Effect of online counselling on caregivers of people with dementia to enhance their self-efficacy and improve patient’s behavioral and psychological symptoms of dementia

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Research Background
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Q & A
“Survey on the Stress and Needs of Caregivers of people with dementia”

Sample size: N=279

Period: June, 2011 to January, 2012

Methodology: Self completion (online / paper-and-pen)

Recruitment: Via Jockey Club Centre for Positive Ageing (JCCPA) websites and talks organized by JCCPA
Investigated areas:
- Willingness to participate in dementia E-learning program
- Preference to participate in dementia E-learning program
- Expectations from dementia E-learning program
- Manuscript currently under review by Clinical Gerontologist
Caregivers are in favour of online channel, and prefer e-learning mode vs other means.
Caregivers mostly expect to learn from the E-learning program about handling behavioural and psychological symptoms of dementia.

<table>
<thead>
<tr>
<th>Top Three Expected learning goals</th>
<th>Count</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Handling BPSD</td>
<td>108</td>
<td>25.7</td>
</tr>
<tr>
<td>Improving understanding and communication with care recipients</td>
<td>79</td>
<td>18.8</td>
</tr>
<tr>
<td>Delaying dementia progression</td>
<td>75</td>
<td>17.8</td>
</tr>
</tbody>
</table>
www.ADCarer.com 耆智同行
- Developed specifically for family caregivers of people with dementia (PwD)
- Funded by “Walk with Professor Kao” CUHK Walkathon
- Target those less accessible to in-person psychoeducational interventions
Theoretical framework of website contents
- Coaching skills
- Cognitive behavioural theory
- Grief counselling
- Neuroscience psychology
- Personality typology
- Positive psychology
- Rational emotive behavioural therapy
- Satir Model
Three phases

Phase I: Basic training on caring skills
Phase II: Intermediate trainings on enhancing the well-being of caregivers
Phase III: Individualised support and assistance

Benefits: Caregiving self-efficacy, handling patients’ behavioural and psychological symptoms of the dementia (BPSD)
1 What is Dementia?

You may have heard information about dementia from television and newspapers, but do you know what the symptoms of dementia are? Do you know how physicians diagnose dementia?

Have you ever wondered why people have dementia, and what will happen after a person develops dementia?

This session will answer the above questions. Please leave a message at the end of each chapter or in the forum if you have further questions.
Research Background

http://www.ADCarer.com/

About this program: It's not only about caregiving skills
Welcome to this program.
Have you ever encountered the following situations as a caregiver?

- I can't tell you why but I just couldn't do it!
- I am too tired to go on!
- I know I've done enough, but I still want to do more!

Listen to your body
When you are agitated
When you are exhausted
When you are struggling
Take care of yourself
Facts about ADCarer.com

- Hit rate: 53,223 (as of March, 2013)
- Unique visitors: 5,490 (as of March, 2013)
- Some participants who completed the intervention expressed willingness to pay for the service, ranging from US$65 to US$380
Sample size: N=26
Period: January to August, 2012
Methodology: Online intervention
  - Online chatroom
  - Counsellor feedback within 48 hours
Duration: Nine weeks for each case
Recruitment: Self-referral
Method

- Theoretical framework: Cognitive-behavioural therapy
- Outcome measures:
  - Revised Scale for Caregiving Self-Efficacy (RSCSE): responding to disruptive behaviours / controlling upsetting thoughts (SE-CUT)
  - Neuropsychiatric Inventory Questionnaire (NPI-Q): BPSD of patients and caregiver distress
## Results

### Caregiver demographics:

<table>
<thead>
<tr>
<th>Major caregiver characteristics (N=26)</th>
<th>Count (%)</th>
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<tbody>
<tr>
<td><strong>Carer gender</strong></td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td>19 (73.1%)</td>
</tr>
<tr>
<td><strong>Relationship with patient</strong></td>
<td></td>
</tr>
<tr>
<td>Children</td>
<td>17 (63.0%)</td>
</tr>
<tr>
<td><strong>Carer age range</strong></td>
<td></td>
</tr>
<tr>
<td>51-60</td>
<td>12 (46.2%)</td>
</tr>
<tr>
<td><strong>Carer education level</strong></td>
<td></td>
</tr>
<tr>
<td>Secondary</td>
<td>14 (53.8%)</td>
</tr>
<tr>
<td><strong>Carer employment</strong></td>
<td></td>
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<tr>
<td>Full-time</td>
<td>11 (42.3%)</td>
</tr>
<tr>
<td><strong>Stage of dementia (Patient)</strong></td>
<td></td>
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<tr>
<td>Early to moderate stage</td>
<td>9 (34.6%)</td>
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</tbody>
</table>
Results

Total score in NPI-Q (12-item) ($p = .003$, two-tailed) and distress score (12-item) ($p = .012$, two-tailed) reduced significantly.
Discussion & Conclusion

- Nine-week online counselling program
- Reduced behavioural problems in older people with dementia
- Ease family caregiver stress
- Limitation
  - Small sample size
  - No control group
Thanks

Q & A