

Social Work Roles and Patient Centered Models

Striving for Client and Caregiver Interdependence

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Learning Objectives



At the conclusion of this activity, the participant will be able to:

- ✓ Describe the epidemiology of living situations and relationship role changes and barriers faced by clients and spousal/significant others as they become caregivers of MS and SCI/D.
- ✓ Identify and describe the different roles Social Workers utilize with MS and SCI/D clients and their caregivers to help them achieve independence/interdependence.
- ✓ Identify “Best Practice” strengths-based, patient-centered models that can be used with MS and SCI/D clients and their caregivers.
- ✓ Describe resources/self-management toolkit and how they can be utilized with MS and SCI/D clients and their caregivers.

Epidemiology of SCI/D and MS Veterans and Caregivers

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Agenda



1. Caregiver Research/Epidemiology: Demographics, living situations and significant relationships/marriage; Best Practice Models of SCI/D and MS Clients and Caregivers
– Alicia Sloan
2. Social Work Roles and Implementation into Social Work Practice
– Warren McCluney
3. Two Models, Case Study Analysis and Group Discussion
– Sandra Koenig
3. Presentation of Resources/Self Management Toolkit – Online Resources and Handouts – Alicia Sloan
4. Audience Questions, Comments ?????

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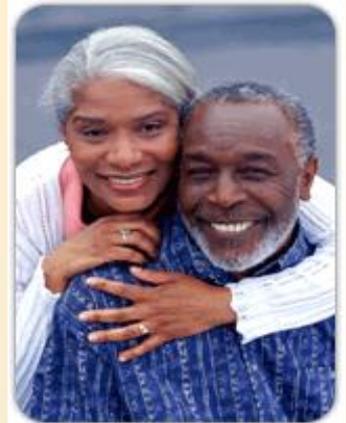
**“Actually, I only come here to lie down.
I can’t get any rest at home!”**

Research and Bikinis?!

What do “Research” and “Bikinis” in Las Vegas have in common?



VA SCI/D and MS Social Workers



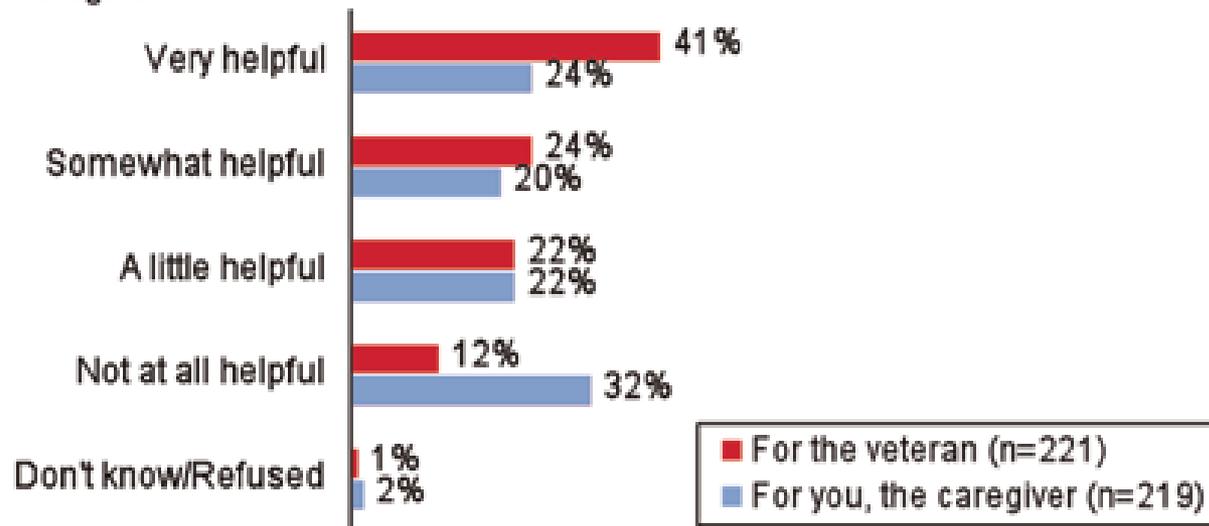
- 42,766 Veterans with MS; 16,000+ receive care at VA
- 42,000 Veterans with Spinal Cord Injury; 25,000 receive care at VA
- Utilize traditional social work roles to assist Caregivers and Veterans
 - Strengths- based
 - “Person” / “Client” Centered
 - “Best Practice” models
 - Lead clients to a positive sense of self and interdependence

(MSCOE, 2012; Curtin, 2012)

How Helpful Are We To Caregivers?

“How helpful has the care/case manager or social worker been in locating, arranging, and coordinating suitable care and resources?”

Veteran has one or more case managers



(Caregivers of Veterans – Serving the Homefront Study, 2010)

Caregivers

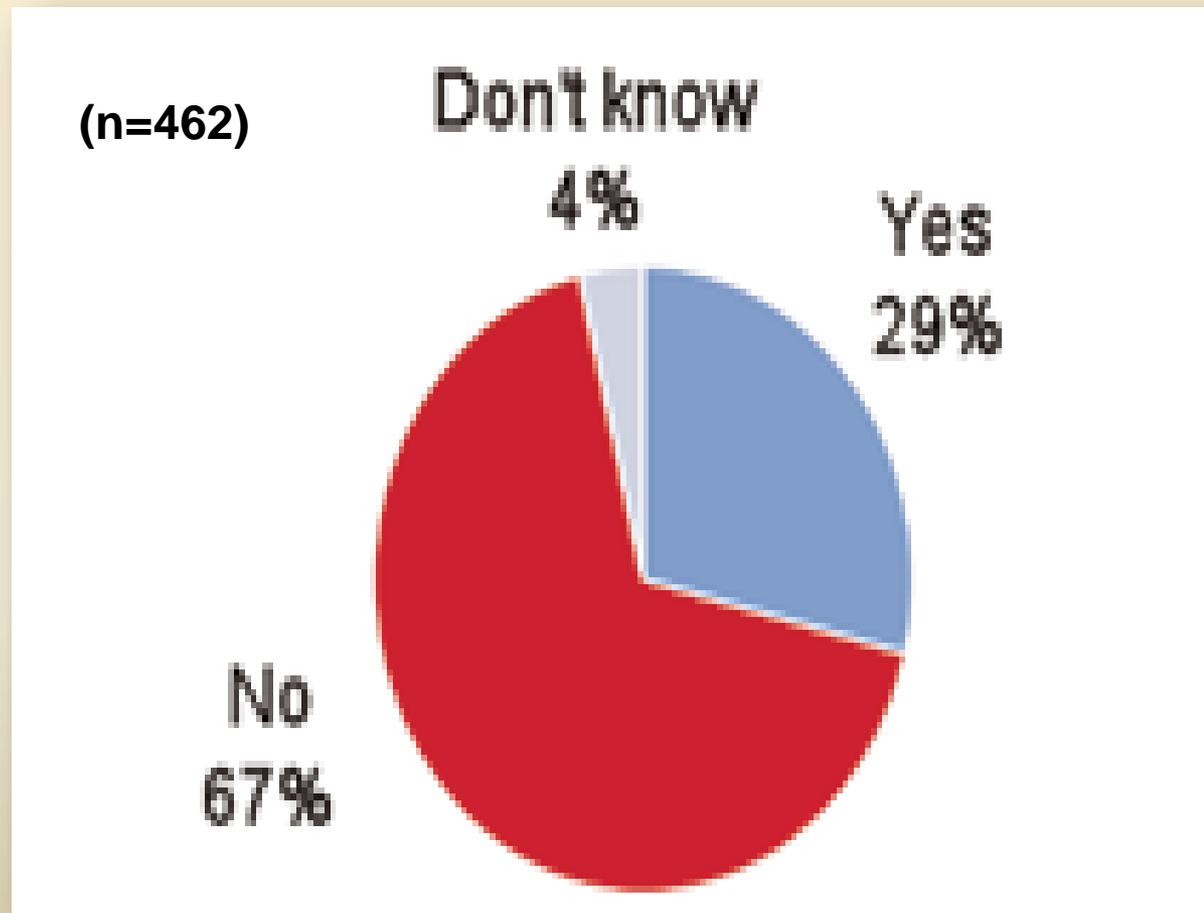
“People expect to become caregivers for their children and parents. They do not expect to become caregivers for their spouse.”



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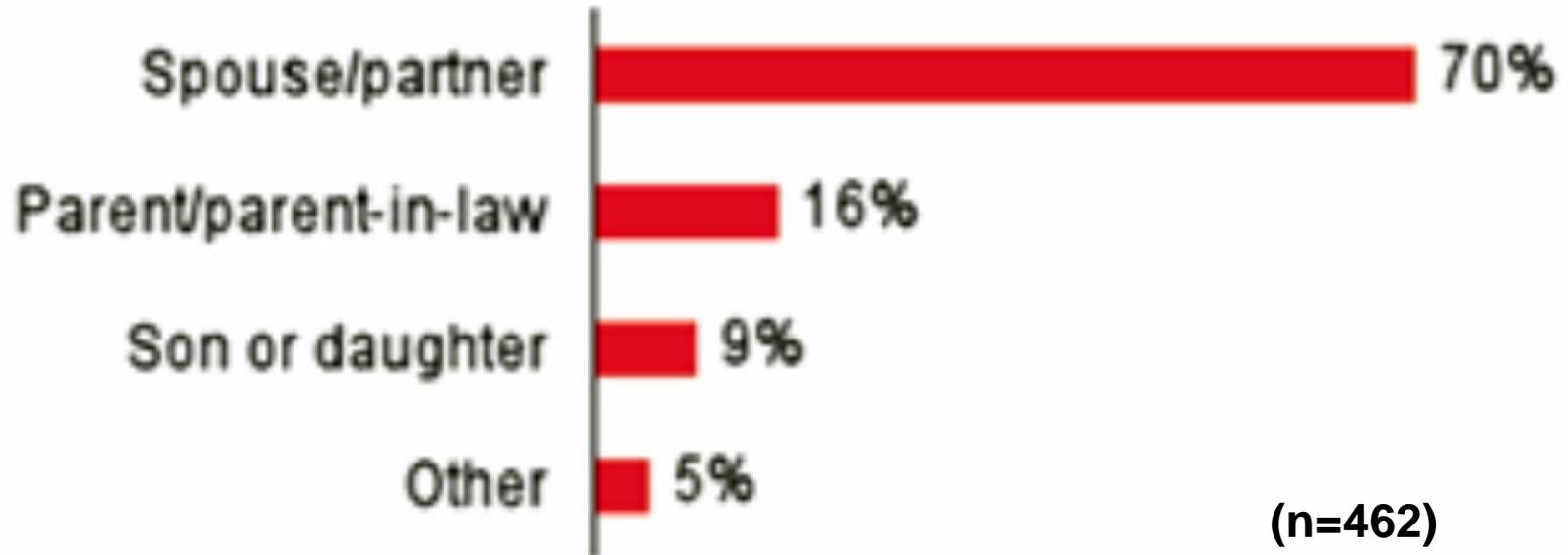
(Courts, Newton, & McNeal, 2005)

Caregiving - Did We Have a Choice?



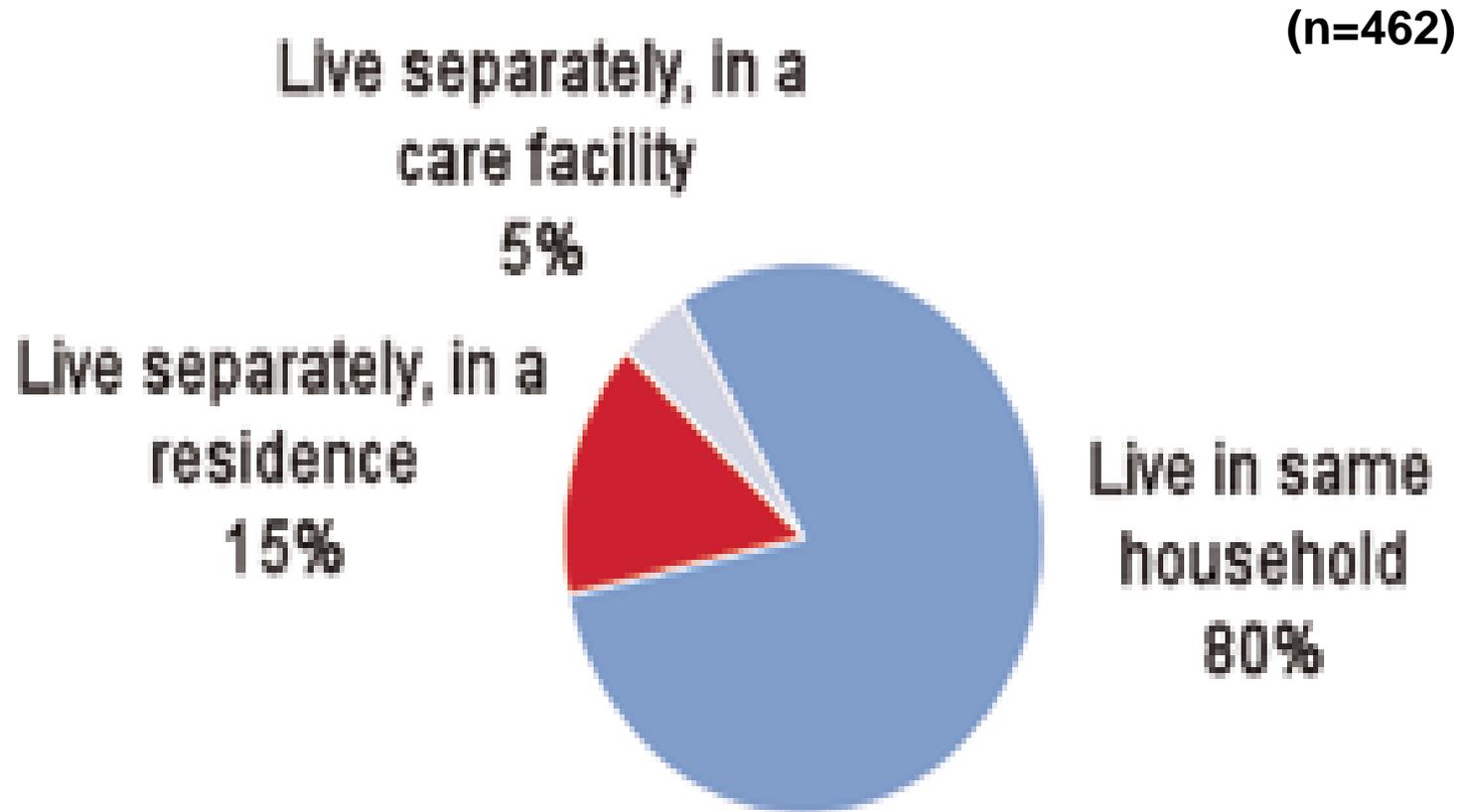
(Caregivers of Veterans – Serving the Homefront Study, 2010)

Who are the Caregivers?



(Caregivers of Veterans – Serving the Homefront Study, 2010)

Who are the Caregivers?



(Caregivers of Veterans – Serving the Homefront Study, 2010)

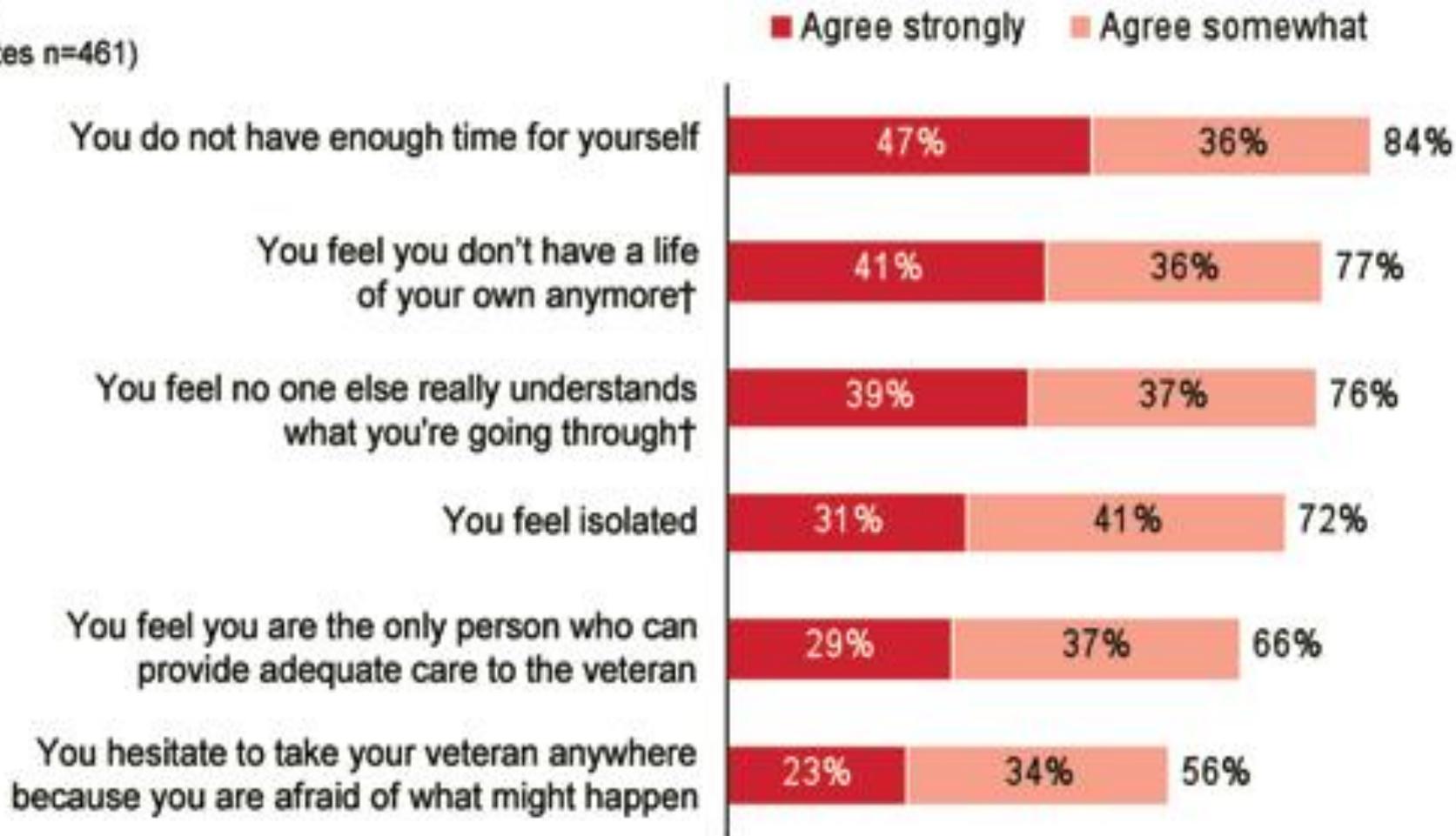
Caregiver Demographics Veteran vs. National Statistics

	Caregivers of Veterans (n = 462)	Caregivers of Adults Nationally (n = 1,307)
Female caregiver	96%	65%
Spousal caregiver	70%	6%
Caregiver lives with care recipient	80%	23%
Primary caregiver	82%	53%
Caregiving for 10 years or more	30%	15%

(Caregivers of Veterans – Serving the Homefront Study, 2010)

Emotional Impact of Caregiving

All
(n=462)
(† indicates n=461)



(Caregivers of Veterans – Serving the Homefront Study, 2010)

Top Challenges Faced by Caregivers of Veterans



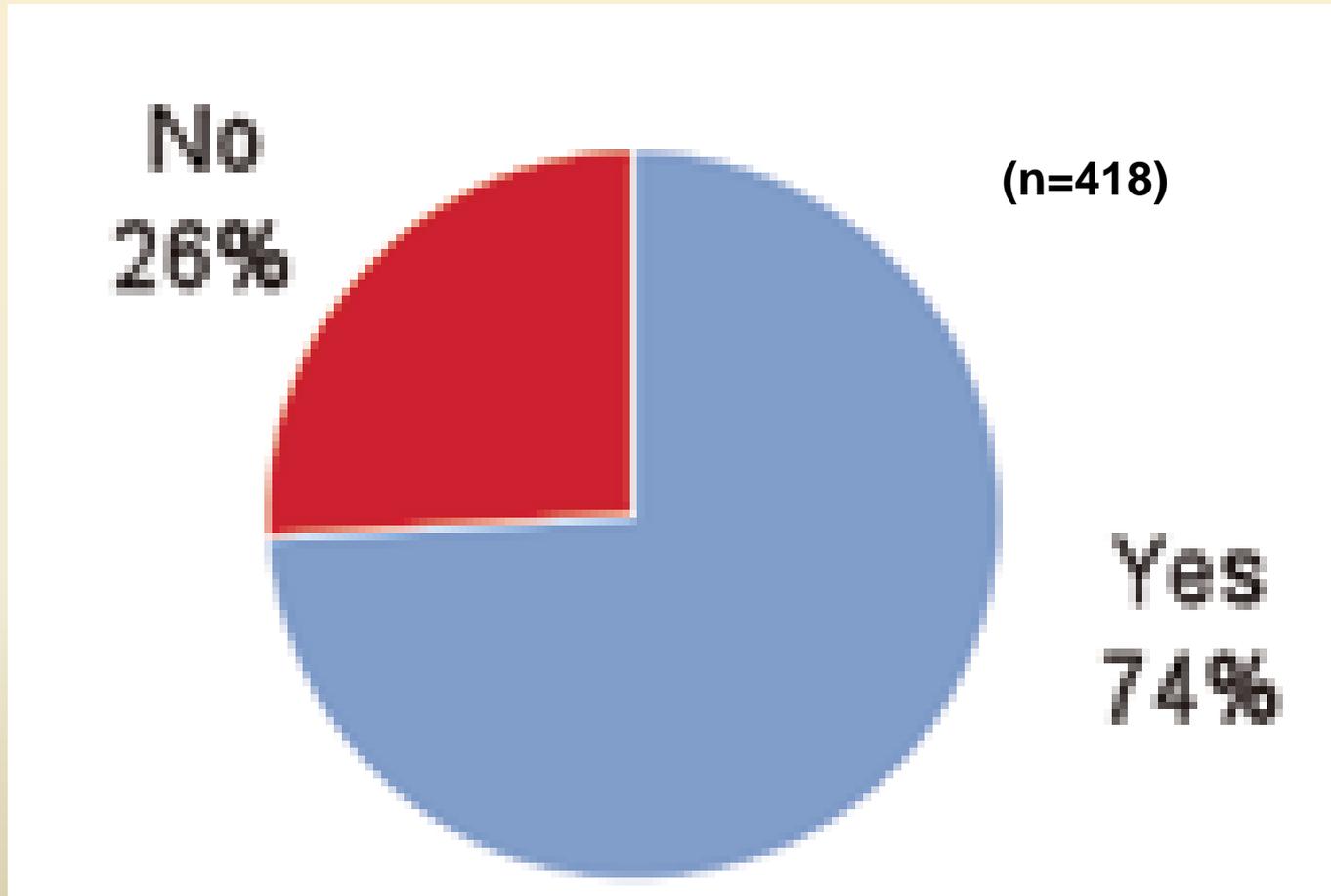
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Each experienced by at least 2/3 Caregivers:

1. Not knowing what to expect medically with Veteran's condition
2. Not being aware of Veterans Affairs (VA) services that could help
3. Not knowing how to address PTSD or mental illness
4. Difficulty getting through bureaucracies in order to obtain services
5. Not knowing where to obtain financial assistance
6. Not knowing where to turn to arrange a break from caregiving
7. Not knowing where to obtain specialized care
8. All but the first of these challenges are more commonly noted by caregivers of veterans who have TBI.

(Caregivers of Veterans – Serving the Homefront Study, 2010)

Marital Strain from Caregiving



Caregivers of Veterans – Serving the Homefront Study, 2010.

Veterans with SCI/D Study 2012



Bing Images

- 231,000 - 311,000 people in U.S. living with SCI
- Roughly 42,000 Veterans with SCI;
 - 25,000 receive care from VA.
- Multiple medical diagnoses
- Mostly male (>97%)
- 45 and 64 years old. Over 30% over the age 65.
- Frequent users of healthcare = average of 21 visits per year.
- Influx of new SCI injuries from current conflicts
- Women Veterans with SCI – small subpopulation, although increasing number of women in military:
 - Younger, less likely to be married, less social support, higher burden of disease
 - Unique healthcare needs: reproductive health, osteoporosis management

VHA National Patient Care Database (NPCD) study, Curtin, 2012.

People with SCI



- People surviving now from severe spinal cord injury (SCI), who 10-20 years ago would not have survived
- Life expectancy increasing.
- U.S. average age of persons with SCI = 40 years
- > 40% over age 45
- 35% over age 65
- National registry of Veterans with spinal cord dysfunction:
 - Veterans with SCI - older than general population of persons with SCI.

(Robinson-Whelen and Rintala, 2003)

SCI Caregivers



- 37% Veterans have Informal Caregivers
- Caregivers mostly women
- Average age 53.
- Caregivers = average 12 hours a day.
- 1/3 Veterans rated caregiver “fair or poor“ health.
- 1/4 Veterans think caregiver unlikely to be able to provide same level of care in 5 years.
- >50% Veterans reported: No one else willing/able to provide assistance if primary family caregiver became unable to care for them.
- Caregiving significantly interferes with quality of life

(Robinson-Whelen & Rintala, 2003; Unalan, 2001.)

What do Veterans & Caregivers Need?



Bing Images

- “It is important for those of us with MS to have a support team including friends and family members. In my own case, I have some great friends who understand my situation and offer tremendous physical and emotional support.”
~ Veteran with MS, www.va.gov/MS
- "It doesn't matter if you don't feel well or if you're having a bad day, their needs get met." ~ Caregiver of Veteran with SCI/D
www.caregiver.va.gov/connection_teresa.asp

Caregiving Focus Group Study



Key Findings:

- Caregivers focus on their loved one, not on themselves.
- Hesitant to share duties with other family members:
 - No one can care for their loved one as well as they do
 - Feel guilty leaving their loved one with anyone else
 - Have no one to ask for help
 - Waiting for people to volunteer
 - Would not feel comfortable using respite service "just for themselves"...Only use it to get things done like shopping or laundry.
 - Want to know how to do a better job as a caregiver or improve loved one's quality of life.

Best Way to Approach Caregivers (In this order):

1. Resources: How to help Carepartner and improve as Caregivers.
2. Caregiver Support/Respite.

(The National Family Caregivers Association and the National Alliance for Caregiving Focus Group Study, 2001.)

Impact of MS Caregiving on Relationships

Benefits and burdens of caregiving:

- Strengthens relationships
- Loss of personal identity
- Limited support systems and resources

More MS Caregiver research needed in these areas:

- Which services most helpful and necessary to support caregivers
- How couples cope with relationship changes transition of partner to caregiver
- Develop interventions to facilitate and support role changes and prevent relational strain



Bing Images

(Kraft, et al., 2008)

Impact of MS Caregiving on Relationships



Mutch (2010) Qualitative Study, 8 Couples

- Experience of caring for a spouse with MS
- Major Motivating Factors
 - ❖ Commitment of Marriage
 - ❖ Marriage Vows
- “Worry” - Underlying Theme
 - Worry as a genuine concern for the spouse
 - Worry due to the unpredictable nature of MS
- “Living by the Clock”
 - Lost spontaneity in life
 - Every activity required a great deal of planning

Impact of MS Caregiving on Relationships

Cheung & Hocking (2004) in-depth interview, study of MS spousal caregivers:

- What gives caregivers courage to “weather illness and adversity in life” and “shape their way of living and coping”:
 - ☑ Personal meanings
 - ☑ Values
 - ☑ Concerns
 - ☑ Past experiences
 - ☑ Future hopes and dreams
 - ☑ Connections with partner and others



Bing Images

MSCoE Caregiver Research



Veterans with MS Perception of Caregiving:

- Male Veterans w/MS who are married or living with someone, and/or RRMS reported high level of support from their Caregiver. Higher than married women Veterans w/MS.

(Williams, Turner, Haselkorn, et al., 2004)

- The greater perceived social support from Veteran with MS & perceive greater affectionate support from Caregiver, less depression in Veteran.
- Men with MS report greater perceived social support and greater perceived emotional/information and tangible support compared to women with MS.

(Bambara, Turner, Williams & Haselkorn, 2010)

Caregivers of Veterans w/MS

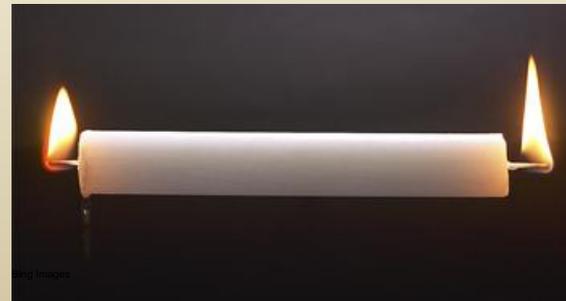
- “Supportive qualities” of Caregiver significant for better DMT adherence.

(Siegel, Turner & Haselkorn, 2008)

Impact of MS Caregiving on Relationships

- Caregiver and Carepartner stress is highly correlated.
- They feel they are battling against resources.
- Caregivers struggle to keep their own identity.
- Help Caregivers “make sense” of who they are and their caregiving experiences.
- Facilitate sense making together: caregiver and care partner.

(Pakenham, 1998, 2008; Edmonds et al, 2007; Cheung & Hocking, 2004)



Person-Centered Models

- Use with Caregivers
- Person-centered models and social work roles:
 - Help alleviate caregiver burden/stress
 - Create interdependence w/caregiver and care partner
 - Encourage caregiver to share responsibilities
- Caregiver assessments (Zarit Burden Scale, etc.)
 - ✓ Evaluate at baseline
 - ✓ Re-evaluate after implementing model.



Person-Centered MSCOE Education & Support



- **Monthly Caregiver Call:** MS Social Worker Facilitated
Conference Calls: 4th Monday of every month
Time: 11am-12noon PT, 12-1pm MT, 1-2pm CT, 2-3pm ET
How: Call 1.800.767.1750, code 43157#
[www.va.gov/MS/articles/Education/Free Monthly Educational Conference Calls.asp](http://www.va.gov/MS/articles/Education/Free_Monthly_Educational_Conference_Calls.asp)
- **MSCOE Website:** www.va.gov/MS
- **Stories:** www.va.gov/MS/Family_is_Everything.asp
- **Newsletter:** www.va.gov/MS/Newsletters.asp

Person-Centered Models

- Sandy will describe in more detail:
 - PACT Model
 - Personal Futures Model
- Other models to consider:
 - Prepared Family Caregivers “COPE” Model
 - Share The Care Model



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“Prepared Family Caregiver” Model

- Used with MS Caregivers
- Acronym **COPE**

Creativity

Optimism

Planning

Expert information

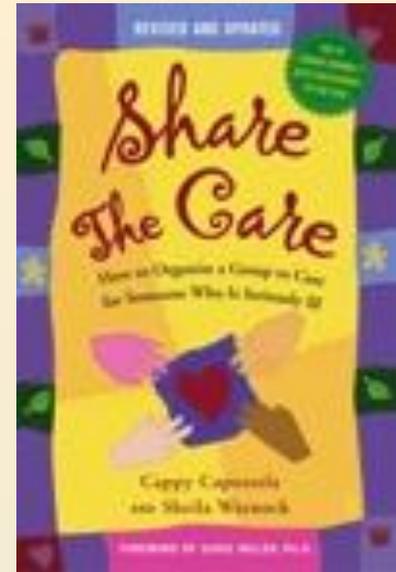


- Teaches family caregivers how to develop and carry out plans for medical and psychosocial problems
- Coordinates with MS care plan
- Empowers family members and patients for coping with illness
- Helps to moderate caregiver stress.

(Houts, Nezu, et al., 1996)

“Share the Care” Model

- MS experts like it! (Holland, Schneider, Rapp, Kalb, 2011)
- Developed by “caregiver friends” of a friend with cancer.
- Family, neighbors, business associates and acquaintances - turns them into a powerful caregiver "family".
- Uses volunteer care coordinators to bring in family, friends, church groups, and others who can help with care needs and provide respite for caregivers.
- www.sharethecare.org



Other Person-Centered Tools

- Online calendars for caregiver “sharing”:

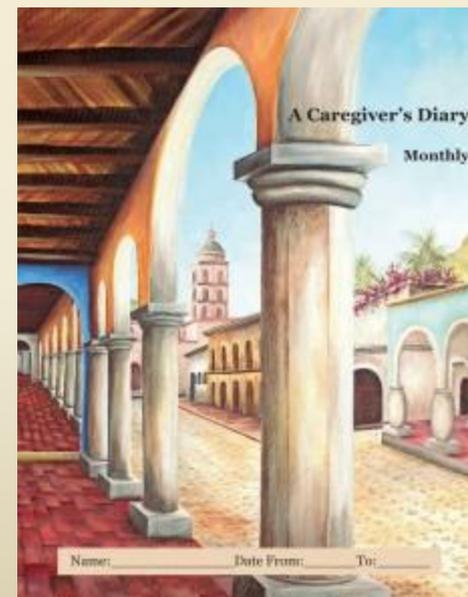
www.carecalendar.org
www.caringbridge.org
www.takethemameal.com



- Caregiver planning diary:

www.acaregiversdiary.com

- Daily Documentation
- Organizing Daily Programs
- Health and Nutrition Medications/Vitamins
- Exercise and Hygiene
- Doctor Appointments and Outings
- Doctor Contact Information
- Pharmacy and Prescription Information
- Documentation transcribed to Doctors



Family Caregiving 101 Website



- National Family Caregivers Association (NFCA) and the National Alliance for Caregiving (NAC) collaboration
- Leaders in the movement to better understand and assist family caregivers
- “It’s not all up to you!”
- www.familycaregiving101.org
- Assist a caregiver: www.familycaregiving101.org/assist
- Tips on how to communicate with a Caregiver in order to help: www.familycaregiving101.org/assist/communicating.cfm
- Links to online depression screening (Patient Health Questionnaire "PHQ-9"):
http://www.mentalhealthamerica.net/llw/depression_screen.cfm

NASW Standards

- NASW Standards for Social Work Practice with Family Caregivers of Older Adults.
 - ❖ Standards and ethics that reflect core elements of social work practice on behalf of family caregivers
 - ❖ Advise social workers who address family caregiving needs in various professional settings
 - ❖ Can be applied to Caregivers of any population.
 - ❖ Warren will go into specific Social Work roles applied to Caregivers as our clients.

(National Association of Social Workers, 2010)

Social Work Roles: Reducing Caregiver Stress and Increasing Resilience

Warren A. McCluney, MSW, LMSW

Spinal Cord Injury/Disorders (SCI/D) Coordinator

Veterans Affairs Medical Center

Lake City, FL



Social Work Roles

We can use traditional Social Work roles to:

- Empower Veterans and their Caregivers
- Decrease daily stress
- Help cope with stressors on a daily basis

(Dietrich, 2012)

Social Work Roles



Social Work Roles

- Define terms in the context of social work
- Move beyond semantics
- Examples from literature and professional experience
- How roles positively impact caregiving through empowerment of both Veteran and Caregiver.

Social Work Roles

- Role expectations not clearly understood by general public & other professionals
- Many diverse roles in social work
- Opportunity for creativity in practice

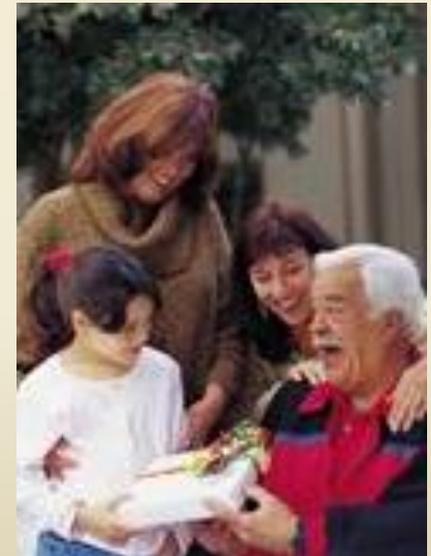
(Suppes & Cressey Wells, 2003)

THE END IS
NOT NEAR -
YOU MUST
LEARN
TO COPE!



Caregivers

- Who are they really?
- They are “we”



Loss



“ My parents’ deaths left a double-edged legacy: awareness of both the sorrow and the generosity of the human heart.”

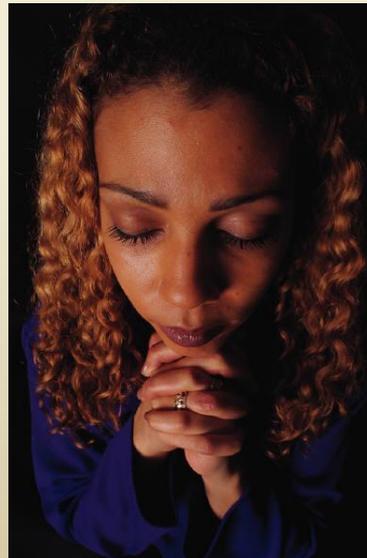
“Nowhere perhaps is this paradox more played out than the daily stage of family caregiving, where the unsuspecting can find themselves in a chaotic journey in which the only certainty is the demise of their loved one.”

(McLeod, 2003)

Powerlessness

“These caregivers are on a path seemingly without end, subjected to the stresses and guilt of watching another’s pain without being able to erase it, witnessing a love one dying without being able to prevent it. “

(McLeod, 2003)



Sacrifice

“They quietly sacrifice personal agendas to look after those in need, often sandwiched between child care and jobs, and usually without notice.” (McLeod, 2003)



Loyalty

“Live a world apart from everyday reality and wonder if they will ever be normal again.”

“These loyal souls-many who do not recognize themselves as caregivers - work largely without professional help, feeling they can and must do everything alone.”

(McLeod, 2003)



Devotion

“There is no question about taking on this role: They do so compelled not only by the dictates of society, but also the mandates of the heart.”

(McLeod, 2003)



Support



“They bathe, feed, dress, shop for, listen to, and transport frail parents , spouses, children, friends, relatives, and neighbors.”

“Night and day they torment over how to keep loved ones out of nursing homes, how to give adequate medical attention and make life and death decisions when they have not been trained to do so.”

(McLeod, 2003)

Social Work Role: Empowerment

Helping individuals, families, groups and communities to:

- Increase their personal, interpersonal, socioeconomic, and political strength.
- Develop influence towards improving their circumstances.

(Barker, 2003)

Social Work Role: Broker

- Micro and mezzo systems influences:
- Links Caregivers with community resources and services
- Sensitive to Caregiver roles and needs

(Zastrow & Kirst-Ashman, 1997)

Social Work Role: Enabler

- Help Caregiver learn coping strategies for different situations or transitional stress
- Convey hope
- Help reduce feelings of resistance and ambivalence of Caregiving role
- Help prioritize and break down problems into parts that may be solved more readily

(Barker, 1995)

Social Work Role: Mediator

- Involves resolving issues or problems that may be involved the micro, mezzo, or macro systems.
- Remains neutral

(Kirst -Ashman, 1997)

Social Work Role: Educator

- Providing information and teaching skills to Caregiver and other provider systems.
- Convey information clearly so it's understood by the Caregiver and other entities.

(Zastrow and Krist-Ashman, 1997)

Social Work Role: Facilitator

- Bringing people together: family and other providers
- Foster an environment of mutual respect and support among family and Caregiver.
- Facilitate an open line of communication.

(Baker, 1995)

Social Work Role: Negotiator

- Represents the Caregiver when navigating through an agency or health care system
- Achieving cohesiveness whenever possible
- Not neutral

(Zastrow and Krist-Ashman, 1997)

Social Work Role: Advocate

- Provide support for a course of action on behalf of the Caregiver and Veteran.
- Goal: Advocate for or maintain social justice.
- One of the most important roles for a social worker despite potential difficulties.

(Mickleson, 1995; Zastrow & Krist-Ashman 1997)

Social Work Role: Case Manager

- Locates services and assists Caregiver to access services.
- Address Caregiver's biopsychosocial and spiritual issues
- Educate provider team members on "person in environment" social work perspective
- Important for complex situations

(Zastrow and Krist-Ashman, 1997)

Person-Centered Models

Sandy Koenig, MSW, LCSW, ACSW, OTR/L
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Learning Objectives

- Understand the definition of patient center care.
- Define Person Aligned Care Teams (PACT)
- Describe the difference between system centered and person-centered.
- Understand how we move toward person centered outcomes utilizing person centered models.
- Describe two person centered tools one can utilize in practice to assist the client and caregiver.

Person-Centered Planning

“Person-centered planning celebrates, relies on, and finds its sober hope in people’s interdependence. At its core, it is a vehicle for people to make worthwhile, and sometimes life changing, promises to one another.”

~ John O’Brien

Person Centered Planning

- Originally used with people with disabilities and traumatic brain injury (TBI).
- Ongoing problem-solving process to help people with disabilities plan future.
- Depends on commitment of a team who care about the focus person.
- Focus on individual (Caregiver/Veteran) and vision of the future.
- Person-centered team identifies opportunities for the Caregiver/Veteran to:
 - Develop personal relationships
 - Participate in their community
 - Increase control over own life
 - Develop the skills and abilities needed to achieve these goals.

(PACER: Minnesota Parent Training and Information Center, funded by the U.S. Department of Education's Office of Special Education Programs)

Patient Centered Care Defined

- Health care that establishes a partnership among practitioners, patients, and their families.
- Ensures decisions respect patients' wants, needs, and preferences.
- Patients have education and support they need to make decisions and participate in their own care.

(Institute of Medicine, 2011)

VA Person Aligned Care Teams (PACT)

- A systems redesign model
- Medical home model of health care delivery
- Empowers Veteran to have a more active role in health care
- PACT team: Veteran, Caregiver, MD, SW, RN and other professionals and non-professionals
- Improve patient satisfaction, clinical quality, safety and efficiencies

(Patient Centered Medical Home Model Concept paper, 2012)

PACT and Social Work

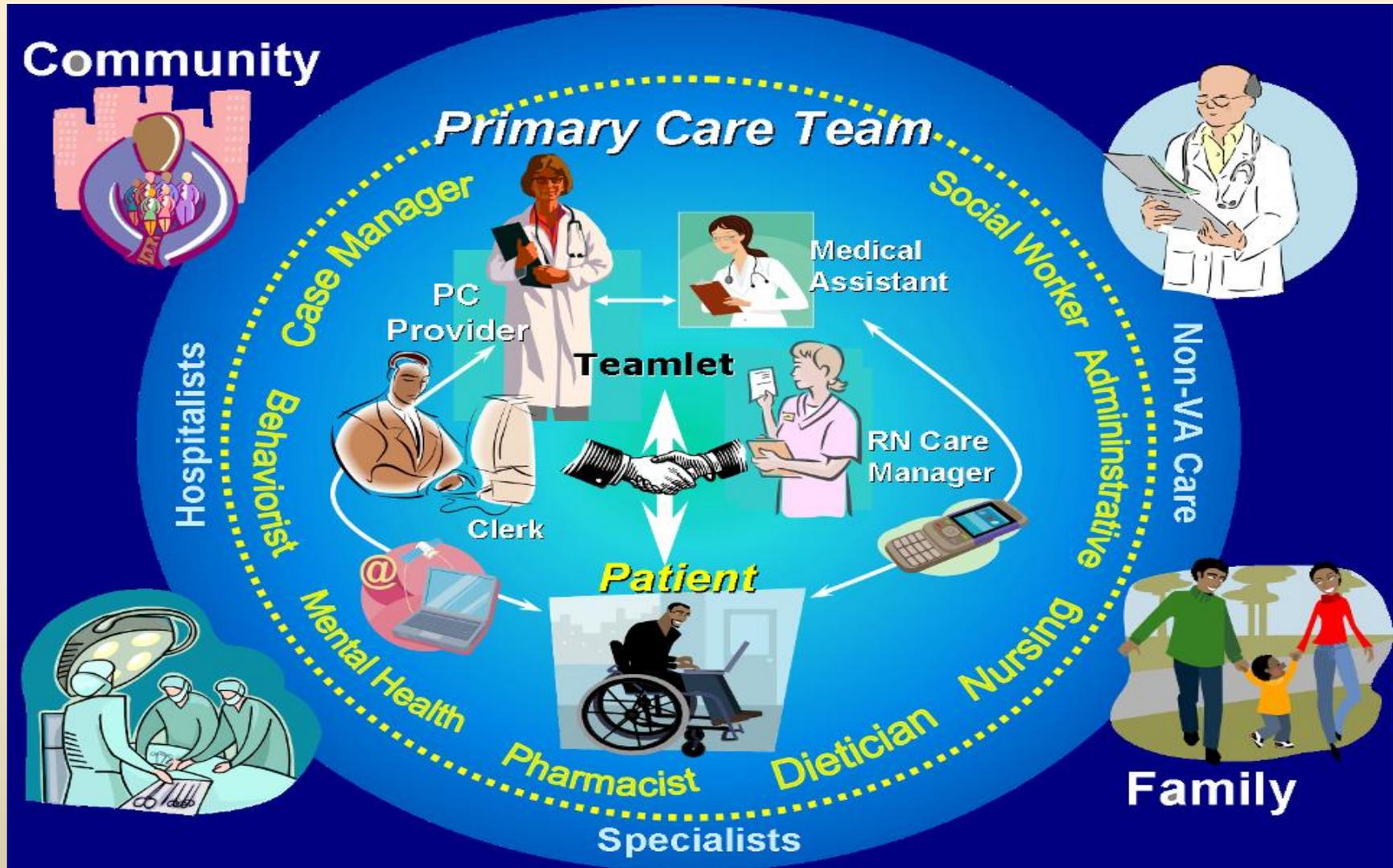
PACT Model

- Encourages Veteran/Caregiver to become partners with healthcare team
- Veteran/Caregiver at the center & partner of the team.
- Based on empowering Veterans/Caregivers to become active in healthcare needs.

Social Work Profession

- Fits nicely into this model because we value empowerment of people.
- Our role as a Social Worker is to empower those we serve.

PACT Model



PACT Model: Social Work Goals

Goals for Veteran/Caregiver/Significant Others

- Encourage them to tell their story
- Empower them to be active in healthcare plan
- Advocate for them to express their goals
- Educate and assist them with access to needed resources
- Help them identify support system
- Consult with PACT team members to clarify goals and needs

Beth Mount, PhD

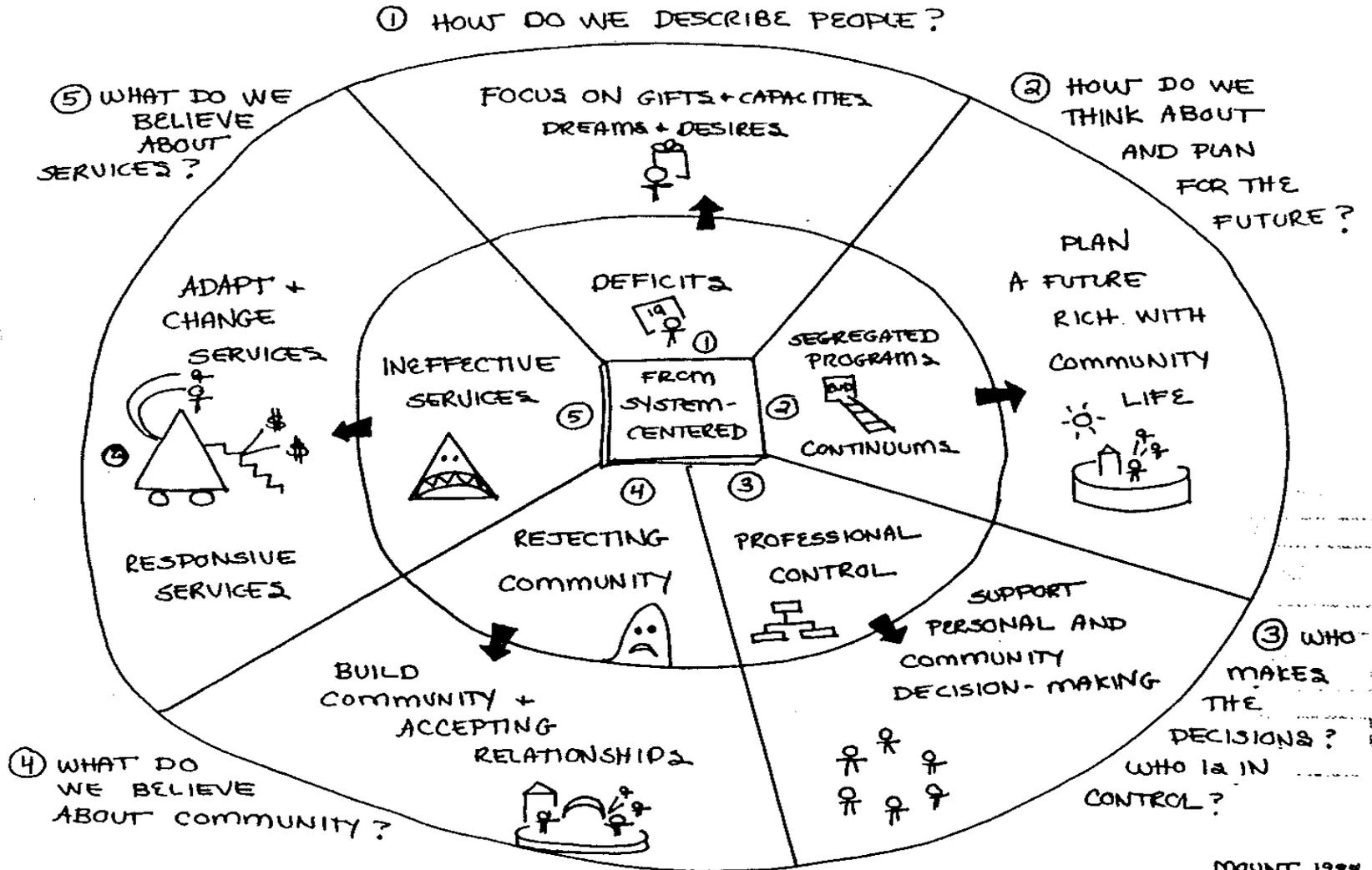
“Beautiful Justice”

TEDx Creative Coast Conference, Savannah, GA May 2012

<http://www.youtube.com/watch?v=IXMALqo4E24>

THE TURNING POINT IN HUMAN SERVICES

Contrasting System-Centered and Person-Centered Assumptions



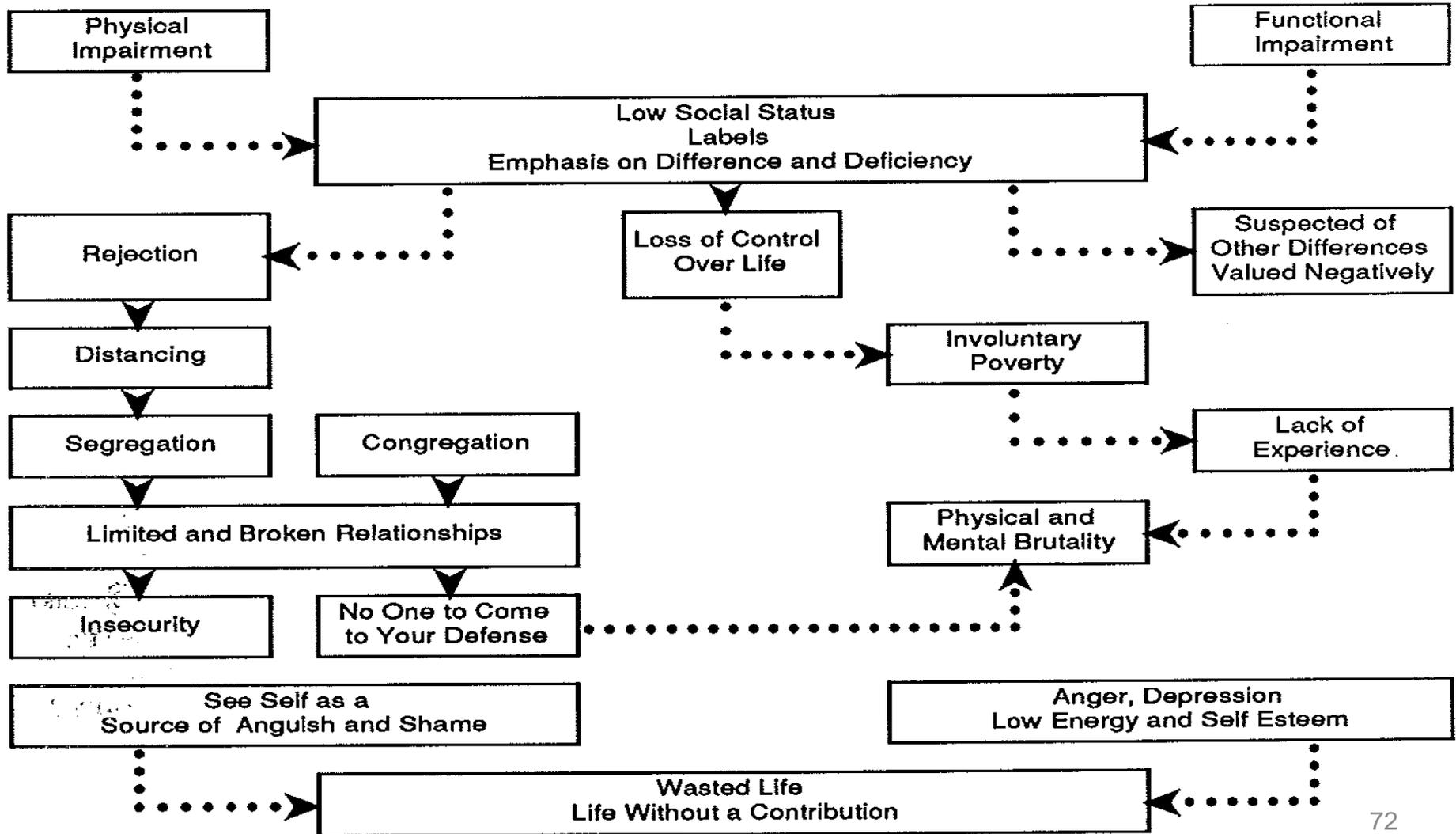
MOUNT, 1988

“Personal Futures Planning” Model

- A process to help us listen to people with disabilities
- Ongoing process of personal, organizational and community change
- Organize person-centered team to listen to focus person’s dreams and desires
- Take action over time to accomplish dreams

(Middle Manager Training Project - The University Affiliated Program of NJ,1990)

COMMON EXPERIENCES OF PEOPLE WITH DISABILITIES



Personal Futures Plan: Task of the Facilitator

- Who is the person?
- What are their unique gifts?
- What is the dream inside the person?
- How will this dream challenge us to change the system?

(Mount, 1990)

Person Centered Planning: Role of Facilitator

- Organizes person-centered team to find opportunities and capacities with client.
- Supports client by getting to know them and their dreams and capacities.
- Helps develop support network take action to focus on client's dreams.
- Identifies barriers and obstacles
- Strategizes opportunities.

(Mount, 1991)

Robert & Cathy: Case Example

- Robert, 52 year old Veteran
- Incomplete C-4 spinal cord injury from a MVA 4years ago (not injured during active duty)
- Recently divorced from Wife/Caregiver, Cathy (20-year marriage)
- 2 children, ages 17 and 15
- Cathy works full time outside the home.
- Robert has one living parent (father), but strained relationship
- Robert is an inpatient in Rehab unit
- Homeless since divorce
- Robert remains in contact with his children and they visit him
- Cathy remains involved but does not want to assume caregiver role.

Robert, the Veteran

Who is the person?

- Highly motivated in rehab to become more independent.
- Hopes to walk one day.
- Want to start a career in computer programming
- Wants to live independently
- College educated
- Attends church
- Involved in son's football team
- Able to communicate his needs
- Positive outlook for the future
- Wants to remain friends with Cathy
- Wants to be involved with his children

Robert's Gifts

What are his unique gifts?

- Highly motivated to improve his physical abilities and become more independent
- A “yes” person - does not give up!
- Can advocate for himself
- Well versed in computers
- Spiritual
- Family-oriented

Robert's Dream

What is his dream?

- Wants to live in his own apartment
- Wants to be independent
- Wants to walk
- Wants to work
- Wants to drive
- Wants to have friends
- Wants to stay involved in his children's life

Robert's Dream

How will the dream change the system?

- Can articulate his goals
- Resourceful - will not take “no” for an answer
- Pushes his limits
- Well liked by staff who work with him
- Provider team can envision his future
- Goals are shared among team members

Cathy, Ex-Wife & Caregiver

Who is the person? What are her gifts?

- Kind, caring and concerned
- Feels she can not give anymore - anxious
- Smart and educated
- A good mother - focused on her children
- Wants to remain friends with Robert but can't live with him.
- Spiritual
- Described by Robert as a good wife and mother

Cathy's Dream

What is her dream?

- Wants to see Robert improve
- Hopes Robert can live independently
- Fearful Robert will end up in a nursing home
- Wants to move on with her life and be happy with her decisions to divorce
- Wants her children to be involved with Robert
- Wants to develop her career
- Wants to be independent

Robert's "Person Centered" Team

1. Social Worker
2. Nurse
3. Nurse Manager
4. Occupational Therapist
5. Physical Therapist
6. Physician
- 7. Robert**
8. Church Member
9. Friend from football
10. Children
11. Cathy

Person-Centered Teams

- Roles changed based on tasks or new directions
- Old boundaries for action may change to allow for new action.
- Plans may change roles and create new agendas for action.
- Members create new channels and connections to accomplish goals.
- Members use informal networks and contacts to open doors in the community.

(Mount, 1990)

Tools for Change

- Need a champion
- Identify supports (circle of support)
 - ✓ Church group
 - ✓ Football team
 - ✓ Provider staff
 - ✓ Other Veterans
 - ✓ Ex- wife
 - ✓ Extended family
 - ✓ Friends

Person-Centered Models of Care: Desired Outcomes

- Focus person is empowered
- Focus person feels more in control of future
- Support group becomes “stakeholder”
- Responsibility shared among support group members
- Focus person feels a sense of ownership in the process
- Focus person is less isolated
- Focus is on capacities, gifts, and dreams for the focus person, not the disability

Facilitator Role

- Create a person-centered team
 - Include Veteran, Caregiver, friends, staff, associates, community
- Identify a champion
- Share decisions with Veteran, Caregiver, family and friends
- Empower Veteran and Caregiver to express their story, define needs and goals, set action plan
- Respond to people in the group based on shared responsibility and person commitment

Who Should Be Involved In Personal Futures Planning?

- Is the focus person willing and interested to have a person-centered team involved in their life?
- Do you feel a sense of commitment in working with the focus person?
- What will the focus person teach your organization and those working with him or her?

Group Exercise: Audience Participation!

Personal Futures Plan:

- How can we utilize personal futures planning to assist the Caregiver?
- Who can you identify to be a part of the person-centered planning group?
- How will you empower the Caregiver?
- Who in the community will you involve?
- Are there any organizations you might include?
- Which staff will you include?

Janet, the Veteran

- age 33, multiple sclerosis, Diagnosed with RR MS 9 years ago
- Air Force 3 years – Bosnia, PTSD from sniper fire
- Wants to go to college to pursue a career, but doesn't know what she wants to do.
- Facial numbness, slurred speech,
- Difficulty writing because of her shakiness.
- Depression, fatigue
- Avonex, no recent exacerbations.
- Unable to work
- Can do housework slowly and in limited portions at a time
- Can walk slowly, uses cane, walker or w/c, depending on how she feels
- No children
- In individual and marriage therapy in the community through Tricare insurance
- Goes to VA MS Clinic
- She expressed she has a tendency to take things personally if there is invalidation or interpersonal conflict
- She would like better coping skills
- Lives in small town, some friends, most family live on East Coast
- Would like marriage to work, but wants to also be happy.
- Goes to church

Rick, Husband & Caregiver

- Age 36, Active Duty Air Force, currently trains soldiers
- Overly attentive caregiver
- Doesn't want divorce. Angry Janet would consider it.
- "Janet needs me! I would never leave her!"
- Afraid of what will happen to her without his support
- Doesn't admit his over-protectiveness affects his wife negatively.
- Likes to be in the room during every appointment. Fearful of his wife forgetting important health information that would help him as a caregiver.
- Goes to private marriage therapist with wife. Wants to stay married.
- Family in same town they live in
- Would love to have children, but not sure if it's good for Janet.
- Attends church with Janet sometimes

Rick and Janet

- Get to know Rick, the Caregiver, and Janet, the Veteran with MS.
- What are their dreams and goals?
- Who is the person?
- Spend time getting to know them well.
- What works for them?
- What doesn't work for them?
- Who is in their circle of support?

Summary

- We can apply person-centered models and resources in our work with Caregivers as clients.
- Personal Futures Planning is an easy model to apply to both Caregivers and Carepartner.
- Being aware of the relationship between Caregiver and Carepartner.
- Being aware of other people as resources in Caregiver's & Carepartner's circle.
- Make use of online tools and resources.

Caregiver “Self Management” Toolkit

- **Personal Futures Planning Toolkit**
- **Caregiver Resources & Websites**
- **Caregiver “Sharing” Websites**

Personal Futures Planning Toolkit

1. Mount, B. Middle Manager Training Course in Person Centered Planning, New Jersey University Affiliated Program.
2. Mount, B. (1991). *Making Futures Happen: A Facilitators Guide to Personal Futures Planning*. Minnesota Bookstore.
3. Mount, B. and Zwernik, K. (1994). *Making Futures Happen: A Facilitators Guide to Personal Futures Planning*. Reprinted by Minnesota Governor's Planning Council on Developmental Disabilities. Retrieved July 14, 2012.
http://www.mncdd.org/extra/publications/Making_Futures_Happen.PDF
4. Amado, A. N. and Mc Bride, M. (2001). *Increasing Person-Centered Thinking: Improving the Quality of Person-Centered Planning: A Manual for Person-Centered Planning Facilitators*. Minneapolis, Minnesota: University of Minnesota, Institute on Community Integration. Retrieved July 14, 2012. <http://rtc.umn.edu/docs/pcpmanual1.pdf>
5. Mount, B., Brown, M., Hibbard, M., O'Neill, J. & Riggs, D. (2003). *Personal Futures Planning for individuals with TBI: Facilitator's manual. 2nd Edition*. New York: Research and Training Center on Community Integration of Individuals with TBI, Mount Sinai Medical Center. Retrieved July 14, 2012.
http://www.mssm.edu/static_files/MSSM/Files/Research/Centers/Traumatic%20Brain%20Injury%20Central/Facilitators%20Manual.pdf
6. Beth Mount's Website: <http://www.capacityworks.com/books.html>

Caregiver Resources & Websites

VA Websites

- VA Caregiver Website Toolbox: www.caregiver.va.gov/toolbox_landing.asp
 - Caregiver Workbook: www.caregiver.va.gov/pdfs/Caregiver_Workbook_V3_Module_1.pdf
- VA MSCOE website: www.va.gov/ms/
- VA Spinal Cord Injury/Disorders website: www.sci.va.gov

Other Websites for Caregivers

- American Academy of Family Physicians - A Practical Guide to Caring for Caregivers (with Zarit Burden Scale): www.aafp.org/afp/2000/1215/p2613.html?printable=afp
- University of Alabama at Birmingham - Caring for Caregivers - SCI InfoSheet #17: www.spinalcord.uab.edu/show.asp?durki=22479
- Christopher and Dana Reeve Foundation: www.christopherreeve.org/site/c.mtKZKqMwKwG/b.4453201/k.1B08/Caregivers.htm
- Communication Tips & Assisting a Caregiver: www.familycaregiving101.org/assist
www.familycaregiving101.org/assist/communicating.cfm
- Consortium of MS Centers (CMSC): www.mscares.org/cmssc/News/Web-Sights-MS-Caregivers-2.html
- National MS Society: www.nationalmssociety.org/living-with-multiple-sclerosis/relationships/index.aspx
A Guide for Caregivers: <http://www.nationalmssociety.org/search-results/index.aspx?q=caregiver%2C+care+partner&start=0&num=20>
- Paralyzed Veterans of America: www.pva.org/site/c.ajlRK9NjLcJ2E/b.6306123/k.B389/Caregivers_Support.htm
- Rosalynn Carter Institute for Caregiving: www.rosalynncarter.org
- Spinal Cord Injury Information Network: www.spinalcord.uab.edu/show.asp?durki=21680&site=1021&return=21830
- United Spinal Association: <http://www.unitedspinal.org/2011/11/15/help-support-our-caregivers/>
- Website caregivers to other caregivers, personalized information, and local resources: www.agingcare.com/Caregiver-Support

Caregiver “Sharing” Websites

- **The Family Caregiver Forum**, National Family Caregiving Association: www.thefamilycaregiver.org/ed/bb/index.cfm
- Online calendars for caregiver “sharing”:
www.carecalendar.org
www.caringbridge.org
www.takethemameal.com
- Caregiver planning diary: www.acaregiversdiary.com
- Caregiver book: www.sharethecare.org
- Caregiver support and sharing: www.familycaregiving101.org
- Caregivers seeking information and support: www.caring.com

www.caring.com/blogs/smile-of-the-week

If I look like I could use a nap, offer to sit with my loved one for a few hours some afternoon.



Caregiver Assessment Tools

- Zarit Burden Scale (Zarit, 1980)
www.aafp.org/afp/20001215/2613.html
- Caregiver Strain Index (CSI) (Robinson, 1983)
www.npcrc.org/usr_doc/adhoc/caregiver/Caregiver%20Strain%20Index.pdf
- Caregiving Tasks in MS Scale (CTiMSS) (Pakenham, 2007)
 - Email Dr. Ken Pakenham: kenp@psy.uq.edu.au
- Caregiver Reaction Assessment Scale (CRA) (Given et al., 1992)
 - Email Dr. Barbara Given, Michigan State University. barb.given@hc.msu.edu
- CAREQOL-MS: Caregiver Quality of Life (Benito-Leon, 2011)
www.sciencedirect.com/science/article/pii/S0895435610002866

Presentation References

Note: To connect directly to websites listed, make sure you are in “Slide Show” view and hover mouse over hyperlink and click.

- Bambara, J., Turner, A., Williams, R., and Haselkorn, J. (2011) Perceived social support and depression among Veterans with multiple sclerosis. *Disability and Rehabilitation*, 33(1): 1–8.
- Barker, R. (1995). *The Social Work Dictionary* (3rd ed.) National Association of Social Workers/N A S W Press, Washington, D.C.
- Caregivers of Veterans – Serving the Homefront study (2010).
www.caregiving.org/data/2010_Caregivers_of_Veterans_FULLREPORT_WEB_FINAL.pdf
- Chechak, D., *The Roles of a Social Worker*, retrieved July 15, 2012. www.scribd.com/doc/7852257/The-Roles-of-a-Social-Worker
- Cheung J . & Hocking P. (2004). Caring as worrying: the experience of spousal carers. *Journal of Advanced Nursing* ,47(5), 475–482.
- Committee on Quality of Health Care in America, Institute of Medicine. (2011). *Crossing the Quality Chasm: A New Health System for the 21st Century*. Retrieved July 13, 2012 from www.iom.edu/Reports/2001/Crossing-the-Quality-Chasm-A-New-Health-System-for-the-21st-Century.aspx
- Courts, Newton, & McNeal, (2005). Husbands and Wives Living with Multiple Sclerosis. *Journal of Neuroscience Nursing*, 37:1, 20-27.
- Curtin, C., Suarez, P., Di Ponio, L., & Frayne, S. (2012). Who are the women and men in Veterans Health Administration’s current spinal cord injury population? *JRRD*, 49:3, 351–360.
- Dietrich, M. (2012) Presentation: Preventing Burnout & Building Resilience for Caregivers. Shands Vista, Gainesville, FL.
- Edmonds, P., Vivat, B., Burman, R., Silber , E. and Higginson, I. (2007). `Fighting for everything': service experiences of people severely affected by multiple sclerosis. *Multiple Sclerosis* 2007; 13: 660-667.
- Holland, N., Schneider, D., Rapp, R., Kalb, R. (2011). Meeting the Needs of People with Primary Progressive Multiple Sclerosis, Their Families, and the Health-Care Community. *Int J MS Care*. 13: 65–74.
- Houts, P., Nezu, A., Nezu , C. and Bucher, J. (1996). The prepared family caregiver: a problem-solving approach to family caregiver education. *Patient Education and Counseling*, 27, 63-73.

Presentation References

- Kraft, G., Johnson, K., Yorkston, K., Amtmann, D., Bamer, A., Bombardier, C., Ehde,, D., Fraser R., & Starks, H. (2008). Setting the agenda for multiple sclerosis rehabilitation research. Conference Report. Multiple Sclerosis,, 14: 1292-1297.
- Multiple Sclerosis Center of Excellence. (2012). About MSCOE. Retrieved July 13, 2012. www.va.gov/ms/About_the_Multiple_Sclerosis_Centers_of_Excellence.asp
- Mutch, K. (2010). In sickness and in health: experience of caring for a spouse with MS. British Journal of Nursing,19(4), 214-219.
- National Association of Social Workers. (2010) NASW Standards for Social Work Practice with Family Caregivers of Older Adults. Retrieved July 15, 2012. www.socialworkers.org/practice/standards/NASWFamilyCaregiverStandards.pdf
- PACER Center, Inc. (2012) History of PACER Center. www.pacer.org/about/history.asp
- Pakenham, K. (2001). Application of a stress and coping model to caregiving in multiple sclerosis. Psychology, Health & Medicine, 6(1), 13-27.
- Pakenham, K. (2008). The nature of sense making in caregiving for persons with multiple sclerosis Disability and Rehabilitation, 30(17), 1263 – 1273.
- Pakenham, K. I. (1998). Couple coping and adjustment to multiple sclerosis in care receiver – carer dyads. Family Relations, 47, 269–277.
- Patient Centered Medical Home Model Concept Paper. (2012). Retrieved July 13, 2012. www1.va.gov/PrimaryCare/docs/pcmh_ConceptPaper.doc
- Robinson-Whelen, S., and Rintala, D. (2003). Informal care providers for veterans with SCI: Who are they and how are they doing? Journal of Rehabilitation Research and Development, 40:6, 511-516.
- Seigel, S., Turner, A., and Haselkorn, J. (2008). Adherence to Disease-Modifying Therapies in Multiple Sclerosis: Does Caregiver Social Support Matter? Rehabilitation Psychology, 53:1, 73–79.
- Suppes, M. and Cressy Wells, C. (2003). The Social Work Experience: An Introduction to Social Work and Social Welfare. McGraw-Hill Humanities/Social Sciences/Languages, New York, New York.
- Social Work: Roles of a Social Worker. Retrieved July 15, 2012. www.csc.edu/cpsw/sw/careers/roles.csc

Presentation References

- The National Family Caregivers Association and the National Alliance for Caregiving (2001). A Report on Formative Focus Groups: Conducted for The Family Caregivers Self-Awareness and Empowerment Project. Lake Snell Perry & Associates. Washington, D.C. Retrieved on July 15, 2012. www.caregiving.org/research/caregiving-research/general-caregiving
- U.S. Department of Veterans Affairs. (2011). VA Caregiver Support: Teresa's Story. Retrieved on July 15, 2012. www.caregiver.va.gov/connection_teresa.asp
- U.S. Department of Veterans Affairs. (January 2009) VA and Spinal Cord Injury Fact Sheet. Retrieved on July 15, 2012. www1.va.gov/opa/publications/factsheets/fs_spinal_cord_injury.pdf
- Williams, R., Turner, A., Hatzakis, M., Chu, S., Rodriguez, A., Bowen, J., and Haselkorn, J. (2004) Social Support Among Veterans With Multiple Sclerosis. *Rehabilitation Psychology*, 49:2, 106–113
- Yessian, M.R., & Broskowski, A. (1983). *Generalists in human-service systems: Their problems and prospects*. Prentice Hall.
- Zastrow, C., & Kirst-Ashman, K. (1997). *Understanding human behavior and the social environment* (4th ed.). Wadsworth Publishing Company.

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