

Specific Aims of the CARES Research Study

Stroke is the 3rd leading cause of mortality and the leading cause of disability in the United States. Approximately 4,000,000 Americans are living with the effects of stroke. There are over 730,000 new or recurrent strokes every year in the United States with approximately 570,000 survivors at an estimated cost of \$30 billion annually.¹ Survivors of stroke are often left with devastating physical, psychosocial and cognitive disabilities that affect independence in activities of daily living and decision-making. The majority of stroke survivors return home after initial hospitalization and are assisted in the recovery process by a primary family caregiver, usually the spouse.^{2, 3}

This 5-year study proposes to use an advanced practice nurse (APN) with the assistance of an interdisciplinary rehabilitation team to provide education, support, skill training, counseling, and social and community linkages for stroke survivors and their spouses for 6 months post-hospital discharge. The proposed study extends the work on home care in 5 important ways: 1) It addresses the needs of stroke survivors at home, a population that has been studied very little previously. 2) It uses the Clinical Practice Guideline, Post-Stroke Rehabilitation, developed by the Agency for Health Care Policy and Research (AHCPR) to serve as the basis for the intervention and includes spousal caregivers as partners in the rehabilitation process.⁴ 3) It utilizes an interdisciplinary team to provide education, support, skill training, counseling, and community linkages based on the individual needs of the stroke survivor and spousal caregiver. 4) It focuses on reducing the psychological and physical morbidity experienced by the stroke survivor. 5) It also focuses on reducing caregiver morbidity and correlating immune responses of spousal caregivers with depression, burden, perceived stress, and health measures.

The proposed study has 4 specific aims.

1. Improve function, quality of life and perceived health, and decrease depression in stroke survivors by strengthening the dyad's knowledge and skills, their use of social supports and resources, and their problem solving and coping behaviors.
2. Reduce unplanned clinic and emergency room visits, the number, frequency and length of rehospitalizations and admissions to nursing homes among stroke survivors.
3. Decrease depression, burden, and stress, and improve health experienced by spousal caregivers by strengthening the dyad's knowledge and skills, their use of social supports and resources, and their problem solving and coping behaviors.
4. Decrease immune imbalances related to the stress of caregiving by strengthening the dyad's knowledge and skills, their use of social supports and resources, and their problem solving and coping behaviors.

Published randomized clinical trials on the effect of education, support, counseling, and social and community networks on stroke survivors and spousal caregivers in the home setting are sparse. The proposed experimental study is

part of a larger research plan to improve outcomes for stroke survivors and their spousal caregivers post-hospital discharge. It represents an expansion of the investigators' previous research with caregivers of persons with dementia and stroke. Fifty stroke survivors and their spousal caregivers receiving the intervention will be compared to 50 stroke survivors and their spousal caregivers discharged to usual post-stroke home care. A longitudinal study is proposed to investigate differences in the rate of change across the measured variables between treatment and control groups in addition to the static differences in groups at 12 weeks post-discharge. The following 4 hypotheses will be tested:

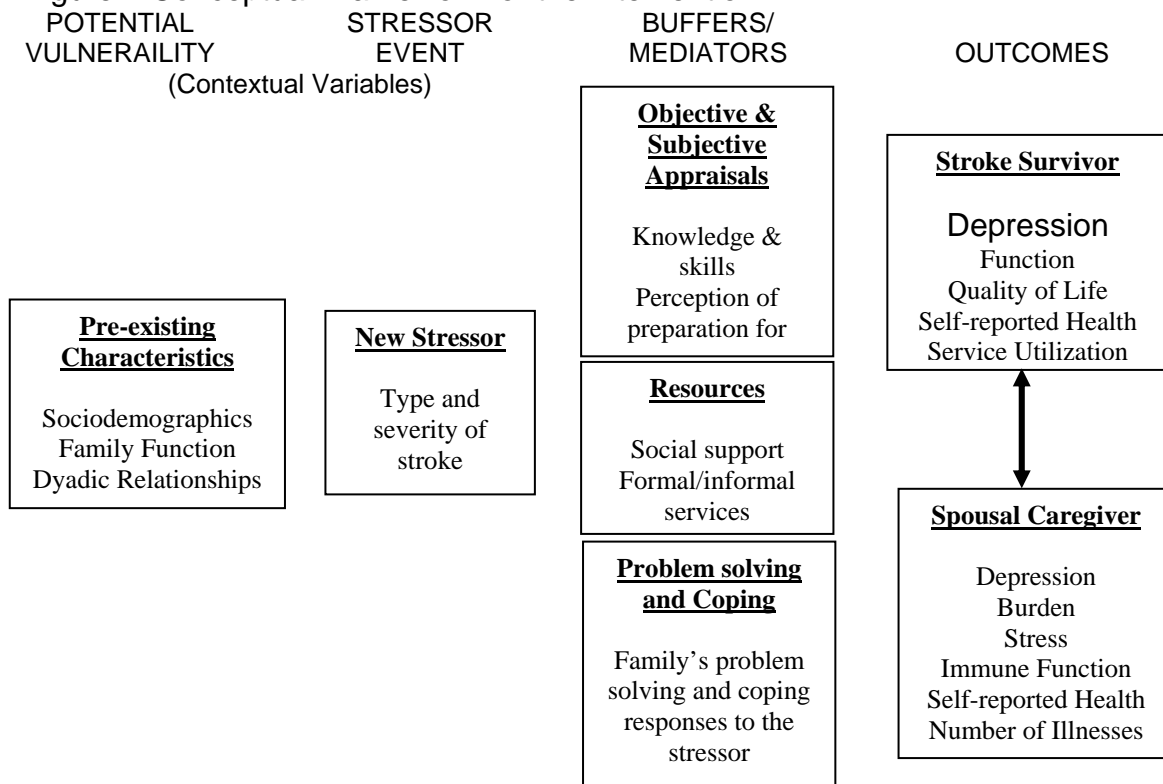
- 1) Stroke survivors who participate with their spouses in the intervention group will report:
 - a) less depression, better function, enhanced quality of life, and better perceived health at 12 weeks post-discharge.
 - b) a greater rate of decline in depression and greater improvements in function, quality of life, and perceived health over the course of the study as compared to stroke survivors in the usual care group.
- 2) Stroke survivors who participate with their spouses in the intervention group will experience:
 - a) fewer unplanned clinic and emergency room visits over 12 months.
 - b) a longer period of time to first rehospitalization.
 - c) fewer total rehospitalizations over 12 months.
 - d) fewer cumulative days of rehospitalization and shorter mean length of time of readmissions over 12 months.
 - e) fewer admissions to nursing homes over 12 months as compared to stroke survivors in the usual care group.
- 3) Spousal caregivers of stroke survivors in the intervention group will report:
 - a) less depression, burden, and stress at 12 weeks post-discharge.
 - b) increased preparation for caregiving, use of social and community supports, and problem-solving and coping behaviors at 12 weeks post-discharge.
 - c) better perceived health at 12 weeks post discharge.
 - d) fewer illnesses requiring physician visits or hospitalizations at 12 weeks post-discharge.
 - e) a greater rate of decline in depression, burden, perceived stress, and illness, and a greater increase in preparation for caregiving, use of social and community support, use of effective problem-solving and coping behaviors and perceived health over the course of the study as compared to spousal caregivers of stroke survivors in the usual care group.
- 4) Spousal caregivers of stroke survivors in the intervention group will have:
 - a) less adverse alterations in cytokine balance at 12 weeks post discharge.
 - b) less cytokine imbalance over the course of the study as compared to spousal caregivers in the usual care group.

Theoretical Basis of the Study Stress and coping theory maintains that coping is a process by which the demands of a threat or challenge are made manageable.⁵ Stroke is an important threat (stressor) in the life of a family.⁶ The

individual and family's appraisal of the threatening event and their problem solving and coping responses help to determine the impact of the stressor on their lives. Appraisal has two components: a) objective appraisal that represents a person's examination of a stressor to determine the nature and extent of the threat or challenge, and b) subjective appraisal that is the process in which a person assesses his/her capacity to manage the threat or challenge. According to Vitaliano and colleagues caregivers' distress, which they postulate is a function of pre-existing vulnerabilities and exposure to caregiving stressors, can be buffered by psychological and social resources.⁷ These buffers (e.g. knowledge, preparation, attitudes, resources, social support) can be manipulated and strengthened, so that, even in the face of an apparently overwhelming stressor, such as a stroke, forces can be marshaled to preserve the person or system.

The intervention proposed here is an extension of the Principal Investigator's previous NINR-funded intervention with caregivers of persons with dementia that combined elements of stress and coping theory as developed by Hill⁸ in the ABCX model, later adapted by McCubbin in the Double ABCX Model⁹ and finally in the T-Double ABCX Model.¹⁰ The conceptual framework for this intervention, illustrated in Figure 1 is based on the work on stress, coping, and adjustment.^{8 9 10-12} The patient's and caregiver's physical and psychological outcomes are a function of their exposure to a stressor (the stroke) and their preexisting vulnerabilities, that are then buffered by their psychological and social resources.

Figure 1 Conceptual Framework for the Intervention



References:

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