Caring for the Family Caregiver

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Overview of Presentation

• National Scope of Caregiving
• A Problem-Solving Perspective of Caregiving
• Evidence that Problem-Solving Training Works
• Developing a Problem-Solving Training Program
National Scope of Caregiving

- Family caregivers the largest group of care providers in the United States  
  *Parish et al., 2003*

- Market value of family caregiving exceeds that spent on formal health care or nursing home care  
  *Vitaliano et al., 2003 and 2004*

- Caregivers have more influence on care recipient health than any single health care provider
Changes in the Health of the Nation

• Increase in rates of chronic disease and disability
• Almost half of the national population has a chronic health condition
• “Epidemic of Survival” – increased life span of persons with developmental and acquired disabilities that require life-long assistance
• Almost 70% of daily health care expenditures attributable to a chronic problem
Family Caregiving in Context

Changes in resource allocation and increases in chronic disease and disability

- Family caregivers function as *de facto* health care providers
- Elevated the status of caregiver to an integral component of the healthcare delivery system
Family Caregivers and Disability

- Many experience considerable problems with depression, anxiety, ill health
- Many experience declines in social support and increased social isolation
- Their ability to cope effectively directly influences the health of the care recipient
Depressed Caregivers

- Report more health problems, more family conflict, more negative attitudes toward care recipient, more negative attitudes from the care recipient, more role captivity, greater loss of self, and more overall distress than nondepressed caregivers.
Depressed Caregivers

- Report less exercise, less social support, a lower sense of competence, greater relational deprivation, more economic strain and greater medication use to calm down than nondepressed caregivers
Family Caregiving
An Agenda for Public Health

• Health and well-being of family caregivers – and their ability to assist their care recipients – is now a **public health priority**  *Talley & Crews, 2007*

• **Healthy People 2010** calls for behavioral and social initiatives to promote the health and quality of life of persons with disability -- as *defined by the WHO* -- and their families
A Caregiving Readiness Model for Developing and Sustaining a Comprehensive Care Plan (CP)

Requirements:
Achieving CP goals requires the sustained, cooperative efforts of the care recipient, family caregivers, other significant caregivers, and a number of trusted professional advisors.

The Tasks of Caregiving: Overall Domains

- Medical
- Legal-Financial-Insurance
- Familial
- Spiritual-Emotional

Caregiver and Care recipient life course trajectories

Necessary steps include:
- Understanding of the landscape of caregiving tasks (e.g., medical > locating a medical specialist) associated with a particular condition.
- Completion of initial assessment with health, legal, financial, and spiritual advisors.
- Initiation and completion of all required tasks using state of science and practice resources.
- Identification of high priority tasks
- Ongoing reassessment and task completion as conditions change
Develop Partnerships with Family Caregivers

- To help family caregivers to be more expert in self-regulation, managing demands
- To help family caregivers operate competently as formal extensions of health care systems
- To help them address tasks and routines “…essential to family functioning”
To Meet These Needs...

- Provide these services in the community to persons in caregiver roles
- Promote use of low-cost service providers to provide training and support to caregivers
- Promote use of long-distance technologies to provide training
A Problem Solving Perspective of Caregiver Adjustment
Effective Interventions for Family Caregivers

• Psychoeducational modalities more effective than others

• Interventions are more effective when they address the needs and concerns of family members as they are perceived and experienced by these individuals
A Problem Solving Perspective of Caregiver Adjustment

*D’Zurilla & Goldfried, 1971*

- General Orientation to Problem Solving
- Problem Definition
- Generation of Alternatives
- Decision Making and Implementation
- Verification
Social Problem-Solving Model
*D’Zurilla et al. (2004)*

- **Constructive Problem-Solving Styles**
  - Positive Orientation
  - Rational Problem-Solving Skills

- **Dysfunctional Problem-Solving Styles**
  - Negative Orientation
  - Impulsive / Careless Tendencies
  - Avoidant Tendencies
Constructive Problem-Solvers

– Ward Off Negative Emotions
– Promote Positive Emotions
– Inhibit Impulsive Reactions
– Motivated toward Solving Problems
– Generate Solutions
– Make and Implement Choices
– Evaluate Progress and Outcome
Caregiver Problem-Solving Abilities Predict Adjustment

- Caregivers with dysfunctional styles report more depression, anxiety, ill health
  - Elliott et al. 2001, Grant et al. 2006
- Care recipients who are with caregivers with dysfunctional styles appear more likely to develop secondary complications
  - Elliott et al., 1999, Kurylo et al. 2004
Problem-Solving Training (PST) for Family Caregivers

• Stroke caregivers  *Review by Lui et al., 2005*
• Mothers of children with cancer  *Sahler et al. 2005*
• Parents of children with traumatic brain injuries (TBI)  *Wade et al., 2006a, 2006b*
• Individuals with cancer and their caregivers  *Houts et al., 1996; Bucher et al., 1999; Nezu et al., 2003*
Problem Solving Training for Caregivers

**PST** teaches skills necessary to be an effective problem solver and can be used to help caregivers

- Have a better understanding of the components involved in interpreting a problem situation
- Increase their actual problem solving skills

*Effective problem solving abilities are predictive of caregiver and care recipient adjustment*
Evidence that Problem Solving Training for Family Caregivers Works

Results from Randomized Clinical Trials
Project FOCUS

Caregiver Links to Understanding Education and Support

project

TLC

1·407·797·1418
Three Common Trajectories of Change in Response to Counseling

PST for Family Caregivers of Stroke Survivors

- 74 primary family caregivers of stroke survivors over 12 week period
- Three-group repeated measures experimental design
- Random assignment to either a PST intervention via telephone, sham intervention, or control group

Grant, Elliott, et al., Stroke, 2002
Effects on Caregiver Depression

- PST
- Sham
- Control

Time 1  Time 2  Time 3  Time 4
Effects on Caregiver Preparedness

Time 1  Time 2  Time 3  Time 4

- PST
- Sham
- Control
Effects on Caregiver Satisfaction with Healthcare Services

Time 1  Time 2  Time 3  Time 4

PST
Sham
Control
Brief PST + Education for Caregivers of Persons with Spinal Cord Injuries

- 60 caregivers (49 women, 11 men) consented to participate for one year
- Randomized into PST + education intervention group or usual-care control group
- PST provided in three individual sessions (baseline, 6 month, 12 month)
- Three measurement occasions

PST tailored to address specific problems identified by each caregiver at each session

Elliott & Berry, Journal of Clinical Psychology, in press
Problem-Solving Training + Education Increases SCI Caregiver Social Functioning Over 1 Year $N = 60$
Problem-Solving Training + Education Reduces SCI Caregiver Dysfunctional Problem-Solving Styles Over 1 Year $N = 60$
PST for Caregivers of Persons with Spinal Cord Injuries

- 61 caregivers (54 women, 7 men) and their care recipients (40 men, 21 women) consented to participate for one year (28 discontinued)
- Randomized into PST intervention group or education-only control group
- PST provided monthly via teleconferencing device
- Three measurement occasions

*PST tailored to address specific problems identified by each caregiver at each session*

_Elliott et al, Behaviour Research & Therapy, in press_
Telehealth and Caregivers

*PST via Teleconferencing*
Problem-Solving Training via Videophone Decreases SCI Caregiver Depression  \( N = 61 \)
Training SCI Caregivers in Problem-Solving via Videophone Increases Care Recipient Social Functioning  N = 61
PST for Caregivers of Persons with Traumatic Brain Injuries

- Family caregivers were randomized into a PST group (29 women and 4 men; average age = 51.3) or a control group (34 women; average age = 50.8)
- Care recipients included 26 men and 7 women in the intervention group (average age = 36.5) and 24 men and 10 women in the control group (average age = 37.2)
- PST involved four face-to-face sessions (baseline, months 1, 4, 8, 12; telephone sessions in other months); education-only control group received monthly educational materials

_PST tailored to address specific problems identified by each caregiver at each session_

_Rivera, Elliott, et al., 2008 APMR_
Education “Control” Group

- Monthly telephone calls
- 10 minutes minimum each
- CGs receive a folder with information to be read before each telephone contact
- Topics included: aging, dental health, disaster preparedness, relaxation, physical fitness, respite, pain
Problem-Solving Training Reduces Caregiver Depression

Caregivers of Persons with TBI  N =67
Significant Effects on Health Complaints
Caregivers of Persons with TBI  N = 67

[Graph showing the comparison between PST and Control groups over time (1 mon, 4 mon, 8 mon, 1 yr)]
Training TBI Caregivers in Problem-Solving Skills Lowers Care Recipient Depression
Developing a Problem-Solving Partnership Program

for Family Caregivers of Persons with TBI
Interventionists, Trainers

• We have used
  – Nurses (with masters degree)
  – Counselors (with masters degree)
  – Retired professional (with Ed.D. in administration)
  – “New” psychologists (recent Ph.D.)
  – Staff member with undergraduate degree in psychology
Tailoring Problem-Solving Training

*Using a Card Sort Technique*

- Card sorts require caregivers to consider problems that may be outside their awareness
- Help caregivers articulate their concern
- Compel caregivers to think about how problems might overlap
- Help caregivers prioritize problems
Frequently Encountered Problems
Caregivers of Persons with TBI

• Dealing with everything by myself
• Feeling overwhelmed with responsibility
• Finding time to be alone
• Loss of husband/wife relationship
• Dealing with violent behavior
• Dealing with their negative, pessimistic attitude
• Dealing with changes in personality
• Keeping a positive attitude all the time
• Having to re-teach and watching the struggle
• Not being able to go places
• Dealing with their anger
• Financial issues
Problems for...

- Husbands of women with TBI
  - Wife’s loss of autonomy
  - Wife’s mood swings
  - Wife’s insecurities and over-protectiveness
  - Wife’s reluctance to leave the home
  - General change in lifestyle
Problems for...

• Wives of men with TBI
  – Changes in husband’s personality
  – Changes in husband’s memory, cognition
  – Husband’s lack of insight, poor acceptance
  – Reduction in financial resources
  – Loss of emotional support, companionship
  – Feeling unable to meet children’s need
What Do Caregivers Want?

Unmet Needs

• Help keeping the house
• Help preparing for the worst
• Have care recipient’s employer, coworker, teacher understand their problems
What Do Caregivers Want?  
Unmet Needs

• Have complete information on drug and alcohol problems and treatment
• To get break from my problems and responsibilities
• To have enough resources from myself and my family
Perceived Importance of Items

Least Important

1. Sexual Relations 21
2. Saying “No” 16
3. Bowel and Bladder Acc. 24
4. Lack of Time 6

Most Important

5. Hateful Attitude 1
6. Patient Cries 5
7. Lack of Appreciation 18
Helping Caregivers Identify Problems

Priorities and Patterns
Helping Caregivers Identify Problems and Progress
Caregiver Partnerships
Reflection and Feedback

• Empowerment Model
This interactive program is designed to offer caregivers 3 techniques to help improve their health and quality of life.

1 - Card Sort
2 - Problem Solving
3 - Stress Relief
General Problem Solving Training

- General Orientation to Problem Solving
- Problem Definition
- Generation of Alternatives
- Decision Making and Implementation
- Verification
Problem Orientation Training

- Develop Self-Regulation Skills
- Promote Positive Affect
- Take Alternative Perspectives
- Promote Positive Expectations
- Identify Negative Cognitive Patterns
Positive Problem Orientation (adaptive thoughts)

1. Problems are normal, ordinary, inevitable events in life.
2. Problems are challenges or opportunities for personal growth or self-improvement instead of threats to be avoided.
3. There is a solution to most problems and I am capable of finding the solutions and implementing them successfully.
4. Solving problems is likely to take time and effort. I like to stop and think instead of acting impulsively. I do not give up too easily if a solution is not quickly discovered. Instead, I try my very best to succeed, and if I cannot, I will either accept the problem as unchangeable in its current form and try to view it differently, or I will go get help.
Negative Problem Orientation (maladaptive thoughts)

1. Problems are my fault. Something is wrong with me that I have problems.
2. Problems are threats to be avoided or to be attacked immediately without hesitation or plan.
3. I cannot cope with problems effectively because the problem is unsolvable. I am not capable of solving problems successfully. It is better if someone else solves my problems for me.
4. A competent individual should be able to solve problems quickly and with little effort. My failure to solve problems is because of my inadequacy or incompetency. Someone else should solve my problems for me.
Problem Orientation

Explore feelings about caregiver role and responsibilities:

Hello ____. How are things going this week? Hello ____. We decided the last time we talked that this would be a good time to call you this week. How are you and ____ doing? How are you handling your role as a caregiver? How are you handling the responsibilities you’ve had to assume as a caregiver? How does it make you feel?

Emphasize optimistic attitude toward solving problems, in carrying out problem-solving steps, and in viewing caregiving as a set of challenges; encourage involvement of survivor in planning strategies to solve caregiving problems.
Problem-Solving Skills Training

- Identify and prioritize problems
- Proactively consider options
- Develop and use assertion skills
- Think rationally about their own needs
- Develop time-management plans
- Review problem solving skills
Caregiving problem:

Caregiver’s feelings about the problem:

Possible causes of the problem:

Goals:
1.
2.
PROBLEM DEFINITION AND FORMULATION
Remember to use simple and specific language!


What about this situation makes it a problem for you? What are the obstacles? What are the conflicts?

What are your goals? Are they realistic?
GENERATING ALTERNATIVES
Remember to use simple and specific language!

State the problem-solving goal(s) from the PDF worksheet

Generate as many alternative solutions as possible. Remember:
(1) quantity leads to quality;
(2) don't judge the solution ideas until later;
(3) think of both strategies and tactics.
Begin each contact with a review of each problem, goal(s), and planned activities identified from previous telephone contact:

**Step 1:** Caregiving problem #1

**Step 2:** Goal(s)

**Step 3:** Planned activities

Did the caregiver implement their planned activities? ____Yes  ____No
If no, what factors hindered their implementation?

**Step 4:** Evaluation:
Did their plan work? Did they weigh advantages and disadvantages?
Problem resolution? ____Yes  ____No  Emotional well-being ____Yes  ____No?
Time/Effort? ____Yes  ____No  Personal/social well-being? ____Yes  ____No
RECORD OF COPING ATTEMPTS

Description of problem situation:

Thoughts (before, during, and after the situation):

Feelings (before, during, and after the situation):

Actual coping behavior (how did you deal with it?):
Training Overview for Caregiver
Sequencing Visits, Contacts

CLUES

Training Session #1: Home Visit

• Get to know each other
• Talk about ways to solve problems you are having
• Decide on the best time for our next contact by phone
• Decide on date and time for our next home visit
Training Overview for Caregiver
Sequencing Visits, Contacts

**CLUES**

**Phone Contact #1:**

- Check in to see how you are doing
- Review the problem solving process we discussed during the home visit focusing on problem definition and possible solutions
- Confirm time for our next phone contact
Training Overview for Caregiver Sequencing Visits, Contacts

**CLUES**

**Phone Contact #2:**

- Check in to see how you are doing
- Review the problem solving process we discussed during the home visit focusing on solutions you tried and your satisfaction with the results
- Confirm time for our next home training session contact
Training Overview for Caregiver Sequencing Visits, Contacts

CLUES

Training Session #2: Home Visit

• We will walk through a problem you have had as a caregiver and discuss your thoughts and feelings about the situation
• We will apply the problem solving process to your problem
• We will review the solution worksheet to better understand the results of your problem solving
• You will be asked to think about another problem to solve using the steps we have learned, during our next phone conversation
• Confirm time for our next phone contact
Closing Remarks
Scientists: Brain injuries from war worse than thought
By Gregg Zoroya, USA TODAY

“Scientists trying to understand traumatic brain injury from bomb blasts are finding the wound more insidious than they once thought. They find that even when there are no outward signs of injury from the blast, cells deep within the brain can be altered, their metabolism changed, causing them to die, says Geoff Ling, an advance-research scientist with the Pentagon….”

20,000 vets' brain injuries not listed in Pentagon tally
By Gregg Zoroya, USA TODAY

“At least 20,000 U.S. troops who were not classified as wounded during combat in Iraq and Afghanistan have been found with signs of brain injuries, according to military and veterans records compiled by USA TODAY…..”
PTSD after TBI is rare ..... 

AND NOW....

- **37.4%** of OIF/OEF veterans with a mild TBI history also had either PTSD or depression  
  *RAND Corporation 2008*

- **42%** of OIF/OEF veterans with a mild TBI history also had PTSD symptoms  
  *Lew et al., JRRD, 2007*

- Mild traumatic brain injury occurring among soldiers deployed in Iraq is strongly associated with PTSD (43.9%) and physical health problems 3 to 4 months after the soldiers return home  
  *Hoge et al., NEJM, 2008*
Suicide Risk  JAMA August 13, 2008

• .....the suicide risk was increased for former active duty veterans … and for veterans diagnosed with a selected mental disorder.
Family Life and Suicide

ARMY SUICIDE EVENT REPORT 2007

- Failed *marital/intimate relationships* were reported for 50% (n = 55) of completed and 41% (n = 383) of attempted suicide events among Army personnel.

- Most of these failed relationships occurred close in time to the suicide behaviors. For suicide cases, 37% of the total sample had a failed intimate relationship within 30 days of the suicide.

New Demands, Impending Needs
Family Members of Veterans with Acquired TBI
God and the soldier, all men adore in time of danger and not before.

When the danger is passed and all things righted,
God is forgotten, and the soldier slighted

Francis Quarles (1592-1644)
Online Resources

http://www.braininjuryresources.org/

http://www.birf.info/

http://www.bobwoodrufffamilyfund.org/about_brain_injury.shtml

http://www.biausa.org/

http://www.avbi.org/

http://www.tbiguide.com/
Online Resources

http://www.woundedwarriorproject.org/

http://www.cdc.gov/ncipc/tbi/TBI.htm

http://www.caregiver.org/caregiver/jsp/home.jsp

http://www.nfcacares.org/

http://www.caregiver.com/

http://www.rosalynncarter.org/
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