

**MHSA**  
Prevention and Early Intervention  
Care Pathways (Caregiver support groups)  
FY2017-2018

Table of Contents

Program Information	2
Executive Summary	3
Enrollment and Completion	4
Demographics	5
CES-D 20	8
Caregiver Self-Assessment	9
Satisfaction	11

The Riverside County Office on Aging (OoA) serves as the main gateway for information and referral assistance to seniors countywide, as well as to family caregivers. The OoA provides supportive services through its Family Caregiver Support Program (FCSP). With MHSA Prevention and Early Intervention (PEI) funding, OoA fully implemented the Care Pathways program in June 2011. Care Pathways is a 12 week, two-hour class offering education and group support to caregivers of a friend or loved one, 60 years of age or older. The program holds scheduled meetings in the targeted areas of Western region (Rubidoux, East-Side Riverside, Casa Blanca, and Moreno Valley); Mid-County region (San Jacinto, Lake Elsinore, Perris, Romoland, and Winchester) and Desert region (Thermal, Mecca, Coachella, Palm Springs, Indio) of Riverside County. The classes are also provided in English and in Spanish.

There is a maximum capacity of 15 participants per class. The program is structured to accommodate caregivers throughout the workshop series. If a participant misses a class within a 12 week session, the facilitator of the group will follow-up to encourage attendance and document any challenges he or she may be experiencing. Workshop Support Group Topics include: Living with Dementia; Signs of Stress & Stress Reduction Techniques; Communicating in Challenging Situations; Legal Issues Related to Challenging Situations; Managing Medications; How to Talk to the Doctor; Learning From Our Emotions; Taking Charge of Your Health; Grieving—Natural Reaction to Loss; Health Lifestyles; Preventing Caregiver Burnout.

### *Outcomes Evaluation*

The Care Pathways program's main goals are to reduce the risk for depression and to impact the caregivers' sense of well-being by reducing the emotional distress of caregivers by providing useful information and the opportunity to share and bond with others. To evaluate program outcomes two measures are used, including the CESD-20 for depression and the AMA caregiver Self-Assessment.

- Centers for Epidemiological Studies-Depression Scale-20 (CESD-20) — a 20-item scale developed by The National Institute of Mental Health. The CESD-20 is designed to measure current levels of depressive symptomology with emphasis on the affective component. The measure is administered at the start of participation in Care Pathways and at the conclusion of the program.
- American Medical Association's (AMA) Caregiver Self-Assessment Questionnaire — designed to measure indices of emotional and physical distress. This measure is completed at the beginning of the program and at the conclusion of the program.

### ***Enrollment***

During the 2017-2018 fiscal year, 237 individuals participated in the Care Pathways program support groups. About three-quarters (76%) of all participants enrolled completed the program. Care Pathways enrollment showed 38% of participants were from the West, 29% from Mid-County, and 33% from the Desert region. The majority (84%) of participants were female, and 55% were age 60 or older. The majority (85%) of the support group participants had been providing care for 1 to 10 years. The race/ethnicity of the participants was 52% Caucasian, and 32% Hispanic/Latino, and 9% Black/African American. The caregiver's relationship to the person being cared for was often a parent (49%) or a spouse (30%).

### ***Depression Decreased***

On follow-up Care Pathways participants depression decreased based on CESD-20 scores. On average, scores significantly decreased from a mean score of 16.4 to 13.3

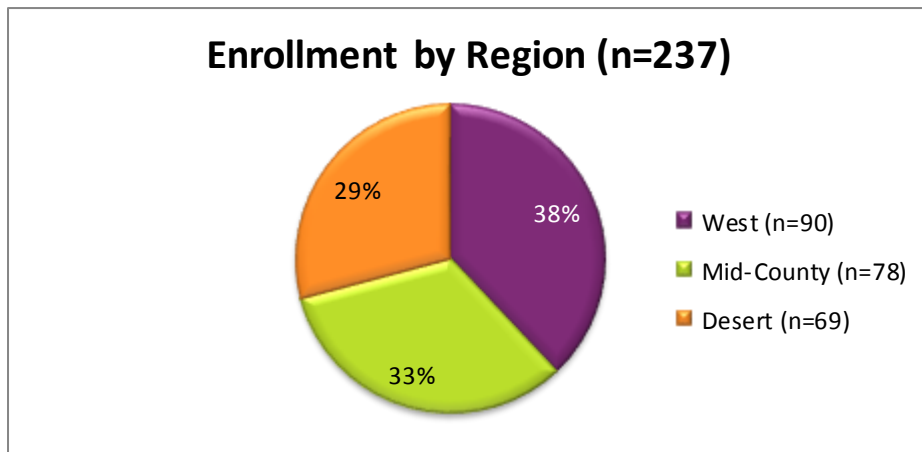
### ***Feelings of Distress Decreased***

Caregivers' average AMA-Caregiver Self-Assessment Questionnaire scores had a statistically significant decrease by the end of the program. A 14% decrease was observed in participants who reported feeling completely overwhelmed, which is indicative of pre-program high levels of caregiver distress and shows the effectiveness of the program in decreasing distress.

### ***Caregiver Satisfaction was High***

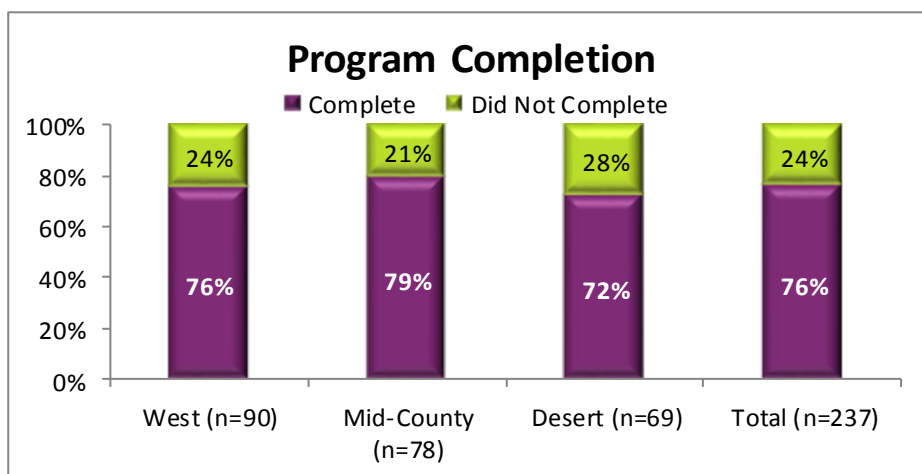
Caregivers reported high levels of satisfaction; 99% of participants who completed a satisfaction survey reported that the support groups helped them in reducing the stress associated with being a caregiver; and 95% of participants reported that they would recommend the support group to friends in need of similar help.

Figure 1. Enrollment by Region



The Care Pathways program enrolled 237 participants during the 2017-2018 fiscal year. The Western region enrolled more people than Mid-County and Desert. See Figure 1.

Figure 2. Program Completion



Countywide, 76% of participants completed the program. Mid-County had the most participants complete the program with 79%. The Desert region had the lowest completion rate with 72%. See Figure 2.

Table 1. Contract Completion

Actual Total Completed	Contract Expectations	Contract Completion
180	144	125%

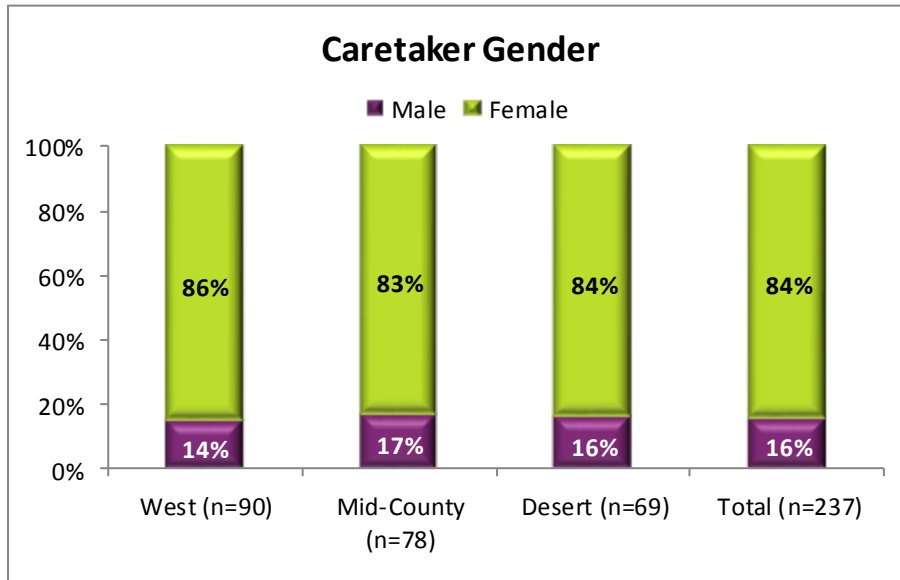
Table 2.. Program Completion History

Fiscal Year	Enrolled	Completed	Percent Completed
2013-2014	301	211	70%
2014-2015	237	181	76%
2015-2016	273	146	53%
2016-2017	212	173	82%
2017-2018	237	180	76%

Countywide, The Office on Aging was contractually obligated to have 144 participants complete the program. Across all three regions 180 participants completed the program, which accounts for 125% of the contract expectation. Contract expectations and completion can be seen in Table 1.

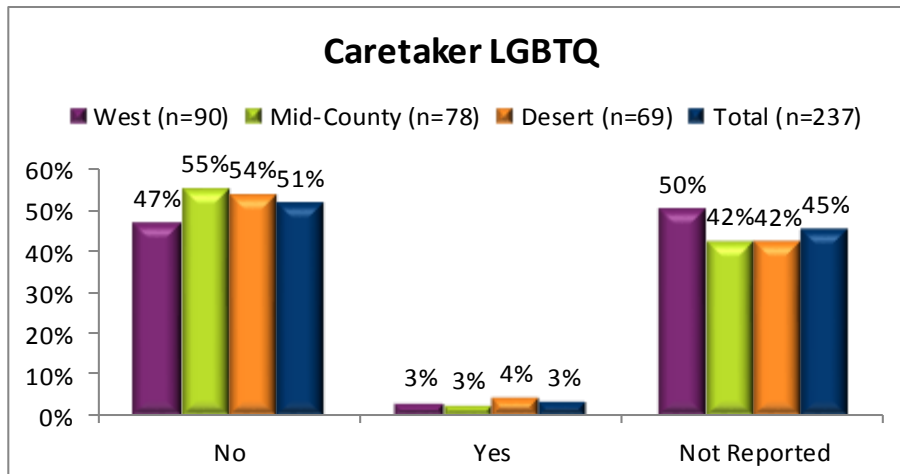
Table 2 provides enrollment, completion, and the completion rate for fiscal years 2013-2014, 2014-2015, 2015-2016, 2016-2017, and 2017-2018.

Figure 3. Caretaker Gender



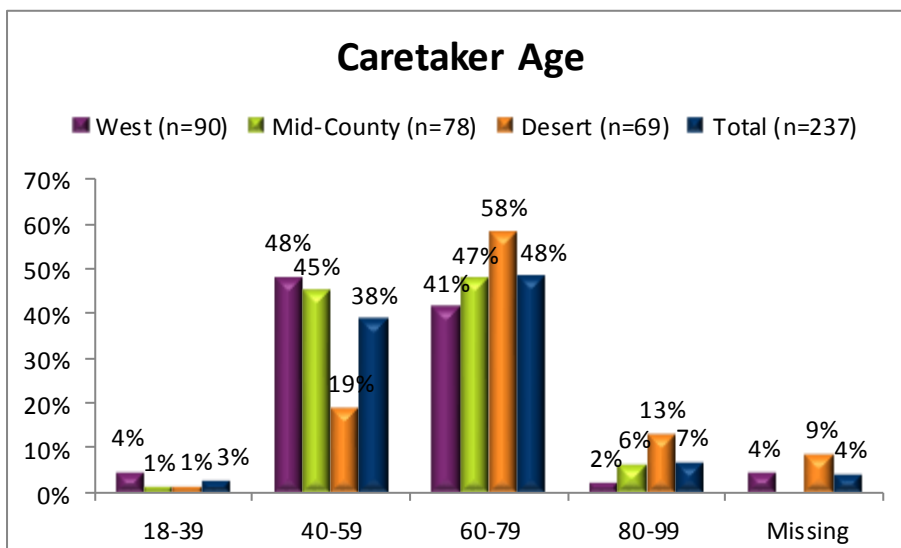
Countywide, the majority of caregiver participants reported being female (84%). The Western region served the highest percentage of females (86%).

Figure 4. Caretaker LGBTQ



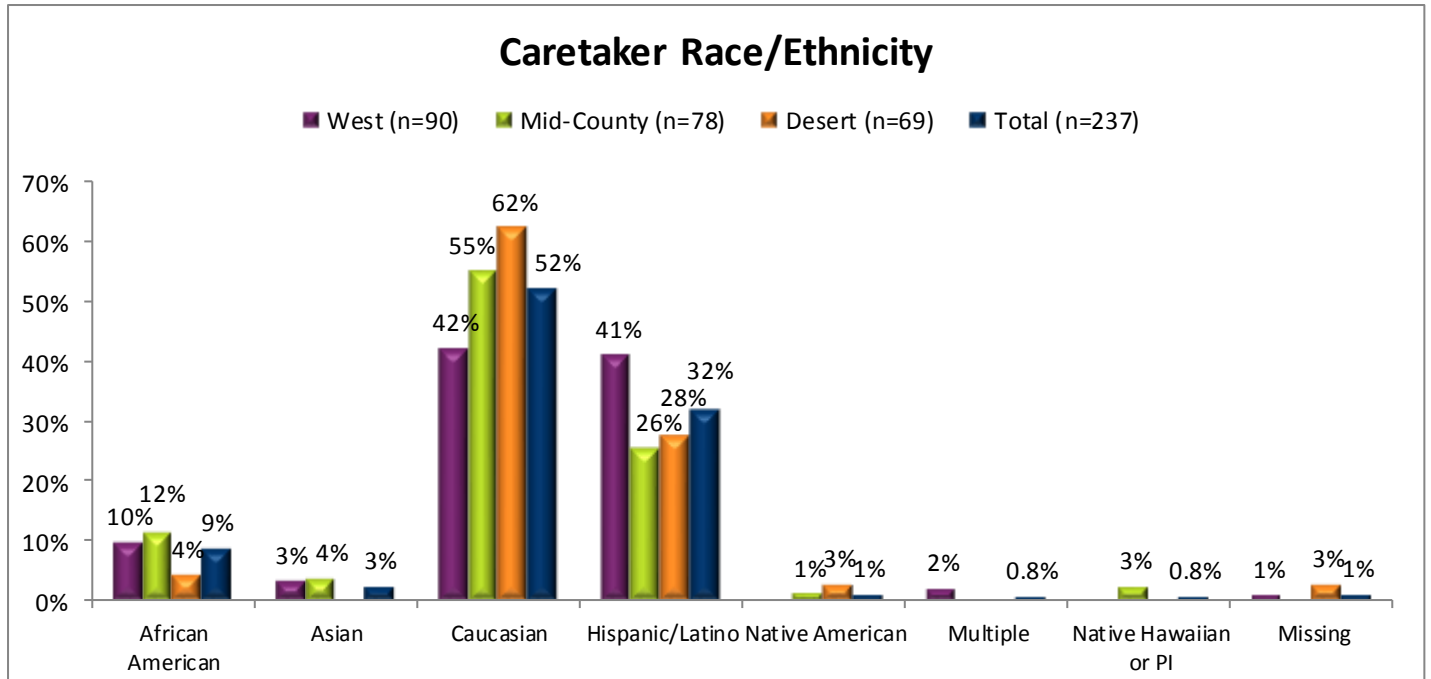
Countywide, the majority of caregiver participants reported that they did not identify as LGBTQ (57%). Over a third of participants (45%) did not answer the question.

Figure 5. Caretaker Age



Almost half (48%) of the caregivers participating in support groups were in the age category of 60-79. The average age of participants 61 years old.

Figure 6. Caretaker Race/Ethnicity

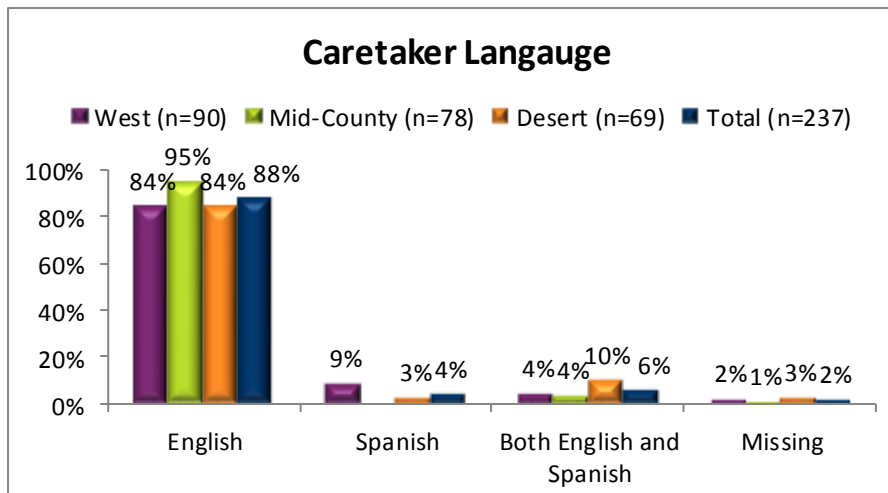


Half of caregivers were Caucasian (52%), about one-third were Hispanic/Latino (32%), and 9% were African American. Table 3 provides a breakdown of specific Hispanic/Latino identities reported by participants. The majority of caregivers that reported being Hispanic/Latino identified as Mexican/American (62%).

Table 3. Specific Hispanic/Latino

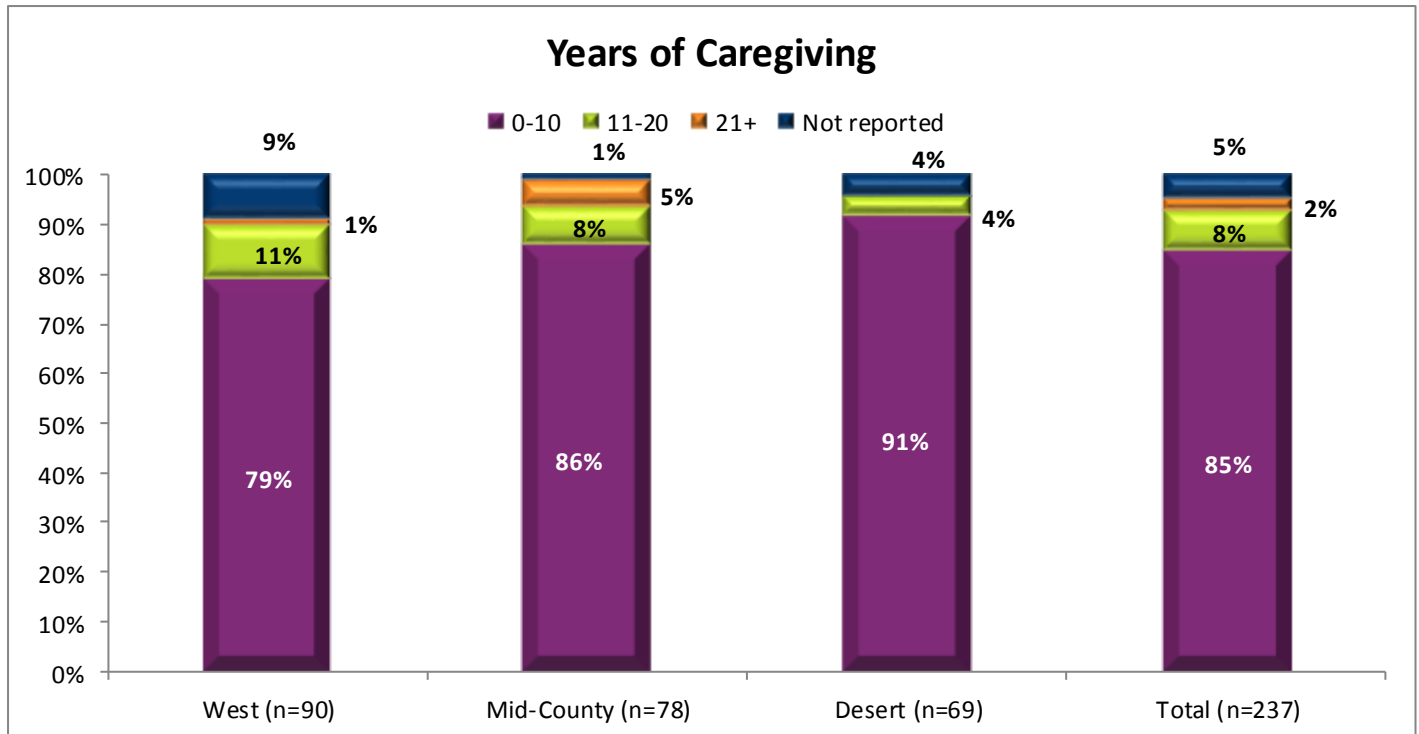
	Hispanic/Latino				
	Not Specified	Mexican/American	South American	Central American	Other Hispanic
West (n=37)	24%	70%	3%	-	3%
Mid-County (n=20)	20%	55%	-	10%	10%
Desert (n=19)	47%	53%	-	-	-
Total (n=76)	29%	62%	1%	3%	5%

Figure 7. Caretaker Language



The majority of participants preferred to speak English (88%). Classes were provided in both English and Spanish as needed.

Figure 8. Years of Caretaking



The majority (85%) of all caregivers had spent 0 to 10 years providing care at the time of enrollment. The average time spent providing care was 4.8 years.

Table 4 Love One Cared for by Caretaker

Loved One Cared For										
	Sibling	Sibling-	Grandparent	Spouse	Parent	Step	Parent-in-law	Other Family	Friend	Missing
West (n=90)	2%	-	3%	20%	58%	1%	7%	1%	3%	4%
Mid-County (n=78)	3%	3%	1%	33%	50%	-	5%	4%	1%	-
Desert (n=69)	4%	-	4%	39%	36%	3%	4%	-	4%	4%
Total (n=237)	3%	1%	3%	30%	49%	1%	6%	2%	3%	3%

Table 4 details the relationship of the Caregivers and Loved Ones. The most common Loved Ones cared for were parents and spouses respectively.

Table 5. Veteran

Veteran			
	Yes	No	Missing
West (n=90)	8%	70%	22%
Mid-County (n=78)	8%	85%	8%
Desert (n=69)	7%	78%	15%
Total (n=237)	8%	77%	15%

The majority of participants were not veterans (70%).

Table 6. Disability

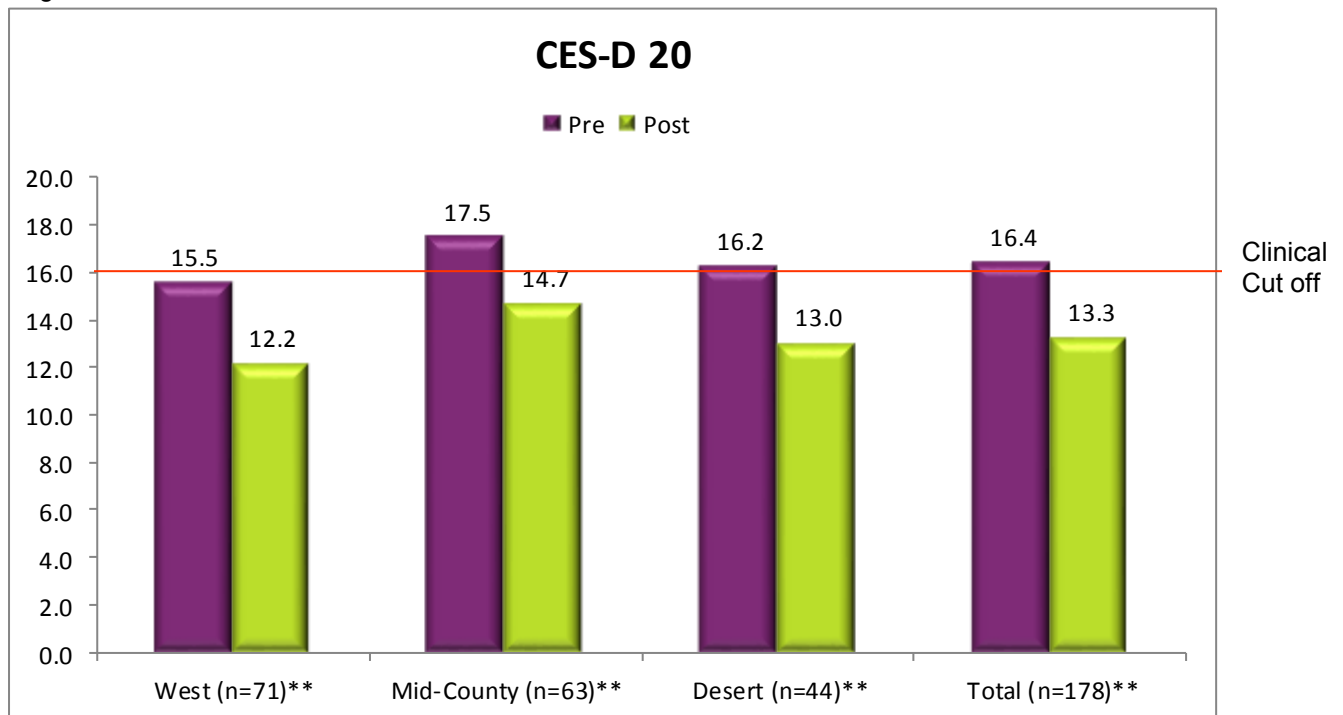
Disability			
	Yes	No	Missing
West (n=90)	10%	71%	19%
Mid-County (n=78)	14%	77%	9%
Desert (n=69)	12%	74%	15%
Total (n=237)	12%	74%	14%

The majority of participants reported not having any disabling conditions (74%).

The Center for Epidemiological Studies-Depression Scale (CES-D) is a 20-item scale that was developed by The National Institute of Mental Health. Respondents are asked to choose from four possible responses in a Likert format, where “0” is “rarely or none of the time (less than 1 day)”, and “4” is “almost or all of the time (5-7 days)”. Scores range from 0 to 60, higher scores reflect greater levels of depressive symptoms while lower scores reflect lower levels of symptoms. A score of 16 or greater suggests a clinically significant level of psychological distress. It does not necessarily mean that the participant has a clinical diagnosis of depression. In a general population, about 20% would be expected to score in this range.

Countywide there were 178 matched pairs of pre to post measures. **Average CESD-20 scores decreased significantly from pre to post Countywide**, and also for all regions individually. Countywide, average post scores showed a 19% decrease from intake scores. Nearly half of the participants (49%) were above clinical level at the beginning of the program, and decreased to 30% above the clinical level at the end of the program.

Figure 9. CES-D 20

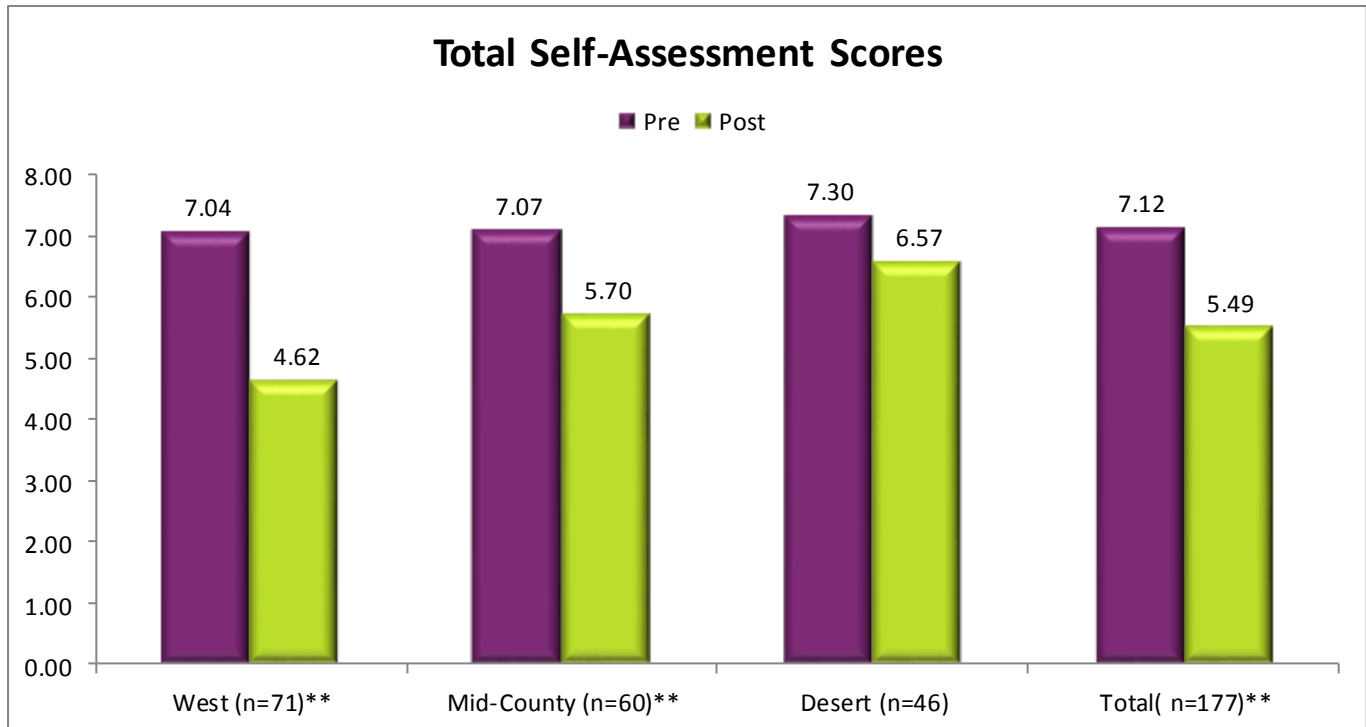


\*\* Significance  $p < .01$



This 18-item, caregiver self-report measure was devised by the American Medical Association as a means of helping physicians assess the stress-levels of family caregivers accompanying chronically ill older adult patients to their medical visits. It has been adopted by the Office on Aging to assist caregivers with assessing their own stress levels and emotional well-being. Caregivers are asked to respond either “Yes” or “No” to a series of statements, such as “During the past week or so, I have felt completely overwhelmed” and “During the past week or so, I have felt strained between work and family responsibilities.” In addition, for questions 17 and 18, family caregivers are asked to rate their level of stress, and perception of their current health on a 1-10 scale, respectively.

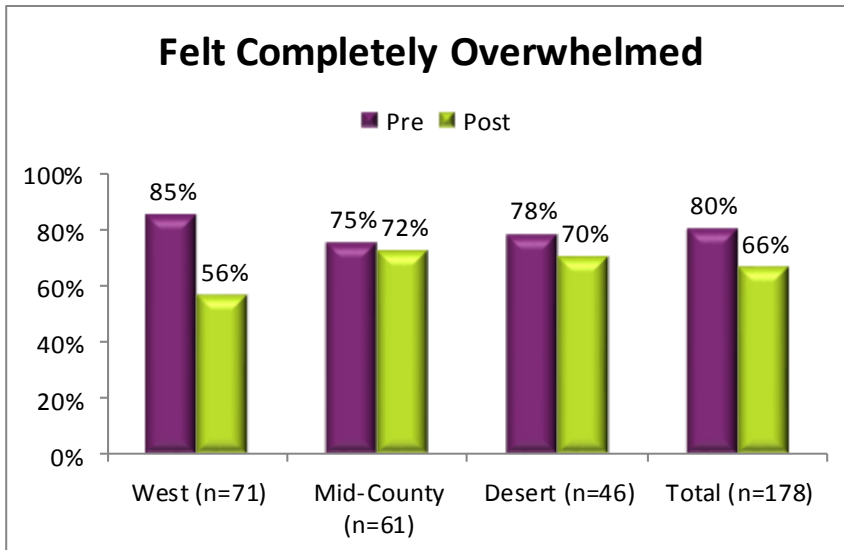
Figure 10. Total Self-Assessment Scores



\*Significance  $p < .05$     \*\*Significance  $p < .01$

Results on post measures showed a statistically significant decreases in reported levels of distress. Figure 10 shows pre to post ratings for question items 1-16.

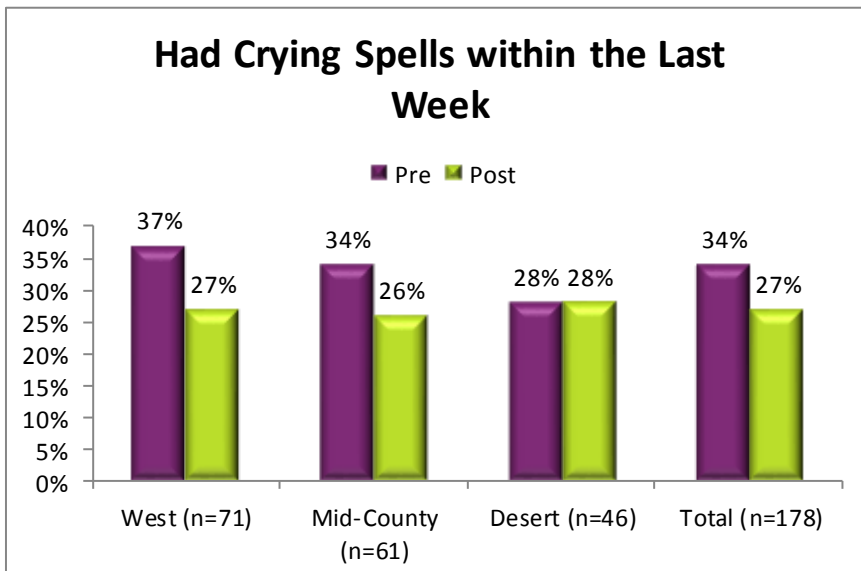
Figure 11. Self-Assessment: Felt Completely Overwhelmed



Caregivers' distress could also be indicated from answering yes to question #4 "Felt completely overwhelmed", or question #11 "Had crying spell(s)" within the past week.

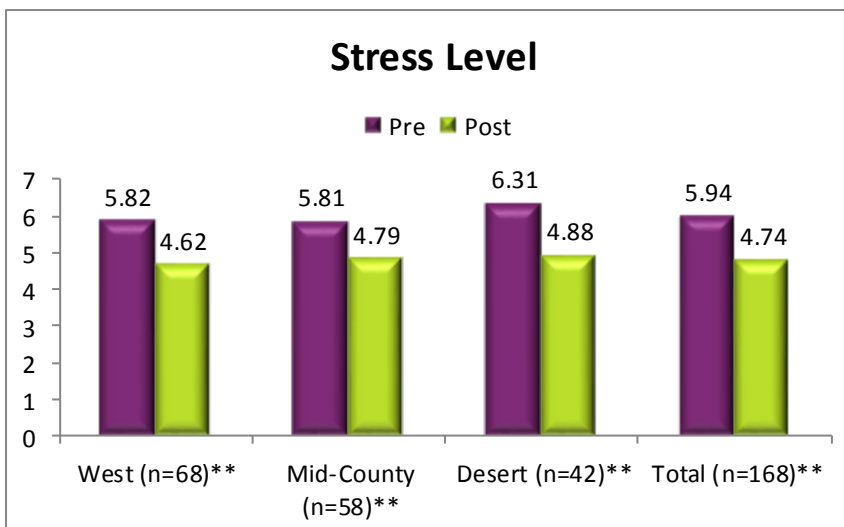
Participants reported feeling less overwhelmed at the end of the program Countywide (See Figure 11).

Figure 12. Self-Assessment: Had crying spells within the last week



Caregivers also reported fewer crying spells from the beginning of the program to the end (See Figure 12).

Figure 13. Self-Assessment: Stress Level



Caregiver scores for question #17, "On a scale of 1 to 10, with 1 being "not stressful" to 10 being "extremely stressful," please rate your current level of stress," showed a statistically significant decrease of stress levels Countywide. Scores at post decreased to below the cutoff level of "6" which indicates levels of stress decreased on average.

\*Significance  $p < .05$  \*\*Significance  $p < .01$

A total of 199 caregivers completed a satisfaction survey at the conclusion of the caregiver support groups. Results are shown in Table 7 below. Overall, caregivers were highly satisfied with the support received from the program. Caregivers also reported having reduced levels of stress and being able to cope more effectively in their caregiver role as a result of the program, and would recommend the program to a friend.

Table 7. Satisfaction

	Poor	Fair	Good	Excellent
1. How would you rate the quality of service you have received from the support group leader?	-	-	3%	97%
	No, definitely not	No, generally not	Yes, generally	Yes, definitely
2. Has the support group helped to reduce some of the stress associated with being a caregiver?	-	1%	20%	79%
	None of my needs have been met	Only a few of my needs have been met	Most of my needs have been met	Almost all of my needs have been met
3. To what extent has the support group met your needs?	-	4%	38%	57%
	No, definitely not	No, I don't think so	Yes, I think so	Yes, definitely
4. If a friend were in need of similar help, would you recommend this support group to him or her?	-	-	5%	95%
	No, definitely not	No, not really	Yes, generally	Yes, definitely
5. Has attending the support group given you methods to solve problems in your role as caregiver?	1%	-	16%	83%
	No, this seemed to make things worse	No, this really didn't help	Yes, this helped	Yes, this helped a great deal
6. Has attending the support group with other caregivers been helpful?	-	-	15%	85%
	No, definitely not	No, I don't think so	Yes, I think so	Yes, definitely
7. If you were to seek help again, would you return to this support group?	-	1%	13%	86%
	No, definitely not	No, I don't think so	Yes, I think so	Yes, definitely
8. Has attending the support group helped you to cope more effectively in your role as caregiver?	-	-	16%	84%
	Quite dissatisfied	Mildly dissatisfied	Mostly satisfied	Very satisfied
9. In an overall, general sense, how satisfied are you with the support you have received from this group?	2%	1%	10%	87%

Comments
<p>“This group has been wonderful for me. Not only have I been given great information from care pathways but we as a group also give each other tips, support and laughs. I will miss everyone! Most important for me was being reminded how important it is to take care of me so I can care for them.”</p>
<p>“The support group has been very informative of educational. Members were also helpful being able to relate to each other's situation.”</p>
<p>“So helpful to talk to others that understand and don't judge! Wish it didn't have to end. I am so appreciative of respite help to be able to come, I would not have been able to come without it.”</p>
<p>“I feel that this group would have been better if it had been smaller (less people) I think it was too many of us trying to share our experiences. I feel that the lecture part was rushed at times and it seemed that 2 hours were not enough time. I suggest that you have groups with no more than 7 or 8 people per group, that way the lecture is not rushed and everyone has the "same" amount of time to share what they want to share. Thank you for this group. it was very helpful.”</p>
<p>“I am pretty sure I am a better caregiver because of the knowledge I've received here. Also, being with others and sharing similar experiences has helped me a lot.”</p>