

The Chinese University of Hong Kong The Nethersole School of Nursing

CADENZA Training Programme CTP004 – Dementia: Preventive and Supportive Care

Chapter 8: Dementia Caregiving: Assessment and Interventions for Family Caregivers

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Content

- Ø Family caregiving: definitions and implications
- Ø Prevalence of family caregivers
- Ø Impacts of dementia caregiving on family caregivers
- Ø Theoretical models in family caregiving
- Ø Assessment on outcomes of family caregiving
- Ø Promoting the quality of life of dementia family caregivers



Family Caregiving: Definitions and Implications

Definitions of Family Caregiving

- No standard or consistent definition
- Vary among the following dimensions
 1. Types of caregiving task
 2. Intensity and duration of care
- Differentiate the caregiving from inter-generational, inter-spousal or other familial aid with the consideration of the decisive factor of **dependence**



Definitions of Family Caregiving

Characteristics of family caregiving

- **Extraordinary care**
 - means that the caregiving tasks engaged by the caregivers exceed the boundary of normal spousal or family responsibility
- **Voluntary care**
 - means that the care provided by the family members is voluntary and does not involve any monetary compensation

An update of definition:
Family caregiving is defined as the act of **helping** someone you care about who is **chronically ill** and who is **no longer able to care for themselves**

Definitions of Family Caregiving

Impact of definitions of family caregiving

- Estimation on **prevalence** of caregiving and **cost of care** depends very much on working definitions of family caregiving



Example:

Parker and Lawton (1994) used the result of a national caregiving survey conducted by Green (1988) in the UK and indicated that the total estimated number of caregivers was **reduced to one fourth** if a **more restrictive definition** of family caregiving was employed in the same study.

Prevalence of Family Caregivers

Prevalence of Family Caregivers

Estimation of prevalence of family caregivers

- Ties with the definitions used, methodology of survey employed, and variables included in the survey

In a national caregiving survey conducted by National Alliance for Caregiving and the American Association of Retired Persons (1997), the brief results show:

- Nearly **one in four** US households with a telephone has at least one caregiver (estimated over 22 millions).
- **20%** of households has provided care to persons with **dementia** or related symptoms (estimated over five millions).

Prevalence of Family Caregivers

Activity 1 : Caregiving population and the economics of caregiving in the United States:

http://www.thefamilycaregiver.org/who_are_family_caregivers/care_giving_statistics.cfm

Activity 2: Profiles of family caregivers in the United States:

<http://www.caregiving.org/data/04keyfindings.pdf>

Impacts of Dementia Caregiving on Family Caregivers

Impacts of dementia caregiving

Three fundamental questions:

1. What are the impacts of caregiving on family caregivers as **compared with non-caregivers**?
2. Does caregiving have a linear effect on caregivers with different **demographic characteristics** (i.e. spousal vs adult children caregivers; female vs male caregivers; young vs old caregivers)?
3. Are caring of frail elderly with dementia **more stressful, and burdensome** than those with other diseases?



Impacts of dementia caregiving

Difference between caregivers and non-caregivers

- Caregivers experience
 - Poorer psychological well-being
 - Poorer subjective well-being
 - Lower level of physiological functioning
 - Lower level of self-reported health
 - Lower self-efficacy
 - Poorer sleep quality
 - Poorer memoriesas compared with non-caregivers
- The rate of caregivers with clinical depression (e.g. using versions of the Structured Clinical Interview for DSM-IV) was double as compared with community-residing older adults (22% vs 11%)

Impacts of dementia caregiving

Difference between caregivers and non-caregivers

- The rate of caregivers with **clinical depression** (e.g. using versions of the Structured Clinical Interview for DSM-IV) was **double** as compared with community-residing older adults (22% vs 11%)

The effects of caregiving on caregivers (compared with non-caregivers)

<http://www.sciencedaily.com/releases/2008/08/080812102611.htm>



Impacts of dementia caregiving

- Ø Caregivers with different demographic characteristics
- Ø Caregiving is influenced by:
 1. **relationship** of caregivers to the care recipient
 2. **gender** of caregivers
 3. **types of disease** of care-recipient

Impacts of dementia caregiving

Spousal caregivers vs adult children caregivers

- **Spousal caregivers:**
 - had a **lower income**
 - reported significantly more doctors visits and **poorer self-rated health**
 - exhibited **lower levels of well-being** (e.g. stress symptoms / lower levels of affect balance and life satisfaction)
 - had the **lower frequent of club attendance** as compared with adult children caregivers



Impacts of dementia caregiving

Male caregivers vs female caregivers

- **Female caregivers:**
 - tended to report higher levels of **depression, anxiety, and general psychiatric symptomology**, and lower level of life satisfaction than men caregivers
 - spent **more time** on caregiving than men in terms of the number of caregiving tasks performed
 - tended to be exposed to **greater caregiving demands** than men, especially in terms of time spent on caregiving, and the performance of hands-on, day-to-day caregiving activities
 - experienced **higher burden** than men



Impacts of dementia caregiving

Dementia and non-dementia family caregivers

- Dementia family caregivers are more likely to experience:
 - high level of care **involvement**
 - higher level of **stress and low level of self-efficacy**
 - higher level of **social, physical and emotional strain**
 - **poorer mental health and physical health**



Theoretical Models in Family Caregiving



Theoretical Models

Theoretical models

- Provide a framework to explain how family caregiving influences the well-being of caregiver
- Give insight to predict caregivers' outcomes and to inform development of caregiver supportive interventions

Theoretical Models



Pathway for inquiry of family caregiving

Describing the phenomenon and exploring the **roles, needs and burden**



Identifying the **predicative factors** in mental or physical health of the caregivers



Transforming the process to the **explanation of the phenomenon**

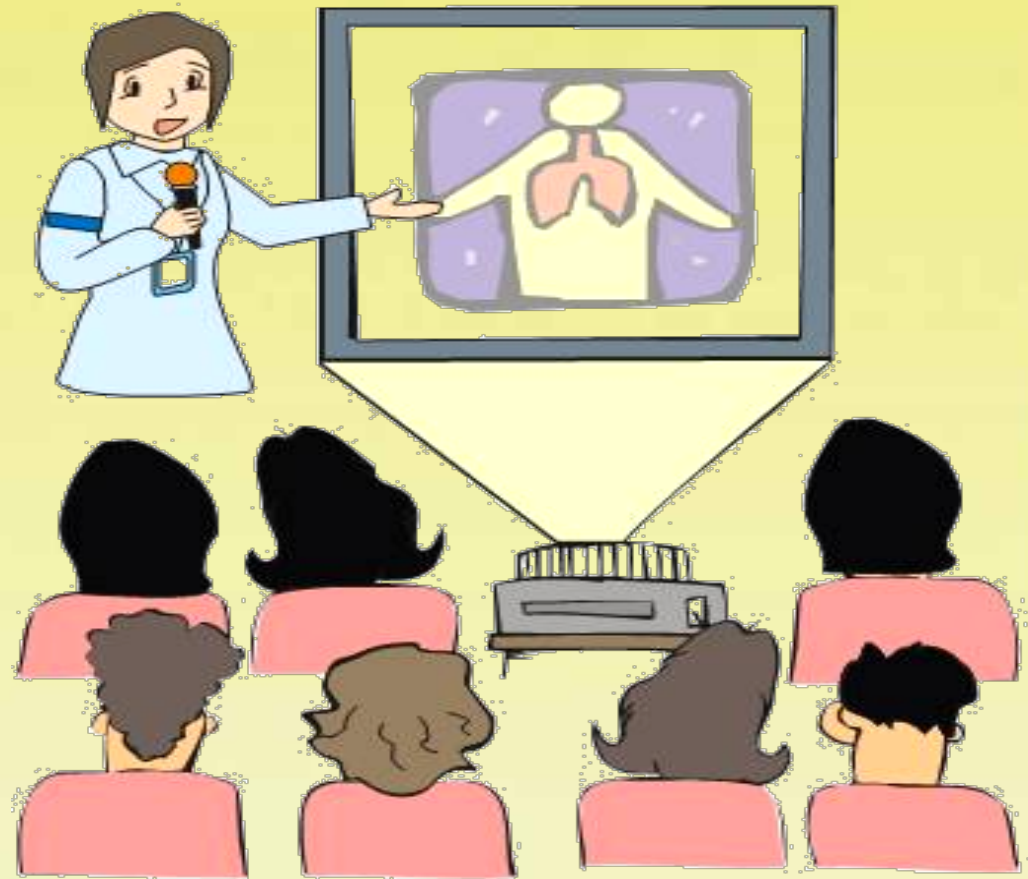


Widening the line of inquiry by examining the **process** of family caregiving

Theoretical Models

Three models include:

1. Basis x-y-z model
2. Stress-coping model
(most widely used)
3. Adaptation model



Theoretical Models

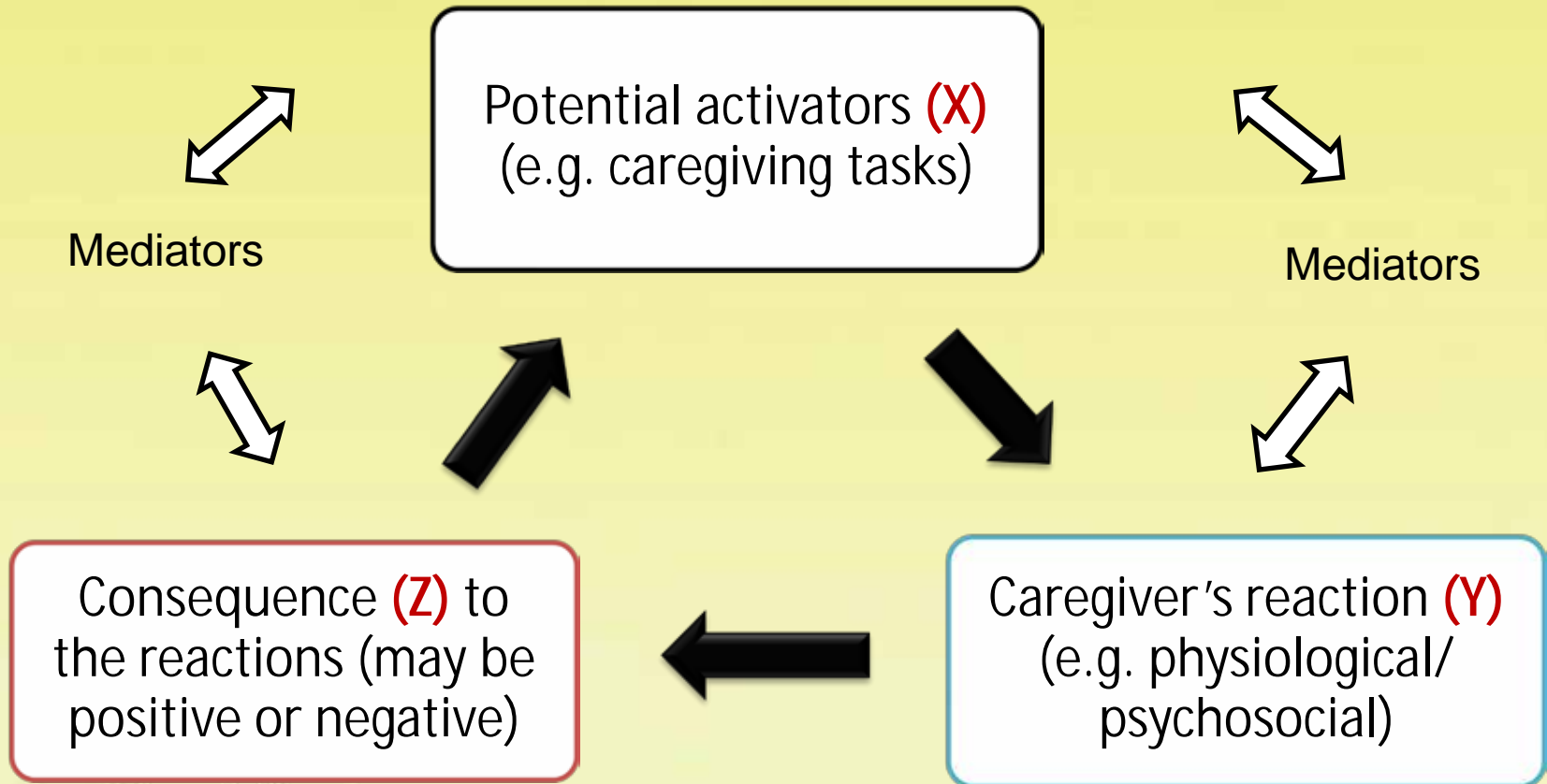


Basis X-Y-Z stress model

- Focuses on interactions between individual and the environment
- Consists of 4 elements:
 1. Potential activators (X) (e.g. caregiving tasks)
 2. An individual reaction (Y) (may be physiological, or psychosocial aspects)
 3. The consequence (Z) to the reactions (may be positive or negative)
 4. Mediators are thought to be the filters and modifiers that act on each stage of the X-Y-Z sequence to produce individual variations

Theoretical Models

Basis X-Y-Z stress model



Theoretical Models

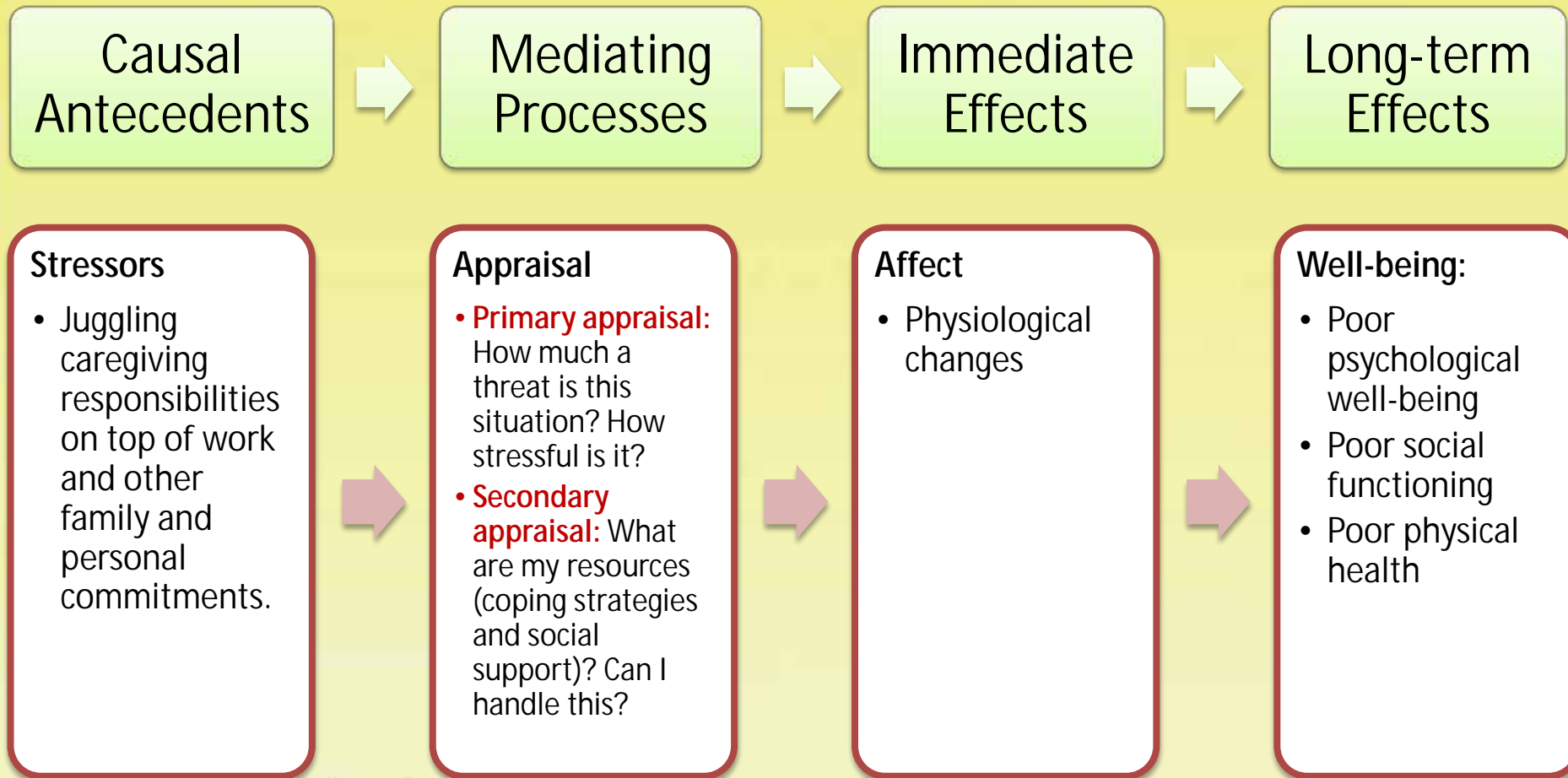
Stress-Coping Model

- According to the cognitive phenomenological theory of psychological stress, behavioral, physiological and psychological responses are the results of primary and secondary appraisal process between the person and the environment
- Primary and secondary appraisals
 - Help to determine if situations are irrelevant, beneficial or threatening by taking into consideration of personal and environmental factors, and coping mechanisms



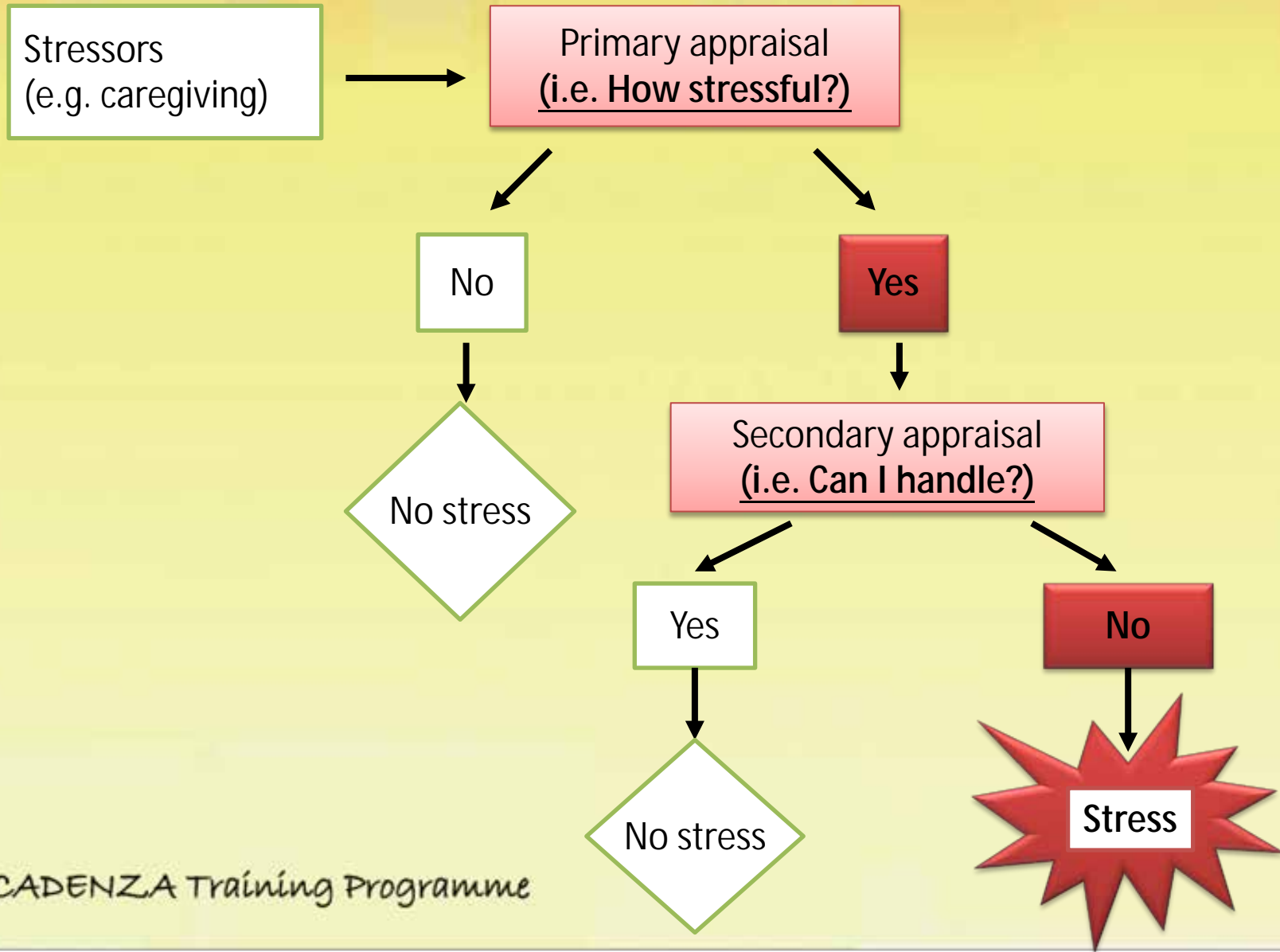
Theoretical Models

Stress-Coping Model



Theoretical Models

Stress-Coping Model



Theoretical Models



Adaptation model consists of three elements:

1. Background and context:

- Care receiver and caregiver **characteristics and the context** of the caregiving situation are often conceptualized to determine the types of caregiving activities the individual engage in
- Individual differences in **attitudinal variables** help to explain how a situation can be appraised as stressful by one person and beneficial by another

2. Intervening process:

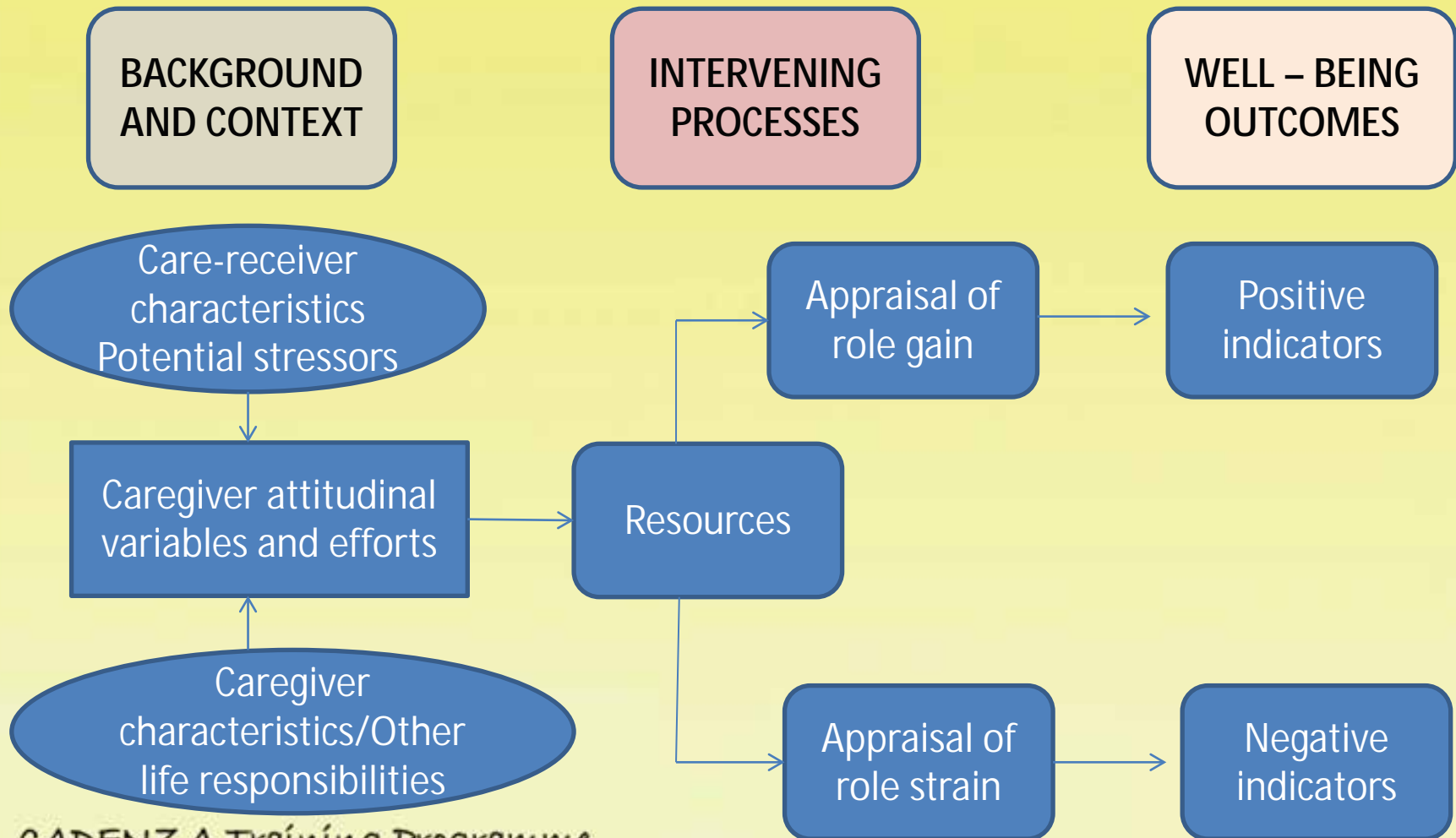
- Is a process of adapting to family caregiving
- Includes resource and appraisals
- The appraisal is determined by the interaction of caregiver's internal resource, attitude and effort

3. Well-being outcomes

- The positive and negative well-being outcomes are regarded as the consequence of respective appraisals

Theoretical Models

Adaptation Model



Theoretical Models

Comparison of theoretical models

- Stress-coping model is the **most widely used** in dementia caregiving
- Models developed in 80s and 90s had heavily geared towards the negative side of caregiving, for example, psychiatric and physical morbidity of caregivers
- **Adaptation model** takes a balance perspective to address **both positive and negative consequences** of caregiving



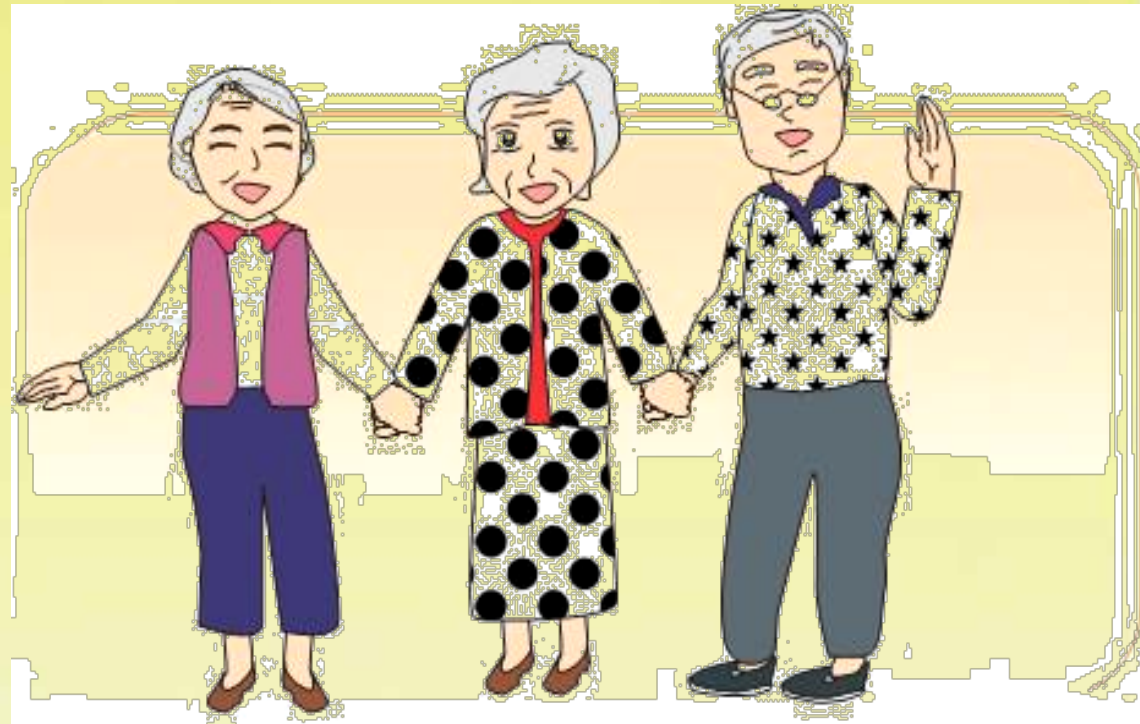
Assessment on outcomes of family caregiving



Assessing outcomes of family caregiving

Common family caregiving outcome variables:

1. Burden
2. Psychiatric morbidity
3. Physical morbidity
4. Positive side of caregiving



Assessing outcomes of family caregiving

Assessment of burden

- **Psychological or emotional strains** as a consequence of the caregiving responsibility of the family members who took care of the impaired older adults
- Two dimensions
 - **objective burden** (i.e. events or activities associated with negative caregiving experience, practical consequences of physical and behavioral changes of the care recipient)
 - **subjective burden** (i.e. emotional reactions of caregivers)
- Multidimensional concepts
 - **psychological, emotional, social, physical and financial burden**



Assessing outcomes of family caregiving

The Zarit Burden Interview

- Description:
 - Is regarded as a single dimension of burden scale
 - Is considered as the first burden scale to evaluate the **subjective impact of caregiving**
 - Was primarily designed to use in research and program evaluation purposes
 - Consists of 29 items but was shortened to 22 items



Assessing outcomes of family caregiving

The Zarit Burden Interview

- Scoring method & interpretation:
 - Can assign a rating in each item by a 4-point Likert scale (never to nearly always; 1-4).
 - A total burden score can be obtained by summing all item scores
 - A higher score indicates a higher burden



Assessing outcomes of family caregiving

The Caregiver Strain Index

- Description:
 - Is a multi-dimensional burden scale
 - Consists of 13 items
 - Covers items, such as feeling of inconvenience, confinement, adjustment, competing demand, upsetting behaviors, needing the care receivers to be different, feeling overwhelmed sleep disturbance, and physical and financial strain.

Assessing outcomes of family caregiving

The Caregiver Strain Index

- Scoring method and interpretation:
 - Answers each item in Yes/No format & sum up the scores (Yes=1 and No=0)
 - Obtains a score of 7 or greater indicating a high level of stress

Assessing outcomes of family caregiving

The Cost of Care Index

- Description:
 - Is also a multi-dimensional scale
 - Consists of 20 items in 4-point Likert scale
 - Covers five dimensions of caregiving, including personal and social restrictions, physical and emotional health, value items, the care recipients as provocateur, and economic cost



Assessing outcomes of family caregiving

The Cost of Care Index

- Scoring method and interpretation:
 - Asks caregivers to respond to each question by checking “strongly agree”, “agree”, “disagree” or “strongly disagree”
 - Total score ranges from 20 to 100
 - Higher score indicates higher risk



Assessing outcomes of family caregiving

The Caregiver Burden Inventory

- Description:
 - Is a multi-dimensional burden scale
 - Was designed specifically to assess caregivers of cognitively impaired older people.
 - Consists of 24 items in 4-point Likert scale ranging from never (0) to always (4)



Assessing outcomes of family caregiving

The Caregiver Burden Inventory

- Scoring method & interpretation:
 - 24 items divides into 5 factor subscales (physical burden, time dependence burden, developmental burden, physical burden, social burden and emotional burden)
 - A higher score indicates higher burden



Assessing outcomes of family caregiving

Indicators for **psychiatric morbidity**

- Ø Global rating of mental health
- Ø Centre for Epidemiological Studies Depression Scale (CES-D)
- Ø Geriatric Depression Scale
<http://www.stanford.edu/~yesavage/Chinese3.html>
- Ø General Health Questionnaire
- Ø Structured Interview for DSM-IV



Assessing outcomes of family caregiving

Indicators for **physical morbidity**

- ρ Global physical health ratings
- ρ Physical symptoms index
- ρ Objective physiological parameters, e.g. blood pressure and heart rate, immune function, and etc
- ρ Health service utilizations, such as physician visits, aggregate use of health services, and drug utilization
- ρ Health related behaviours, including alcohol consumption, smoking behavior, sleep, and eating behavior/nutrition



Assessing outcomes of family caregiving

Indicators for **positive outcomes**

- ρ Uplifts
- ρ Caregiving satisfaction
- ρ Rewards
- ρ Gratifications
- ρ Finding meaning through caregiving
- ρ Benefits
- ρ Positive affect
- ρ Life satisfaction

Promoting the quality of life of dementia family caregivers



Interventions: Theoretical Frameworks

∅ Interventions in family caregiving include:

1. Stress process models
2. Motivational theories
3. Personal control theory
4. Competence-environmental press framework

Interventions: Theoretical Frameworks

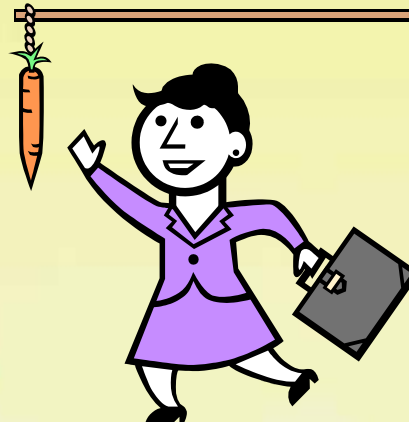
1. Stress Process Model

- Points out the importance of **psychosocial factors** in influencing caregiver well-being.
- Numerous studies have supported the psychosocial resources play an important role in mediating the effect of stressors on caregiver well-being
- Resources include **coping responses, caregiver appraisal, and social support**
- Enhancement of **coping skills** of caregivers to manage the demand of caregiving is one of interventions that bases on the model

Interventions: Theoretical Frameworks

2. Motivational Theories

- Fulfilling personal goal leads to initiation of behaviors
- Caregivers motivates to learn new skills or strategies to address his or her personal goal in caregiving
- Individual skill training program for caregivers is based on the theories



Interventions: Theoretical Frameworks

3. Personal Control theory

- Suggests that caregivers may be motivated to learn to maintain his or her control over important life domains
- A sense of efficacy is developed after successful use of strategies to manage the problems
- Pathway of mechanism involves 5 steps
 1. Caregivers motivated to maintain control.
 2. Caregivers adapts new care strategies.
 3. Care strategies are effective solutions to new problems.
 4. Caregiver feels sense of self-efficacy.
 5. Caregiver burden is reduced
- Behavior management techniques towards disturbing behaviors of demented elderly are considered as one of interventions that bases on personal control theory

Interventions: Theoretical Frameworks

4. Competence-environmental press framework

- The framework suggests a **fit between the individual and environment** so that an optimal behavior is obtained
- **Environmental modification** is a technique that bases on the framework. It is believed that change the environment can promote the functioning and desirable behaviors of demented elderly
- A well maintained function and behavior can reduce caregivers' burden, e.g. creating doorways that are interesting and safe for exploration can minimize the risk of success exit seeking in residential settings

Interventions: Evidence Based Practice

Basic principles

- **Increases internal resource of family caregivers**
 - e.g. knowledge and skill in caregiving, psychological adjustment
- Reduces demand from caregiving responsibilities
 - e.g. respite service
- **Increases external resource**
 - e.g. peer support, promote relationship between care-recipient and caregivers
- Bolsters positive effects of caregiving
 - e.g. recognition of caregiving duties



Interventions: Evidence Based Practice

1. Education to caregivers

– Intervention

- Provides education or information to caregivers in terms of formation about AD and the disease process, the enhancement of communication with the patient, stress management, and the management of problem behaviors

– Effects:

- Some of the educational programs showed beneficial effects on caregivers, including increased **knowledge on disease process, reduced caregiver negative effect and communication hassles, increased feeling of competence and independence, and improved communication** with patients
- Unfortunately, a review stated that the improvement to knowledge through intervention does not consistently lead to improvement of caregiver psychological well-being



Interventions: Evidence Based Practice

2. Respite

– Intervention

- Respite can provide a break for caregivers from caregiving

– Effects:

- Most studies examining the effects of respite reported positive results, such as **positive changes in mood, and quality of life, improved on measures of overload, worry & strain, and depression, improvement in symptoms and sleep and delayed institutionalization.**



Interventions: Evidence Based Practice

3. Caregiver training

– Intervention

- Caregiver training mainly focuses on enhancing the particular skills of caregivers to facilitate them to care of their family members. The trainings include **enhancement of communication skills, use of prosthetic memory aid and behavioral management** techniques.

– Effects:

- The empirical evidence provides a preliminary support about the effectiveness of trainings in **promoting the positive affect or decrease in stress of caregivers**, or reduction of repetitive verbalization. However, caution should be taken in interpreting the results because of small sample size in these studies.

Interventions: Evidence Based Practice

4. Counseling

– Intervention

- Counseling may be given individually or in groups. It aims at validating caregiver experiences. Counselors will provide encouragement and support for caregivers

– Effects:

- Individual and family counseling have yielded positive outcomes in **reducing burden, depression and psychiatric symptoms**

Interventions: Evidence Based Practice

5. Support groups

- Intervention
 - Through face to face discussion or computer support network
 - Groups may incorporate therapeutic programs such as **education on dementia, relaxation training and stress management, and role-played problem-solving strategies.**
- Effects:
 - Results were mixed
 - Some of the positive findings of the support group included increased knowledge about AD, improved confidence in decision making, and decreased caregiver burden and reduced depression.
 - Several studies failed to support the relationship between support group attendance with distress, strain, and life satisfaction. However, high levels of usefulness and satisfaction were consistently reported by caregivers after participation of the group.

Interventions: Evidence Based Practice



6. Multi-component interventions

– Objective

- To examine whether the combined effect of multi-component interventions compared with control conditions would result in less upset and fewer depressive symptoms for caregivers in active interventions at the 6-month follow-up.

– Method

- A multisite randomized trial was adopted. Each site tested different theory-driven interventions and used randomized clinical trial procedures to test hypothesis about the effects of interventions. The interventions included the provision of individual information and support strategies, group support and family system efforts, psychoeducational and skill-based training approaches, home-based environmental strategies, and enhanced technology systems.

Interventions: Evidence Based Practice



Multi-component interventions

– Key findings

- Active interventions were superior to control condition in reduction of caregiver burden. **Only one site** (Miami) reported a significant reduction in depressive symptoms ($p=.034$) in the combined **family therapy plus technology** treatment condition compared with the control condition. Also, active interventions were superior to control conditions for Hispanics, non-spouses, and caregivers with lower education.

– Conclusion

- **Intervention should have multiple components** and includes elements that target different aspect of caregiving experience, and specific characteristics of caregivers.

Interventions: Evidence Based Practice

Implications on practice

- Empirical evidence tends to support that interventions which are comprehensive, intensive, and individually tailored are more likely to achieve positive outcomes than those lacking these characteristics
- In literature review, many existing intervention studies are methodologically weak, such as weak experimental designs, problematic sampling, and randomized strategies, and the use of inadequate outcome measures
- There is a pressing need to: (1) the optimal mix of intervention components, (2) choose appropriate outcome measures, (3) have methodological rigorous design and larger sample size with diverse population, (4) incorporate the use of technology in future caregiver intervention



Summary

We have highlighted ...

- ü Definitions and prevalence of family caregiving
- ü Effects of family caregiving
- ü Theoretical models of family caregiving
- ü Commonly used assessments on family caregiving
- ü Interventions for dementia family caregivers



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End of Chapter 8

