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The Calgary Chinese Elderly Citizens' Association (CCECA) 'CARERS Program'

Final Report

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EXECUTIVE SUMMARY

The CARERS program is an evidence-based training program developed by Sinai Health System of Reitman Center in Toronto. The program aims to support people affected by dementia, both people living with dementia and their caregiver, and to enhance the skills and efficacy of caregivers of people with dementia; and for care-recipients to participate in a concurrent group for social interaction and physical and mental stimulations.

The program combines therapeutic principles for managing stress and burden with innovative and empirical approaches to education and skills training that uses:

- Problem Solving therapy (PST) a structured, research-based intervention based on cognitive behavioral principles that follow a logical sequence to identify, prioritize, explicitly defined and develop solutions for main problems, and ;
- b) Simulated patients as actors trained to stimulate real-life situations, so that caregivers enact the challenging situations that they are facing at home.
- c) Staff training were held in March and April by qualified trainers from the Reitman Center, and additional training in June and July to further enhance and practice our skill set. We organized three groups, two in Cantonese (one group in April to June, and other in July to September) and one in Mandarin (April to June) with total participants of 16 caregivers. Each group lasts for 10 weeks with one session per week.

The 10 weeks session include:

- a) Educational and practical information about the management of behavioural and psychological symptoms of dementia
- b) Resources available city-wide to get support when needed
- c) Using PST to lead participants to identify the underlying reasons of their problems, and to lead them to identify possible solutions.
- d) Journal to encourage the participants to take notes, challenges encountered throughout the week, solutions that works
- e) Using stimulation to role play their real-life situations to provide caregivers an opportunity to practice techniques and skill learned as well as solutions identified in dealing with difficult situations or challenges at home
- f) Care-recipients joined an activity-based program concurrently that optimizes residual cognitive capacity.

After the completion of the 10 weeks session, a 1-year maintenance group is in place where caregivers meet once a month to provide continuous support of each other. The first maintenance group was held in July 2017.

Prior to the 1O-week session, each participant was to ask to conduct a pre-assessment in measuring their stress level, symptoms on feeling burden and depressive, self-perceived ability to carry out the

role as a caregiver and sense of mastery, and sense of loneliness. We also asked on the ability of the dementias to perform basic activities of daily living. The same assessments were conducted again after the completion of the 10-weeks session. Data were input into the template provided by Reitman Center for analysis.

An analysis report was sent to us and the results show that on average participants reported statistically significant less caregiver burden, less overload, and decreased feeling of loneliness after the completion of the Program. Significantly improved mastery of the caregiving role and greater use of self-rewarding activities as a coping strategy, were also reported by this group of caregivers upon completion of the Program.

OBJECTIVES & IMPLEMENTATION

As we are under an agreement with Reitman Center to run the CARERS program according to their standard, we are bounded by the design and structure of the program. Thus only minor adjustments were made due to the culture difference to ensure the effectiveness of the program. These include:

- a) More time was allocated on PST (identifying problems) than stimulation as Chinese, especially tradition seniors, are more introverted and seldom show their emotions in public. Thus it is difficult for caregivers to role play their emotions and real life situation.
- b) Care-recipients were put in an activity-based group rather than an art-based group. Traditional upbringing for Chinese are often disciplinary and focused on academic learning rather than creativity. It would be difficult for care-recipients to do any activity that require their creativity such as drawing.
- c) The design for the one year maintenance group is meant to be self-running where caregivers gathered and share and support of each other without any facilitators' presence. However, to ensure the effectiveness and to meet the objective of the maintenance group, we have decided to place a facilitator to provide guidance in running the group.

IMPACT FOR PEOPLE LIVING WITH DEMENTIA

Caregivers participated in the program gained more knowledge on the nature and reasons for behavioural and psychological symptoms of dementia (BPSD), acquired specific techniques to manage BPSD and to enhance their relationship between themselves and the care-recipient, which help they to better manage care-recipients at home and improve their relationship. In return, caregivers' emotion and psychological have also improved. Analysis shows that they are happier, feel less stress and less burden after completion of the program.

CAREGIVER'S STORY

Wendy was the primary caregiver of her husband, Bob who was diagnosed with dementia. Bob has illusions and confused with day and night. At least three to four times a week, Bob would wake Wendy up in the middle of the night and asked her to cook because he thought that he had guests visiting and Wendy had to prepare meals for the visitors. Wendy was stressed out and exhausted. She felt isolated because she had no time for herself and lack of sleep. She cried a lot during the CARERS sessions and complained that their children would not listen nor help her.

Through the program, Wendy had gained knowledge and information on dementia. We had used Problem Solving Therapy (PST) to help Wendy to identify her real problem(s) and set goals so that she could find ways to solve her problem(s).

With the simulated patient, Wendy would repeat the scenario; the facilitators were able to see Wendy's emotion and her challenges. The facilitators guided her to express her emotions and to enhance her communication skills. Wendy attended our monthly Maintenance Session regularly. She was happy to

gain peer support and meet friends in the program. We can see that Wendy has applied what she has learned from the program and she is less stressed now. CARERS program promotion through radio interview



Concurrent group for care recipient

