The Parent Care Readiness Program: Stateofsciencecaregiving-Geriatrics.com

Proactive Preparation for Late Life: A Task Oriented Intervention for Adult Children and Their Aging Parents

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Support

- John A. Hartford Foundation Geriatric Faculty Scholars Program
- CMHA, The University of Alabama
- Department of Defense, Health Promotion Command
- The University of Alabama, Research Advisory Committee (x2)
- NIH STTR to be submitted 1 Aug 06
Elder/Parent Care Defined

Parent care refers to the informal, unpaid care provided to an elderly parent who has some degree of physical, mental, emotional, or economic impairment that limits his/her independence and necessitates ongoing assistance of some form.
Demographics

- Rise in life expectancy
- US has highest rate of employed mothers who work fulltime
- Primary caregivers are adult children
- Striking increase in the # of Primary CGs carrying an increasing burden... working alone, w/o secondary caregiver help (34%-53%) Bean poled generational structure... “4” generational families have become the norm
- Population of 65 and older expected to double by 2030
- Over 65 = 18 yrs and younger
- Fertility rates declined; fewer CGs, smaller nuclear families
- More women entering the formal work force; fewer primary caregivers
< Employed caregivers >
#1 Human Resource Problem of the 21st Century

The U.S. Department of Health and Human Services reports the following about employed caregivers:

- One half of all caregivers are employed (NFCA, 2001).
- 20-50% of workers are dealing with a caregiving situation (Family Care America, 2000).
- Men and women report needing to modify their work schedules and that they miss some work because of caregiving responsibilities (MetLife, 2003).
- The total number of employed caregivers in the US is expected to be over 15 million, approximately 1 in 10 employed workers (National Alliance for Caregiving, 2003).
- Caregivers have more stress-related illnesses, use company health care plans more frequently, experience decreased work productivity, and have higher rates of absenteeism & job turnover; and loose approximately 5 – 12 days of work annually with an estimated cost of $400,000 per 5,000 workers, and 73 % of early departures and later arrivals (US Department of Health & Human Services, 2006).
#1 Human Resource Problem of the 21st Century:

- Employed caregivers cost the US employers $29 billion a year, which translates to an annual cost of $1,142 per employee (absenteeism, partial absenteeism, coming in late, and leaving early) (MetLife Juggling Act Study, 1999).

- Caregivers for the elderly describe lower work performance, reduction in overall physical well-being, and reduced levels of vocational and home satisfaction (Kossek, Colquitt, and Noe, 2001).

- The majority (70%) of employers believe that personnel problems associated with caregiving have increased over the past 10 years, and 92% expect personnel problems associated with distal and proximal care giving to increase (Family Care America, 2001).

- Employee based eldercare programs have a positive payback to the employer of 2.5 to 5 times the cost (The MetLife Study of Sons at Work, 2003).

- 13% of the labor force report having elderly parent care responsibilities & 40% expect to provide elder care in the next five years.

- New stage of life has been added > an average of 19 years added to life expectancy this past century.
Other Challenges...Problems....

- Complicated long term care industry
- Caregiving response often more reactive
- Emphasis on pathological...not the successful or normal
- Evidence-based screening of information needed
- Translation by experts for lay providers-care recipients
- Family - individual, community-based tailoring needed
- Information overload > Smorgasbord of resources
Table 1: Search engine results on distance caregiving

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The Internet

- Caregivers turn first to the Internet for health information (29%), followed by consultation with doctors (28%), family or friends (15%), and other health professionals (10%).
- Of those who use the Internet, nearly 90% search for information about the care recipient's condition or treatment.
- More than half seek information about services available for care recipients.
- 40% look for support or advice from other caregivers.
- More than 33% of respondents indicate that they need help with information about balancing work and caregiving responsibilities. (NAC & AARP, 2004)
What employed CGs need:

- Easy access to resources and services
- Assistance with the management and coordination of care and services
- Ease of time restraints and stress relief
- Respite from their responsibilities
- Consultation and referral
- Education and support
- Flexible hours of telecommuting
- Financial assistance.
Positive and Negative Consequences Associated with *Parent Care*

**Benefits of parent care**
- development of closer kinship ties;
- the achievement of intrinsic goals like the mastering of caregiving tasks;
- the fulfillment of the commitment to "honor one's mother and father"
  - (e.g., Kramer, 1997)

**Adverse consequences**
- depression
- stress
- work spillover
- role strain
- burden
  - (e.g., Thompson, Futterman, Gallagher-Thompson, Rose, & Lovett, 1993)
Rewards of Caregiving

- Satisfaction in fulfilling the caregiving role
- Closer relationships with friends & family
- Political advocacy
- Greater personal insight
- Feelings of personal growth
- A renewed sense of purpose in life

(Harris, 2002; Kramer, 1997; Lawton, Moss, LKleban, Glickman, & Rovine, 1991; Miller, 1989; Motenko, 1989; & Worcester & Quayhagen, 1983)
Intergenerational Planning Needed

- Life course perspective > Parent care is a normal, predictable, midlife developmental task
- Proactive, intergenerational planning before parent care needs arise can promote successful aging, reduce worry, and ease the transition of adult children into parent care roles
- Parker, et al. (2003) Geriatric Care Management
A model of successful caregiving: Developing and sustaining a parent care plan

**Adult Child**

**Parent**

*Parent & adult child life course trajectories*

**Comprehensive Parent Care Plan**

- Medical
- Legal Financial Insurance
- Family Social
- Spiritual Emotional

Tasks

Updated across the life course
A model of successful caregiving: Developing and sustaining a parent care plan

Achieving PCP goals requires the sustained, cooperative efforts of the parent, their spouse or significant other, their adult child/children, and a number of trusted professional advisors.

A Parent Care Plan must be updated across the life course.

Individual Parent Care tasks are often interrelated.

**Necessary Steps:**

- Acknowledgment of the developmental task of parent care.
- Completion of initial assessment with health, legal, financial, and spiritual advisors.
- Identification of high priority tasks.
- Initiation and completion of all required tasks.
- Ongoing reassessment and task completion as conditions change.
A model of successful caregiving: Developing and sustaining a parent care plan

Developing & sustaining a comprehensive plan requires the collaborative efforts of many advisors and the continued support & cooperation of the family and the parent.
Since you've decided to start using condoms every time you have sex, it's important to set a start date.
Results of the Parent Care Assessment Help Identify Informational Needs and Tasks: Intervention Provides Impetus for Action and Tailored Informational Support

Tailored Intervention: Medical Messages

Tailored Intervention: Legal & Financial Messages

Tailored Intervention: Social-Familial Support

Tailored Intervention: Spiritual Messages

Tailored Intervention: Other Messages

Assessment data processed

Clinical Intervention

Since you’ve decided to start using condoms every time you have sex, it’s important to set a start date.
The Parent Care Readiness Program:
Stateofsciencecaregiving-Geriatrics.com

Web-based program
- Internet access (anywhere)
- Share information
- Program and Links updated
- Data secure
Since you've decided to start using condoms every time you have sex, it's important to set a start date.

IIS / ASP.NET

Provides web pages and handles user requests

SQL

Provides secure data and scoring of assessment

Reporting Services

Provides customized reports
Web

- Demo Page
- Registration Page
- Login Page
- About Us Page
- Assessment > Tailored Intervention
- Customized User Page
Assessment Page

- Allows you to start @ any section
- Links to information to help you complete the assessment
- Ability to complete at your own pace
- Previous answer will re-populate (i.e., appear)
Customized User Page

- Individualized report
- Specific to geographic location
- Customized links
- Print or export report (PDF, TIFF, or EXCEL format)
- Modify assessment and reproduce report
Parent Care Readiness Program

- Assessment > Tailored Intervention

- Tools:
  - Parent Care Readiness Assessment
    - 50 task items validated by human service professionals
    - Four domains of Parent Care Tasks

- Methods:
  - Age - Graded Workshops <> Program access as part of an organizational benefit package
    - Faith based
    - Military
    - Corporate
    - Other organizations
  - Task-related State of Science Information
    - CD ROM
    - Web site
Parent Care Readiness Assessment

- Rating of importance of each parent care task
- Completed or not?
- Satisfaction with completed tasks
- Time priority on uncompleted tasks
- Algorithms developed in keeping with Trans-theoretical Model of Change
Staging Items and Algorithm: Parent Care Readiness Assessment

1. How important is the task? 
   1. If NOT IMPORTANT, 1-3
   2. If VERY IMPORTANT

2. Has the task been completed? 
   1. If NO
   2. If YES

3. What is the level of satisfaction with the completed task? 
   1. LEVEL OF SATISFACTION 4-5
   2. LEVEL OF SATISFACTION 1-3

4. Timing:Plans to complete the task in: 
   1. 1-3 months
   2. 3+ Months

Has the task been completed? If YES with high level of satisfaction (4-5)
Stage as MAINTENANCE

Stage as important task and progress to plans to complete the task

STAGES OF CHANGE

PARENT CARE PLAN
ACTION
PREPARATION
CONTEMPLATION
PRE-CONTEMPLATION
Intervention Methods

- Age-graded interventions with high risk groups within organizations
- Group workshops/educational sessions tailored for participants
  - Focus on tasks most salient to participants in each of the domains
  - Salience defined as tasks that are “important but not completed” or “completed but not satisfied”
  - Movie clips related to specific tasks
- Individual activity with Parent Care CD-ROM and web links
Research to Date

- Total of 10 professional journal publications, 3 chapters, and 12 refereed presentations
- Standardization Process of the Parent Care Readiness Assessment
  - Interdisciplinary input in development (Parker et al, 2002, GSA)
  » Largest Geriatric Care Management Association
  » John A. Hartford Scholars
  » Elder Law Practitioners
  » Geriatric Health Care professionals
Research to Date

- Clinical Trial > US Air War College (Parker et al, 2002, Geriatric Care Management; Parker et al, 2003, GSA);

- Feasibility study > 2 large Faith-based communities (Myers, Klemmack, & Parker, 2004, J. Family Ministry)

- Parent - Adult Child Congruence Baylor University, Waco Study (Myers, et al. Roff et al, 2004)
Findings from US Army War College: Long distance care giving study

**Purpose(s):**
- Are certain officers at greater risk because of care giving issues?
- Does the existence of a care giving plan reduce anxiety/worry? 
  *(Parker et al., 2003 Military Psychology)*

**Presence of a satisfactory plan significantly reduces worry/anxiety even when all relevant variables are controlled**

**At greater risk:**
- Females
- Perfectionists
- Only child / no siblings
- Prior care giving experience
Completed parent-care tasks > measures of parent care self-efficacy

<table>
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<tr>
<th>Domain</th>
<th>Confidence &amp; # tasks completed</th>
<th>Confidence &amp; # of tasks completed with satisfaction</th>
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<td>Spiritual-Emotional</td>
<td>.31*</td>
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*p<.05
Parker et al., 2003, GSA
Initial Clinical Trial Outcomes: US Air War College

Conducted clinical trial to determine if participants in the Parent Care Intervention Program complete more parent care tasks than do members of a control group.

14/22 responded at point two (3 months after assessment/intervention), 7/14 had completed one or more parent care tasks.

One (1/24) member of the CG completed 6 parent care tasks based on his parent care assessment.

War with Iraq was declared within a few weeks after the Clinical trial was initiated (pending submission to Practice Concepts, the Gerontologist).
Examples of Parent Care Tasks & State of Science & Practice Information by Domain

Taken from military & faith-based Interventions
US Air War College
First Presbyterian studies
Included with Every Assessment

National Association of Elder Law Attorneys

Locate a Geriatric Physician

National Association of Professional Geriatric Care Managers

AARP in Your State: Alabama

Alabama Department of Senior Services
Examples of Major Task Categories of Parent Care

- >Social/Familial
- Medical
- Legal/Financial/Insurance
- Spiritual/Emotional
Family-Social

- Develop a plan that would allow your parent to remain safely in her/his home as long as possible. Evaluate the safety of your parent's current living situation (possibility of falls, isolation, scams). Employ strategies (e.g., panic-button service) and home enhancements to help prevent falls (e.g., take less than five medications, balance-related exercise, grab bars, etc.).
Family-Social Task 3

Safety for Older Consumers Home Safety Checklist:
http://www.cpsc.gov/cpscpypub/pubs/701.html

National driver’s safety resource:
http://www.aarp.org/families/driver_safety/

Local driver’s safety resource:
http://www.eyes.uab.edu/driving/
State of Science & Practice Information  >  Adult Residence Options

- Independent living/senior residential communities
- Assisted living
- Homes for the aged
- Adult foster care

- Continuing care retirement communities
- Nursing homes
- Special dementia care programs
Care IN the Home

- Home health services
- Home nursing care
- Personal care services
- Homemaker and home chore services
- Home and community-based waiver services
- Pharmaceutical and infusion therapy companies
- Home repair, maintenance, and security
- Friendly visitor program
- Telephone reassurance program
- Hospice
- Home delivered Meals
- Respite care
- Durable medical equipment and supply companies
State of Science & Practice Information

Adult Care *Outside the Home*

- Adult day care
- Respite care
- Congregate meals
- Transportation service
- Community-based services
State of Science & Practice Information
Assisting your parents with the hired caregiver

✦ **Types:**
  - Homemaker care
  - Home health care aide
  - Skilled care
    - Geriatric care managers
    - RNs, LPNs
    - Occupational therapists (OT)
    - Physical therapists (PT)
    - Speech language pathologists
    - Registered dieticians (RD)
    - Respiratory therapists (RT)
Major Task Categories of Parent Care

• Social/Familial
• Medical
• Legal/Financial/Insurance
• Spiritual/Emotional
Medical Task 1

Understand what a geriatric assessment is, and discuss and determine with your parent how involved or knowledgeable he or she would like you to be about his/her functional status, health condition, and overall medical profile.
Medical Task 1

- Geriatric physician national search: [http://caregivers-usa.org/prof/geriatric_physicians.html](http://caregivers-usa.org/prof/geriatric_physicians.html)


Good docs are careful to observe two principles of good geriatric care:

- Avoid dismissing treatable pathology as concomitant of old age*
- Avoid treating natural aging processes as if they were diseases *

* > iatrogenic effects

Medical vs. Social Interventions

Geriatric Care = Team Care
Geriatric Assessment:

- Social & Medical History
- Physical Exam:
  - vital signs
  - behavior & appearance
  - sensory (ears/eyes)
  - dental
  - skin
  - chest/cardiovascular
  - abdomen/genitourinary
  - extremities
  - neurological
- Laboratory assessment
- Mental status exam
- Spirituality assessment
- Environmental assessment
Geriatric Assessment:

- **Functional assessment**
  - ADLs (e.g.):
    - feeding
    - dressing
    - ambulation
    - toileting
    - bathing
    - continence
    - grooming
    - communication

- **IADLs (e.g.)**
  - reading
  - writing
  - cooking, cleaning, shopping, climbing stairs, using telephone, managing medication, managing money
Geriatric Problems: Series of I’s

- Immobility
- Instability
- Incontinence
- Intellectual impairment
- Impairment of vision and hearing
- Irritable Colon

- Inanition (malnutrition)
- Impecuniosity (not enough $)
- Iatrogenesis
- Insomnia
- Immune deficiency
- Impotence
- Isolation (depression)

Source: Kane, Ouslander, & Abrass (1996)
Major Task Categories of Parent Care

• Social/Familial
• Medical
• Legal/Financial/Insurance
• Spiritual/Emotional
Task 3: Legal-Financial-Insurance

Determine the full extent of your parent's health/life insurance coverage, social security, military as well as Medicare and Medicaid entitlements.
Legal-Financial-Insurance Task 3

- **BenefitsCheckUp - NCOA's Online Screening Service:** [http://www.benefitscheckup.org/](http://www.benefitscheckup.org/)

- **UA Elder Law center:** [http://www.uaelderlaw.org/links.html](http://www.uaelderlaw.org/links.html)

- **Eligible veteran dependents and survivors:** [http://members.aol.com/forvets/dd214.htm](http://members.aol.com/forvets/dd214.htm)

- **Long term care scenarios:** [http://www.caremanager.org/](http://www.caremanager.org/)
Long term Care Insurance

- Be sure the policy approximates the difference between your parent’s daily income and the daily cost of a NH.
- Coverage should include all levels of care from custodial to skilled, as well as care for forms of dementia to include Alzheimer’s Disease.
- It should not require your parent to be hospitalized before becoming eligible for benefits.
- Should include inflation protection and be guaranteed renewable (company cannot cancel the policy).
- Your parent will have to undergo a rigorous physical and mental evaluation... many are turned down.
Long term Care Insurance

- LTC Insurance in relative infancy; learning curve still in place setting benefits/premiums
- Most options cover various community-based options (NHs; home health; adult day care; respite-care services)
- Can help preserve income and savings
- Costs assumed by individual
- Generally not available once a disabling long-term illness has struck
- Premiums very expensive for people older than 70 years of age
Major Task Categories of Parent Care

- Social/Familial
- Medical
- Legal/Financial/Insurance
- Spiritual/Emotional
Spiritual-Emotional Task 3

- Secure a video or oral history from your parent.
Spiritual-Emotional Task 3

Oral History Questionnaire
http://www.ec-online.net/Knowledge/articles/oralhx.htm

Legacy Project
http://www.legacyproject.org/index.html

American Family Interactive Tree
http://www.pbs.org/americanfamily/tree/
Complete Oral or Written History & facilitate a life review

- A life review...
- Preserves the past & gives a personal legacy to the future
- Preparing a video or an oral history helps conserve life stories whether they are everyday experiences or special events
- Getting to know a loved one through reminiscing can help families discover many positive qualities about an older relative
- Enhances self-understanding and provides a source of personal continuity
- Aids in achieving a sense of meaning to one’s...
- Help is readily available
End of Life Issues

- Involves legal and spiritual/emotional factors
- It may be that discussions about choice(s) and late life decision making distract us from the reality of death… dying is simply not a choice."
- Faith often helps a person develop a perspective on life and death!
Why this category?

- Consistent with teaching to “honor father and mother”
- Americans’ beliefs in God and trust in clergy
- Empirical findings of associations between spirituality & successful aging & health good health
- Life course context for family & support resources
State of Science & Practice Information

Successful Aging

• Avoiding Disease and Disability
• Maximizing Cognitive (Intellectual) and Physical Fitness
• Active Engagement with Life
• Positive Spiritual Growth and Development

Shared spirituality will help with the tasks ahead
Spirituality has been found clinically relevant (positively associated) in over 850 studies with:
• Illness Prevention
• Coping with Illness
• Recovery from Surgery
• Improved Treatment Outcomes
  » (Koenig, et al., 1999; Crowther, Parker, Koenig, Larimore, & Achenbaum, 2002)
Faith-based organizations are excellent sponsors of intergenerational parent care planning education and activities.

Future Development

Submit to Practice Concepts, The Gerontologist

Develop CE for NASW & other professional organizations

Further evaluate

• Submit two Fast Track STTRs:
  – NIA
  – DOD

• Purpose:
  – Expand clinical trials
  – Revise and update Program
  – Provide Web Parent Care Readiness Intervention Program to American families, corporations, & other organizations via aged-graded interventions
Extramural Programs
Reserved for Small Business

SMALL BUSINESS INNOVATION RESEARCH (SBIR) PROGRAM

SMALL BUSINESS TECHNOLOGY TRANSFER (STTR) PROGRAM
SBIR and STTR
Program Descriptions

☞ SBIR:  Set-aside program for small business concerns to engage in federal R&D -- with potential for commercialization.

☞ STTR:  Set-aside program to facilitate cooperative R&D between small business concerns and U.S. research institutions -- with potential for commercialization.
### Table 5. Three Rounds of Interdisciplinary Review of the Parent Care Readiness Program

<table>
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<tr>
<th>Round 1: Task reviews</th>
<th>Round 2: Domain Reviews</th>
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<tr>
<td>Melanie Allen, MSW</td>
<td>Medical&gt; Richard Allman, MD, MPH</td>
<td>Russell Morgan, Ph.D.</td>
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<tr>
<td>Rebecca Allen, Ph.D.</td>
<td>Legal&gt; Daniel Marson, PhD, JD</td>
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<td>Lou Burgio, Ph.D.</td>
<td>Spiritual&gt; Harold Koenig, MD, MPH</td>
<td>Linda Harootyan, MSW</td>
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<td>Lynn Campasi, JD</td>
<td>Familial&gt; Ronald Toseland, Ph.D.</td>
<td>Judson Hennington, JD</td>
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<td>Sheryl Cook, BS, CGRC</td>
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<td>Martha Crowther, Ph.D., MPH</td>
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<td>Claudia Fine, MSW, MPH, CMC</td>
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<td>Barbara A. Soniat, LICSW, Ph.D.</td>
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<td>Rhonda Talley, Ph.D.</td>
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<td>Daniel Winstead, MD</td>
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Phase I Research Aims:

1) To use the expertise of subject matter experts (practice & research) in the field of aging to review and revise the current version of Parker & Associates' Parent Care Readiness program;

2) To update and further automate state and national elder care resource directories so that end-users of the Parent Care Readiness materials can quickly locate local and regional resources to help them in their elder care activities;

3) To incorporate the changes resulting from Aim 1 and 2 activities into the current StateofScienceCaregiving-Geriatrics.com web site in preparation for evaluation through focus groups and multi-site clinical trials to occur during Phase II of this STTR, and ultimately for the establishment of a national web site in Phase III.
PCR Program

Phase II Research Aims:

- Conduct a multi-site clinical trial:
  - (1) PCR Assessment only (no print out) (control),
  - (2) PCR Computer Program report only (includes the hardcopy of the results of the PCR Assessment and tailored intervention report), and
  - (3) PCR Computer Program (PCR Assessment and tailored report), workshop, and follow-up consultation (Figure 2, Research Design & Analysis) to determine if participants in the Parent Care Readiness Program, when compared to members of a control group.
Parent Care Readiness Intervention Program

Phase III Aims:

- Establish a national web site in with a commercialization partner.
- Further market and improve the evidence-based and user friendly quality of the Parent Care Readiness Intervention Program.
WEBS:

www http://.stateofsciencecaeregiving-Geriatrics.com

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