detail. Weinrich et al. stated that potential caregivers were affiliated with an assisted living center; however, it was not mentioned how many people there were in total associated with the assisted living center nor how they were recruited for the study. Done et al. did not provide participant age, gender, education, and the relationship to the person with DAT or the dementia stage. Haberstroh et al did not provide background information on the control participants.

Systematic Bias:
Weinrich et al introduced experimenter bias by informing participants in advance that they would fill out pre and post tests. Roque et al did not treat groups equally with the exception of the intervention, as five of the seven

caregivers were provided with information prior to training. No rationale was given for this, and participants were then not split for statistical analysis. Both Done et al and Haberstroh et al have potential for recruitment bias as participants were recruited via self-inclusion. This may have biased only those highly motivated individuals to participate. Furthermore, in both Done and Haberstroh, these "RCT's" were not truly randomized. Done used weight block randomization, which was done by geographical location. This provides potential for socioeconomic differences between the groups; however, the data is not provided so verification is not possible. Haberstroh allocated participants to groups as per their time preferences, not through random assignment.

Small Sample Sizes: A major limitation of these studies is the small sample sizes. This causes the power to be insufficient which may have led to type II statistical errors.

Duration of Follow-Up: None of the studies had long-term follow-up. As dementia is a progressive disease, this makes it difficult to determine long term effects of caregiver training as the disease for the person with DAT progresses.

Non-Reproducibility of Training:
Only Weinrich et al provided specific details of the training that was administered. Roque et al never specifically states how training occurs or what strategies are trained; they only provide a chart of 20 observed strategies. Haberstroh introduces the TAnDem training program; however, the authors fail to provide specifics in the paper. While the paper did indicate the reader could contact the author for specifics, the writer has yet to receive a reply. Done et al used the Assessment of Awareness about Communication Strategies (AACS) test, which they developed for the purpose of this study. However, a copy of the AACS, the transcript, and the tips taught for each of the ten communication breakdowns was not provided. A reference was provided for the booklet though. The lack of reproducibility of training is a major limitation of the studies reviewed, as it eliminates much of the clinical application a reader hopes to glean from these papers.

"Bottom Line" Not Discussed: None of the papers make reference to relative risk reduction, absolute risk reduction in treated groups, or the number needed to treat when considering the communication training intervention vs. no intervention at all.

Discussion

This paper critically reviewed the outcomes of communication skills training on the familial caregivers of people with DAT. Although there is clearly a need for additional research in this area, the studies included in this review provide a moderate level of evidence for the effectiveness of training communication strategies to the familial caregivers of people with DAT.

Despite methodological flaws, all studies examined consistently reported benefits of training the familial caregiver; however, since the specifics of training were not provided, clinicians are unable to incorporate said strategies into his or her practice making clinical verification of the effectiveness of these strategies impossible. Currently all published studies in this area contain small sample sizes and no research has moved beyond a pilot study stage. This could potentially be due to reasons such as a lack of funding, challenges in recruitment, or a lack of knowledge on the part of the public to push for more research as deteriorating diseases of older adults, such as Alzheimer's dementia, are on the increase in the developing world as population ages, and will strain our already limited health care resources.

While the studies evaluated did not show a reduction in caregiver burden, knowledge of caregiver communication strategies increased. Breakdowns in communication lead to earlier institutionalization of older adults. If familial caregivers are better equipped with strategies to promote positive communicative interactions, this may lead to a delay in institutionalization time, thus increasing the quality of life and relationships for persons with DAT and their familial caregivers, as well as decrease the economic burden on an already taxed health care system.

Recommendations

Future Research

- Large-scale studies need to be conducted to elucidate specific strategies that are and are not effective to improve communication between persons with DAT and their familial caregivers.

- Studies are needed to identify the relative benefit of communication skills strategy training to familial caregivers of persons with different stages of DAT.

- Evaluation of the amount of benefit communication training skills training has relative to other types of intervention is warranted.

Conclusion

The body of evidence that familial caregivers of people with DAT benefit from communication skills training continues to grow. This offers hope for increasing family support while decreasing the economic burden to the health care system relative to institutionalization of older adults with DAT.

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