

Caregiver grief: Study of Alzheimer's and related dementia caregivers participating in Proyecto BienEstar in Puerto Rico

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Introduction

The definition of grief or bereavement is often accompanied by the Kubler-Ross model of the five stages of grief. Psychiatrist, Dr. Elizabeth Kubler-Ross first published this model in her book, *On Death and Dying* [1]. According to her model, the five stages of grief include: denial, anger, bargaining, depression, and acceptance. It is commonly thought grief or bereavement occurs after the death of a loved one. However, predeath or anticipatory grief is often experienced by family members and caregivers of those with debilitating or slowly progressive diseases. A qualitative study shows 68% (n=173) of informal caregivers of patients with Alzheimer disease reported grief of their loved one even though they were still alive [2]. Another study of 201 informal caregivers revealed higher levels of grief were associated with dysfunctional coping strategies, depressive symptoms and decreased positive states of mind [3]. With this study, we aim to demonstrate a tailored interventions which promotes the wellbeing of caregivers and targets the overall management of dementia, such as Proyecto BienEstar offered in Puerto Rico, helps caregivers heal through the grieving process.



Figure 1: Kubler-Ross 5 Stage Model of Grief

Project Content

Proyecto BienEstar is a program for patients with Alzheimer's and related dementias and their caregivers. Participants are from Bayamón, Carolina, and San Juan, Puerto Rico. To participate in the program, caregivers must be 21 years or older, care for the patient at least for four hours a day, live with the patient, do not receive payment for caregiving, and assume most of the responsibility in paying attention to and supporting the patient for everyday needs. The Project consisted of six interventions, free of cost and no more than 45 minutes each, offered in person or through video or telephone calls. The first session orients the caregiver about program services. The second session offers an individualized management plan for the caregiver in the program. The third session orients family members about the program and work to create a family action plan. The fourth session provides individualized emotional support to the caregiver. The fifth session provides education about the management of Alzheimer's and related dementias. The final session reviews all the pillars of the program and concludes the intervention.

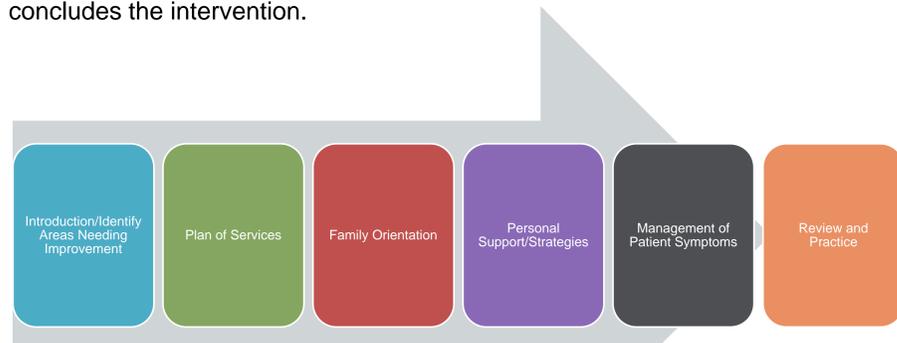


Figure 2: Proyecto BienEstar Interventions

Participants

A total of 54 caregivers were selected, comprised of 13 males and 41 females with an average age of 64 (64.33, SD= 12.674). Time to complete the intervention, and time between the first questionnaire and the last, ranged from 3 to 11 months, with the average time being 6.5 months.

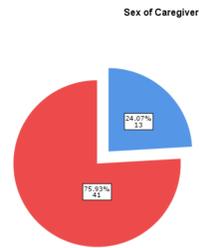


Figure 3: Sex Distribution of Caregivers

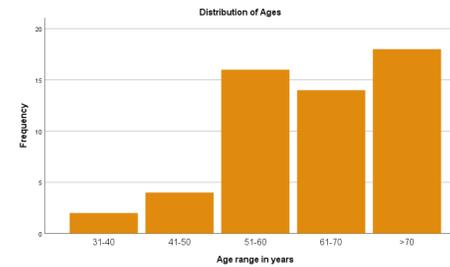


Figure 4: Age Distribution of Caregivers

Methods

1. Questions grouped pertaining to each stage of grief using the Kubler-Ross model (scan QR code below to see chosen questions)
2. Cronbach-Alpha analysis in SPSS for each subset of questions to ensure adequate internal consistency
3. Calculation of composite scores to represent each of the 5 subsets
4. Pairwise *t*-tests to compare initial versus follow-up scores for each domain



Selected Questions Grouped by Domain

Results

Given the nature of the questions within each domain, the following key can be followed:

- Higher score = less denial
- Higher score = less anger
- Higher score = more bargaining
- Higher score = more depression
- Higher score = less acceptance

		Paired Samples Statistics			
		Mean	N	Std. Deviation	Std. Error Mean
Pair 1	Denial1	19.8367	49	6.38144	.91163
	Denial2	21.1020	49	5.57616	.79659
Pair 2	Anger1	44.4878	41	10.33470	1.61401
	Anger2	45.5610	41	11.32927	1.76934
Pair 3	Bargaining1	1.3243	37	1.43477	.23587
	Bargaining2	1.7568	37	1.97773	.32514
Pair 4	Depression1	11.7826	46	6.31018	.93039
	Depression2	8.5435	46	5.68705	.83851
Pair 5	Acceptance1	6.8085	47	4.45088	.64923
	Acceptance2	5.3404	47	3.54031	.51641

Table 1: Paired Sample Statistics
'1'= Intake questionnaire
'2'= follow-up questionnaire

Results Cont.

		Paired Samples Test							
		Paired Differences		Std. Error Mean	95% Confidence Interval of the Difference		t	df	Sig. (2-tailed)
		Mean	Std. Deviation		Lower	Upper			
Pair 1	Denial1 - Denial2	-1.26531	6.52807	.93258	-3.14039	.60977	-1.357	48	.181
Pair 2	Anger1 - Anger2	-1.07317	13.37421	2.08870	-5.29459	3.14825	-.514	40	.610
Pair 3	Bargaining1 - Bargaining2	-.43243	1.84903	.30398	-1.04893	.18407	-1.423	36	.163
Pair 4	Depression1 - Depression2	3.23913	5.52644	.81483	1.59798	4.88028	3.975	45	.000
Pair 5	Acceptance1 - Acceptance2	1.46809	3.83265	.55905	.34278	2.59339	2.626	46	.012

Table 2: Paired Differences

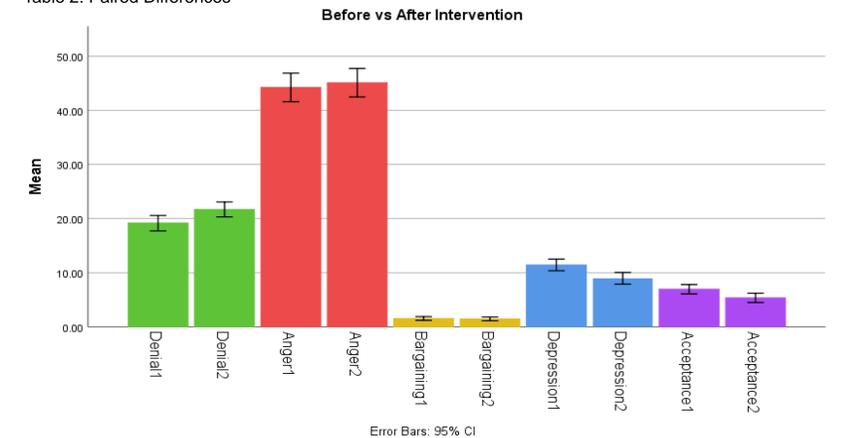


Figure 5: Adjusted Before vs After Intervention

- *Depression was significantly reduced after the intervention (p=0.00)
- *Acceptance was significantly increased after the intervention (p=0.012)

Conclusions and Future Directions

Results of this study suggest caregiver completion of a supportive and educational intervention, such as Proyecto BienEstar, may help caregivers heal through the grieving process. A larger sample size is warranted to see if in fact, an intervention such as the one delivered significantly addresses all domains. A future study may want to specifically design a questionnaire targeting each domain to ensure accurate results. Additional studies are necessary to garner more support and education for caregivers to ease their hardship and ensure they are taken care of appropriately and their needs are considered.

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