

Critical Review:

Does communication training for informal caregivers aid people with dementia's quality of life?

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This critical review examines the literature on communication training for informal caregivers and quality of life outcomes for their family members with dementia. Included studies are all randomized clinical trials. The evidence provided is suggestive of an increase in quality of life following intervention. Clinical recommendations and suggestions for further research are included.

Introduction

The number of people living with dementia is rising in Canada, with a projected doubling by 2031 (ASC, 2012). Many people with dementia receive care at home from family caregivers, and often they prefer to stay in their own homes (Schultz, 2002). Communication between people with dementia and their family members can be a significant challenge, so caregiver communication training programs have been developed to help family and professional caregivers cope with the challenges of providing such care (Ripich, Wykle, & Niles, 1995). The training has not been uniform, but can include DVDs, group training, or individual training (Ripich, Wykle, & Niles, 1995; Done & Thomas, 2001; Haberstroh, Neumeyer, Krause, Franzmann, & Pantel, 2011; Liddle et al., 2012; Terri, McCurry, Logsdon, & Gibbons, 2005).

Many studies of communication training provide evaluative measures of the effects of the training on the caregiver's quality of life and caregiver burden (Schulz et al., 2002). There are few studies, however, that examine whether such training improves the quality of life for people with dementia. The role of Speech Language Pathologists should encompass educating caregivers, advocating for clients with dementia, and providing interventions that demonstrate clinical benefit (ASHA, 2005). Therefore, understanding whether caregiver communication training does indeed improve quality of life is an important clinical question.

Quality of life is subjective, and can include concepts such as general feelings about one's life, as well as social, physical, and psychological aspects (Logsdon, 2002). The communicative and cognitive challenges of dementia can make quality of life measures difficult to obtain. In moderate and severe stages of dementia, proxy reports are necessary. (Ready & Ott, 2003). Nevertheless, quality of life is one aspect of general

well-being that should be assessed for clients with dementia.

Objectives

The primary objective of this critical review is to analyze the body of research examining effects of communication training for informal caregivers of people with dementia on the quality of life of the people with dementia. As well, implications for clinical practice and further avenues of research will be discussed.

Methods

Search Strategy

Computerized databases such as CINAHL, SCOPUS, PubMed, and Google Scholar were searched using the following terms: (dementia AND caregiver training AND communication). Reviewing the references of an article found through these searches provided more studies for review.

Selection Criteria

Included papers were required to provide a quality of life measure for adults with dementia (Alzheimer's type, vascular dementia, or mixed etiology) who lived at home. Communication intervention needed to be provided for their informal caregivers. The quality of life measurement did not need to be the main focus of the research. The type of caregiver communication intervention and the method of measuring quality of life were not specified.

Data Collection

The literature review revealed 3 papers that met the selection criteria described above. All were mixed randomized clinical trials.

Results

Randomized clinical trials (RCTs) provide a strong level of evidence for an intervention. Because participants are randomly assigned into intervention and control groups, a change in outcome measures is likely due to the intervention and not other factors.

Haberstroh et al. (2011) researched the effects of TANDEM communication training for 22 in-home caregivers on the quality of life of care receivers with either Alzheimer's Disease, Vascular Dementia, or a dementia of mixed etiology. Treatment consisted of 5 weekly sessions on attention, comprehension, remembering, and self-help led by a professional trainer, followed by a continuing support group to facilitate maintenance. Controls were waitlisted to receive the same training. Testing was completed pre- and post-intervention for both the intervention and control groups. Quality of life was measured via proxy reports of caregivers on the QoL-AD.

Appropriate ANOVAs on results of caregiver-completed QoL-AD showed post-training improvements in quality of life for the treatment group only.

In Haberstroh et al.'s study (2011) the QoL-AD was answered by caregivers in proxy. This is of concern because the caregivers who participated in the intervention were required to keep daily diaries, and doing so may have made them more sensitive to the care receivers' quality of life independent of the TANDEM intervention. The QoL-AD is also designed to be answered by both the caregiver and the care receiver, so using only the proxy reports raises questions as to the validity of the results. The participants in this study were all Caucasian, which causes concern with generalizing the study's results to other populations. Finally, although the study began with random allocation, two participants moved from intervention to control due to time constraints, possibly affecting the validity of the results.

The study was well-designed. However, the above concerns limit the clinical relevance of this research. Overall this study provides a suggestive level of evidence.

Liddle et al. (2012) examined the effects of MESSAGE and RECAPS training for their informal caregivers on the well-being of 36 (29 completing) people with medically-diagnosed dementia. Two in-home DVD-based training sessions were provided, which taught communication (MESSAGE) and memory (RECAPS) strategies to caregivers. Two researchers (either psychologists or speech pathologists) oversaw training

sessions, answered any questions, and collected outcome data. Testing was completed pre-intervention and 3 months later for both the intervention and control groups. Care receivers' quality of life was measured with the Cornell Scale for Depression in Dementia (CSDD) and completed by the caregiver during an interview. The researchers also designed a 5-point Likert scale with faces from unhappy to happy for the person with dementia to complete.

Appropriate analysis of the CSDD and the Likert scale showed no significant difference between intervention and control groups. However, data did show an approach to significance for reports of frequency of depressive behaviours reported by caregivers in the intervention group.

Several methodological factors hinder the results of Liddle et al.'s (2012) research. First, both quality of life measurements used may have provided inaccurate results. The CSDD is designed to be completed by both the person with dementia and the family member, but was only completed by the family member due to burden. Because this test was completed via a proxy report by family members unblinded to the condition, the results are less reliable. The Likert face scale has validity concerns, as it was used in a population who has been found to have impaired emotional recognition (García-Rodríguez, Casares-Guillén, Ellgring, & Frank, 2012). Another concern is the reason for increased frequency of depressive behaviours. Caregivers who received the training might report more depressive behaviours simply because the training may sensitize them to depressive behaviours they have not previously noticed. All of the data may be affected by the fact that those who collected the data were not blinded to the condition of participants, which may have altered their interview style, and thus, responses. Finally, internal validity is a concern due to only 81% of initial participants completing post-test measures.

The concerns above reduce the level of evidence provided by Liddle et al.'s (2012) work. Overall, this study provides an equivocal level of evidence.

Teri, McCurry, Logsdon, and Gibbons (2005) studied the quality of life of 95 family caregivers and care recipients who were diagnosed with possible or probable Alzheimer's disease following their caregiver's participation in STAR therapy. STAR therapy included training in communication, strategies for helping with problem behaviours, and increasing support for the caregivers. Consultants in STAR therapy met the participants in their homes each week for 8 weeks, then called them once a month for 4 months. Testing was administered pre-intervention, post-intervention (2

months, with 83 responses), and at 6 months (with 66 responses). Quality of life for care receivers was measured via the QoL-AD, which was completed both by care recipients and by their caregivers. However, only data for proxy reports were given in the paper.

An appropriate statistical general estimating equation was used, which the authors report is considered to have advantage over other methods when analyzed. Caregivers in the intervention group reported significantly greater quality of life for their family members at the 2-month testing compared to those in the control group. At the 6-month follow up, there was still a trend for reported higher quality of life, and it was statistically significant when controlled for ethnicity.

Interviewers in this study were blind to treatment assignment, which strengthens the evidence (due to the lack of possible bias in the interview process). However, the 69% response rate to the 6-month follow-up raises concerns about internal validity. The proxy QoL reports also affect the strength of evidence due to the possible bias on the part of the family members (who were necessarily unblinded to treatment condition), lack of inter-rater reliability measures, and the fact that the QoL-AD was not administered as designed.

The response rate and the use of proxy reports diminish the ability to rely on this research clinically. Teri et al.'s (2005) study provides a suggestive level of evidence as a whole.

Discussion

Research shows mixed results regarding quality of life outcomes for people with dementia following their family members' participation in communication training. Two of the three studies did find significantly improved quality of life following caregiver communication training. The third study (Liddle et al., 2012) did not, but inherent limitations in its design and in participant attrition limit its level of evidence.

The fact that all studies were randomized does give credence to the results. Although blinding was not always present, and one study (Haberstroh et al., 2011) did not end up being entirely randomized, the overall evidence is stronger due to the randomized design.

Results are difficult to interpret, due to differences in type, duration, and follow-up between studies (though all had a common theme of communication training). The population also causes challenges with study, due to the high caregiver burden, possible co-morbidities

due to age in general, and degenerative nature of the condition meaning that participant loss is likely over time, as seen in the reviewed studies. Therefore, long-term follow-up would be difficult to complete. The fairly homogeneous participants in the studies are also a limitation for generalizability of the study results.

Proxy reports of QoL throughout the studies are of concern because they may provide inaccurate data on care receivers' true quality of life. However, they are often unavoidable in this population, due to the inherent cognitive and communication difficulties. Current QoL measures such as the QoL-AD are not designed for those at moderate to severe stages of dementia (Logsdon et al., 2002). Also, the concept of QoL differs across studies, which means that it can be difficult to compare one measure with another.

Despite these challenges of interpretation, two factors which may have affected the results are the individualization and duration of the training. Both studies with improved quality of life measures offered more individualized and longer training sessions. The Haberstroh et al. (2011) and Teri et al. (2005) training methods lasted for 5 and 8 weeks, respectively, while Liddle et al.'s (2012) training method was only for 2 sessions. The training for the first two studies was quite individualized and participatory, with group participation and problem-solving for Haberstroh et al. (2011) and individualized strategy planning for Teri et al. (2005). Even though Liddle et al. (2012) did have trainers present while participants watched the DVDs in-home, the DVDs were not interactive. Therefore, it is possible that participants did not internalize the training provided by Liddle et al. to as great a degree as they did with the other programs.

In general, these studies provide a suggestive level of evidence that communication training for caregivers improves the quality of life for people with dementia. Further research with larger numbers of participants, blinded interviewers, and reports of quality of life not provided by proxy (for those with mild dementia), would be beneficial to strengthen evidence for caregiver communication training.

Clinical Implications

Because of the difficulty in studying this population and in measuring their quality of life, these findings of improved QOL following caregiver communication training are clinically compelling. However, due to one study's finding (Liddle et al., 2012) of increased report of depressive behaviours following such intervention, care should be taken in a clinical context to watch for general well-being of clients and suggest referrals to

other support agencies as necessary. Nevertheless, it appears that caregiver training (possibly especially when of longer duration and somewhat individualized) does have a positive general effect on QOL and can be helpful for clients with dementia and not only their family members.

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