Evidenced-Informed Training Intervention For Puerto Rican Caregivers of Persons with ADRDP

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Background

- The program followed the Michigan State University Model developed by Dr. Louis Burgio and it was sponsored by the Administration on Aging.
- The REACH Out evidence-informed caregiver support program was designed to promote the health and well-being of adults caring for persons with dementia in the home.
- Two hundred and twelve (212) Caregivers completed all components of the REACH-OUT intervention program. A six month period follow up intervention was completed with 90 participants.
Educational components of the program

- Education about dementia, caregiving and stress
- Helping the caregiver stay healthy using a health passport
- Keeping the home safe for the dementia patient using a home safe checklist
- Teaching the caregiver how to maintain emotional well-being, through relaxation using the signal breath relaxation technique
- Behavioral management
- Enhancing social support
Basic delivery elements of the intervention

- Intervention occurs over a six (6) months;
- Six (6) in-home sessions, approximately one (1) to one and a half (1 1/2) hours in length;
- Caregivers received a Caregiver Notebook that contained educational information about dementia, self-care, safety and other relevant caregiver issues. Caregiver Notebook also included copies of all action plans for behavioral problems. The Caregiver Notebook served as a tool for organizing the intervention materials and a resource guide for the caregiver to use after the intervention;
Basic delivery elements of the intervention

• The Case Managers reviewed specific issues related to Dementia, Caregiving and Stress using education material provided in the Caregiver Notebook;

• The Case Managers provided *individualized action plans* to address targeted problems such as care recipient behaviors, caregiver health, behavior and social support;

• The Case Managers taught caregivers how to enhance their emotional wellbeing. This was done by teaching relaxation techniques, and Pleasant Events Training.
Project outcomes measurements

- REACH Demographic Form,
- Zarit Burden Scale (13 items),
- Caregivers Questionnaire,
- REACH OUT Risk Appraisal,
- Treatment Fidelity Form; and,
- REACH OUT Satisfaction Questionnaire
Findings and their implications

- Based on the 212 caregivers:
  - geographic location: 112 (53%) caregivers lived in urban areas while 100 (47%) lived in rural areas, non-urban areas. Proportion of urban and rural was almost similar.

- Caregivers gender: There were more female caregivers (144 or 68%) than male caregivers (68 or 32%).

- Gender of the care recipient: seventy three percent (156) were females and twenty seven percent (56) males.

- Only two persons were under sixty years of age and seven (7) were Veterans.

- The relationship data is in reference to the connection between the person with dementia and their primary caregiver. Data reflects the following: Parent (131 or 62%); Spouse (60 or 28%); other relative or Non-relative (21 or 10%).
Satisfaction Scale

- This 23-item questionnaire was administered to the caregivers at a post assessment. It included questions regarding satisfaction with types (i.e., specific components) and quality of service.
  - Findings showed a very high degree of satisfaction and acceptability of the program, including evaluation of individual treatment components and number of home visits and phone calls.
  - Results from this survey indicate enthusiastic support for the information that was provided to caregivers. Over 92% of the participants indicated positive responses to this intervention for each question on the survey.
  - Responses were slightly less enthusiastic about some components of the intervention (Signal breath technique and health passport) than others (stress and home safety).
  - Very few people found any of the components unhelpful.
  - The number of home visits and phone calls appears to be sufficient for delivery of this intervention.
Effectiveness:

• As result of this intervention the participant caregivers showed significant improvements in all outcome measurements:
  ▫ Reduced sense of caregiver burden (Zarit Pre and Post Scale)
  ▫ Diminished levels of perceived stress (Zarit Pre and Post Scale)
  ▫ Improved levels of perceived health (Final Evaluation Questionnaire)
  ▫ Diminished caregiver health symptoms (Final Evaluation Questionnaire)
  ▫ Reduced levels of depression (Final Evaluation Questionnaire)
Effectiveness:

• Significantly positive pre-post effects were found on measures of caregivers’ health and well-being, namely: decreased burden, depression and frequency of behavior problems; increased perception of social support and enhanced caregiver/care manager satisfaction with the program.
The approach: training to train.

To Whom: Support group facilitators of the Alzheimer Association (training sessions using the material and techniques developed by the program).

Objective: to replicate the content with the Support group members or caregivers.

How: Twenty leaders participated in five training sessions providing them with most of the material offered to the caregivers in the REACH OUT Project (Caregivers’ notebook, Training manual for group facilitators).

Content of the sessions were:
- Information about dementia and Alzheimer
- Risk Factors Appraisal at home
- Zarit Scale to measure stress
- Health and Care giving (Helping the caregiver stay healthy using a health passport
- Hospitalizations
- Home Security and Protection using a home safe check list
- Communication with Alzheimer patients
- Behavior management
- Teaching the caregiver how to maintain emotional well-being through relaxation using the signal breath relaxation technique
- Enhancing social support
- Wellbeing and Pleasant events
- Visits
- Conflict resolution
CONCLUSION

• This is the first and only Caregiver Intervention program designed to attend the needs of the Alzheimer caregiving population in Puerto Rico.

• The pre and post analysis on the outcome measures such as Zarit Scale, Risk Appraisal and Satisfaction Questionnaire suggest that the intervention was conducted effectively.

• Results suggest positive changes in caregiver outcome measures and on care recipient risk behaviors. Specifically, after intervention, caregivers reported less subjective burden on the burden scale as it was used pre and post and six months after follow up session. They also reported increased social support and fewer feelings of frustration toward care recipients.
CONCLUSION

• Caregivers in general reported improved self-rated health; fewer risk behaviors such as leaving the care recipient unsupervised and wandering.
• In terms of satisfaction and acceptability, the findings showed a high degree of satisfaction and acceptability of the program, including the evaluation of individual treatment, educational components and number of visits and phone calls.
• The training offered to the Support Groups of the Alzheimer Association proved to be effective in continuing services to the caregivers reached by the support groups.
Lessons learned

• The need is real, is here, it will grow larger and larger each day and we must act to address it the best way possible;
• Service providers addressing the need of this population are scarce or almost non-existent
• Community involvement and public policy are needed

This is the challenge