

## **Critical Review:**

### **What effect do group intervention programs have on the quality of life of caregivers of survivors of stroke?**

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This critical review examines the evidence regarding the effectiveness of group intervention programs for caregivers of people affected by stroke. Study designs include randomized clinical trials, non-randomized trials and single group pre-post test. Overall, the evidence gathered from this review is inconclusive. Recommendations for future research and clinical practice are provided.

#### ***Introduction***

Stroke is a disease with severe consequences for patients and their families. Following stroke caregiver burden is common. As many as 95% of caregivers experience changes in their lives after stroke, as they cope with the patient's physical and cognitive impairments, as well as emotional, behavioral and personality changes (Larson, Franzen-Dahlin, Billing, von Arbin, Murray, & Wredling, 2005).

High levels of burden are related to deterioration of the caregiver's quality of life, which has been shown to adversely affect many aspects of the patient's recovery (Visser-Melly, van Heugten, Post, Schepers, & Linderman, 2004). Providing caregivers with support therefore may not only improve the caregiver's quality of life but the patient's quality of life as well. There is no consensus over the definition of 'quality of life'. Indicators of quality of life that have been suggested in the literature are perceived health status, coping strategies and satisfaction with life (Larson et al., 2005).

Attempts have been made to develop and evaluate group interventions for caregivers of stroke survivors. Some interventions have focused on the provision of information, where others have focused on providing education and counseling. The effectiveness of these interventions however is inconclusive (Eldred & Sykes, 2008). As active members in an interdisciplinary team approach to stroke, speech-language pathologists must be knowledgeable in current controversies surrounding the effectiveness of group intervention programs for caregivers of people affected by stroke. The evidence surrounding the quality of life outcomes of caregivers should be critically examined and understood, so that the discerning clinician may appropriately contribute to the decision-making process.

#### ***Objectives***

The primary objective for this paper is to critically evaluate the available literature regarding the effectiveness of group based intervention programs for improving the quality of life of caregivers of survivors of stroke. The secondary objective for this paper is to provide evidence based recommendations for multidisciplinary teams working with people affected by stroke.

#### ***Methods***

##### Search Strategy

Articles related to the topic of interest were found using the following computerized databases: CINAHL, SCOPUS, PubMed, and ProQuest. The following strategies were used:

[(spouse) or (caregiver) and (stroke)].

The search was limited to articles written in English.

##### Selection Criteria

The following inclusion criteria were applied:

- Group based intervention
- Intervention study for caregivers of stroke patients
- Intervention study for caregivers and stroke patients, if the intervention for the caregivers was described
- Use of one or more outcome measure for caregiver's quality of life, including: perceived health status, psychological health, coping strategies, stress, social support, depression, anxiety or stroke related knowledge.

##### Data Collection

Results of this literature search yielded five articles congruent with the aforementioned selection criteria. Two of the studies were randomized clinical trials.

Two studies were non-randomized clinical trials. One study was a single group pre-post test.

## **Results**

### Randomized Clinical Trials

Franzen-Dahlin, Larson, Murray, Wredling and Billing (2008) conducted a randomized clinical trial that investigated the effects of a support and education group intervention program on caregiver's psychological health, perceived social support, stroke knowledge and level of satisfaction with services. Intervention consisted of six meetings over six months and a follow up meeting after a further six months. Topics included symptoms and occurrence of stroke, risk factors, treatment, personality changes and social aspects. Caregivers of patients at a Swedish University Hospital were approached for participation. A total of 253 caregivers were approached. A total of 100 caregivers accepted the invitation and were randomly allocated to an intervention or control group. Investigators were blinded. The mean age of the caregivers who did not accept the invitation to participate was higher. Based on a repeated measure ANOVA results indicated that the level of stroke knowledge was significantly higher in the intervention group at 12 months. There were no significant differences found between the caregivers in the intervention and control groups with regards to psychological health, perceived social support or level of satisfaction with services. When those spouses who attended 5-6 sessions were compared to those who attended 1-4 sessions, it was found that those who attended the majority of sessions had significantly improved psychological health. Based on these results the researchers concluded that encouraging full participation in group interventions is essential to obtaining beneficial psychological results.

This randomized clinical trial was well designed with blinded researchers. Selection criteria were described with appropriate detail; however sampling was limited due to the large number of caregivers who declined. Sampling was also limited because all of the participants were from one hospital. This limited sampling suggests that the results from this study are only representative of a subset of individuals who care for people affected by stroke. Information regarding spouse and patient age and number of strokes per patient was provided, however crucial demographic data such as spouse's education level and time since stroke onset that could impact the effectiveness of the intervention were omitted. Franzen-Dahlin et al. (2008) clearly defined the intervention program and provided adequate information in their procedures such that the

measures were well understood and the study could be replicated. The instruments used to evaluate outcome measures were appropriate, however participants filled out the same stroke related knowledge form which may have influenced the learning process and may have led to testing/measurement artifact. With only 20 caregivers attending 5-6 meetings, the beneficial effects of the treatment may have been diluted.

This study directly examined the research question of this review. Based on the methodological issues stated above, including the limited sampling and low attendance rate, the findings of this study and implications in clinical practice can be considered suggestive.

Rodgers, Atkinson, Bond, Suddes, Dobson and Curless (1999) conducted a randomized clinical trial that investigated the effect that a stroke education program had on caregiver's perceived health status, knowledge of stroke, and satisfaction with services. The stroke education program consisted of one, one hour small group education session for in-patients, followed by six, one hour education sessions following discharge from the hospital. Topics included improving stroke related knowledge, increasing awareness of available services, and time for caregiver's questions. Patients and their caregivers at a local hospital were randomized as a pair, resulting in 107 caregivers in the intervention group and 69 caregivers in the control group. Investigators were blinded to final allocations. Attendance for the stroke education program was low, with only 20/107 caregivers attending three or more sessions. Based on non-parametric techniques results indicated that there were no differences in caregivers perceived health status, except for social functioning in which caregivers in the intervention group had lower sub scale scores. Caregivers in the intervention group had significantly higher stroke related knowledge compared to the control group. No differences were found between the groups with regards to satisfaction with services. The researchers concluded that improving caregiver's stroke related knowledge may not improve health status or other psychological outcomes. Researchers recommended further research regarding the ideal content, delivery and duration of group intervention programs.

This study was well designed with blinded investigators. Selection criteria were reported in detail; however sampling was limited due to participant exclusion if they lived outside of the study area. This suggests that results of this study are limited to only a subset of the stroke population. The unbalanced assignment of caregivers is another

downfall, which was due to the fact that some patients did not have a caregiver. Rodgers et al. (1999) clearly defined the intervention program. The reliability and validity of the knowledge of stroke scale and satisfaction with services instrument were not tested. The use of these instruments is a downfall of the study and affects the reliability of the results. Six month outcomes for the short form health survey questionnaire were only available for 106/176 caregivers. This was considerably less than the researcher's original power calculations, which may have led to type II error.

Based on the methodological issues stated above, including limited sampling, low attendance rate and the issues regarding the instruments used for testing, the results of this study and their ability to affect clinical decisions are considered to be equivocal.

#### Non Randomized Clinical Trials

Wilz and Barskova (2007) conducted a non-randomized clinical trial to investigate the effectiveness of a cognitive behavioral group intervention program targeting caregiver's quality of life, anxiety, and depression. Patients and their caregivers from six rehabilitation centers were recruited by solicitation. The first 38 interested caregivers were allocated to the intervention group, and attended 15 bi-monthly, one and a half hour group sessions. Topics included expressing emotions, psycho-education, cognitive restructuring, problem solving, etc. Subsequent participants formed a gender and education matched control group and were given informational support over the telephone, but no formal intervention. A second control group from a previous study (Wilz, 2007) consisted of 51 spouses, also matched on the basis of gender and education. Systematic differences between groups were reported, specifically stroke severity and time since stroke. Based on several non-hierarchical regression analyses results indicated spouses in the intervention group had significantly improved physical and environmental quality of life immediately after the intervention. Long term results, taken six months post-test, indicated spouses in the intervention group had significantly improved psychological, social and environmental quality of life and lower rates of depression. When four spouses, who participated in fewer than eight sessions, were removed from the analyses outcome differences were more obvious and the long term effect of anxiety was also statistically reduced in the intervention group. Based on the results the researchers suggested that in order to improve caregiver's quality of life and other mental health variables such as depression, a multi-component group intervention program that not only

includes education but also cognitive behavior therapy techniques is recommended.

Selection criteria were reported in detail; however, samples may not represent the general stroke population. Without randomization this study was subjected to selection and allocation bias, because the first eager patients and caregivers were allocated to the intervention group. The attrition rate in the second control group was 33%, compared to only 5% and 6% in the intervention and first control group respectively. It is questionable why the authors would have chosen this second control group from a previous study, with such a high attrition rate. However, this difference in attrition rate may suggest that the opportunity for any type of psycho-social support may have a positive effect on caregiver's participation. Intervention effects may also have been skewed due to the presence of outliers, caregivers who attended less than 8 sessions. The researchers acknowledged this when these caregivers were removed from statistical analyses and outcome differences between groups became more obvious. The intervention design and content were described with appropriate detail such that the measures were well understood and the study could be replicated. Measurement instruments were appropriate and had previously been used with spouses of stroke patients. Instruments were also tested for internal consistency. Systematic differences between groups were accounted for in statistical analyses as covariates in the regression analysis.

Despite the non-randomized design of this study and the methodological flaws concerning participant allocation, this study provided detailed demographic data and used valid and reliable instruments. Therefore the results of this study and their clinical implications can be considered suggestive.

Van den Heuvel, de Witte, Nooyen-Haazen, Sanderman and Meyboom-de Jong (2000) conducted a non-randomized clinical trial that investigated the effect of a group support program on caregivers stroke related knowledge and the use of coping strategies. The researchers also compared the group support program to a home visit program; however for the purpose of this critical review this was not examined. The group support program consisted of eight weekly two hour sessions spread over two months. Topics included stroke occurrence, feelings experienced, how becoming a caregiver has changed their lives, etc. Caregivers were recruited through general practitioners, hospitals, home care services, rehabilitation centers and the media. When caregiver's enrollment was received they were assigned in blocks of 8-13 to the group support

program or the control group. The number of participants decreased during the finals blocks, leaving 130 caregivers in the intervention group and 49 in the control group. Short term (1 month post test) and long term results (6 months post test) were analyzed. One month post test 20 caregivers had dropped out of the intervention group and seven caregivers had dropped out of the control group. Six month post test a further 10 caregivers dropped out of the intervention group and a further four from the control group. The results of paired t-tests indicated that one month post test caregivers in the intervention group had significantly improved knowledge of patient care, knowledge about self efficacy and the coping strategy seeks social support. There were no differences found between groups with regards to caregiver strain, mental well being, vitality, amount of social support, and satisfaction with social support or assertiveness. Six months post test caregivers in the intervention group had significantly improved knowledge about patient care, knowledge about self efficacy, seeking social support and amount of social support. No differences were found with regards to caregiver strain, mental well being, vitality, and satisfaction with social support or assertiveness. Based on these results the researchers concluded that group intervention programs that include both education and focus on coping are effective.

The researchers recruited through multiple outlets, which lead to a more diversified sample and allows the results to be generalized to the general stroke population. A down fall of this study is the unbalanced assignment of caregivers, which may have lead to selection and allocation bias. The group support program was described in detail with respect to both content and design. Appropriate instruments were used with internal consistency values provided for each test. Participant withdrawal was another downfall of this study, with a total of 41 caregivers dropping out after six months. However, authors did document this and provide intention to treat analyses.

This study included a control group and used valid and reliable measurement instruments. However, based on methodological issues, such as lack of randomization, the unbalanced assignment of caregivers and the high rate of participant withdrawal the results of this study are considered to be suggestive.

#### Single Group, Pre-Post Test

Louie, Liu and Man (2006) conducted a single group pre-post test study to investigate the effects of a stroke education program on improving caregivers stroke related knowledge, perceived health status and stress levels. A total of 59 patients and 32 caregivers were recruited from a local rehabilitation

center to participate in a stroke education program, which consisted of two, one-hour meetings. Topics included etiology, risk factors, caregiver skills, etc. Post-test measurements were taken one, two and four weeks post test. Based on a repeated measure ANOVA, results indicated caregivers had significantly improved stroke related knowledge after attending the stroke education program. There were no significant differences found with regards to perceived health status or stress levels. Based on these results the researchers concluded that although a two hour stroke education group may improve caregivers stroke related knowledge, a longer more intensive program may be required to improve other psychosocial factors.

Selection criteria were described in detail. While the objective of this study was to investigate caregivers of persons affect by stroke, the small sample size drawn from one location makes it difficult to generalize the results to the stroke population as a whole. Another limitation of this study is the lack of a control group, which makes it difficult to attribute any changes solely to the stroke education group and not to other confounding variables. Louie et al. (2006) clearly defined the intervention program. The reliability and validity of the measurement instruments however are questionable. The Stroke Knowledge Test used was reviewed by only four panel members and pilot tested on only 10 in-patients before use in the study. The Relative's Stress Scale was translated by local occupational therapists and pilot tested on only 20 caregivers before use in the study. No quantitative measurements regarding the reliability or validity of these instruments were provided. This study was conducted in Hong Kong, China and therefore cultural differences must be considered when generalizing the results to other populations. For example, the majority of stroke patients in this study were women (51 out of 54), which is a drastic difference compared to other studies conducted in different parts of the world where the sex of caregivers is more balanced (Wilz & Barskova, 2007).

Based on the reduced quantity and quality of information provided, including the small sample size, lack of a control group, and the use of instruments with questionable reliability and validity, the results of this study can be considered equivocal.

#### ***Recommendations***

All five studies reviewed found a correlation between group intervention programs and improved outcome measures for quality of life. However, a number of weakness were found in the design and

procedures of these studies, including small sample size, participant selection bias, and a lack of discussion regarding the validity and reliability of the measurement tools used. These weaknesses reduce the strength of evidence obtained from these studies.

### Future Research Implications

It is recommended that further research be conducted to clarify and confirm the relationship between group intervention programs and improved quality of life for caregivers of stroke survivors. In order to improve the strength of evidence provided by the existing literature, the following recommendations have been made:

- (i) Larger sample sizes and better experimental designs are required to improve the strength of the evidence in this area of clinical research.
- (ii) Additional research should include the development of standardized indicators for quality of life in this population. This would allow future researchers to use consistent and appropriate measurement tools.
- (iii) Further research should consider how caregiver's characteristics, such as age, gender, initial burden and type of relationship between the caregiver and the patient may influence outcomes.
- (iv) In the future, qualitative research should be conducted that focuses on the subjective factors that influence a caregiver's decision to not attend group meetings.

### Clinical Implications

Due to the limited strength of evidence provided from the reviewed articles, clinicians should be cautious when implementing the findings from these studies into practice. Clinicians who do implement or recommend a group intervention program for caregivers of stroke survivors should consider the following:

- (i) The content, timing and duration of group intervention programs must be continually evaluated, as caregiver's needs and circumstances are continually changing.
- (ii) Factors such as travelling and having to leave the patient alone may play an important role in the caregiver's attendance rate. Efforts should be made to remove these barriers when a group intervention program is being planned.

- (iii) The content of the group intervention program should focus not only on increasing caregiver's knowledge, but improving other outcome measures of caregiver's quality of life, including: perceived health status, psychological health, coping strategies, stress, social support, depression, anxiety or stroke related knowledge.

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