

Family Caregiver Interventions: Where are We & What's Next?

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People....

- ◆ **There are four kinds of people in the world. Those who**
 - *have been caregivers,*
 - *are currently caregivers,*
 - *will be caregivers,*
 - *will need caregivers.*

Rosalynn Carter

The Case for Caregiving as a National Public Health Priority



Caregiving plays a unique and valuable role in our society. As the number of caregivers grows, the issues surrounding caregiving have gained national attention from a variety of sectors...National adoption of public health priorities is guided by specific principles (Rao, Anderson, & Smith, 2002).

These principles include large burden, major impact with respect to health costs or consequences, and potential for prevention.

CDC's Assuring Healthy Caregivers (2008).

Value of Family Caregiving is Staggering



- In 2009, 42.1 million Americans provided unpaid care to another adult with ADL limitations at any given point; 61.6 million at some time during the year.
- Economic value of their unpaid contributions = \$450 billion. (Walmart sales = \$409 billion)
- Caregiving doesn't end with placement.
- Without this “informal” workforce, the entire health care and LTSS system would be in jeopardy.

Feinberg et al., 2011

Caregiver - The Hidden Patient



AT RISK FOR:

- Depression (>50% depressed)
- Extreme fatigue, stress, anger/ frustration
- Anxiety, upset, feeling overwhelmed
- Guilt
- Financial loss
- Social isolation
- Physical health problems/Morbidity
- **Mortality**

Coon et al., 2003 ; Ory et al., 1999; Schulz, et al, 1995;
Schulz & Beach, 1999; Vitaliano et al., 2003

Variations in the Impacts of Caregiving



- **Non-Hispanic Whites:**
chronic fatigue, depression, anxiety, burden, self-reported anger & frustration, substantive risk for mortality
- **African Americans:**
Less depression and “burden” but less self-care behavior & poorer self-rated health; higher positive aspects of caregiving
- **Latinos:**
high levels depression and anxiety & greater physical complaints BUT less distress over behavioral problems of the care-recipient & less reported “burden”; less acculturated higher positive aspects of caregiving
- **Chinese:**
less self-reported depression and “burden” but significant problems managing difficult behaviors and significant family conflicts about caregiving

CHOW ET AL., 2000; COON ET AL., 2012; COON ET AL., 2004;
GALLAGHER-THOMPSON ET AL., 2010; HALEY ET AL., 2004;
WU ET AL., 2010

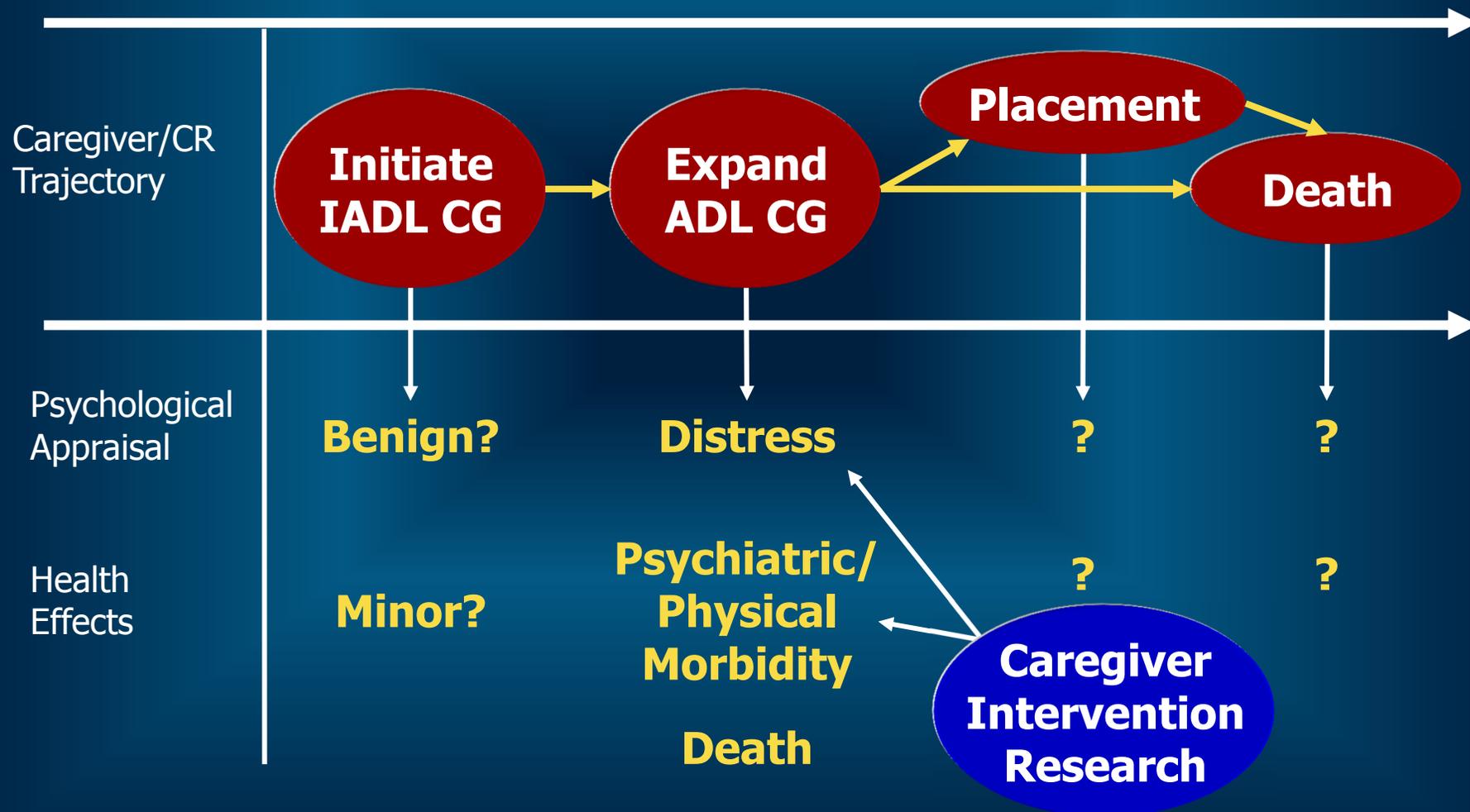
Caregiving as a Health Disparity



- Hidden patients
- Rarely assessed for health issues and needs
- Lack time or energy to engage in health promoting strategies
- Compared with noncaregivers, experience significant gaps in the quality of their health and health care
- Highlights need for caregiver interventions

Coon et al., 2003; Gitlin & Schulz, 2012

Chronic Stress Trajectory of Caregiving



What's Successful? Implementing Caregiver Interventions



- ◆ Education alone.
- ◆ Care Management.
- ◆ Respite.
- ◆ Support Groups.
- ◆ Environmental.
- ◆ Technological.
- ◆ Education & Skill Training (CR, CG, both).
- ◆ Psychotherapy/Counseling.
- ◆ Multi-component.

Coon, et al., 2012; Coon & Evans, 2009; Gallagher-Thompson, & Coon (2007).



Cooperative agreement among: NIH (NIA and NINR)

6 Intervention sites

- Birmingham
- Boston
- Memphis
- Miami
- **Palo Alto**
- Philadelphia
- Coordinating Center
- Pittsburgh



California Site: Psychoeducational Skill Building Groups



- always time-limited (e.g. 6-10 sessions)
 - **Coping with Caregiving** (ADRD): 10 sessions
- usually 6-10 caregivers who commit to attending weekly
- detailed agendas with specific goals; a structured treatment manual
- active in-class participation to learn skills
 - CBT based mood and stress management skills
- extensive use of home practice

(Beck et al., 1979; Lewinsohn et al., 1986; Coon et al., 2003; Coon, Gallagher-Thompson, & Thompson, 2003; Gallagher-Thompson et al., 1988; 2001; 2003; 2007; 2008; 2010)

CWC vs. ESP

ANOVA F^a

	T ^b	E ^c	T x E ^d	d ^e
CES-D, Total	4.96 *	0.05	0.09	.36
CES-D, Well Being	0.68	0.22	0.00	
CES-D, Depressive Affect	5.14**	0.21	0.21	.26
CES-D, Somato-Motor	1.66	0.05	0.00	
CES-D, Interpersonal	6.52**	0.31	1.33	.30
Positive Coping	6.77 **	0.09	0.00	.35
Negative Coping	2.86*	0.48	2.51	.33
Support Satisfaction	0.06	0.05	0.01	
Negative Interaction	3.60**	2.69	0.05	.29
RMBPC Conditional	2.20	0.19	0.41	

*p < .06; **p < .05.

^b T = Treatment main effect, ^c E = Ethnicity main effect, ^d T x E = Treatment X Ethnicity interaction

^e The effect size values for Cohen's d correspond to the significant F in each row.

Community Partners Wish List



- Evidence based; empirically supported
- User Friendly- Staff Ready (minimal training)
- Complementary to existing programs
Respite, care management, support groups
- Appeal to & be effective with caregivers from diverse backgrounds
- Less “intensive” and less structured “time away”
POWERFUL! (The “Pill”, the Silver Bullet)
...and, preferably something we already do.

CarePRO: Care Partners Reaching Out



- 10 Weeks of Psychoeducational/ Skill-building Groups & Coach Calls (alternating weeks)
- Built on CBT principles
 - Mood management
 - Stress management
 - Effective communication
 - TBR & Problem solving
 - Pleasant Events
- Over 600 Arizona and Nevada family caregivers.
- Partners: ASU (CCLRCBH), Alzheimer's Association, Area Agencies on Aging, state units on aging.

CarePRO Evaluation

- **Primary outcomes** (focused on original trial)
 - **Symptomatology** (caregiver depression)
 - **Quality of life** (positive/adaptive coping, negative coping; negative social interactions).
- **Secondary outcomes**
 - **Quality of life:** caregiver burden; patient memory/behavior problem impact, caregiver self-efficacy, caregiver target complaints
 - **Social validity:** caregiver perceptions of the utility of project services (e.g., ability to continue to provide care at home),
 - **Social significance:** cost of implementation; amount of service utilization (particularly for underserved).
- **Timing**
 - Pre/Post (3, 6, 12 months)

Samples

	Arizona (n = 532)		Nevada (n = 214)	
	CG	CR	CG	CR
Age (M, SD)	65.3 (11.3)	78.6 (8.8)	64.4 (11.7)	78.5 (8.9)
Female (%)	76.9	47.7	89.7	42.5
Male (%)	23.1	52.3	10.3	57.5
Spouse (%)	61.1	--	57.0	--
Veteran (%)	10.2	38.8	6.2	39.0
Hispanic or Latino	10.3	9.0	8.1	7.4
White (non-Hispanic)	84.8	83.5	84.6	83.6

Key Outcomes at 3 Months

	Arizona (n = 448)		Nevada (n = 189)	
	<i>p value</i>	<i>ES</i>	<i>p value</i>	<i>ES</i>
Depressive symptoms	<.001	1.17	<.001	.50
Negative coping	<.001	.26	<.001	.49
Caregiver bother	<.001	.49	<.001	.53
Negative social support interactions	<.001	.18	<.001	.23
Positive coping	<.001	.25	<.001	.34
Satisfaction with received support	=.003	.17	<.001	.36

Quality of Life Indicators at 3 Months

	Arizona (n = 448)		Nevada (n = 189)	
	<i>p value</i>	<i>ES</i>	<i>p value</i>	<i>ES</i>
Memory & behavior problems	<.001	.26	<.001	.32
Target complaint stress	<.001	1.21	<.001	1.60
Leisure time satisfaction	<.001	.46	<.001	.35
Positive aspects of caregiving	<.001	.22	<.001	.38
Caregiving self-efficacy	<.001	.45	<.001	.50
Caregiver prep (self)	<.001	.51	<.001	.68
Caregiver prep (CR)	<.001	.48	<.001	.69
Knowledge of formal care services	<.001	.79	<.001	.89

Preliminary Findings: Social Validity

	Arizona (n = 448)		Nevada (n = 189)	
	<i>%</i>	<i>% great deal</i>	<i>%</i>	<i>% great deal</i>
Overall benefit	99.4	85.0	100	87.2
Memory loss	97.8	74.5	98.1	78.0
Confident behavior prob.	98.7	74.4	99.4	82.9
Life easier	96.9	57.7	96.3	70.7
Ability to care	96.9	62.4	98.8	75.6
Improve CR's life	89.3	41.1	93.0	65.6

Individual (& Group) Costs

	Arizona		Nevada	
	<i>N = 8</i>	<i>N=12</i>	<i>N=8</i>	<i>N=12</i>
Phase I (training & supervision)	\$802 (\$6,415)	\$606 (\$7,267)	\$906 (\$7,248)	\$691 (\$8,290)
Phase II (supervision)	\$497 (\$3,979)	\$403 (\$4,831)	\$595 (\$4,760)	\$484 (\$5,802)
Phase III	\$379 (\$3209)	\$323 (\$3,881)	\$468 (\$3,745)	\$399 (\$4,787)

Phase I Costs: REACH II \$1,214 per caregiver (Nichols et al., 2008)

Phase III Costs: NYU Intervention \$1,402 (Paone, 2009)

REACH II Intervention



- 600 ADRD caregivers (African American, Hispanic, non-Hispanic white)
- A **multi-component** in-home individual intervention, combined with telephone support groups through CTIS system, that addressed five areas linked to caregiver risk profile:
 - Safety Issues
 - Social Support
 - CR Problem Behaviors
 - Emotional well-being
 - Self-care and Health Behaviors

(Belle et al., 2006)

Findings



- Hispanic/Latino and White/Caucasian caregivers in the REACH II Intervention significantly greater improvement in quality of life
- Black/African American spouse caregivers also experienced greater improvement
- Prevalence of clinical depression was lower among caregivers in REACH II intervention participants
- Trend toward difference in placement, but only 6 month follow-up

CarePRO (Over 800 Served)



Arizona

- Initial (448)
- Transition (84)
- Sustain (80)
- 12 more groups planned.

Nevada

- Initial (189)
- Transition (25)
- Sustain (12)
- 8 more groups planned.

Case Example

- ◆ Valeria is a 57-year-old Latina who has been caring for her 64-year-old husband Ernesto. The couple has an 18-year-old grandson living with them who provides minimal assistance with Ernesto's care. She came to the group stating that after 25 years of marriage, she was having a difficult time understanding her husband's behavior: he was diagnosed with Alzheimer's disease a little over a year ago, and in this short period of time, had his driver's license revoked and lost contact with many of his friends.

Behavioral Chain

Trigger → **Behavior** → **Reaction**

The only thing that you as a caregiver have control over are TRIGGERS and REACTIONS.

Occasionally, however, we can't change the TRIGGERS. During those times, changing how you REACT to the behavior could keep the situation from getting worse.

Strategies Caregiver Can Use to Prevent the Problem Behavior

- 1. Set out fresh clothes for him and reward him when he wears them; give him a compliment on how nice he looks or make him his favorite breakfast.**
- 2. Hide the outfit he really likes where he cannot find it.**
- 3. Buy him several pairs of the same pants and shirt so that he thinks he is wearing his favorite outfit**
- 4. When he goes to bed, take his clothes and put them in the laundry machine. Set the machine on the soak cycle so that if he looks for them and notices they are wet, he will need to find something else to wear.**

Mood Management

- ◆ **Learn new forms of “self-talk” so that you can be encouraging yourself mentally as you go through the day.**
- ◆ **Three steps to managing your feelings:**
 - 1. Stop and identify current thoughts.**
 - 2. Challenge & replace unhelpful thoughts.**
 - 3. Pay attention to how you feel.**

Thought Record

Situations	Current Thoughts	Feelings	Challenge & Replace	New Feelings
<p>My neighbors and children will see my husband in the same clothes.</p>	<p>Everyone will think I don't care about my husband.</p> <p>Everyone will still think he is dirty and his clothes are dirty.</p> <p>My children will think I have given up.</p>	<p>Stressed. Guilty. Sad. Embarrassed.</p>	<p>I told my neighbors. They asked for information about Alzheimer's. I took my daughter with me; they all told me how much they believe I do for Ernesto.</p> <p>My children say "You are smarter than ever"; "You do a great job"; "We hope our spouses love us as much as you love Papa".</p> <p>He is clean; he is happier; We are not arguing.</p>	<p>Less trapped and less guilty. Happier. More relaxed. Less embarrassed with those who know me.</p>

Social Support & Effective Communication

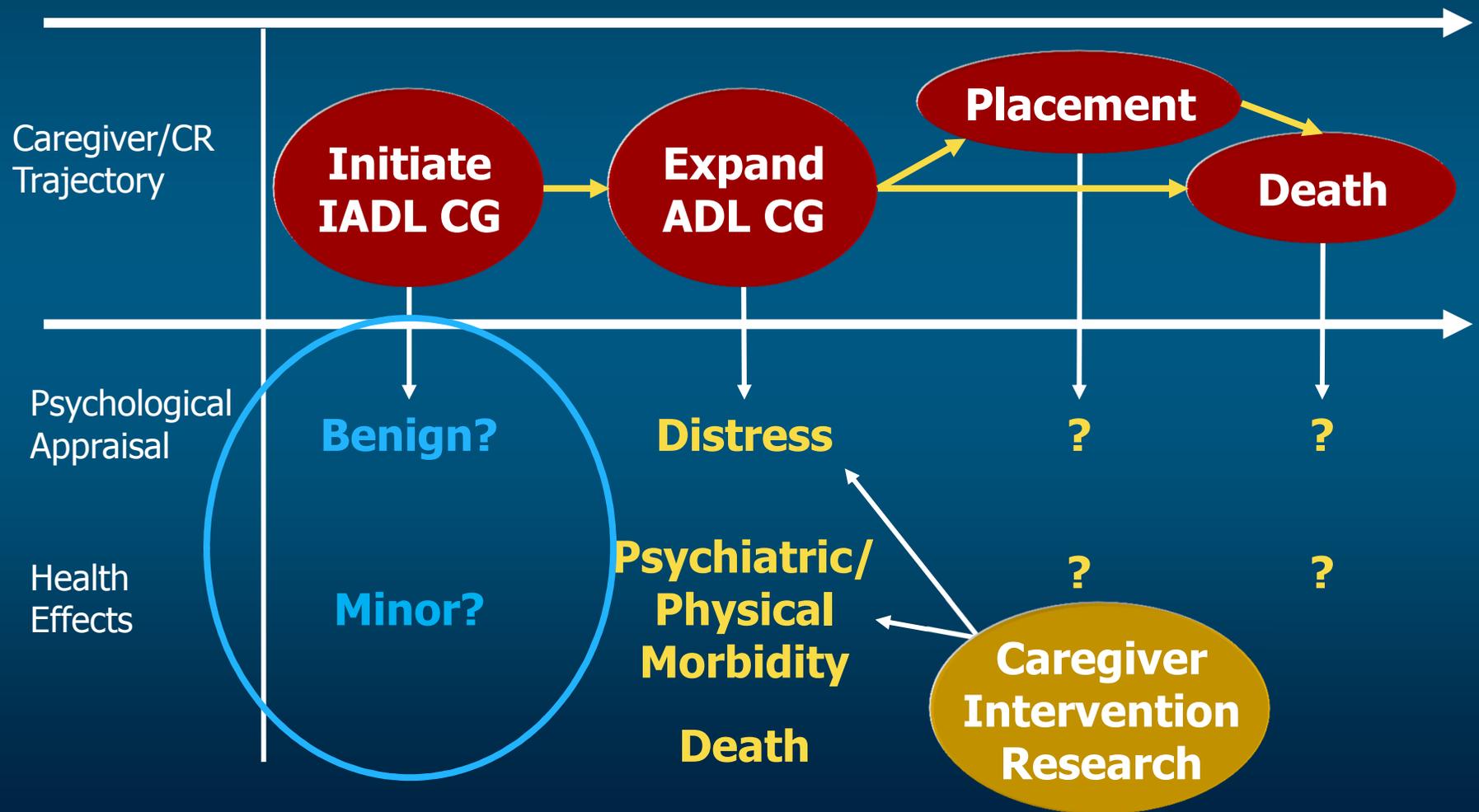
- ◆ *We get by with a little help from our friends....*
- ◆ *Or in spite of ...?*

AVOID TOXICS!!!

IDEAL Communication

<i>Identify</i>	<i>Describe</i>	<i>Express</i>	<i>Assert</i>	<i>Listen</i>
<p>Identify the particular situation Identify with whom and when you want to be assertive.</p>	<p>Describe below what you think and feel about the situation.</p>	<p>Express what you would like the listener to do for you. If you can offer something in return, express that.</p>	<p>Assert why you need what you are asking and how it can be of help.</p>	<p>Listen carefully to the response. If they can fulfill the request, THANK THEM; and state how/when you will do what you offered to them. If the listener is unresponsive or cannot fulfill the request, then negotiate. Is a different time or part of the request possible?</p>

Chronic Stress Trajectory of Caregiving



EPIC: Early Stage Partners in Care



- Little evidence supporting early stage interventions to date; only 1 RCT reported impact on some EP outcomes (Logsdon et al., 2010)
- Developed EPIC
 - EPIC Group based dyadic intervention (Early stage individuals & care partners)
 - Education, skill building, stress inoculation
 - Communication
 - Relaxation
 - Problem solving
 - Self-care Activities (Pleasant Events)
 - Care Values & Preferences
 - Preparedness

Coon & Whitlatch, 2013



CARE VALUES

INDEPENDENCE

- Do things for self
- Come/go as you please
- Organize daily routines in your own way
- Spend money how you want
- Have something to do
- Have time for self
- Make own financial decisions

ACTIVITIES WITH OTHERS

- Do things with others
- Be with family/friends
- Be part of family celebrations
- Keep in touch with the past
- Keep in touch with distant family and friends

WHO HELPS OUT

- Keep the same doctor
- Choose the family who helps
- Have reliable help
- Choose who is excluded from helping you

REDUCING FAMILY STRESS

- Reducing your family's or friends' worries, concerns and how to cope with physical demands, emotional strain, and financial impact related to your care.
- That CP not put his/her life on hold for you
- Have money to leave the family

SAFETY

- Feel safe inside the home
- Be in touch with others in an emergency
- Be safe from crime

Reamy et al, 2011



Four Pleasant Events a Day Keep the Blues Away

- ◆ Don't have to be huge pleasant events.
- ◆ Must be Consciously Chosen, and Deliberately Done to experience control.
 1. Events Control Mood.
 2. To some extent you can control events.
 3. Therefore, you can control mood.

Stress MGT: Mindful Breath

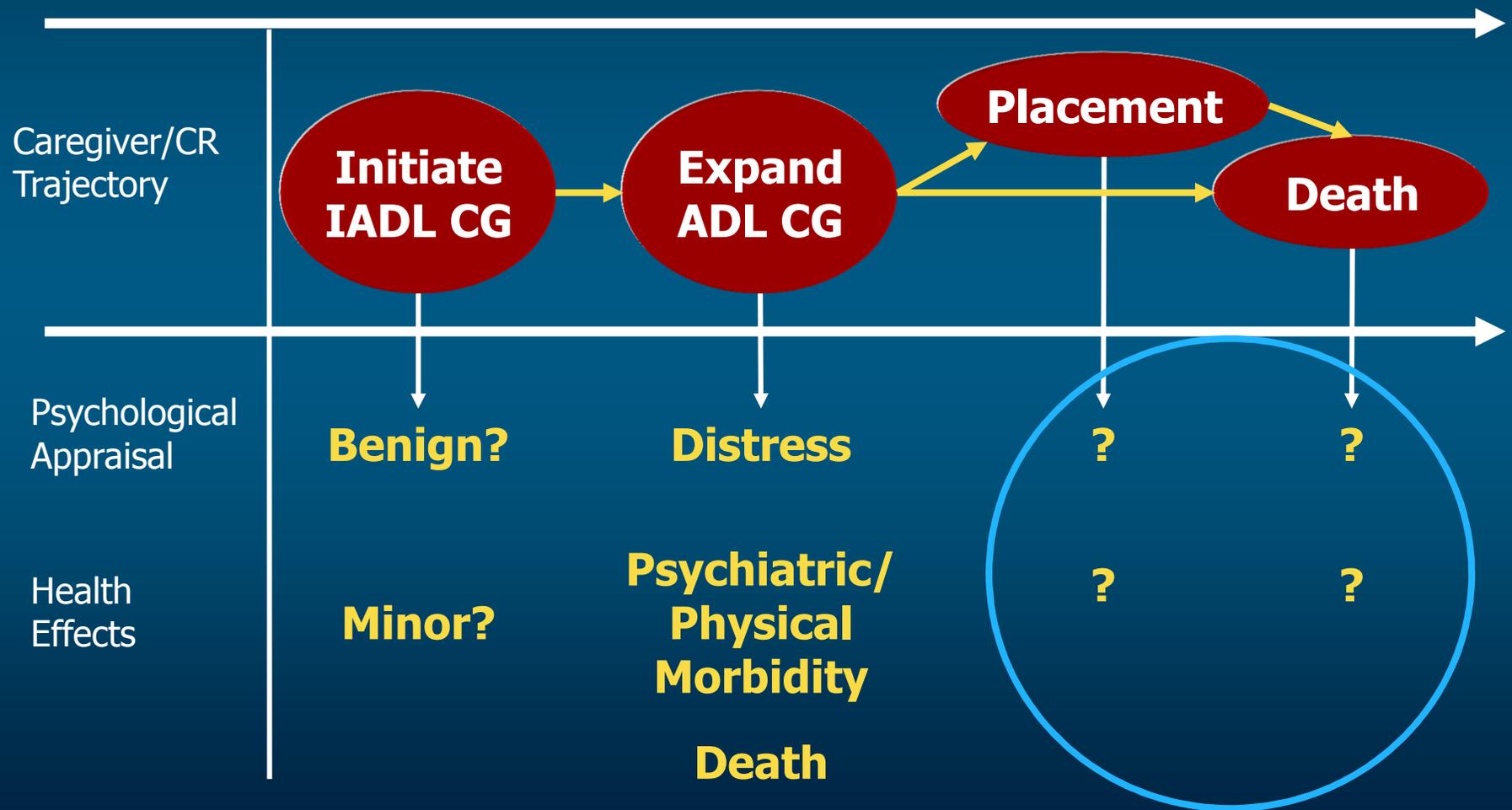
- ◆ **Body & Mind Scan**
- ◆ **Choose a word that represents relaxation for you**
 - (peace, relax, calm)
- ◆ **Four deep breaths; mouth your word during exhale**
- ◆ **Rate tension** (before & after)
- ◆ **Practice!**
- ◆ **Alternative:**
 - Tense muscles on inhale and release while mouthing your word.

EPIC Project Results

Coon & Whitlatch, 2013

Measure	EP		CP	
	<i>p</i>	<i>Effect size</i>	<i>p</i>	<i>Effect size</i>
Dyadic strain negative	< .01	.48	< .05	.31
Care Preparedness	< .05	.34	<.001	.56
CES-D/ Depressed Affect	< .01	.28	< .05	.32
DQoL Negative Affect	<.001	.43	<.001	.73
QoL total	< .01	.33		
DQoL (self esteem)	< .05	.36		
Problem Solving Self Efficacy			<.001	.54
Knowledge- EP's LTC wishes			<.001	.83

Chronic Stress Trajectory of Caregiving



Post-Bereavement & Post-Institutionalization



- 217 Care-Recipients died within 18 months of randomization; end-of-life dementia care and effects on bereavement

Schulz et al., NEJM, 2003

- 180 Care-Recipients were placed in a long-term care facility within 18 months of randomization; effects of placement transition

Schulz et al., JAMA, 2004

Caregiver Responses after Placement



- No significant change in either depressive symptomatology (CES-D) or anxiety (STAI)
- CES-D was higher for caregivers who were married to the care recipient, visited more frequently, or were less satisfied with help received from others
- Anxiety was higher for caregivers who visited more frequently, or were less satisfied with help received from others

Schulz et al., *JAMA*. 2004;292:961-967

LTC: Comments from the Field

Coon, Walker, Felix, Keaveny, & Allen (2011)

What are the needs of LTC family caregivers?

- ◆ Reassurance about the facilities and the process
- ◆ Emotional support; grief and worry (loneliness for spouses)
- ◆ Permission to place (“not the enemy”)
- ◆ Heroes & Advocates (reciprocal relationship)

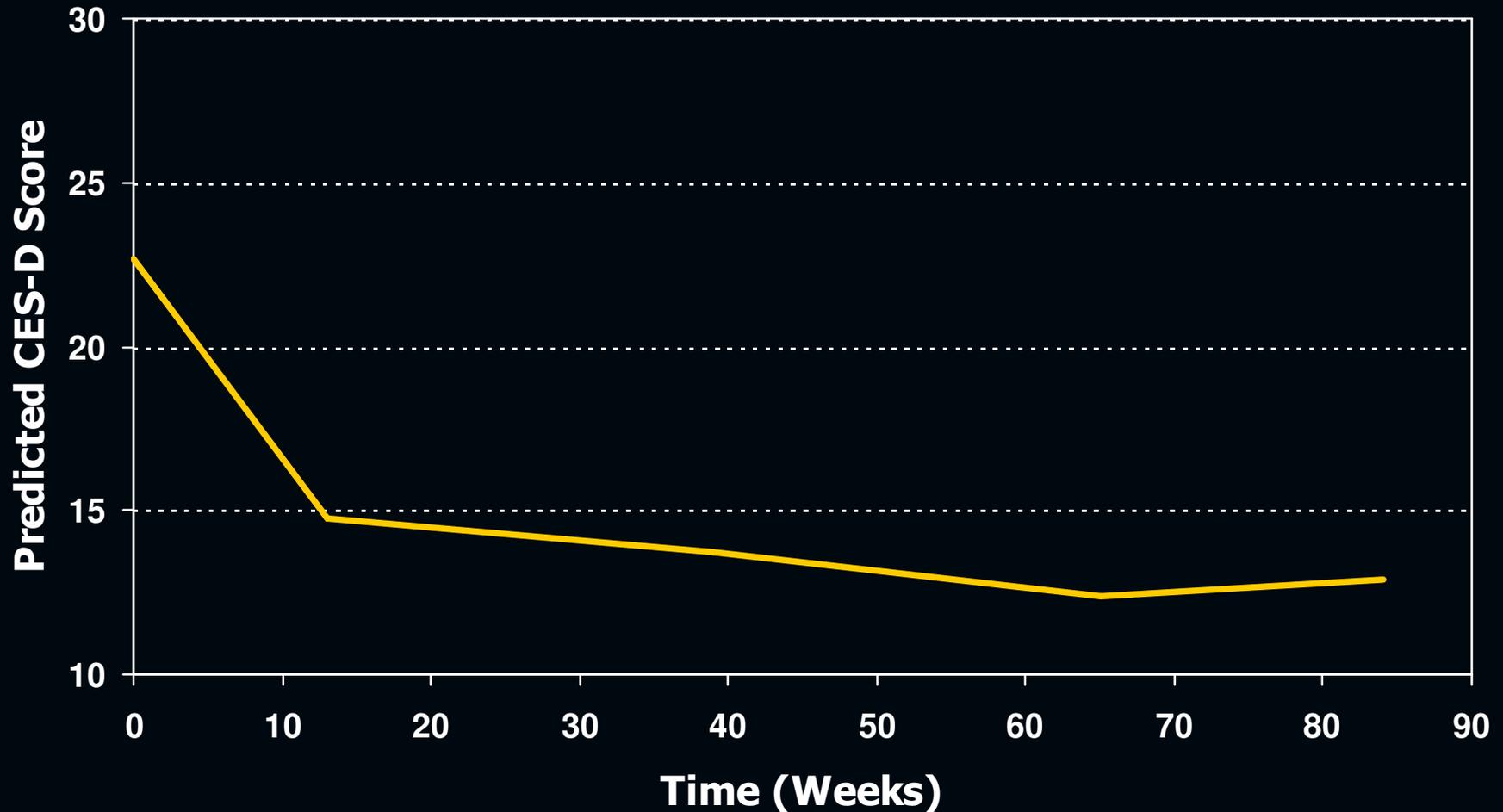
LTC: Comments from the Field

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Ways to address needs

- ◆ **ADRD & LTC education**
- ◆ **Public Awareness Campaigns**
- ◆ **Tools to change perceptions**
- ◆ **Referrals: Lifeline to the Outside World**
- ◆ **Communication skills**
 - Help families create more meaningful connections with dementia patients (Staff)
 - Dealing with difficult family members (Staff)
 - Enhance communication with staff and other family members about problems (Families)
 - Mediation between family members (Both)

Post-Bereavement CES-D Scores Function of Time Since Death (n=217)



Schulz et al. *NEJM*. 2003;349:1936-1942.

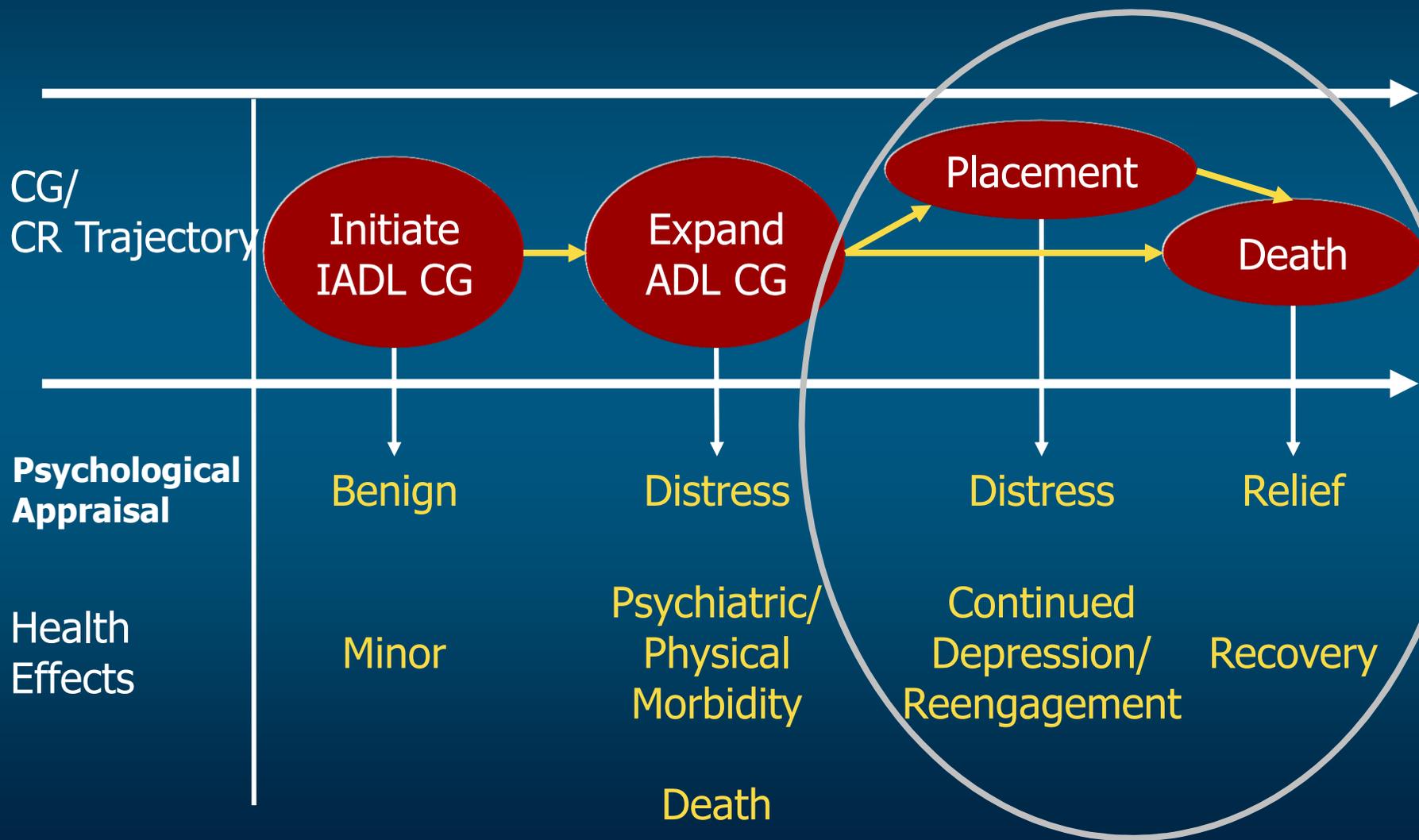
Caregiver Responses after Care Recipient Death



- Significant declines in depressive symptoms (3 months); Substantially below caregiving levels (12 months).
- Death relief to care recipient (90%); self (72%)
- Complicated grief associated with higher levels of pre-loss burden and depressive symptoms, more cognitively impaired care recipients.
- Those in psychosocial intervention less likely to report complicated grief. Those in CWC, in particular.

Holland et al., 2009; Schulz et al., 2003; Schulz et al., 2006

Chronic Stress Trajectory in Caregiving



Caregiver Interventions:

***So, Aren't We Done
Yet?***

Interventions Needing Additional Support



- ◆ **Respite**
 - **Effective use of “down time”**

- ◆ **Care Management & Memory Clinics**
 - **The “Box”**

- ◆ **Support Groups**
 - **Self-efficacy as Moderator (Rabinowitz et al., 2006)**

Challenges & Opportunities for Paradigm Shift



- Care Management and Behavior Change
 - Professionals vary in the prior training, theoretical frame, interest, what counts at work
 - Outcomes often depend on caregiver behavior change and provider behavior change skills
 - Opportunity to learn/do more vs. negative “add-on”
 - Critical for sustainability of programs
 - Implications for Assessment & Intervention

Sustaining Behavior Change



- Skills for Living
- Home practice, Maintenance Guides & Boosters
- Target both High-Risk & Large Segments of the Population: STS?
- Take the “Long View” of Outcomes (Steps for Prevention)
- Multiple Disciplines Working in Partnership
- Bridging the Research & Community Gap
- Multiple Levels of Intervention & Multiple Strategies

– (Coon & Thompson, 2003; Coon, Lipman, & Ory, 2003; Coon, Gallagher-Thompson & Thompson, 2003; Coon et al., 2005)

A Call for Multiple Levels of Intervention



- ◆ **Individual**
I&R/Helpline, skill-building groups, psychotherapy.
- ◆ **Interpersonal**
Early stage groups for spouses.
- ◆ **Organizational/System**
MCO/CBO care pathway partnerships.
- ◆ **Community**
Media campaigns or CCRC.
- ◆ **Policy**
NFCSP, AMA Caregiver Self Assessment Tool, AZ Respite Tool

COON, ORY, & SCHULZ, 2003

Coon's To Do List



- Outreach, Recruitment, & Assessment & (Systematic Treatment Selection)
- Multigenerational families
 - Kinship care; grandparents caring for grandchildren
 - Intergenerational programs
- Training providers to involve caregivers as partners in care
- Intervention Integration for Providers (e.g., home health)

Coon's To Do List (continued)



- Placement interventions
- Bereavement interventions
- Stepped care
- Maintenance of gains (e.g., grad groups)
- Translation/adaptation for other impairments/illnesses and age populations
 - Down's; special needs teens; Kinship care; SMI/CMI adults
 - Vulnerable caregivers
- What is the role of technology? Can we afford it? Smart homes & privacy?

Aging & Behavioral Health Projects

Family Caregiver of Dementia Patients in LTC

CarePRO: Care Partners Reaching Out

EPIC: Early Stage Partners in Care

Prostate Cancer Couples Project

For information, please call:

(602) 496-1239

1-877-852-5420 (out of area)

(English/Spanish)