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

Group: Non Facilitated

Group: Facilitated
Results: Caregiver Strain

• No difference by group

• No difference by time
Results: Caregiver Strain

Caregiver CSI by time and treatment condition

- Group: Facilitated
- Group: Non Facilitated
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

Group: Non Facilitated

Group: Facilitated

Time

CESD

1.0 1.5 2.0 2.5 3.0 3.5 4.0

11

17

11

17

16
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 listserv)
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