



Cyber Support for Family Caregivers: Psychosocial Outcomes

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Purpose

To evaluate whether psychosocial outcomes in family caregivers of people with chronic disease differ, based on the format of a 12-week online support group

Online peer directed support

Online professionally facilitated support





Background & Significance

- **>50 million Americans care for family members with chronic illness**
- **Family (informal) caregiver numbers are surging**
- **~ 60 % of informal caregivers are employed**
- **Lack of research on online support for employed, informal caregivers**
- **Personal interest in the topic**





Sample

- At least 21 years old
- Employed at least part-time
- Access to the Internet
- Read and write English
- Provide care to family member with a chronic condition





Method

- **Randomized longitudinal design comparing two types of online support groups (OSG) run for 12 weeks**
 - Peer directed
 - Professionally facilitated
- **On three principal measures**
 - QOL (Caregiver QOL Index)
 - Caregiver strain (Modified Caregiver Strain Index)
 - Depressive symptoms (CES-D)
- **At four timepoints (0, 6, 12, 16 weeks)**



Groups

- Peer directed

Peer directed communication moderated by PI for keeping on track and providing encouragement

- Professionally moderated

By doctorally prepared CNS

Different topic of focus for each of 12 weeks



Results: Peer-directed Group

- 24 subjects completed a demographic data form and at least 1 of the study questionnaires.
- 15 completed the study questionnaires at all 4 timepoints.
- 22 Female; 2 Male
- 23 Caucasian; 1 Hispanic
- Average age: 50.17 years





Results: Professionally Facilitated Group

- 20 subjects completed a demographic data form and at least 1 of the study questionnaires.
- 14 completed the study questionnaires at all 4 timepoints.
- 18 Female; 2 Male
- 16 Caucasian; 2 African American
- Average age: 49.84





Results

- **Provided care for:**
Mother, father, sister-in-law, brother-in-law, mother-in-law, etc.
- **Disease/condition of care receiver:**
Parkinsonism, Alzheimer, cerebral palsy, deaf, multiple sclerosis, brain injury, respiratory disease, depression, hypertension



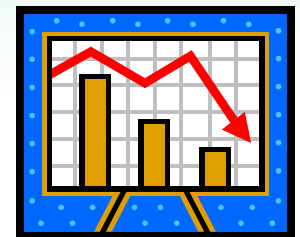
Results

- **Care provided: dress, feed, exercise, complete care, emotional support, order and/or administer medications, pay bills, “fix” things**
- **Range of time as a caregiver: 6 months to 29 years**
- **Range of hours per week as a caregiver: 5 to 168**



Results

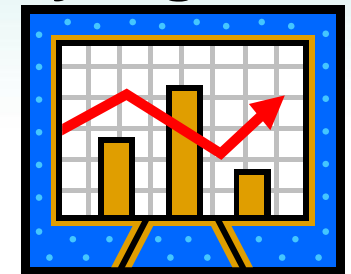
- Some subjects completed **ONLY** the demographic form and the first questionnaire.
- Data from these were removed from the statistical analysis, because responses over time were not available.
 - 3 subjects removed from peer directed analysis
 - 0 subjects removed from professionally facilitated analysis
- Total: data from 21 peer directed; 20 from professionally facilitated





Results: QOL

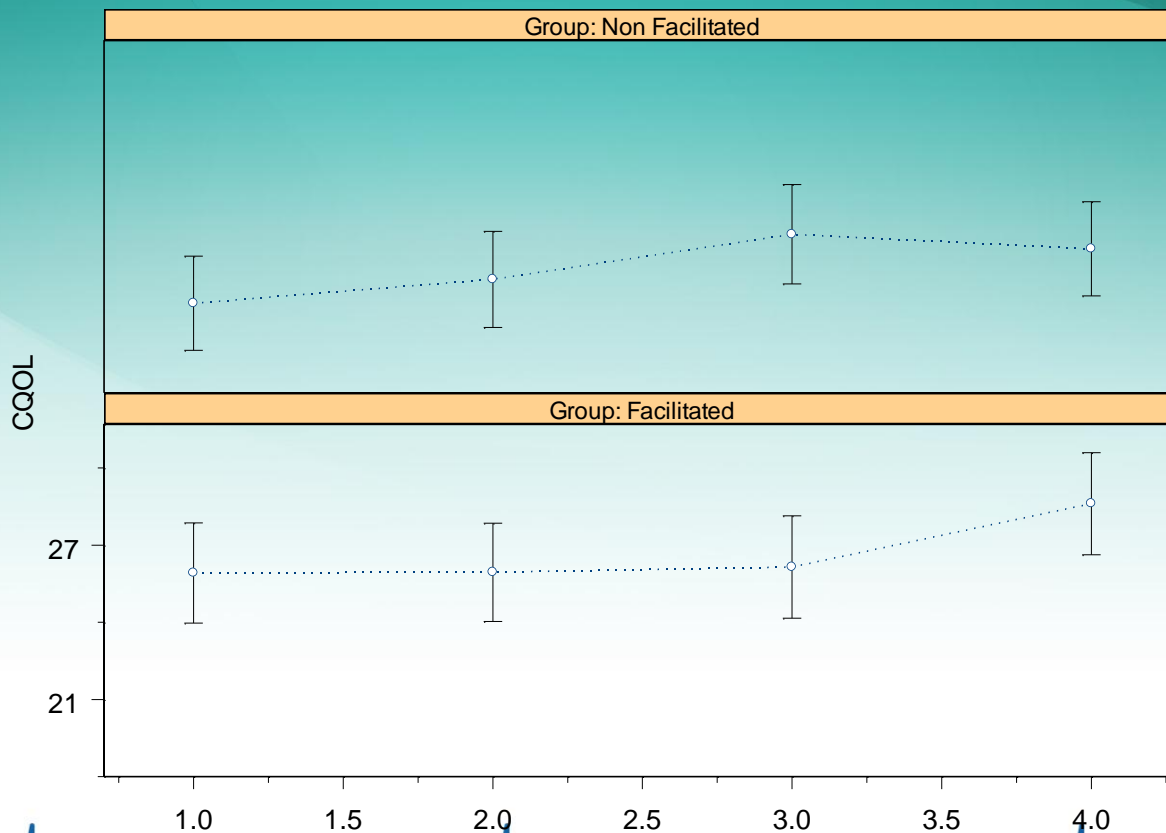
- No significant difference between the groups
- Facilitated versus peer directed
 - Peer directed had higher (but not significant) QOL scores between time 1 and time 4
 - Professionally Facilitated had significantly higher QOL scores between time 1 and time 4





Results: QOL

Caregiver quality of life by time and treatment condition





Results: Caregiver Strain

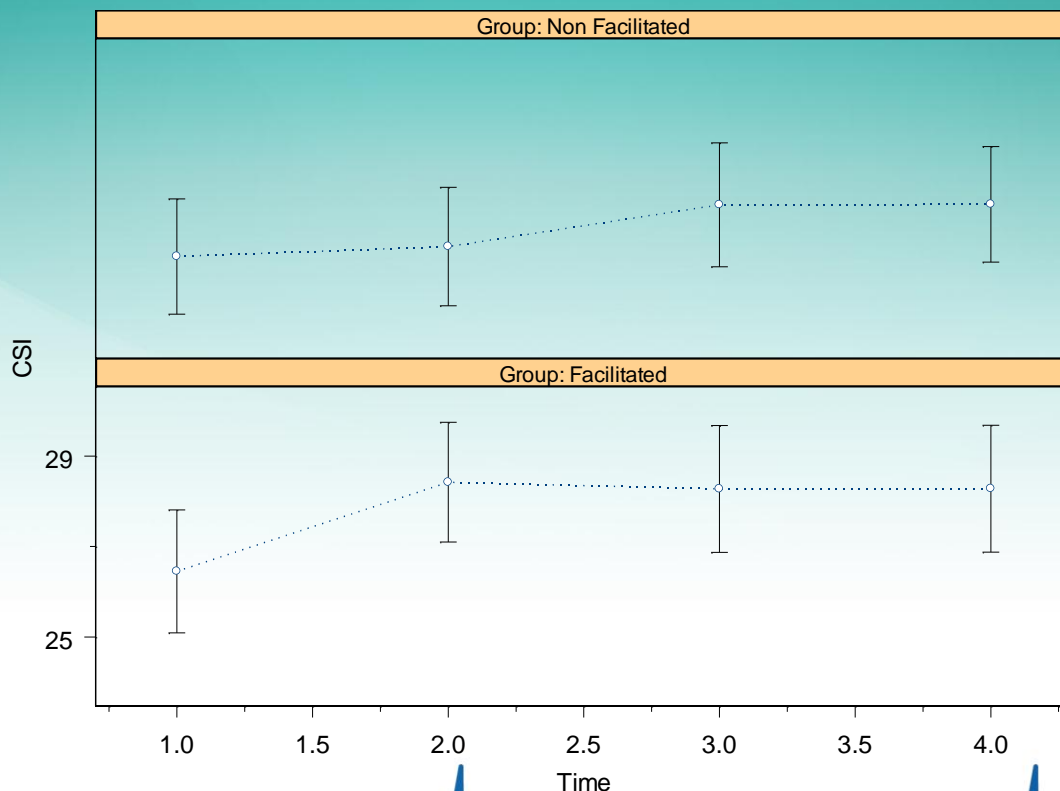
- No difference by group
- No difference by time





Results: Caregiver Strain

Caregiver CSI by time and treatment condition





Results: Depressive Symptoms

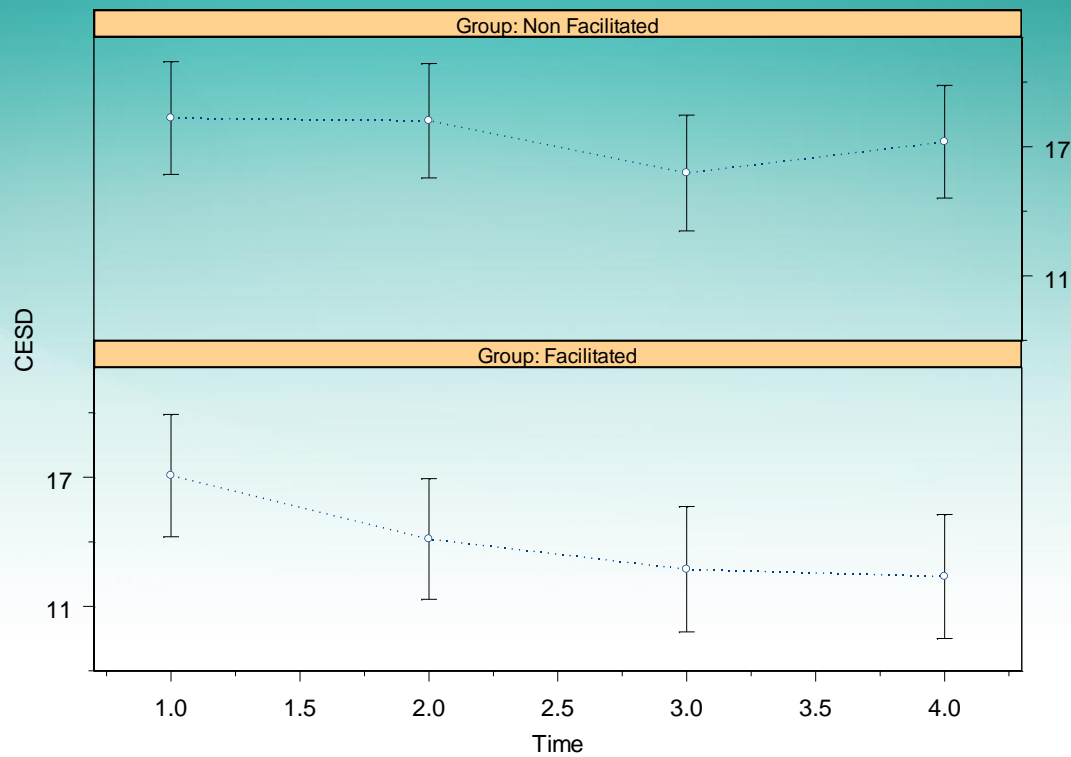
- No significant difference between groups.
- Peer directed reported more depressive symptoms to start. These decreased at timepoint 3 and then increased at timepoint 4
- Professionally Facilitated group reported fewer depressive symptoms to start. These decreased over each timepoint





Results: Depressive Symptoms

Caregiver CESD by time and treatment condition





Limitations

- 60 subjects needed (determined by power analysis)
- 41 subjects completed the study
- 29 subjects completed questionnaires at all four timepoints
- Some subjects completed the questionnaires, but did not participate in the online support groups
- Some subjects participated in the online support groups, but did not complete the questionnaires



Implications for Practice

- **Support available 24/7**
- **Professionally Facilitated online support may help decrease depressive symptoms**
- **Professionally Facilitated online support may improve perceived QOL**





Implications for Practice

- Over sampling is recommended, because of drop in and drop out during longitudinal studies
- Participation in online support may be uneven
- Difficult to measure outcomes of online support (see above)
- Ease of access may affect participation (research listserve)





Implications for Practice

- **Additional research, larger groups, more male and minority representation**
- **Anecdotal reports: some wanted the group to continue beyond the study phase**



Follow-up

- Peer directed group completed in October 2011 (n=21)
- Another Professionally Facilitated group began in October 2011
- Addition of these subjects will provide the power deemed necessary to answer the study questions fully

