Dilemmas for Supporting Caregivers

- Caregivers don’t know they are caregivers
- Caregivers seek help too late
- Caregivers will not use services when we believe they could benefit from them
- We frequently cannot demonstrate that support services make a difference

Diversity among Caregivers

- Familial relationship (spouse, child)
- Ethnicity cultural values & beliefs
- Condition or functional level of the care receiver

Diversity

- Resources
  - Social support
  - Formal supports
  - Physical and mental health
  - Financial
- Other obligations
  - Employment
  - Family obligations
Diversity in Experience

- Comfort level with role
- Relationship between CG & CR
- Overload or interference with life
- Anxiety or stress
- Depression
- Positive feelings

Past Research Findings

- Support programs most effective for reducing burden when appropriately “timed and dose”
- Multiple-component, comprehensive support services have had most impact.

Knowledge Gaps & Implications

- Lack of information for targeting services
- Current practice uses “shot gun” approach
  - Services go unused or are used too late
  - Efficient use of resources requires effective allocation of support services

Tool kit limited

Shot-Gun Approach: Case Example of Respite Use

- Research findings of caregivers offered free or low-cost respite
  - 1/3 never used it
  - 1/3 used it for less than 2 months
  - 1/3 used it from 9 months to 2 years

Preferences (Values)  Risks (Needs)
Interpretation
Preference
Risk
Informed Choice

What would a good tailor do?

Measure

Explore Preferences

Construct a pattern

Consult with customer
Sew the Dress

What would a good tailor do?

- Measure (Assess)
  - size
  - Preferences
- Draw a Design
- Consult with Customer
- Sew (Create a care plan)
- Adjust/fit (Follow-up)

Adjust the Fit

How Will We Be Effective?

- Right diagnosis (Identify the needs)
- Appropriate goal (Cure or symptom?)
- The right medicine (Correct service)
- The right dosage (Sufficient quantity)
- At the right time (Prevention not cure)
- Increase Compliance (Take the medicine)

Analogy to Medicine

- Identify caregivers’ needs
- Understand goals for intervention
- Match services with goals
- Appropriate quantity
- At the correct time
- Increase compliance

Risks of Not Tailoring

- Family Caregivers
  - Depression
  - Stress
  - Poor health
- Care Recipients
  - Unmet needs
  - Poor quality of care
  - Inappropriate placement

Foster Informed Choice

- Provide relevant information
  - Gather information
  - Interpret information
- Provide relevant options
  - Preferences (it's lens)
  - Available
  - Eligible
Vision for TCARE®

- Facilitate collaboration between care managers and family caregivers to:
  - Determine needs & preferences through an assessment process
  - Strategically match community services to meet the identified needs
  - Make informed choices about support services

1. What is TCARE®?

TCARE®?

- Systematic approach to serving family caregivers
- Evidence-based process:
  - Grounded in the Caregiver Identity Theory
  - Reflects current knowledge of research about caregiver interventions
  - Seeks to ensure quality and equality

Tailored Caregiver Assessment and Referral Process

- An assessment tool to assess caregiver’s needs
- An assessment process that provides guidance for
  - Understanding caregivers needs
  - Strategically selecting and recommending services
  - Consulting with caregiver’s to give them the opportunity for informed choice
  - Creating a care plan that caregivers will embrace and follow
- A process that requires follow-up because caregiving is understood to be a process of change

Caregiver Identity Change Theory

Identity Discrepancy
Caregivers Experience Distress

- When their behavior doesn’t match their personal rules
- “It’s not what you are doing - It’s how you feel about it”

2. How was TCARE® developed?

Characteristics of a Useful Assessment Tool

- Captures the full range of differences among family caregivers
- Sensitive to change
- Easy to use
- Understandable and transparent
- Instructive
  - Care manager knows how to use the information to guide practice

Series of Studies and Demonstrations

- Literature reviews & synthesis of findings
- Focus groups to share theory
  - Caregivers
  - Care Managers
- Measurement development
- Iterative development of protocol and tools
- Testing of protocol and tools
- Randomized studies
League of Experienced Family Caregivers (LEFC)

Seeking the Wisdom of Family Caregivers

www.familycaregivers.uwm.edu

Collaboration & Partnerships

• Florida, Georgia, Michigan, Wisconsin, Washington, Minnesota
• Wide range of agencies
  – Area Agencies on Aging
  – Home Health Agencies
  – Chapters of the Alzheimer’s Association
  – ADDGS – Demonstration projects
  – Aging and Disability Resource Centers
  – Private Care Managers

3. The TCARE® Process

What does TCARE® Screen do?

• Checks temperature
  🥵
• Determines whether
  – caregiver could benefit from a more in-depth assessment

Six Steps & Six Tools

Tools for Implementation

1. Caregiver Assessment Form
2. Assessment Summary Sheet
3. Service Selection Maps (decision algorithms)
5. Care Plan Consultation Worksheet
6. Care Plan
TCARE® Helps Identify

- Presence of depression
- Types and levels of stress
- Appropriate goals for supporting caregivers
- Strategies to meet goals
- Array of services consistent with goals and strategies

TCARE® is a Teaching Process

- Assessment is not enough – this is about caregiver consultation
- TCARE® values & supports caregivers’ choice (Care Plan Options)
- TCARE® values “good care management skills” –
  - It is an aid not a substitute
- Goal is to facilitate self management by caregivers
  - Assessing strengths and needs (six types of caregivers)
  - Linking with services
- More time spent up front – less time overall
  - Prevention, not Crisis

Preliminary Findings

4. Benefits of using TCARE®

- Caregivers
  - Lower levels of identity discrepancy*
  - Lower levels of stress burden*
  - Lower levels of depression*
  - Lower levels of relationship burden
  - Higher levels of uplifts
  - * Statistically significant at p<.05

Benefits of TCARE®

- Standardized Assessment
  - Guarantees equal opportunity for caregivers to obtain help
  - Not dependent on individual care managers’ knowledge or skills

Benefits of TCARE® for Families

- Maximize impact of support services by
  - Gaining compliance with care plans
  - Optimizing service use
  - Minimizing stress & depression
Benefits for Care Managers

- Informs intervention and care plans
  - Focus on prevention—not crisis
  - Focus on strategies—not services
  - Basis of assessment of success

Benefits for Organizations

- Potential Savings
  - Less time spent in crisis management
  - Costs associated with inappropriate allocation of services
  - Costs associated with delay of support
  - Unnecessary or premature placement

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- Langloth Foundation

TCARE® Development Team

Rhonda J.V. Montgomery, PHD (UWM)
Karl Kosloski, PHD (UNO)
Mary Brintnall-Peterson, PHD (UW-Extension)
Jeannine M. Rowe, MSW (UWM)
Dale Adler, MSW (Gerontology Programs Consultant)
Jessica Jacobs, MSW (UWM)
Team of UWM graduate students

Rhonda J.V. Montgomery, PHD
P.O. Box 786
University of Wisconsin - Milwaukee
Milwaukee, WI 5320
rm@uwm.edu
UWM.TCARE.EDU
familycaregivers.uwm.edu
Identity Discrepancy

• Caregivers experience distress when:
  – Their appraisal tells them that there is incongruence between behavior & personal identity rules

Typical Tool Box for Intervention

• Education Programs
  – Information
  – Skills
  – Emotional/Psycho-educational
• Support Groups
• Counseling
• Respite
• Case Management

Who Is Helped By a Shot-Gun Approach?

Correct Service?

Yes

No

Correct Implementation?

Yes

No

Correct Time?

Yes

No

No effect

Helps Client

Typical Tool Box for Intervention

• Education Programs
  – Information
  – Skills
  – Emotional/Psycho-educational
• Support Groups
• Counseling
• Respite
• Case Management

Screening Tool

The Assessment Form

Relatively Brief & Relatively Easy
Goal I: Maintain Identity

Strategies:
A. Change personal rules for care
B. Reduce or minimize workload
C. Support positive self appraisal
D. Reduce generalized stress

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