Nearly 5 million Americans live with the after-effects of stroke. There are 700,000 new persons with stroke each year at a cost for care of $57.9 billion annually. Most persons surviving a stroke return home after initial rehabilitation treatment and are cared for by family members, usually women. Family members [relatives and friends] manage and/or influence many aspects of care for the person with stroke, e.g., helping with activities of daily living, scheduling appointments with healthcare providers, providing physical care and emotional support, etc. The profound changes that can accompany stroke create considerable challenges for those individuals and their families. The National Institutes of Health have pointed to a need for research using innovative technology to support family caregivers.

Using Friedemann's framework of systemic organization as a guide, this study investigated outcomes of Caring~Web©: a Web-based, in-home intervention of support for caregivers of persons with stroke in northern Ohio and southern Michigan during the first year after rehabilitation treatment. Caring~Web© provided this support through four mechanisms: 1) an opportunity to Ask the Nurse, a nurse specialist and the rehabilitation team, any questions or discuss issues related to caring; 2) a non-structured discussion via an email Discussion Group that connected the caregiver with other study participants and the nurse specialist; 3) Educational Information about stroke, caring, and caregivers from other linked Web-sites; and 4) customized educational information, such as nutrition or stress and coping, provided in a Tip of the Month educational format.

The primary aims of the study were met, in that Caring~Web was examined to see if it: 1) improved the caregiver's well being, e.g. perceived depression and life satisfaction and 2) reduced the care recipients' use of healthcare services, e.g. healthcare provider calls and visits, emergency department visits, and hospital readmission and nursing home placement rates. The secondary aim was also met, as the caregivers’ experience of caring was described; that is, problems and successes the caregivers encountered.

One hundred three caregivers were enrolled between May 2002 and December 2004 and randomized into two groups, with 73 subjects completing the study (n=36 Web users, n=37 non-Web users). There were 18 (25%) male subjects and 55 (75%) female subjects in the study. Of these, there were 34 (47%) wives, 16 (22%) husbands, 13 (18%) daughters, 1 (1%) son, and 9 (12%) other relatives or friends. Sixty-two (85%) subjects were White, 9 (12%) were Black, 1 (1%) was Hispanic, and 1 (1%) was American Indian. The subjects' average age was 55 years and the average years of education were 13. Twenty-seven (37%) subjects worked full-time, 12 (16%) worked part-time, and 34 (47%) did not work. Although some caregivers owned a computer, all subjects in the study had limited Internet experience.

The Web users group was given access to Caring~Web© with Web pages specifically designed for this project. Through these pages, caregivers were able to ask questions of a nurse specialist backed-up by rehabilitation team members, discuss issues with other caregivers and the nurse via an e-mail discussion group, and obtain educational information on stroke and issues of caring. The control group (non-Web users) continued with their usual care routine. All subjects completed a brief, telephone interview bi-monthly for a year on their healthcare service use and the experience of caring, and were asked additional questions quarterly for measures of well being.
The Web and non-Web users’ well being were compared and differences between groups over time were analyzed. Using a mixed model analysis of variance, no significant differences (p<.05) in depression scores were found between the groups, or over time (i.e., baseline, and 3, 6, 9, and 12 months). Mean scores for both groups over time ranged from 9 to 14, below a score of 16 that indicates some degree of mental distress. There were also no significant differences (p<.05) in mean life satisfaction scores over time or between the two groups using a mixed model analysis of variance. Mean scores for both groups (range = 21 to 25) indicated that the caregivers felt neutral or were moving toward being slightly satisfied with their lives.

There were, however, significant differences based on a Mann-Whitney U test between the Web and non-Web users groups in emergency department visits (p=0.001) and readmissions to a hospital (p=0.0005) for the health of the care recipient. Over the year of the study, the Web users group had 13 fewer visits for care recipients to an emergency department, saving approximately $7618.00 in healthcare costs based on average charges for an emergency room visit in the Midwestern United States (U.S.). Their care recipients also had 27 fewer readmissions to a hospital, saving approximately $600,000.00 based on average charges for a hospital stay in the U.S in 2004 [adjusted for inflation of 1.0448 for 2006]. Due to the small number of occurrences, nursing home placement was not statistically analyzed. In the Web users group, one care recipient was placed in a nursing home after 7 ½ months. In the non-Web users group, 3 care recipients were placed in nursing homes between months 2 and 4. Not only were there more caregivers who placed their care recipient in a nursing home, they did so much sooner than the caregiver in the Web users group. The average monthly cost for a nursing home stay in the Midwestern U.S. is $3810.00 - $11580.00.

There were 2455 problems and 2687 successes reported by all the caregivers during their interviews for the first year of caring. These data were collected to provide an in-depth description of the experience of caring, not to determine the effect of the intervention, and were analyzed using Colaizzi’s rigorous method of content analysis. Three themes emerged from the problems: being frustrated in day-to-day situations (system maintenance in Friedemann's terms), feeling inadequate and turning to others for help (coherence), and struggling and looking for "normal" in caring (system maintenance versus change). Three themes were also attributed to the successes: making it through and striving for independence (system maintenance), doing things together and seeing accomplishments in the other (coherence) and reaching a new sense of normal and finding balance in life (individuation and system maintenance).

The Caring~Web© intervention targeted at caregivers reduced emergency department visits and hospital readmissions, as well as impacted nursing home placement rates for persons with stroke, thus decreasing costs associated with healthcare utilization. This research is relevant to public health, since family caregivers control the healthcare decisions of their care recipients. Caring~Web provided immediate web-based education and support for these caregivers, so they could make informed decisions about the care needs for persons with stroke. Another outcome of this study is an expanded knowledge of the experience of new caregivers of persons with stroke during the first year of caring at home. Friedemann’s framework has aided in the conceptualization of the experiences of these caregivers and the outcomes of the Caring~Web intervention.

These study outcomes provide direction to healthcare professionals in working with caregivers and in designing cost-effective programs of care. The end product of this program of stroke- and caregiver-centered research is an empirically validated, Web-based intervention that has the potential to be exported to multiple geographical sites and used by caregivers who are homebound, hard-to-reach, in rural settings, or do not have existing services. In addition, this intervention may be adapted to other chronic conditions, such as dementia.