

Health Promotion in Family Caregivers





Gayle Acton, PhD, RN



Associate Professor

**The University of Texas at Austin
School of Nursing**



Who are caregivers?

- A vast majority of caregivers are women.
- On average, caregivers are in their mid-fifties, and have an income of \$35,000.
- Seven in ten caregivers do not have a college degree.
- 96% receive no payment for caregiving.

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- **Caregiving is a full-time job even for those who are employed outside of the home.**
 - **In addition to the time spent at their job, caregivers spend an average of 40 hours a week caring for their loved one.**
 - **Caregivers who do not work outside of the home spend twice as much time, 80 hours a week, caring for their loved one.**
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Employment Status

- **About 35% of caregivers currently work outside of the home.**
- **One in five caregivers stopped working primarily to care for their loved one.**

Effect of Caregiving on Career

- **60% of caregivers have missed days at work due to their caregiving responsibilities.**
- **Caregivers have missed an average of 17 work days per year due to caregiving.**
- **More than one-third report that they have reduced their work hours, lost income, or have become less effective at work.**

Financial Aspects of Caregiving

- **Caregivers report that caregiving has affected their personal finances.**
- **Nearly a quarter report that caregiving has affected their finances greatly.**
- **The financial impact on the caregiver increases as the disease progresses.**

Financial Aspects (contd.)

- **64% are concerned about having enough money to care for their own needs as they grow older.**

Quality of Life

- **Caregivers report that caregiving has caused stress within the family**
- **Many caregivers feel they do not have enough time for themselves**
- **About 1/3 become depressed and say they don't know if they can continue caregiving**
- **Caregiving stress can worsen as patient condition worsens**

Sleep

- **Almost half of all caregivers feel that they are not getting enough sleep.**
- **Caregivers whose patients have moderate or severe conditions are more likely to report a lack of sleep than those caring for patients with a mild condition.**

Caregiver Health

- **Research findings**

Caregiver Health

Collectively, research shows caregivers:

- **Have more sleep problems**
- **Lowered cellular immunity**
- **Elevated blood pressure responses**
- **Higher levels of depression**
- **Poorer physical health**
- **More illness-related symptoms**

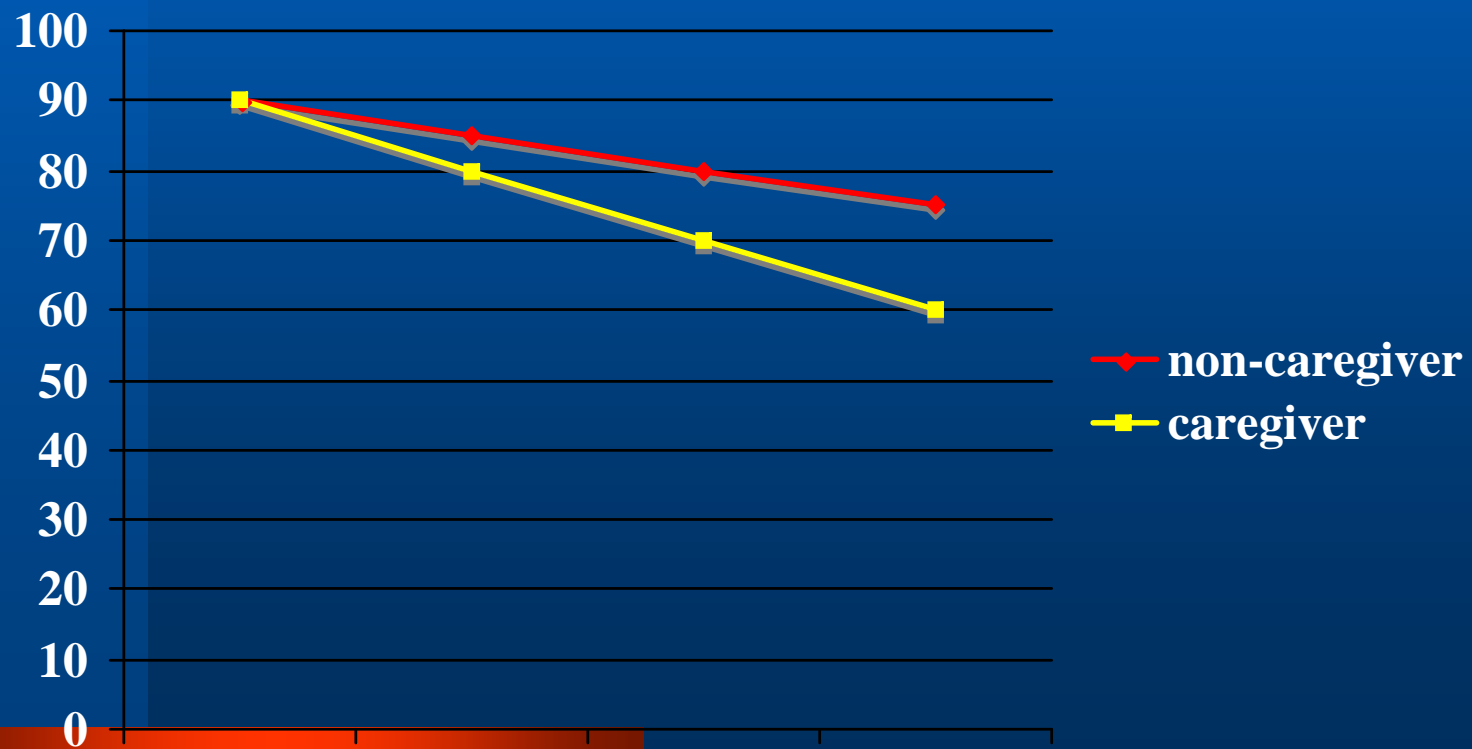
Caregiver Mortality

- Caregivers who report increased strain due to caregiving duties, have mortality risks 63% higher than non-caregivers
- Schulz & Beach (1999). *JAMA*

Acton Meta-Analysis

- Reviewed 73 studies from 1979-2000 testing interventions to reduce the burden of caregiving
- Only 2 of the studies reported physical health outcomes
 - sleep quality
 - number of doctor visits

Immune Function of Caregivers



Empiric Evidence of Immune Function Changes

Chronic Stress in Caregivers of Dementia Patients is Associated with Reduced Lymphocyte Sensitivity to Glucocorticoids


Bauer, Vedhara, Perks, Wilcock, Lightman, & Shanks. (2000)
Journal of Neuroimmunology 103(1), 84-92

Study


Compared demographically matched caregivers and non-caregivers on multiple immune function indicators

Findings

Caregivers reported greater distress and a decreased immune function response as compared to non-caregivers.



The authors also tested whether or not chronic stress leads to an overall down-regulation of the immune system and they concluded that, consistent with prior research, chronic stress is associated with global, and perhaps permanent changes in immune function.



Dr. Sharon Lewis

**Professor, Schools of Nursing and Medicine
Castella Distinguished Professor of Nursing
Clinical Nurse Scientist, GRECC, South
Texas VA, University of Texas Health
Sciences Center, San Antonio, Texas**

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Study Purpose

Compare the effect of relaxation therapy for male and female spousal caregivers of Alzheimer's patients

Variables

- **Quality of life**
- **Emotional distress**
- **Bioinstrumentation monitoring**
- **Natural killer cell number & function**

Spouse Caregivers

- 16 males
- 45 females
- Average age = 70

Relaxation Therapy

- Professionally made 30-minute relaxation therapy tape used for eight weeks
- Biofeedback training

Results

- **Men had significantly lower levels of depression, stress, anxiety, and anger-hostility, and subjective burden than women.**

Results

- **Men had a significantly higher percentage of natural killer cells (NK) than women.**
- **Women also had significantly lower NK cells than non-caregivers**

Conclusions

- **Study results suggest that there may be gender differences in the effect of chronic stress on the immune system.**

Health Practices of Caregivers

- **Research shows that health promotion practices differ between caregivers and non-caregivers**

Acton Study

- **Study purpose:**
- **To compare health practices of family caregivers with demographically-matched non-caregivers**

Acton (2002). Western Journal of Nursing Research

Sample

- 46 family caregivers
- 50 non-caregivers
- Matched on: age, gender, ethnicity, education, and income


Variables

- **Importance of health promotion**
- **Barriers to health promotion**
- **Self-efficacy for health promotion**
- **Physical activity**
- **Nutrition**
- **Stress management**
- **Interpersonal relationships**
- **Spirituality**

Findings

Family caregivers scored significantly lower on:

- Importance of health promotion
- Self-efficacy for health promotion
- Physical activity
- Quality of interpersonal relationships
- Stress management
- Sleep quality and numbers of hours
- Spiritual growth

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- **Caregivers scored significantly higher on:**
 - **Barriers to health promotion**



● **There were no differences in:**

- Nutrition

- Numbers of medications

Stress Mediation

- Does practicing health promoting behaviors, help mediate (lessen) the negative effect of stress on well-being

Test of Stress Mediation

Variable	<i>r</i>	<i>R</i>	<i>F</i>	<i>p</i>	<i>FChg</i>	<i>p</i>
Equation 1 ^a						
Stress	.51	.26	15.04	.000	15.04	.000
HPSCB	.80	.64	36.47	.000	43.16	.000
Equation 2 ^b						
HPSCB	.79	.63	72.97	.000	72.97	.000
Stress	.80	.64	36.47	.000	.62	.436



Findings

- **The negative effect of stress on well-being was reduced to non-significant levels**
- **Thus, those caregivers who engaged in more health promoting behaviors experienced less negative effect of stress on well-being**

Divergent Findings

- A study of preventive health practices by Matthews and colleagues showed (n = 319) that caregivers do engage in similar health promoting activities as non-caregivers.

Matthews, Dunbar-Jacob, Sereika, Schulz, & McDowell (2004).
Journal of Gerontological Nursing

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- However, both past and current health promotion practices were measured and the sample scored lower on *current* than past health promotion activities
 - This indicates that engagement in health promotion had decreased
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Health Promotion Interventions for Family Caregivers

Acton Focus Group Study

- **Needed to learn caregivers' perceptions of health promotion needs**

Purpose

- **The purpose of the study was to use focus group research methods to gain insights into how family caregivers take care of their health and what they need to care for themselves**

Focus Group Questions

- How do you take care of your health?
- What keeps you from taking care of your health?
- What helps you take care of your health?
- What do you need to help you take care of your health?

Sample

- **N = 10 (7 females, 3 males)**
- **Mean age = 60**

Themes

- Things other people tell me
- I come second
- Not enough time
- Support and resources

Things Other People Tell Me

- Group reported that they were repeatedly told to take care of themselves

“My sister always tells me to take care of myself, but she just doesn’t understand”

I Come Second

- **Group reported that they were too busy to take care of themselves**

“I just can't think of myself right now, I have to think of my husband first”

Not Enough Time

- **Group said that they knew they should take better care of themselves, but they did not have enough time**

“I’d like to exercise and lose weight, but there is no time”

Support and Resources

- **Group reported that they would like to take better care of themselves, but they needed respite, support from other family members, information and ideas**

“I just don’t have enough money to go to the doctor, his care is so expensive”

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- **The group also said that they would love to have a mentor to guide them through the tough times**

Self-Care Interventions

- **Teel and Leenerts piloted a series of telephone-based sessions (healthy habits, self-esteem, focus on positive, role overload, communication, and meaning) between APNs and caregivers (n = 6)**
- **Findings were geared toward delivery and receipt, rather than outcomes**

Lewis R01

- Relaxation therapy intervention has been expanded in a competing continuation R01, to include 2 classes on health promotion

Intervention Content Expanded

- **Stress and relaxation**
- **Grief, loss and depression**
- **Coping**
- **Challenging behaviors**
- **Positive thinking**
- **Healthy living**
- **Becoming a healthy caregiver**

Outcomes for Health Behaviors

- **Health Promoting Lifestyle Profile II**

- Walker, Secrist, & Pender

Physical activity

Nutrition

Stress

Health responsibility

Spiritual growth

Interpersonal relationships

N=27 (pre and post tests)

Data Analysis

- **Simple paired t-tests**

Findings

- Means on the posttests were significantly higher than pretests on **physical activity** and **nutrition**
- Means on the posttests were significantly lower than the pretests on **stress**

Exercise Programs

- In 1997, King and Brassington demonstrated that family caregivers would participate in a home-based, 4-month, moderate-intensity physical activity program
- Findings showed a decrease in ambulatory blood pressure and anger expression
- King & Brassington (1997). *Annals of Behavioral Medicine*



Exercise Program

- In 2002, Castro and colleagues assigned 100 female caregivers to either a 12-month, home-based, exercise program or attention control condition (telephone-based nutrition education program).

Castro, Wilcox, O'Sullivan, Baumann, & King (2002). *Psychosomatic Medicine*

Findings

- **Exercise participation rate was 74% (3 exercise sessions per week)**
- **Exercise participants showed increased knowledge of the benefits of exercise**
- **Exercise participants showed increased motivational readiness for exercise**

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- **Both groups improved significantly in perceived stress, burden, and depression**
 - **Lower baseline depression scores were associated with better exercise adherence**
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Health Promotion Intervention Development

- **There are few, if any, comprehensive health promotion interventions for family caregivers**

Hallmarks

- **Interventions for family caregivers must be individualized, to some degree**
- **Interventions must meet the caregivers' needs**

Hallmarks

- Intervention programs must address issues related to caregiving duties - **PRIOR** to interventions aimed at health promotion

Hallmarks


- **Multicomponent intervention programs have been shown by multiple meta-analytic studies to be most effective in reducing stress and burden and increasing caregiving skills**

Hallmarks


- **Thus, interventions aimed at health promotion must also be multicomponent in nature**



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- **For example,**

Intervention programs should first assess care receiver problematic behavior and address any behavior problems prior to instituting a health promotion intervention



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- **Such an intervention strategy must be individualized because each caregiving situation is different**

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- **Caregivers are usually very reluctant to think about themselves when they are struggling with caregiver duties**

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- **But, if you can show caregivers that you are interested in helping them, willing and able to help them with their caregiving duties, then they may be able to engage in a program to learn to better care for themselves**
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My Research in Health Promotion

- With funding from two NIH-funded centers of excellence at the University of Texas at Austin School of Nursing,
- **The Center for Health Promotion**
- **Southwest Partnership Center**
- We are developing a comprehensive, multicomponent health promotion intervention program for caregivers

Program Components

- **Pre-intervention assessment of care receiver problematic behaviors and caregiver coping skills**
- **Individualized intervention to address behavior problems and coping**

Program Components

- **Stress management**
- **Nutrition**
- **Physical activity**
- **Sleep**
- **Healthy living**

Strategies

- **Didactic presentations**
- **Role-playing**
- **Demonstrations**
- **Discussions**
- **Tailoring**
- **Goal attainment**
- **Sharing experiences**

Progress

- **We are currently testing the format, delivery, timing, and structure of the program**
- **Preliminary results show that caregivers are very interested in the program, they come to the sessions, they engage and participate and express appreciation for the information**

Outcomes Testing

- **Presently, we do not have enough subjects to test the outcomes (sleep, stress, nutrition, physical activity) for significance, but the numbers are trending in the right direction**



Hispanic Family Caregivers

- **Funding from the Southwest Partnership Center has allowed us to work with a consultant to adapt the intervention for Hispanic Family caregivers**

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- **Currently we are preparing to test the intervention with English-speaking Hispanic samples**

Spanish Translation

- **We have also translated the intervention to Spanish and with funding from the Center for Health Promotion Research, will begin back translation, validation, and evaluation of the intervention in Spanish-speaking Hispanic samples this fall**

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- **Ultimately, we plan to conduct a randomized clinical trial in a multi-ethnic sample of family caregivers**
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**Thank you very much for
your time and attention!**



