AHA/ASA Scientific Statement

Evidence for Stroke Family Caregiver and Dyad Interventions
A Statement for Healthcare Professionals From the American Heart Association and American Stroke Association

Tamilyn Bakas, PhD, RN, FAHA, Chair; Patricia C. Clark, PhD, RN, FAHA; Margaret Kelly-Hayes, EdD, RN, FAHA; Rosemarie B. King, PhD, RN, FAHA; Barbara J. Lutz, PhD, RN, CRRN, FAHA; Elaine L. Miller, PhD, RN, CRRN, FAHA; on behalf of the American Heart Association Council on Cardiovascular and Stroke Nursing and the Stroke Council

Abstract—Stroke is a leading cause of severe, long-term disability. Most stroke survivors are cared for in the home by a family caregiver. Caregiver stress is a leading cause of stroke survivor institutionalization, which results in significant costs to the healthcare system. Stroke family caregiver and dyad intervention studies have reported a variety of outcomes. A critical analysis of 17 caregiver intervention studies and 15 caregiver/stroke survivor dyad intervention studies was conducted to provide evidence-based recommendations for the implementation and future design of stroke family caregiver and dyad interventions. (Stroke. 2014;45:2836-2852.)

Key Words: AHA Scientific Statements • caregivers • clinical trials • depression • evidence-based practice • outcome assessment (health care) • stroke

Stroke is one of the leading causes of severe, long-term disability,1 with a majority of stroke survivors requiring the assistance of a family caregiver.2 A family caregiver is defined in this context as a relative, partner, personal friend, or neighbor who provides assistance to an adult with a chronic or disabling condition such as stroke.3 Although family members may not consider themselves caregivers, this term is commonly used in the literature to represent family or informal (unpaid) caregivers.

Family caregiver stress is commonly associated with long-term institutionalization of stroke survivors, resulting in significant costs to the healthcare system.4-8 Family caregiver stress can also result in other negative outcomes for both survivors and their caregivers.7 For example, caregiver stress has been shown to interfere with rehabilitation of the survivor2 and can result in social isolation, declining health, and increased risk of mortality for the caregivers.9,10 Depression is especially prevalent in stroke family caregivers,7,11,12 with some studies reporting higher depression rates in the caregivers than in the survivors for whom they provide care.11,13

Miller and colleagues14 made recommendations for family caregiver education and support across inpatient, outpatient, and chronic care settings based on clinical practice guidelines and existing research. These recommendations involved (1) caregivers serving as integral members of interdisciplinary teams, (2) assessment of caregiver needs and concerns, (3) follow-up contacts and referrals, (4) counseling focused on problem solving and social support, (5) provision of stroke-related information, and (6) attention to the emotional and...
physical health of caregivers. Similar recommendations have been published by others. The recommendations of Miller and colleagues were developed using the American Heart Association guidelines for applying classification of recommendations and level of evidence (Tables 1 and 2). The columns represent the size of treatment effect for interventions, with each class indicating how the recommendations should be stated on the basis of the risk-benefit ratio. The rows represent an estimate of certainty (precision) of the treatment effect, with Level A involving data from multiple randomized, clinical trials or meta-analysis, Level B from a single randomized trial or nonrandomized studies, and Level C from consensus opinion of experts, case studies, or standard of care. Although many of the recommendations of Miller and colleagues were rated as being Class I (should be performed), most were based on Level C evidence or working group consensus. Furthermore, there was insufficient detail about whether family caregiver or dyad interventions improved survivor or caregiver outcomes and about the specific types of interventions that improved outcomes. Dyad interventions are those that target both the family caregiver and the stroke survivor as a pair as active participants in the intervention. Common outcomes of family caregiver and dyad interventions include caregiver and survivor anxiety, depressive symptoms, health-related quality of life, service use, knowledge, and satisfaction. Caregiver preparedness, burden, stress, and strain are also commonly found in the literature. Positive outcomes are examined less

Table 1. Applying Classification of Recommendations and Level of Evidence

<table>
<thead>
<tr>
<th>Size of Treatment Effect</th>
<th>Class I</th>
<th>Class IIa</th>
<th>Class IIb</th>
<th>Class III No Benefit or Class III Harm</th>
</tr>
</thead>
<tbody>
<tr>
<td>Benefit/ Risk</td>
<td>Benefit &gt; Risk</td>
<td>Benefit &gt; Risk</td>
<td>Benefit &gt; Risk</td>
<td>Procedure/Treatment</td>
</tr>
<tr>
<td>Should be performed/ administered</td>
<td>Additional studies with focused objectives needed</td>
<td>Additional studies with broad objectives needed</td>
<td>Additional registry data would be helpful</td>
<td></td>
</tr>
</tbody>
</table>

**Level A**
- Multiple populations evaluated
- Data derived from multiple randomized clinical trials or meta-analyses

**Level B**
- Recommendation that procedure or treatment is useful/effective
- Sufficient evidence from multiple randomized trials or meta-analyses

**Level C**
- Recommendation that procedure or treatment is useful/effective
- Only expert opinion, case studies, or standard of care

Suggested phrases for writing recommendations:
- Should be performed/ administered
- Is recommended
- Is indicated
- Is useful/effective/beneficial

**Comparative effectiveness phrases**: treatment/strategy A is recommended/indicated in preference to treatment B; treatment A should be chosen over treatment B.

**Comparative effectiveness phrases**:
- Treatment strategy A is recommended/indicated in preference to treatment B.
- Treatment A should be chosen over treatment B.

**COR III: No Benefit**
- Not indicated
- Should not be administered/other
- Not useful/beneficial/effective

**COR III: Harm**
- Potentially harmful
- Causes harm
- Associated with excess morbidity/mortality
- Should not be performed/administered/other.

*Data available from clinical trials or registries about the usefulness/efficacy in different subpopulations such as sex, age, history of diabetes mellitus, history of prior myocardial infarction, history of heart failure, and prior aspirin use. A recommendation with Level of Evidence B or C does not imply that the recommendation is weak. Many important clinical questions addressed in the guidelines do not lend themselves to clinical trials. Although randomized trials are unavailable, there may be a very clear clinical consensus that a particular test or therapy is useful or effective.

†For comparative effectiveness recommendations (Class I and IIa, Level of Evidence A and B only), studies that support the use of comparator verbs should involve direct comparisons of the treatments or strategies being evaluated.
frequently. The purpose of this scientific statement is to critique, analyze, and synthesize the evidence on the impact of family caregiver and dyad interventions on stroke survivor and caregiver outcomes. Synthesizing the evidence adds to the science pertaining to family caregiver interventions but also, more important, provides the foundation for evidence-based recommendations to design family caregiver programs to improve the care of stroke survivors and their families in various practice settings. Four questions were addressed in this review and critique:

**Question 1:** Do family caregiver and dyad interventions improve stroke survivor outcomes?

**Question 2:** Do family caregiver and dyad interventions improve caregiver outcomes?

**Question 3:** What types of family caregiver and dyad interventions are most effective for improving stroke survivor and caregiver outcomes?

**Question 4:** What recommendations can be made for designing and implementing family caregiver and dyad interventions that improve stroke survivor and/or caregiver outcomes?

**Methods**

We conducted a critical analysis of published research on family caregiver interventions in the context of stroke. This process involved reviewing titles, abstracts, and full-text articles for relevance to the topic using the following inclusion criteria: (1) written in the English language; (2) published from January 1990 through October 2012; (3) used a quasi-experimental or experimental research design; (4) involved a stroke caregiver intervention; (5) included stroke survivor outcomes and/or stroke family caregiver outcomes; and (6) was implemented during any part of the stroke care continuum (acute hospitalization, inpatient rehabilitation, home care, long-term care). Dissertations, books, and conference proceedings were excluded.

We searched MEDLINE, PubMed, CINAHL, and PsycINFO using the keywords stroke, family, caregiver, interventions, experimental studies, and quasi-experimental studies. Additional sources were located from reference lists of relevant articles. The PRISMA (Preferred Reporting Items for Systematic Reviews and Meta-Analyses) flow diagram was used to track the search process (Figure). Review templates were used for selecting articles for review and for summarizing and grading classes and levels of evidence. Relevant articles were abstracted into tables with columns that addressed author/year, purpose, sample, methods, main findings, and critique comments and then further summarized in Tables I and II in the online-only Data Supplement. Consensus was reached on article inclusion by at least 2 reviewers, consistent with guidelines by the Joanna Briggs Institute. The studies were critiqued with the use of criteria from the CONSORT (Consolidated Standards of Reporting Trials) and TRENDS (Transparent Reporting of Evaluations with Nonrandomized Designs) statements. The studies were also assessed for threats to validity. Studies were then sorted by outcomes (Table 3) and intervention characteristics (Table 4). Frequencies and percentages of articles based on intervention characteristics are provided in Table 4 for further analysis to determine the most common intervention characteristics. Findings were then synthesized into sections for recommendations (Table 5). The American Heart Association guidelines were used for making decisions about classes and levels of evidence for the recommendations (Tables 1 and 2).

**Results**

The PRISMA flow diagram for our review is depicted in the Figure. Our initial search resulted in 319 records identified through database searching and 47 articles identified by reviewing reference lists of existing review articles. After removing duplicates, we screened 206 records and excluded 83 because they were not relevant to stroke. We then assessed 123 full-text articles for eligibility and excluded 84 articles for a variety of reasons. Specifically, 10 compared home with inpatient rehabilitation recovery, 49 did not test a caregiver intervention or were descriptive studies from an existing trial, and 25 tested a stroke survivor intervention that involved caregivers but the caregivers were not the target of the intervention. Thirty-nine articles remained, representing 32 unique intervention studies. Of these 32 eligible studies, 17 involved a caregiver intervention focused primarily on the caregiver and 15 involved a dyadic intervention that involved both AHA/ASA* Recommendations

| Class I | Conditions for which there is evidence for and/or general agreement that the procedure or treatment is useful and effective. |
| Class II | Conditions for which there is conflicting evidence and/or a divergence of opinion about the usefulness/efficacy of a procedure. |
| Class IIa | The weight of evidence or opinion is in favor of the procedure or treatment. |
| Class IIb | Usefulness/efficacy is less well established by evidence or opinion. |
| Class III | Conditions for which there is evidence and/or general agreement some cases may be harmful. |

Therapeutic recommendations

| Level of Evidence A | Data derived from multiple randomized clinical trials or meta-analyses |
| Level of Evidence B | Data derived from a single randomized trial or nonrandomized studies nonrandomized studies |
| Level of Evidence C | Consensus opinion of experts, case studies, or standard of care |

Diagnostic recommendations

| Level of Evidence A | Data derived from multiple prospective cohort studies using a reference standard applied by a masked evaluator |
| Level of Evidence B | Data derived from a single grade A study or one or more case-control studies, or studies using a reference standard applied by an unmasked evaluator |
| Level of Evidence C | Consensus opinion of experts |

*AHA/ASA indicates American Heart Association/American Stroke Association.
survivors and caregivers as active participants in the intervention. Findings were critiqued and then summarized according to the 4 research questions.

Critique of the 39 Articles Representing 32 Different Intervention Studies

**Designs**

Of the 32 intervention studies, 22 (69%) were randomized, controlled, clinical trials; some involved randomizing in blocks ranging from 6 to 13 caregivers. Block randomization is typically used to ensure equal groups. Other studies incorporated a wait-list control group, crossover controlled, or time lag design. Three studies used a single-group design, although one of these studies compared its group with a historical comparison group matched on depression and demographics. Nevertheless, these studies should be interpreted with caution because of their weak designs. Two studies allocated participants on the basis of the wards in which they received care. Wilz and Barskova used a quasi-experimental design in which they allocated the first 38 participants to the treatment and the next 38 matched on education and sex to a control group. A second control group consisted of 51 couples from a prior study. It is unclear why these researchers chose not to randomize their participants.

As for the randomized, controlled, clinical trials, only 1 trial provided details about the methods used for sequence generation, allocation concealment, and implementation. These are key criteria from the CONSORT and TREND statements. Blinding of data collectors was found in a number of studies, however. Most studies were not based on either an explicit or implied conceptual model, another key criterion from the TREND statement.

**Samples**

The samples used in the 32 studies ranged from 17 caregivers to 486. Fifteen of the studies involved a dyad intervention in which survivors were enrolled. Nine of the studies had samples sizes <50 caregivers, although much can be learned from these small studies. Some reported effect sizes for a larger trial, and others reported positive caregiver outcomes such as reduced depressive symptoms, improved problem solving and preparedness, and improved knowledge and satisfaction. The small sample sizes resulted in the lack of significant caregiver outcomes in other studies. Although pilot studies are important to test and refine new interventions, larger studies that are adequately powered to detect significance on key outcomes are important to determine efficacy. Some of the larger studies tended to be more successful. For instance, Kalra and colleagues tested their intervention in a well-designed randomized, controlled, clinical trial with 300 caregivers. However, large sample sizes do not guarantee significant results.
<table>
<thead>
<tr>
<th>Outcomes</th>
<th>Studies With Significant Results (P&lt;0.05)</th>
<th>Instruments Used</th>
</tr>
</thead>
<tbody>
<tr>
<td>Survivor physical function (disability, motor, cognitive, upper extremity, physical dependence, negative reaction)</td>
<td>Kalra et al,25 2004 (Barthel); Clark et al,26 2003 (Barthel); King et al,27 2007 (motor and cognitive within); Gräsäl et al,28 2005 (upper extremity); Burton and Gibbon,29 2005 (physical dependence, negative mood)</td>
<td>Barthel Index, Functional Independence Measure motor and cognitive subscales; Ashworth Spasticity Scale; Nottingham Health Profile</td>
</tr>
<tr>
<td>Survivor anxiety and depression</td>
<td>Kalra et al,25 2004 (anxiety and depression); Boter et al,30 2004 (anxiety); Smith et al,31 2004 (anxiety)</td>
<td>Hospital Anxiety and Depression Scale</td>
</tr>
<tr>
<td>Survivor health-related quality of life</td>
<td>Kalra et al,25 2004; Boter et al,30 2004 (SF-36 role/emotional); Burton and Gibbon,2005 (SF-36 general health); Louie et al,32 2006 (SF-36 physical, within)</td>
<td>EuroQOL Visual Analog Scale; SF-36 Health Survey; Nottingham Health Profile</td>
</tr>
<tr>
<td>Survivor social function (adjustment, activity, family function, reintegration)</td>
<td>Burton and Gibbon,2005 (social isolation); Dennis et al,21 1997 (social adjustment worse); Forster and Young,21 1996 (social only for mildly disabled); Goldberg et al,33 1997 (social activity); Mant et al,34 2000 (stroke clubs); Clark et al,35 2003 (social recovery, family function); Kalra et al,36 2004 (social functioning); Tilling et al,37 2005 (reintegration worse)</td>
<td>Nottingham Health Profile (social isolation); Social Adjustment Scale (worse); Frenchay Activities Index; McMaster Family Assessment Device; Reintegration to Normal Living Index (worse)</td>
</tr>
<tr>
<td>Survivor service use (rehabilitation services, illnesses, emergency room visits, hospital readmissions, fewer hospital days and home care days, institutionalization, and costs)</td>
<td>Boter et al,30 2004; Gräsäl et al,28 2005 (more occupational therapy, more outpatient care, illnesses, institutionalization); Mant et al,34 2000 (less physiotherapy, less speech therapy); Pierce et al,35 2009 (caregiver-reported emergency room visits and hospital readmissions); Forster et al,36 2009; Tilling et al,37 2005 (fewer hospital and more home care days); Shyu et al,38 2010 (institutionalization); Kalra et al,2004; Patel et al,39 2004 (costs)</td>
<td>Demographic form; resources multiplied by unit costs in UK currency; caregiver-reported service use by the stroke survivor</td>
</tr>
<tr>
<td>Survivor knowledge and satisfaction</td>
<td>Lincoln et al,40 2003 (both); Louie et al,41 2006 (within knowledge); Rodgers et al,42 1999 (both); Dennis et al,43 1997 (satisfaction); Forster et al,44 2009 (satisfaction); Tilling et al,45 2005 (satisfaction community services worse; satisfaction information recover better)</td>
<td>Perceived knowledge developed for study; A Stroke Knowledge Test; Knowledge of Stroke Scale; Patient Satisfaction Scale; Satisfaction with Hospital Services Scale; satisfaction scale developed for study; Satisfaction With Stroke Services (Pound); Pound Satisfaction Scale (worse)</td>
</tr>
<tr>
<td>Caregiver preparedness (includes confidence, self-efficacy, competence, quality of care)</td>
<td>Grant,46 1998; Grant et al,47 2002; King et al,48 2007 (within); Shyu et al,49 2008 (nurse perception of preparedness, caregiver preparedness); van den Heuvel et al,50 2000; van den Heuvel et al,51 2002 (confidence, self-efficacy); Hartke and King,52 2003 (competence); Shyu et al,53 2010 (quality of care)</td>
<td>Preparedness for Caregiving Scale; new 30-item confidence measure for confidence and self-efficacy; Caregiver Competence Scale</td>
</tr>
<tr>
<td>Caregiver burden, stress, and strain (includes task difficulty, threat appraisal, and mood)</td>
<td>Bakas et al,54 2009 (task difficulty, threat appraisal); Hartke and King,55 2003 (burden); Kalra et al,56 2004 (burden); Kim et al,57 2012 (burden); Draper et al,58 2007 (stress); Perrin et al,59 2010 (strain); Burton and Gibbon,60 2005 (strain); Dennis et al,61 1997 (mood)</td>
<td>Oberst Caregiving Burden Scale; Burden Interview; Caregiver Burden Scale referenced as Caregiver Strain Index; Family Caregiver Burden Tool; General Health Questionnaire; Caregiver Strain Index; Appraisal of Caregiving Scale</td>
</tr>
<tr>
<td>Caregiver anxiety and depression</td>
<td>Kalra et al,25 2004 (both); King et al,26 2007 (within anxiety, within and between depression); Dennis et al,27 1997 (anxiety); Grant,48 1999 (depression); Grant et al,49 2002 (depression); King et al,50 2012 (depression); Smith et al,51 2012 (depression); Wilz and Barskova,52 2007 (depression)</td>
<td>Hospital Anxiety and Depression Scale; Tension Anxiety Subscale from Profile of Mood States; Center for Epidemiological Studies Depression Scale; Hospital Anxiety and Depression Scale; Beck Depression Inventory</td>
</tr>
</tbody>
</table>

(Continued)
Despite a few significant survivor outcomes (Short Form-36 [SF-36] role emotional; fewer rehabilitation services, reduced anxiety), did not find significant group differences with respect to caregiver outcomes. Reasons for attrition were not discussed in most studies except to indicate the number enrolled and the number completing the study. Several articles included tables with demographic data for both stroke survivors and caregivers. Descriptions and group comparability of caregiver demographics and outcomes were not provided or tested in most other reports. Assessing for baseline differences on key demographics (eg, caregiver sex, relationship, social class) and other characteristics is another important criterion in both the CONSORT and TREND guidelines.

### Interventions

Treatment fidelity was rarely described in the 32 studies. The CONSORT and TREND statements advocate for details about the interventions and how they are delivered. Treatment fidelity consists of 5 components: treatment design, training, delivery of treatment, receipt of treatment, and enactment. Treatment design includes the theoretical background of the intervention and information about the dosage for both the treatment and control groups (length, number, content, and duration of contacts). Training for the interveners should be described, as well as how the intervention is delivered and evaluated (eg, evaluation checklists).

Receipt, defined as how well participants understood the intervention, and enactment, that is, how participants incorporate the intervention into their everyday lives, are rarely addressed in intervention studies. Details about the interventions in the 32 studies reviewed are provided in the Results section under Question 3.

### Outcomes

The reliability and validity of outcome measures were not described or were incomplete for many of the studies. For example, in several studies, it was not clear if the survivor or the caregiver completed the survivors’ data collection forms. In studies in which data were collected from survivors, their cognitive/language skills and ability to respond to questionnaires were not reported. Many of the studies used simple bivariate statistics rather than multivariate analyses to report findings, and few reported intention-to-treat analyses. There was also emphasis placed on significance of findings, with little attention to effect sizes or clinical significance. These are all factors to consider when future intervention research is designed. Results about survivor and caregiver outcomes are presented in the upcoming sections under Questions 1 and 2.

### Generalizability

Many studies had limited generalizability to other populations. Studies involving spouse caregivers may not generalize to those that included adult children or others as family caregivers. In a review by Visser-Meily and...
colleagues,66 distinguishing between adult children and spousal caregivers was of prime importance in stroke caregiver intervention research. Generalizability across settings is also an issue, particularly when comparing studies internationally.

Summary and Best-Designed Studies

Although there are many weaknesses found throughout this review of 32 stroke caregiver and dyad intervention studies, there are strengths. One particularly well-designed study is a randomized, controlled, clinical trial involving 300 stroke caregivers.25 The intervention consisted of hands-on caregiver training on how to handle stroke complications, secondary prevention, information about local benefits and services, training in lifting and mobility techniques, information on providing personal care, and communication strategies to use with the stroke survivor. Skill building in the form of goal setting was provided, along with tailored psycho-education during 3 to 5 inpatient sessions and 1 home visit. Impressive findings were obtained, including improved Barthel Index scores, anxiety, depression, and quality of life for the survivor, as well as reduced burden, anxiety, depression, and improved quality of life for the caregiver.25 A follow-up study documented lower costs for the intervention group compared with the control group at 1 year.41 What was lacking from this intervention, however, was tailoring of the interventions based on the needs of the family caregiver rather than on the needs of the survivor. Future studies should be responsive and tailored to both the needs of the care of the survivor and the unique needs of the family caregiver.

Table 4. Summary Table of 32 Studies that Tested Stroke Caregiver and Stroke Dyad Interventions

<table>
<thead>
<tr>
<th>Intervention Characteristics</th>
<th>f(%)</th>
<th>f(%) Survivor Outcomes (P&lt;0.05)</th>
<th>f(%) Caregiver Outcomes (P&lt;0.05)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Target of interventions</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Stroke caregiver25,27,30,41,44–45,56–63</td>
<td>17 (53.1)</td>
<td>4 (23.5)</td>
<td>16 (94)</td>
</tr>
<tr>
<td>Stroke survivor–caregiver dyad28–32,26–37,28,42,43,57,62,81</td>
<td>15 (46.9)</td>
<td>14 (93.3)</td>
<td>9 (60)</td>
</tr>
<tr>
<td>Target total*</td>
<td>32 (100)</td>
<td>18 (56.3)</td>
<td>25 (78.1)</td>
</tr>
<tr>
<td><strong>Types of intervention (3 types)</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Skill building44,45</td>
<td>2 (6.3)</td>
<td>0</td>
<td>2 (100)</td>
</tr>
<tr>
<td>Psycho-educational29,30,33,37,42,58</td>
<td>7 (21.9)</td>
<td>6 (85.7)</td>
<td>6 (85.7)</td>
</tr>
<tr>
<td>Skill building and psycho-educational25,27,28,30–32,35,41,46–48,50,53,54,55,63</td>
<td>12 (37.5)</td>
<td>8 (66.7)</td>
<td>9 (75.0)</td>
</tr>
<tr>
<td>Skill building and support49</td>
<td>1 (3.1)</td>
<td>0</td>
<td>1 (100)</td>
</tr>
<tr>
<td>Psycho-educational and support9,18,43,51,57,58,61,62</td>
<td>6 (18.8)</td>
<td>3 (50.0)</td>
<td>4 (66.7)</td>
</tr>
<tr>
<td>Skill building, psycho-educational, and support44,52,55,58</td>
<td>4 (12.5)</td>
<td>1 (25.0)</td>
<td>3 (75.0)</td>
</tr>
<tr>
<td>Total types*</td>
<td>32 (100)</td>
<td>18 (56.3)</td>
<td>25 (78.1)</td>
</tr>
<tr>
<td><strong>Tailored vs one size fits all</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Tailored or individualized25,42–44,51,53–57,60,63</td>
<td>27 (84.4)</td>
<td>17 (63.0)</td>
<td>21 (77.8)</td>
</tr>
<tr>
<td>One size fits all43,52,58,59,61,62</td>
<td>5 (15.6)</td>
<td>1 (20.0)</td>
<td>4 (80.0)</td>
</tr>
<tr>
<td>Tailored/one size total*</td>
<td>32 (100)</td>
<td>18 (56.3)</td>
<td>25 (78.1)</td>
</tr>
<tr>
<td><strong>Mode of delivery</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Face to face25,29,31,32,40,41–43,47,49,52,56,59,61,62</td>
<td>15 (46.9)</td>
<td>9 (60)</td>
<td>11 (73.3)</td>
</tr>
<tr>
<td>Telephone36,50,60</td>
<td>2 (6.3)</td>
<td>0</td>
<td>2 (100)</td>
</tr>
<tr>
<td>Web38,55</td>
<td>2 (6.3)</td>
<td>1 (50)</td>
<td>1 (50)</td>
</tr>
<tr>
<td>Face-to-face and telephone27,31,32,40,44–48,51,53,54,57,80</td>
<td>13 (40.6)</td>
<td>8 (61.5)</td>
<td>11 (84.6)</td>
</tr>
<tr>
<td>Mode total*</td>
<td>32 (100)</td>
<td>18 (56.3)</td>
<td>25 (78.1)</td>
</tr>
<tr>
<td><strong>No. of sessions</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>0–425,29,30,31,32,38,39,52,81</td>
<td>8 (25.0)</td>
<td>5 (62.5)</td>
<td>6 (75.0)</td>
</tr>
<tr>
<td>5–925,27,30,31,34,36,40–50,53,54,57,59–60</td>
<td>16 (50.0)</td>
<td>8 (50.0)</td>
<td>13 (81.3)</td>
</tr>
<tr>
<td>10–1447,48,54,65</td>
<td>3 (9.4)</td>
<td>1 (33.3)</td>
<td>3 (100)</td>
</tr>
<tr>
<td>≥1553,57,59,61,62</td>
<td>5 (15.6)</td>
<td>4 (80.0)</td>
<td>3 (60.0)</td>
</tr>
<tr>
<td>Sessions total*</td>
<td>32 (100)</td>
<td>18 (56.3)</td>
<td>25 (78.1)</td>
</tr>
</tbody>
</table>

*Note: Survivor and caregiver outcomes do not add to total of 32 because many studies measured both types of outcomes, whereas some focused on only one or the other. There were 39 articles representing 32 studies. Refer to Tables I and II in the online-only Data Supplement for specific information about each study.

†Skill building: strategies that focus on processes that facilitate (1) problem solving, goal setting, and communicating with healthcare professionals; (2) stress management; (3) hands-on training in such skills as lifting and mobility techniques and activities of daily living; and (4) communication tailored to the needs of the stroke patient. Psycho-educational—provision of information about (1) warning signs for stroke, lifestyle changes, and general resources; (2) managing survivor emotions and behaviour; (3) managing medications and personal care; (4) managing finances and transportation; and (5) managing one’s own emotions and healthcare needs. Support: engaging in interactions with peers for support and advice (eg, support groups, online discussion forums).
Question 1: Do Family Caregiver Interventions Improve Survivor Outcomes?

Tables I and II in the online-only Data Supplement summarize the 32 studies meeting our inclusion criteria (17 stroke caregiver, 15 dyad), and Table 3 categorizes the studies according to significant ($P<0.05$) stroke survivor outcomes. Instruments used also are listed in Table 3. Although significant survivor outcomes are displayed, the many nonsignificant findings in the various studies were too numerous to include in Table 3. Examples of nonsignificant findings are provided in the Results section.

Survivor Physical Functioning

A number of studies found significant improvements in stroke survivors’ physical functioning relative to a control group. Kalra and colleagues$^{25}$ reported significant differences favoring the treatment group in Barthel Index scores at 3 months, and Clark and colleagues$^{26}$ found significant group differences in Barthel Index scores at 6 months. Another study noted a significant improvement in upper-extremity paresis at 4 weeks.$^{28}$ Although King and colleagues$^{27}$ found significant within-group differences in motor and cognitive function as measured by the Functional Independence Measure at both 10 and 18 weeks in a matched historical group study, no between-group difference was found. Burton and Gibbon$^{29}$ found significant improvements in physical dependence and negative mood as measured by the Nottingham Health Profile.

Although there were conflicting findings about improvements in survivor
physical functioning in these stroke caregiver and stroke dyad intervention studies, evidence is emerging in this area. Methodological weaknesses within the studies may partially explain why some studies found significant results whereas others did not.

Survivor Anxiety and Depression

Only a few studies reported significant results with respect to survivor anxiety and depression. Kalra and colleagues reported significant improvements in survivor anxiety and depression at 1 year using the Hospital Anxiety and Depression Scale. Two other studies found significant reductions in survivor anxiety using the same measure, although depression was not significant. Many other studies measured depression with a variety of scales but did not report significant group differences. Although these results may reflect ineffective interventions, it is possible that many of the survivors did not exhibit sufficient depressive symptoms at baseline to demonstrate significant improvements. Researchers are urged in future studies to enroll caregivers of survivors who are depressed or to conduct subgroup analyses of depressed survivors.

Survivor Health-Related Quality of Life

There was more support for stroke caregiver and dyad interventions in terms of health-related quality of life, also commonly referred to as general health perceptions. The most common health-related quality-of-life measures used for stroke survivors include the SF-36 Health Survey, the EuroQOL, and the Nottingham Health Profile (Table 3). Four studies found significant improvements in health-related quality of life in ≥1 subscales of these measures, although the study by Louie and colleagues involved only within-group differences because it used a single-group pretest-to-posttest design. Conversely, some studies found no significant group differences with respect to these measures.

Survivor Social Functioning

Table 3 shows a variety of types of social functioning outcomes. For instance, Clark and colleagues found significant improvements in survivor family functioning using the McMaster Family Assessment Device for their treatment group relative to their control group. Others found significant improvements in social isolation, social activity, social recovery, and stroke support group attendance. Although 1 study reported better social functioning with the Frenchay Activities Index, 2 studies found no significant differences using this measure. Two studies conducted in the United Kingdom reported worse outcomes for stroke survivors in the treatment group relative to the control group in terms of social adjustment and reintegration. Both of these studies involved a “family support organizer,” that is, a social worker who visited the home mainly at the request of the survivor or the caregiver. Thus, there was wide variation in the number of contacts and details of what was covered in these visits.

Survivor Service Use

Service use variables were reported in a number of studies. One study reported increased use of occupational therapy and outpatient care, whereas another reported decreased use of physiotherapy and speech therapy. Although decreasing use of therapy services may imply that the survivor is improving, increased use of services such as occupational therapy and outpatient care may be desirable, connecting survivors to important resources. In other words, it is unclear relative to these variables which outcomes were desired and reflect the best outcomes. Other studies found favorable improvements in terms of fewer illnesses; caregiver reports of emergency room visits; hospital readmissions; hospital days; and more home help; reduced institutionalization; and lower costs. These findings support the notion that stroke caregiver and stroke dyad interventions have the potential to provide significant improvements within our healthcare system. Other studies found no improvement with regard to rehospitalization and institutionalization; however, the numbers of those rehospitalized or institutionalized were small, which may explain the lack of significance.

Survivor Knowledge and Satisfaction

Knowledge and satisfaction are also important outcomes to consider with respect to stroke caregiver and dyad interventions. Stroke survivor knowledge improved in 3 studies but was not significant in 3 others. Part of the problem could be the different knowledge tests developed by the investigators and the possibility that those in the control groups also received basic information about stroke. Satisfaction was significantly improved for treatment relative to control groups in 4 studies. In the Lincoln et al study, patients were significantly satisfied with the information they received on preventing future strokes and emotional support; however, overall satisfaction with services was not significant. In the study by Tilling and colleagues, satisfaction about recovery information improved, although satisfaction about community services worsened. The reason for worsening community services satisfaction is unclear; however, the family support organizers in this study tended to place more emphasis on emotional support and providing a “listening ear” rather than focusing on the assessed needs of the patient. A few studies did not find significant group differences with respect to satisfaction.

Question 2: Do Family Caregiver Interventions Improve Caregiver Outcomes?

Caregiver Preparedness

Table 3 also categorizes the studies according to significant (P<0.05) family caregiver outcomes. Caregiver preparedness, measured in a number of studies, significantly improved for the treatment group relative to the control group in 2 separate studies testing a problem-solving intervention. Another study not only reported significant group differences in terms of self-reported caregiver preparedness but also found that nurses’ perceptions of caregiver preparedness improved. King and colleagues reported a significant improvement in caregiver preparedness within a single-group study but found no significant group differences in preparedness in their randomized wait-list control study. Other studies have found significant group differences with respect to caregiver confidence and self-efficacy, competence, and...
quality of care. These findings overall provide convincing evidence that stroke caregiver interventions promote caregiver perceptions of their preparedness, confidence, self-efficacy, competence, and quality of care, with 1 study documenting improved nurse perceptions of caregiver preparedness.

**Caregiver Burden, Stress, and Strain**

Caregiver burden, stress, and strain are common outcome measures found in the literature. Bakas and colleagues found significant reductions in caregiver task difficulty as measured by the Oberst Caregiving Burden Scale; however, task difficulty with the same scale did not reach significance in the study by Grant and colleagues or in the single-group study by King and colleagues. Burden, as measured by the Burden Interview, was significant in a study by Hartke and King. Several studies found significant group differences using the Caregiver Strain Index; however, other studies, all of which involved dyad interventions, did not find significant changes using this scale. Stress reduction was found in the treatment group in a randomized, wait-list control study, although this reduction was not sustained at 3 months after intervention. Another concept similar to stress or strain guided by the Lazarus and Folkman theory of stress and coping is appraisal. Threat appraisal, defined as the anticipation of harm or loss associated with providing care, was significantly reduced for family caregivers in a skill-building intervention compared with a control group. It is clear from these studies that measuring perceived caregiver burden or strain had mixed results. The use of different outcome measures and types of interventions could have contributed to these mixed results, along with small sample sizes.

**Caregiver Anxiety and Depressive Symptoms**

Anxiety and depressive symptoms are also common outcomes found in the stroke caregiving literature. Two studies reported significant improvements in caregiver anxiety compared with a control group as measured by the Hospital Anxiety and Depression Scale and 1 study that did not have a control group found significant within-group differences in anxiety measured by the Profile of Mood States. The most common measures of depressive symptoms included the Center for Epidemiological Studies Depression Scale, the Hospital Anxiety and Depression Scale, and the Beck Depression Inventory (Table 3). A number of studies reported significant improvements in caregiver depressive symptoms using these instruments, although a few studies reported nonsignificant findings. For example, Pierce and colleagues did not find significant differences in depressive symptoms using the Center for Epidemiological Studies Depression Scale in their Web-based intervention. Bakas and colleagues did not find significant group differences using the Patient Health Questionnaire Depression Scale; however, their sample was small and included caregivers with and without depressive symptoms. Subgroup analyses were later performed with a depressed subgroup and demonstrated medium to large effect sizes. These findings reinforce the point made earlier about the importance of considering enrollment of those who are depressed or of performing subgroup analyses to properly identify changes in depressive symptoms among participants. Nevertheless, the studies reviewed provide convincing evidence that stroke caregiver interventions can improve caregiver depressive symptoms.

**Caregiver Health-Related Quality of Life**

Health-related quality of life as measured by the SF-36 Health Survey yielded significant results in 2 separate studies. Both reported significant group differences for the SF-36 vitality and mental health subscales, and 1 study reported significant improvement in the SF-36 pain, physical function, and general health perception subscale scores. Mant et al reported that social activities, mental health, pain, energy, physical functioning, general health, health-related quality of life, and satisfaction all improved at 6 months. In the 12-month follow-up study by Mant et al, caregiver outcomes, although not statistically significant, were “broadly similar” (p. 1007) to the 6-month results. Other studies have reported nonsignificant findings with respect to the SF-36 general health subscale, suggesting that this measure is probably too global to detect stroke caregiver intervention effects. Using a variety of measures such as the EuroQOL, the World Health Quality of Life Questionnaire, Dartmouth co-op charts, and a single health item, studies have documented significant improvements in health-related quality of life. Two studies measured life changes as a result of providing care using the Bakas Caregiving Outcomes Scale, King and colleagues found significantly better life changes in the intervention group compared with the wait-list control for their intervention involving problem solving and stress management. Bakas and colleagues, on the other hand, did not find significant differences in their small pilot study but have since revised their intervention to include a more detailed assessment of life changes for better tailoring their intervention in a future trial. Another study did not reach significance in terms of life satisfaction after a Web-based intervention. As noted, findings were mixed with respect to health-related quality of life, which might have resulted largely from the use of different quality-of-life measures, some of which were more global in nature. Sample sizes varied widely, as did intervention types. Finally, these mixed findings suggest the importance of ensuring a close fit between intervention components and outcome measures.

**Caregiver Social Functioning**

Although Grant and colleagues reported significantly improved scores on the SF-36 social functioning subscale relative to the support group, Rodgers and colleagues actually reported significantly worse SF-36 social functioning for the intervention group. No other SF-36 Health Survey subscales were significant in the Rodgers et al study. Several explanations for these results seem plausible. First, the SF-36 social functioning items may be confusing for caregivers to respond to because the items refer to changes in social functioning resulting from the caregiver’s own health, not because of family caregiving. Caregivers may have difficulty distinguishing between social functioning as a result of their own health and their inability to get out because they are providing care for the survivor. Another possible explanation may relate to the fact that Rodgers and colleagues tested a “one size fits all” intervention involving 6 face-to-face sessions after discharge. Caregivers typically have a variety of needs that may require a
more individualized approach. Interestingly, however, another study reported worsening social activities in the intervention group compared with a control as measured by the Frenchay Activities Index.40 This intervention required a total of 8 sessions, some of which involved observing the caregiver in the home setting, which may have reduced opportunities for other social activities for the caregivers. These findings certainly deserve attention with respect to how burdensome intervention programs may be for family caregivers and how they may actually reduce the time available to caregivers to enjoy their own social activities. On a more positive note, 1 study found significant differences favoring the intervention group in terms of family functioning at 6 months.26

**Caregiver Coping**

Using the Utrecht Coping List, van den Heuvel and colleagues47,48 found that caregivers’ perceived use of confronting coping strategies and perceived social support were significantly improved after their interventions, which included comparisons among a control and 2 intervention groups. Pierce and colleagues,38 however, in testing a Web-based intervention, did not find any difference in emotional or physical support between the control and intervention groups. Problem solving, a form of coping, was significant in both studies by Grant and colleagues44,45 testing a problem-solving intervention. Although optimism is not a coping strategy per se, it is related to coping, and 1 study reported significant improvements in caregiver optimism as measured by the Revised Life Orientation test after the skill-building intervention, which included emphasis on stress management.50 Findings indicated that interventions aimed at helping caregivers learn new skills and develop better coping and problem-solving strategies, as well as facilitating social support, may be beneficial.

**Caregiver Service Use**

Only 1 study reported a significant finding about caregiver service use. Gräsel and colleagues28 found a significant decrease in the number of physician visits for family caregivers in the intervention group relative to the control group but no other significant differences in terms of caregiver physical or emotional health. The reduction in the number of physician visits could indicate either that caregivers’ health improved or that caregivers did not have the time to schedule their own physician visits. Service use data can be unclear with respect to family caregiving because family caregivers often neglect their own healthcare needs to provide care for the survivor. One study looked at the effects of interventions on costs to the caregiver. Costs were measured by quality-adjusted life-years, as well as number of hours of caregiving per day and annually and the number of days of caregiving. None of these outcomes were significant.41 Overall, few studies have examined caregiver service use, and more research is needed in this area.

**Caregiver Knowledge and Satisfaction**

Six studies documented improvements in caregiver knowledge after their interventions.42,43,57–59 Stroke knowledge improved at 6 months in the Mant et al57 and Rodgers et al43 studies and at 1 month in the study reported by Louie et al.32 A variety of knowledge measures were used, as reported in Table 3. Caregivers were very satisfied with the interventions. For example, in the Perrin et al51 study, the intervention group had mean satisfaction scores of 9.5 of 10. In the King et al37 study, 93% of the study participants ranked the intervention as very helpful. Several studies reported significant group differences favoring the intervention groups for satisfaction.33,34,46,53,57,60 However, 1 study reported nonsignificant findings concerning satisfaction.52 and 1 study actually reported worse caregiver satisfaction scores for the intervention compared with the control.57 The latter study involved the use of a family support organizer and reported worse satisfaction scores for the survivors. Overall, there does seem to be convincing evidence of improved satisfaction for both stroke caregiver and stroke dyad interventions. Satisfaction is an important outcome that should not be overlooked, particularly with today’s focus on patient- and family-centered care.

**Question 3: What Types of Family Caregiver Interventions Are Most Effective for Improving Stroke Survivor and Caregiver Outcomes?**

A total of 39 articles met the criteria for inclusion (Tables I and II in the online-only Data Supplement provide details). The 39 articles represented 32 different studies. Table 4 describes the characteristics of the 32 studies testing stroke caregiver or stroke dyad interventions. Of the 32 studies reviewed, 17 (53.1%) tested interventions that were targeted primarily to the caregiver. Most of these interventions also helped caregivers address the needs of the survivors, but the survivors were not active participants in the intervention. Some of these caregiver intervention studies involved the survivors for data collection purposes, however. For example, 1 study recruited 32 stroke caregiver/survivor dyads for data collection. However, because the survivors were not active participants in the intervention, this intervention study was classified as a caregiver intervention.53 Of these 17 caregiver interventions, 16 (94%) reported significant caregiver outcomes, but only 4 (23.5%) indicated significant improvement in stroke survivor outcomes. One of the 17 caregiver intervention studies found worse social functioning for caregivers in the treatment group relative to the control group.40

Of the 32 studies reviewed, 15 (46.9%) tested interventions targeted to the survivor-caregiver dyad in which both survivors and caregivers were active participants in the intervention. Of these 15 dyad interventions, 14 (93.3%) reported significant survivor outcomes, but only 9 (60%) reported significant caregiver outcomes. One of the dyad interventions did not find any significant findings, attributing this lack of significance to the small sample size.62 Of the 15 dyad intervention studies, 3 (20%) discovered worse outcomes for the treatment group relative to the control group.33,37,43 Those outcomes included worse social functioning for survivors and caregivers,33,43 worse reintegration for survivors,37 and poorer satisfaction ratings for both survivors and caregivers.37

In summary, >90% of the studies testing caregiver interventions resulted in improved caregiver outcomes as opposed to only 24% showing caregiver improvements in the dyad studies. In other words, to improve caregiver outcomes, interventions targeted directly at caregivers may be best. To improve survivor outcomes, dyad interventions may be more effective.
because there were improved survivor outcomes in 90% of those interventions. Future studies need to be clear about whether the intervention is designed to influence the stroke survivor, caregiver, or both. If addressing both, then the intervention needs to include specific content to meet both survivor and caregiver needs. However, a word of caution is warranted because a few intervention studies reported worse outcomes on a few variables for the treatment group.33,37,40,43

The following sections address specifics about the interventions tested. We have included the type of intervention, mode of delivery, frequency of sessions, timing and dosage of interventions, access to experts, and limitations.

**Types of Interventions**

The types of interventions tested in the 32 studies reviewed are also described in Table 4. Types of interventions included skill-building, psycho-educational information, and support. Skill-building interventions involve strategies that focus on processes that facilitate (1) problem solving, goal setting, and communicating with healthcare professionals; (2) stress management; (3) hands-on training in such skills as lifting and mobility techniques and assistance with activities of daily living; and (4) communication tailored to the needs of the stroke patient. Psycho-educational interventions are the provision of information about (1) warning signs for stroke, lifestyle changes, and general resources; (2) managing survivor emotions and behaviors; (3) managing medications and personal care; (4) managing finances and transportation; and (5) managing one’s own emotions and healthcare needs. Support interventions are defined as engaging in interactions with peers for support and advice (e.g., support groups, online discussion forums).

Of the 32 studies reviewed, 12 (37.5%) involved a combination of skill-building and psycho-educational strategies. Of these 12, 9 (75%) resulted in significant caregiver outcomes, and 8 (66.7%) resulted in significant survivor outcomes. For example, Kalra and colleagues25 combined skill building (e.g., goal setting, hands-on training) with psycho-educational strategies (e.g., tailored information about the survivor’s care) in their large, randomized, controlled clinical trial (n=300). Significant outcomes included improvements in anxiety, depression, and quality of life for both caregivers and survivors.25 Caregivers in the treatment group also experienced reduced burden, and survivors showed improved Barthel Index physical functioning scores.25 The treatment group also had lower costs relative to the control group.31

Of the 7 studies (21.9%) that used psycho-educational strategies alone, 6 (85.7%) reported significant caregiver outcomes, and 6 reported significant survivor outcomes. However, most of these outcomes for caregivers and survivors involved increased knowledge42,58 or satisfaction33,37,39,42 but did not improve other important psychosocial outcomes such as depression or quality of life. In fact, 2 of these interventions with primarily psycho-educational content involving family support organizers actually resulted in negative outcomes for the intervention group.33,37 Dennis and colleagues35 found worse social adjustment for survivors in the intervention group, and Tilling and colleagues37 discovered worse social reintegration and satisfaction with community resources for both caregivers and survivors. These findings were similar to those by Rodgers et al,43 who reported worse social functioning for caregivers in a group receiving a psycho-educational support intervention. All 3 of these studies reporting worse outcomes were dyad interventions.

Conversely, skill-building–only interventions (e.g., problem solving) were successful in the work by Grant and colleagues,44,45 resulting in significant improvements in depression, problem solving, preparedness, burden, competence, vitality, role emotional, and mental health among family caregivers. An additional 4 studies (12.5%) combined skill building, psycho-education, and support strategies; of these, 3 studies (75%) reported significantly improved caregiver outcomes, and 1 study (25%) reported significant survivor outcomes.

Overall, it is clear that interventions with only a psycho-educational focus are not as effective and might even result in poor social and satisfaction outcomes. Studies that incorporate skill building (e.g., problem solving, stress management, goal setting) with psycho-educational strategies tend to be much more effective at improving caregiver and survivor outcomes than psycho-education alone. These findings are consistent with those of a systematic review relevant to stroke family caregivers46 and to recommendations provided by Miller and colleagues47 and Lindsay and colleagues.15,16

**Intervention Delivery Design**

Another important characteristic of interventions is whether they are tailored or individualized on the basis of caregiver needs, as opposed to having a “one size fits all” format. According to Table 4, the vast majority of the 32 studies (n=27, 84.4%) used an individualized approach to meet the specific needs of the family caregiver. Of these 27 studies, 17 (63%) had positive survivor outcomes and 21 (77.8%) had positive caregiver outcomes. Only 5 studies (15.6%) used a nontailed approach, and all of these involved face-to-face group sessions.43,52,58,59,62 The study results for improvement in outcomes were not quite as strong for the nontailed studies. For example, Marsden and colleagues62 found no significant differences, although they attributed this to their small sample size. Although Franzen-Dahlin and colleagues59 found improved caregiver knowledge at 1 year on the basis of a subanalysis, the primary findings from their intervention as reported by Larson and colleagues61 were not significant. Although knowledge improved for survivors and caregivers in the study by Rodgers and colleagues,41 caregiver social functioning actually worsened in the intervention group. Braithwaite and McGown48 found only improved caregiver knowledge pretest to posttest, and Draper and colleagues52 noted a significant decrease in caregiver stress at posttest, but this effect was not sustained at 3 months. The results from the 32 studies overwhelmingly supported the tailored approach to interventions as more effective. These results mirror recommendations by Lindsay and colleagues15,16 that caregiver interventions should be specific to the phase of recovery across the continuum of care and to the readiness and needs of survivors and caregivers. Skill-building strategies need to be tailored because some caregivers may need more problem solving as opposed to stress management and vice versa. Miller and colleagues14 recommended detailed assessment of...
caregiver needs and concerns from the caregiver’s perspective to allow individualization of interventions.

Mode of Delivery
The mode of delivery is also an important characteristic to consider when designing interventions to meet the needs of stroke family caregivers. Table 4 includes the breakdown of how the 32 interventions were delivered. Most were delivered either face to face (n=15, 46.9%) or as a combination of face to face and telephone (n=13, 40.6%). Compared with face to face only, the combination of face to face and telephone resulted in slightly higher percentages of significant outcomes for stroke survivors (n=8, 61.5%) and caregivers (n=11, 84.6%). Telephone delivery certainly has advantages in terms of cost and convenience to caregivers, and 2 studies using interventions delivered completely by telephone resulted in significant improvements in caregiver burden and competence,49 as well as caregiver optimism, perceived task difficulty, threat, and satisfaction.50,60 Only 2 studies tested Web-based interventions.38,55 Although the “Caring-Web” intervention of Pierce and colleagues38 did not result in any significant caregiver improvements, benefits were found for stroke survivors, with fewer caregiver-reported emergency room visits and hospital readmissions for the survivor at 1 year. Smith and colleagues35 tested a similar Web-based intervention that included online education and support but also included skill building (stress management, pleasant activities) that resulted in significant improvements in caregiver depression persisting up to 1 year. Although these Web-based interventions look promising, they require computer skills and resources, which may limit access for some stroke caregivers.

Overall, interventions that are delivered face to face or by telephone have strong evidence for improving outcomes for stroke survivors and caregivers. As computers and other “smart” technologies become more widely used among the older population, similar improvements in Web-based and other technologically enhanced interventions may be seen in the future, particularly for those that use a combination of skill building, psycho-educational support. More research should be conducted with these newer delivery methods.

Frequency of Sessions
The number of sessions used in the 32 studies ranged from 033,38,42 to ≥15.13,33,37,42,51,56 Of the 2 studies that used Web-based delivery, 1 had 11 sessions,56 and the other was used as needed.38 The other 2 studies with 0 sessions (intervention designs in which the stroke survivor or caregiver had to initiate a visit) used the services of a family support organizer and tended to have the weakest results, with Lincoln and colleagues42 reporting only increased knowledge and satisfaction and Dennis and colleagues15 reporting satisfaction but worse social adjustment for survivors in the intervention group. Tilling and colleagues37 also used a family support organizer and had an exceptionally large range of visits (0–60; 15 on average). Tilling and colleagues37 also reported worse outcomes for both survivors (poor reintegration and satisfaction) and caregivers (lower satisfaction). These interventions were designed so that the caregiver or stroke survivor had to ask the family support organizer to visit, which explains why some caregivers and caregivers had 0 sessions. The family support organizer interventions clearly had less structure and varied greatly in the number of sessions, which may explain the worse outcomes. One exception, however, was the Mant et al56,57 family support organizer intervention, which resulted in fewer therapy visits for survivors and significant improvements in caregiver outcomes, including quality of life. Although the number of session in the Mant et al56,57 intervention varied, on average, dyads received 2 face-to-face visits and 3 telephone sessions (5 total sessions).

Half of the 32 studies had between 5 and 9 sessions (n=16, 50.0%), with 8 (50.0%) of these demonstrating significant survivor improvements and 13 (81.3%) having significant caregiver improvements in outcomes. Two studies in the group of 16 that had 5 to 9 sessions reported positive survivor and caregiver outcomes but worse social functioning for caregivers in the intervention group.40,43 Although the reason for these negative findings is unclear, it is possible that caregivers participating in the intervention and caring for the survivor may not have had extra time for social activities. This is a concern to keep in mind in the interpretation of these studies. However, from the results from this review, it appears that interventions with 5 to 9 sessions have the best evidence for improving survivor and caregiver outcomes, whereas family support organizer interventions with a large range of sessions (in which caregivers and survivors requested visits that were less structured) tended to have worse outcomes.3,37

Timing of Sessions
The timing of interventions varied considerably, with the distribution of sessions over time from a few weeks to a number of months after stroke. Some studies included caregivers caring for stroke survivors later in the trajectory of recovery,47,48,56,58 whereas other interventions were initiated during acute inpatient rehabilitation,27,40,44–46 One study targeted their intervention toward caregivers of patients who were 6 months to 3 years after stroke,48 and another began the intervention within 8 weeks after discharge to the home setting.50,60 King and colleagues54 also assessed caregivers at 1 year and found continued negative outcomes. The durability of intervention effects also needs to be assessed in many studies, with the need for booster sessions. However, many studies do not examine durability. The lack of research investigating the lasting effects of tested interventions is a concern, given that caregiver or survivor depressive symptoms or other negative outcomes may not surface until several months or years after the stroke, especially if expectations for recovery change. Only a few published studies accessed long-term outcomes.48,57

Access to Experts
Access to experts was specifically mentioned relative to several studies34,59,61 and may have been available but not clearly identified in other interventions. Experts may include such individuals as case managers, nurses, therapists, social workers, psychologists, and in some cases, expert caregivers. Access to experts during the intervention needs to be carefully evaluated and tracked because if this is part of the intervention, it may be a key component that is not being captured in a systematic way. Systematically tracking how often the expert is used and asking caregivers which components of the intervention were most helpful during the course of an intervention are essential in evaluating which aspects of bundled interventions are most important.
Question 4: What Recommendations Can Be Made for Designing and Implementing Family Caregiver Interventions That Improve Stroke Survivor and Caregiver Outcomes?

A number of methodological limitations were found in the 32 studies reviewed. Limitations included such things as small sample sizes not powered to adequately test the hypotheses; high attrition; lack of control groups; lack of description of fidelity to the intervention; varying doses of intervention, ranging from several weeks to months; and differing times in the stroke recovery trajectory, although most survivors were near discharge from a rehabilitation facility.27,40,44–46 Despite these limitations, results found for Question 1 revealed improvements in a number of survivor outcomes, and findings from Question 2 indicated improvements in caregiver outcomes. Question 3 addressed the best types of interventions that resulted in improvements in survivor and caregiver outcomes. Future studies need to be clear if the intervention is designed to influence the stroke survivor, caregiver, or both. If addressing both, then the intervention needs to include specific content to meet both survivor and caregiver needs. Based on the results from this detailed critique and analysis of 32 research studies involving family caregiver interventions and dyad interventions and their impact on stroke survivor and caregiver outcomes, recommendations are provided in Table 5.

A majority of the recommendations in Table 5 were either Class I or Class IIa; most Levels of Evidence were A or B. However, 2 recommendations in Class IIb (might be considered) and 1 recommendation in Class III (interventions that involve only psycho-education) have the potential to jeopardize social functioning in some caregivers or survivors. One recommendation had very limited evidence (Level C) but was recommended as Class I on the basis of group consensus and standards of care (postdischarge assessments with tailored interventions based on changing caregiver needs).

The methodological problems and limited evidence about particular interventions for caregivers of stroke survivors make it difficult to determine with certainty the most effective interventions for survivor and caregiver outcomes. It is reasonable to believe that caregiver interventions are probably useful in improving caregiver outcomes; however, whether caregiver interventions will result in improved outcomes for stroke survivors is unknown. Conversely, it is reasonable to believe that dyad interventions are probably useful in improving survivor outcomes; however, dyad interventions have been shown to have little effect on caregiver outcomes. Nevertheless, it is recommended that caregiver and dyad interventions with a psycho-educational component be combined with a skill-building component to improve psychosocial outcomes such as depressive symptoms and quality of life for survivors and caregivers. The evidence for interventions involving both psycho-education and a support group or a support group only is less strong. Although it is reasonable to think these may provide some caregiver benefit, the evidence is not sufficiently strong to recommend these interventions. Less structured interventions delivered by a family support organizer are not as useful and may jeopardize social functioning in some survivors and caregivers. Interventions that are tailored or individualized on the basis of the needs of caregivers and that are delivered either face to face or by telephone with an average of 5 to 9 sessions are recommended on the basis of this review.

Conclusions

Future research needs to include more rigorous designs with particular attention to the fidelity of the intervention delivery and sustainability of outcomes. Because of high attrition and refusal rates in support group formats, researchers need to consider whether interventions delivered in these formats are the best. Additional consideration needs to be given to the dosage of the interventions and the likelihood that a large number of sessions requiring in-person contact may not be feasible for busy caregivers. Developing intervention sessions that will be feasible to integrate into clinical practice is an important consideration, and the delivery of interventions via telephone35,50,60 and the Web36,55 may be beneficial approaches.

The study by Kalra and colleagues25 was one of the best-designed studies and involved a randomized, controlled, clinical trial of 300 caregivers who received 3 to 5 inpatient sessions and 1 home visit in the intervention group. Their intervention consisted of both tailored psycho-educational topics and skill-building strategies (eg, hands-on caregiver training, goal setting) and resulted in a number of improved survivor and caregiver outcomes and reduced costs.25,41 However, 3 to 5 inpatient sessions and 1 home visit may not be feasible in some healthcare settings, and the tailored psycho-educational topics and goal setting tended to focus more on the care of the stroke survivor than on the family caregiver’s own self-care. It is important to be clear whether interventions are targeted to the stroke survivor, the caregiver, or both. If both, then the intervention must address the needs of both survivors and caregivers. Most studies occurred during the early discharge period. Studies are also needed later in the stroke recovery trajectory. There is also the need for more longitudinal intervention studies that measure sustainability of intervention effects.

Most studies measured only short-term outcomes. Long-term outcomes should be assessed with the intent of discovering new ways to strengthen existing interventions and to use boosters to achieve more positive outcomes in the long-term. Many different measures and outcomes were used across studies, and service use among caregivers (eg, physician visits, hospitalizations) was identified as a gap. Common measures with strong evidence of reliability and validity will allow better comparisons among studies to generate evidence for caregiver interventions. Future research should involve greater collaboration between researchers to design and carry out studies that are comparable because of design inconsistencies.

Family caregivers often ignore their own healthcare needs and are commonly neglected by healthcare professionals in practice settings during the stroke recovery process. For example, 1 stroke caregiver said during a qualitative interview, “When I took my husband to the doctor, everyone asked him how he was doing. I said to the doctor, ‘I know he’s sick, but why doesn’t someone ask me how I am doing?’” Acknowledging caregivers’ identity outside of this role not only is thoughtful and kind but also gives caregivers...
confidence. Because self-care is so difficult, caregivers may need encouragement from healthcare providers to take care of their own needs. Caregiver interventions within practice settings have the potential to improve not only caregiver outcomes (eg, mental and physical health, quality of life) but also patient outcomes (eg, may reduce readmission rates, prevent institutionalization, reduce disability, and improve quality of life). Based on the available evidence, Table 5 provides recommendations for researchers and clinicians who plan to design and implement stroke family caregiver interventions to enhance coordination of care and to better meet the needs of caregivers and survivors after stroke.

Acknowledgments
We acknowledge Lisa Scarton, Anne Leonard, and Connie Land for their assistance.

Sources of Funding
We acknowledge the American Heart Association Council on Cardiovascular and Stroke Nursing for their financial support.

Disclosures

Writing Group Disclosures

<table>
<thead>
<tr>
<th>Writing Group Member</th>
<th>Employment</th>
<th>Research Grant</th>
<th>Other Research Support</th>
<th>Speakers’ Bureau/ Honoraria</th>
<th>Expert Witness</th>
<th>Ownership Interest</th>
<th>Consultant/ Advisory Board</th>
<th>Other</th>
</tr>
</thead>
<tbody>
<tr>
<td>Tamilyn Bakas</td>
<td>Indiana University School of Nursing</td>
<td>NIH/NINR*</td>
<td>None</td>
<td>None</td>
<td>None</td>
<td>None</td>
<td>None</td>
<td>None</td>
</tr>
<tr>
<td>Patricia C. Clark</td>
<td>Georgia State University</td>
<td>None</td>
<td>None</td>
<td>None</td>
<td>None</td>
<td>None</td>
<td>None</td>
<td>None</td>
</tr>
<tr>
<td>Margaret Kelly-Hayes</td>
<td>Boston University School of Medicine</td>
<td>NIH/NINDS*</td>
<td>None</td>
<td>None</td>
<td>None</td>
<td>None</td>
<td>None</td>
<td>None</td>
</tr>
<tr>
<td>Rosemarie B. King</td>
<td>Northwestern University Feinberg School of Medicine</td>
<td>NIH/NINR*</td>
<td>None</td>
<td>None</td>
<td>None</td>
<td>None</td>
<td>None</td>
<td>None</td>
</tr>
<tr>
<td>Barbara J. Lutz</td>
<td>University of North Carolina-Wilmington School of Nursing</td>
<td>NIH/NINR*</td>
<td>None</td>
<td>None</td>
<td>None</td>
<td>None</td>
<td>None</td>
<td>None</td>
</tr>
<tr>
<td>Elaine Miller</td>
<td>University of Cincinnati College of Nursing</td>
<td>None</td>
<td>None</td>
<td>None</td>
<td>None</td>
<td>None</td>
<td>None</td>
<td>None</td>
</tr>
</tbody>
</table>

This table represents the relationships of writing group members that may be perceived as actual or reasonably perceived conflicts of interest as reported on the Disclosure Questionnaire, which all members of the writing group are required to complete and submit. A relationship is considered to be “significant” if (a) the person receives $10,000 or more during any 12-month period, or 5% or more of the person’s gross income; or (b) the person owns 5% or more of the voting stock or share of the entity, or owns $10,000 or more of the fair market value of the entity. A relationship is considered to be “modest” if it is less than “significant” under the preceding definition.

*Significant.

Reviewer Disclosures

<table>
<thead>
<tr>
<th>Writing Group Member</th>
<th>Employment</th>
<th>Research Grant</th>
<th>Other Research Support</th>
<th>Speakers’ Bureau/ Honoraria</th>
<th>Expert Witness</th>
<th>Ownership Interest</th>
<th>Consultant/ Advisory Board</th>
<th>Other</th>
</tr>
</thead>
<tbody>
<tr>
<td>Carolyn Goffman</td>
<td>DePaul University</td>
<td>None</td>
<td>None</td>
<td>None</td>
<td>None</td>
<td>None</td>
<td>None</td>
<td>None</td>
</tr>
<tr>
<td>Linda Pierce</td>
<td>University of Toledo College of Nursing</td>
<td>Rehabilitation Nursing Foundation*: University of Toledo Strategic Enhancement Award*</td>
<td>None</td>
<td>None</td>
<td>None</td>
<td>None</td>
<td>None</td>
<td>None</td>
</tr>
</tbody>
</table>

This table represents the relationships of writing group members that may be perceived as actual or reasonably perceived conflicts of interest as reported on the Disclosure Questionnaire, which all members of the writing group are required to complete and submit. A relationship is considered to be “significant” if (a) the person receives $10,000 or more during any 12-month period, or 5% or more of the person’s gross income; or (b) the person owns 5% or more of the voting stock or share of the entity, or owns $10,000 or more of the fair market value of the entity. A relationship is considered to be “modest” if it is less than “significant” under the preceding definition.

*Modest.
References


2852  Stroke  September 2014


Evidence for Stroke Family Caregiver and Dyad Interventions: A Statement for Healthcare Professionals From the American Heart Association and American Stroke Association

Tamilyn Bakas, Patricia C. Clark, Margaret Kelly-Hayes, Rosemarie B. King, Barbara J. Lutz and Elaine L. Miller

on behalf of the American Heart Association Council on Cardiovascular and Stroke Nursing and the Stroke Council

*Stroke.* 2014;45:2836-2852; originally published online July 17, 2014;
doi: 10.1161/STR.0000000000000033

*Stroke* is published by the American Heart Association, 7272 Greenville Avenue, Dallas, TX 75231
Copyright © 2014 American Heart Association, Inc. All rights reserved.
Print ISSN: 0039-2499. Online ISSN: 1524-4628

The online version of this article, along with updated information and services, is located on the World Wide Web at:
http://stroke.ahajournals.org/content/45/9/2836

Data Supplement (unedited) at:
http://stroke.ahajournals.org/content/suppl/2014/07/17/STR.0000000000000033.DC1

Permissions: Requests for permissions to reproduce figures, tables, or portions of articles originally published in *Stroke* can be obtained via RightsLink, a service of the Copyright Clearance Center, not the Editorial Office. Once the online version of the published article for which permission is being requested is located, click Request Permissions in the middle column of the Web page under Services. Further information about this process is available in the Permissions and Rights Question and Answer document.

Reprints: Information about reprints can be found online at:
http://www.lww.com/reprints

Subscriptions: Information about subscribing to *Stroke* is online at:
http://stroke.ahajournals.org/subscriptions/
## Online Supplemental Material

### Supplementary Table I. Summary of 22 Articles from 17 Different Studies Testing Family Caregiver Interventions.

<table>
<thead>
<tr>
<th>Author(s) (year)</th>
<th>Sample</th>
<th>Design</th>
<th>Skill-building</th>
<th>Psycho-education</th>
<th>Support</th>
<th>Face-to-Face</th>
<th>Telephone</th>
<th>Web</th>
<th>Total # sessions</th>
<th>Survivor outcomes (p&lt;.05)</th>
<th>Caregiver outcomes (p&lt;.05)</th>
</tr>
</thead>
</table>
| Bakas et al., 2009a<sup>60</sup>  
Bakas et al., 2009b<sup>50</sup> | N=40  
T 21  
C 19 | RCT | X  
Problem solving,  
Stress manage,  
Asking HP info,  
skills | X  
Assess Tailored | 8 | 8 |  
Optimism - 4,8,12wks  
Task Difficulty - 4wks  
Threat - 8,12wks  
Satisfaction - 12wks (usefulness, ease of use, acceptability) |
| Braithwaite & McGown 1993<sup>38</sup> | N = 37  
Single group pre-post | X Educ One-size | 1 | 1 | Knowledge pre-post |
| Draper et al., 2007<sup>52</sup> | N=39  
T 19  
C 20 | Random Waitlist control | X  
communication,  
stress manage,  
coping, skills | X Educ One-size | X | 4 | 4 | Stress -post, not sustained at 3mo |
| Franzen-Dahlin et al., 2008<sup>59</sup>  
Larson et al., 2005<sup>61</sup> | N=100  
T 50  
C 50 | RCT in blocks of 10 | X Educ One-size | X | 7 | 7 | Knowledge – 12mo (subanalysis) | Nothing significant in Larson et al., study. |
| Grant, 1999<sup>44</sup>  
Grant et al., 2002<sup>45</sup> | N = 30  
T10Tele  
T10Hom  
C10 | X  
Problem solving Tailored | X | 1 | 7 | 8 | Depression – 2,5wks  
Problem solving – 2,5wks  
Preparedness – 2,5wks |
|  | N = 74  
T37? | RCT | X  
Problem | 1 | 7 | 8 | Depression – 4wks  
Problem solving – 4wk |
### Supplementary Tables to Bakas et al, Evidence for Stroke Family Caregiver and Dyad Interventions

© Copyright 2014 American Heart Association, Inc.

<table>
<thead>
<tr>
<th>Author(s) (year)</th>
<th>Sample</th>
<th>Design</th>
<th>Skill-building</th>
<th>Psycho-education</th>
<th>Support</th>
<th>Face-to-Face</th>
<th>Telephone</th>
<th>Web</th>
<th>Total # sessions</th>
<th>Survivor outcomes (p&lt;.05)</th>
<th>Caregiver outcomes (p&lt;.05)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hartke &amp; King, 2003(^{49})</td>
<td>N=88</td>
<td>RCT</td>
<td>X</td>
<td>X</td>
<td>X</td>
<td></td>
<td>8</td>
<td></td>
<td>8</td>
<td>Burden – 6mo</td>
<td>Competence – 6mo</td>
</tr>
<tr>
<td>Kalra et al., 2004(^{50})</td>
<td>N=300</td>
<td>RCT</td>
<td>X</td>
<td>X</td>
<td></td>
<td></td>
<td>3-5</td>
<td>1</td>
<td>6</td>
<td>Barthel score-3mo</td>
<td>Anxiety-12mo</td>
</tr>
<tr>
<td>Patel et al., 2004(^{51})</td>
<td>N=73</td>
<td>Time Lag Design - quasi</td>
<td>X</td>
<td>X</td>
<td>1</td>
<td>14</td>
<td>15</td>
<td></td>
<td></td>
<td>Burden-12weeks</td>
<td>Lower costs</td>
</tr>
<tr>
<td>Kim et al., 2012(^{51})</td>
<td>N=73</td>
<td>Single group with match history compar</td>
<td>X</td>
<td>X</td>
<td></td>
<td></td>
<td>2 or 3</td>
<td>7 or 8</td>
<td>10</td>
<td>Within Group Motor function - 10, 18wks</td>
<td>Depression - 10, 18wks</td>
</tr>
<tr>
<td>King et al., 2007(^{52})</td>
<td>N = 30</td>
<td>Random wait-list control</td>
<td>X</td>
<td>X</td>
<td>2</td>
<td>8</td>
<td>10</td>
<td></td>
<td></td>
<td>Depression – post Life Change – post</td>
<td></td>
</tr>
<tr>
<td>King et al., 2012(^{54})</td>
<td>N = 121</td>
<td>Random wait-list control</td>
<td>X</td>
<td>X</td>
<td>2</td>
<td>8</td>
<td>10</td>
<td></td>
<td></td>
<td>Depression – post Life Change – post</td>
<td></td>
</tr>
</tbody>
</table>

- Preparedness – 4wks
- Vitality- 4wks
- Role Emotional-4wks
- Mental health – 4wks
- Burden – 6mo
- Competence – 6mo
- Lower costs
- Satisfaction with rehabilitation and instruction looking after patient
- Lower health and societal costs – 12mo
- Within Group Motor function- 10, 18wks
- Cognitive function- 10,18wks
- Depression – post Life Change – post
- Depression – post Health – post
- No outcomes sustained
<table>
<thead>
<tr>
<th>Author(s) (year)</th>
<th>Sample</th>
<th>Design</th>
<th>Skill-building</th>
<th>Psycho-education</th>
<th>Support</th>
<th>Face-to-Face</th>
<th>Telephone</th>
<th>Web</th>
<th>Total # sessions</th>
<th>Survivor outcomes (p&lt;.05)</th>
<th>Caregiver outcomes (p&lt;.05)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Perrin et al., 2010</td>
<td>N = 61 T? C?</td>
<td>RCT</td>
<td>X Problem solving Tailored</td>
<td>X</td>
<td>1</td>
<td>4</td>
<td>5</td>
<td>Support Face-to-Face, Tele- phone, Web</td>
<td>at 6mo or 1yr.</td>
<td>Strain – 1,3mo</td>
<td></td>
</tr>
<tr>
<td>Pierce et al., 2009</td>
<td>N=73 T36 C37</td>
<td>RCT</td>
<td>X Tailored</td>
<td>X Web prn</td>
<td>Web prn</td>
<td>Emergency room visits – 12mo Hospital readmissions – 12mo</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>van den Heuvel et al., 2000</td>
<td>N=257 T 78 home T 130 group C49 control</td>
<td>RCT in blocks of 8-13</td>
<td>X Problem solving Tailored X</td>
<td>X</td>
<td>4 home</td>
<td>8 group</td>
<td>4 home</td>
<td>8 group</td>
<td>Confidence about care – post Confidence in self-efficacy - post Coping confronting – post Coping social support-post</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Shyu et al., 2002</td>
<td>N=212 at 6mo T 49 home T 100 group C38 control</td>
<td>Randomized wards to T or C</td>
<td>X observe skills at home X Tailored</td>
<td>4-5 hosp 2 home</td>
<td>1</td>
<td>8</td>
<td>Institutionalized -12mo</td>
<td>Nurse ratings of caregiver preparedness – discharge Caregiver preparedness – discharge Needs satisfied– discharge (not sustained 1mo)</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Supplementary Tables to Bakas et al, Evidence for Stroke Family Caregiver and Dyad Interventions
© Copyright 2014 American Heart Association, Inc.

<table>
<thead>
<tr>
<th>Author(s) (year)</th>
<th>Sample</th>
<th>Design</th>
<th>Skill-building</th>
<th>Psycho-education</th>
<th>Support</th>
<th>Face-to-Face</th>
<th>Telephone</th>
<th>Web</th>
<th>Total # sessions</th>
<th>Survivor outcomes (p&lt;.05)</th>
<th>Caregiver outcomes (p&lt;.05)</th>
</tr>
</thead>
<tbody>
<tr>
<td>2010</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Quality of care -12mo</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Social functioning worse</td>
<td>Social in T group 3mo</td>
</tr>
<tr>
<td>Smith et al.,</td>
<td>N=38</td>
<td>RCT</td>
<td>X Stress</td>
<td>X Educ videos,</td>
<td>X</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Depression – post&amp;12mo</td>
</tr>
<tr>
<td>2012</td>
<td>T 19</td>
<td></td>
<td>manage,</td>
<td>links</td>
<td>groups</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Usefulness - post</td>
<td>Usefulness in post</td>
</tr>
<tr>
<td></td>
<td>C 19</td>
<td></td>
<td>Pleasant</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Recommend – post</td>
<td>Recommend in post</td>
</tr>
<tr>
<td>Wilz &amp;</td>
<td>N = 124</td>
<td>Quasi</td>
<td>X Problem</td>
<td>X Educ</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Quality of life (physical</td>
</tr>
<tr>
<td>Barskova,</td>
<td></td>
<td>controlled</td>
<td>solving,</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>&amp; environmental) – post</td>
</tr>
<tr>
<td>2007</td>
<td>T 38</td>
<td></td>
<td>stress</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Depression 6mo</td>
</tr>
<tr>
<td></td>
<td>C35info</td>
<td></td>
<td>manage (CBT)</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>U51</td>
<td></td>
<td>Tailored</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

N = Number of subjects; T = Treatment Group; C = Control Group; U = Usual care; cg = caregiver; pt = patient; FSO = Family Support Organizer.

All listed outcomes indicate improvement unless underlined as worse.

Types of interventions include skill-building, psycho-educational, and support.

Skill-building – strategies that focus on processes that facilitate problem solving, goal setting, communicating with health care professionals, stress management, and hands on training in such skills as lifting and mobility techniques, assistance with activities of daily living, and communication tailored to the needs of the stroke patient.

Psycho-educational- provision of information about (a) warning signs for stroke, lifestyle changes, and general resources, (b) managing survivor emotions and behaviors, (c) managing medications and personal care, (d) managing finances and transportation, and (e) managing one’s own emotions and health care needs.

Support – engaging in interactions with peers for support and advice (e.g., support groups, online discussion forums).
## Supplementary Table II. Summary of 17 Articles from 15 Different Studies Testing Dyad Interventions.

<table>
<thead>
<tr>
<th>Author(s) (year)</th>
<th>Sample</th>
<th>Design</th>
<th>Skill-building</th>
<th>Psycho-education</th>
<th>Support</th>
<th>Face-to-Face</th>
<th>Telephone</th>
<th>Web</th>
<th>Total # sessions</th>
<th>Survivor outcomes (p&lt;.05)</th>
<th>Caregiver outcomes (p&lt;.05)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Boter et al., 2004³⁰</td>
<td>N=486</td>
<td>RCT</td>
<td>X</td>
<td>X</td>
<td>1 home</td>
<td>3</td>
<td></td>
<td></td>
<td>4</td>
<td>SF-36Role Emotional 6mo Fewer rehabilitation services 6mo Anxiety 6mo</td>
<td>Nothing significant</td>
</tr>
<tr>
<td>Burton &amp; Gibbon 2005²⁹</td>
<td>N=176</td>
<td>RCT</td>
<td>X</td>
<td>Tailored</td>
<td>1 home</td>
<td>Call in # provided</td>
<td></td>
<td></td>
<td>1</td>
<td>General health 12mo Reduced negative mood 12mo Lower social isolation 12mo Physical dependence 3,12mo</td>
<td>Caregiver strain – 3mo</td>
</tr>
<tr>
<td>Clark et al., 2003³⁵</td>
<td>N=62</td>
<td>RCT</td>
<td>Educ and Couns.</td>
<td>Tailored</td>
<td>3 home</td>
<td></td>
<td></td>
<td></td>
<td>3</td>
<td>Barthel Index -6mo Family Function -6mo Social recovery -6mo</td>
<td>Family Function -6mo</td>
</tr>
<tr>
<td>Dennis et al., 1997³³</td>
<td>N=417</td>
<td>RCT</td>
<td>X</td>
<td>Tailored</td>
<td>Varied 0-17</td>
<td>Varied 0-17</td>
<td>Varied 0-17</td>
<td></td>
<td></td>
<td>Satisfaction – 6mo Social adjustment worse for treatment – 6mo</td>
<td>Satisfaction – 6mo Fewer Mood symptoms, anxiety – 6mo</td>
</tr>
<tr>
<td>Forster &amp; Young, 1996³⁴</td>
<td>N=240</td>
<td>RCT</td>
<td>X</td>
<td>X</td>
<td>8 average home</td>
<td>X as needed</td>
<td></td>
<td></td>
<td>8 average</td>
<td>Social at 6 &amp; 12mo (only for mildly disabled)</td>
<td>Nothing significant</td>
</tr>
<tr>
<td>Forster et al., 2009³⁹</td>
<td>N=265</td>
<td>RCT</td>
<td>X</td>
<td>Tailored</td>
<td>1 for assessment</td>
<td></td>
<td></td>
<td></td>
<td>1</td>
<td>Satisfaction -12mo Fewer hospital days – 12mo Fewer home care days – 12 mo</td>
<td>Nothing significant</td>
</tr>
<tr>
<td>Goldberg et al., 1997³⁵</td>
<td>N=41</td>
<td>RCT</td>
<td>X</td>
<td>X</td>
<td>X monthl</td>
<td>X weekly</td>
<td></td>
<td></td>
<td>not clear</td>
<td>Social activity – 6mo</td>
<td>Nothing significant</td>
</tr>
<tr>
<td>Author(s) (year)</td>
<td>Sample</td>
<td>Design</td>
<td>Skill-building</td>
<td>Psycho-education</td>
<td>Support</td>
<td>Face-to-Face</td>
<td>Telephone</td>
<td>Web</td>
<td>Total # sessions (p&lt;.05)</td>
<td>Survivor outcomes (p&lt;.05)</td>
<td>Caregiver outcomes (p&lt;.05)</td>
</tr>
<tr>
<td>-----------------</td>
<td>--------</td>
<td>--------</td>
<td>---------------</td>
<td>-----------------</td>
<td>---------</td>
<td>-------------</td>
<td>-----------</td>
<td>-----</td>
<td>------------------------</td>
<td>--------------------------</td>
<td>--------------------------</td>
</tr>
<tr>
<td>Grasel et al., 2005&lt;sup&gt;28&lt;/sup&gt;</td>
<td>N=62 T33 C29</td>
<td>Nonexp pts allocate to 1 of 2 wards based on opening</td>
<td>X Therapeutic weekend Tailored</td>
<td>X for caregivers</td>
<td>4 plus 1 weekend</td>
<td>1</td>
<td>6</td>
<td>Fewer illnesses -4wks Occupational therapy and Outpatient care more freq – 4wks Upper Extremity Paresis -4wks</td>
<td>Living at home (not institutionalized or deceased)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Grasel et al., 2006&lt;sup&gt;28&lt;/sup&gt;</td>
<td>N=70 T35 C35</td>
<td>Tailored for caregivers</td>
<td>12?</td>
<td>52?</td>
<td>64 at most</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Lincoln et al., 2003&lt;sup&gt;42&lt;/sup&gt;</td>
<td>N=250 T126 C124</td>
<td>RCT</td>
<td>X Tailored FSO</td>
<td>1hosp 1home Then varied</td>
<td>Varied</td>
<td>6</td>
<td>Knowledge – 4,9mo Satisf-4,9mo</td>
<td>Knowledge – 4,9mo Satisfaction-4,9mo</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Louie et al., 2006&lt;sup&gt;42&lt;/sup&gt;</td>
<td>N=54pts N=32cg</td>
<td>Single pre-post (no control) weak</td>
<td>X transfers and care skills Tailored</td>
<td>X</td>
<td></td>
<td>2</td>
<td>Knowledge –post SF-36 Phys –post, 1mo</td>
<td>Knowledge-post</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mant et al., 2000&lt;sup&gt;46&lt;/sup&gt;</td>
<td>N=323pt N=267cg T156pts C167</td>
<td>RCT</td>
<td>X Tailored FSO</td>
<td>X</td>
<td>1hosp 1home Then varied</td>
<td>3 varied</td>
<td>5 on average</td>
<td>Fewer saw physiotherapist -6mo More stroke clubs-6mo Less speech therapy-6mo</td>
<td>Social activity – 6,12mo SF-36 scores (energy 6mo, mental health 6,12mo, pain 6mo, physical function 6mo, general health 6mo) – 6mo Quality of life -6mo Satisfaction understanding stroke -6mo</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mant et al., 2005&lt;sup&gt;52&lt;/sup&gt;</td>
<td>N=338pt T146pt T110cg C148pt 102cg</td>
<td>RCT follow-up</td>
<td>X Tailored FSO</td>
<td>X</td>
<td>1hosp 1home Then varied</td>
<td>3 varied</td>
<td>5 on average</td>
<td>Fewer saw physiotherapist -6mo More stroke clubs-6mo Less speech therapy-6mo</td>
<td>Social activity – 6,12mo SF-36 scores (energy 6mo, mental health 6,12mo, pain 6mo, physical function 6mo, general health 6mo) – 6mo Quality of life -6mo Satisfaction understanding stroke -6mo</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Marsden et al., 2010&lt;sup&gt;42&lt;/sup&gt;</td>
<td>N=25pt N=17cg</td>
<td>Random cross-</td>
<td>X One-size</td>
<td>X</td>
<td>7 group</td>
<td>7</td>
<td>Trends, but NS due to small sample</td>
<td>Trends, but NS due to small sample</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
### Supplementary Tables to Bakas et al, Evidence for Stroke Family Caregiver and Dyad Interventions

© Copyright 2014 American Heart Association, Inc.

<table>
<thead>
<tr>
<th>Author(s) (year)</th>
<th>Sample</th>
<th>Design</th>
<th>Skill-building</th>
<th>Psycho-education</th>
<th>Support</th>
<th>Face-to-Face</th>
<th>Telephone</th>
<th>Web</th>
<th>Total # sessions</th>
<th>Survivor outcomes (p&lt;.05)</th>
<th>Caregiver outcomes (p&lt;.05)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Rodgers et al., 1999&lt;sup&gt;43&lt;/sup&gt;</td>
<td>N=204pt T31pt C19pt N=176c T42cg C28cg</td>
<td>RCT</td>
<td>X</td>
<td>X group</td>
<td>1inpt</td>
<td>6 disc</td>
<td></td>
<td></td>
<td>7</td>
<td>Knowledge-6mo Satisfaction-6mo</td>
<td>Knowledge-6mo Social Function worse in intervention group-6mo</td>
</tr>
<tr>
<td>Smith et al., 2004&lt;sup&gt;33&lt;/sup&gt;</td>
<td>N=170pt T84pt C86pt N=97cg T49cg C48cg</td>
<td>RCT</td>
<td>X Goal setting Tailored</td>
<td>X every 2 weeks ?</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>6? (every 2 wks for 3mo?)</td>
<td>Anxiety – 3,6mo</td>
<td></td>
</tr>
<tr>
<td>Tilling et al., 2005&lt;sup&gt;33&lt;/sup&gt;</td>
<td>N=340 T170 C170 At 3mo T114 C115 At 1yr T96 C92</td>
<td>RCT</td>
<td>X Tailored FSO</td>
<td>X</td>
<td>X</td>
<td></td>
<td></td>
<td></td>
<td>15 average (1-60)</td>
<td>Reintegration worse for intervention -3mo Satisfaction community services worse for intervention -3mo Satisfaction info about recovery -3mo More home help -3mo Less hospitalization-3mo</td>
<td>Satisfaction worse for intervention-3mo</td>
</tr>
</tbody>
</table>

N = Number of subjects; T = Treatment Group; C = Control Group; U = Usual care; cg = caregiver; pt = patient; FSO = Family Support Organizer.

All listed outcomes indicate improvement unless underlined as worse.

Types of interventions include skill-building, psycho-educational, and support.
Skill-building – strategies that focus on *processes* that facilitate problem solving, goal setting, communicating with health care professionals, stress management, and hands on training in such skills as lifting and mobility techniques, assistance with activities of daily living, and communication tailored to the needs of the stroke patient.

Psycho-educational- provision of *information* about (a) warning signs for stroke, lifestyle changes, and general resources, (b) managing survivor emotions and behaviors, (c) managing medications and personal care, (d) managing finances and transportation, and (e) managing one’s own emotions and health care needs.

Support – engaging in *interactions with peers* for support and advice (e.g., support groups, online discussion forums).