

SOCIAL WORK BEST PRACTICES FOR MS CAREGIVER SUPPORT

VA Social Work Career Development Call
September 25, 2012



Sloan & Webb, September 25, 2012

Presenters

- ❖ Alicia Sloan, MPH, MSW, LICSW
MS Center of Excellence–West
VA Puget Sound Health Care System, Seattle, WA.
alicia.sloan@va.gov
- ❖ Lisa Webb, MSW, LICSW
Virginia Mason Medical Center, Seattle, WA.
lisa.webb@vmmc.org

Acknowledgements:

- ❖ Jamie Wazenkewitz, MPH, MSW, LSWAIC
University of Washington MS Rehabilitation Research & Training Center, Seattle, WA.
wazenj@u.washington.edu
- ❖ Allison Fine, MSW
Counseling for Inner Balance (Private Practice); Accord Associates; Era Living; National Multiple Sclerosis Society, Greater Northwest Chapter, Seattle, WA.
balancemaintains@gmail.com
- ❖ Megan McDaniel, MSW, LICSW,
MultiCare Neurosciences Center of Washington, Tacoma, WA.
megan.mcdaniel@multicare.org



Agenda

1. Epidemiology, Assessment & Models of Treatment for the Informal Caregiver
 - ❖ Alicia Sloan
2. Group Discussion of Case Studies & Current Practice
 - ❖ Lisa Webb



Epidemiology, Assessment & Models of Treatment for the Informal Caregiver

Alicia Sloan, MPH, MSW, LICSW
MS Center of Excellence–West
VA Puget Sound Health Care System
Seattle, WA



Sloan, September 25, 2012

Slide 4

First, I wanted to acknowledge Jamie Wazenkewitz, who worked with me on some of these slides I'm showing today. We presented with Lisa and 2 Other Social workers at the Consortium of MS Centers Conference in San Diego in May.

Jamie is a social worker serving as a research therapist at the University of Washington MS Rehabilitation Research and Training Center.

Some of my slides I presented at the Paralyzed Veterans of America Summit for MS and spinal cord injury. I presented with 2 VA social workers, which we hope to present at a later date on this call.



I just want to start out with a fun, yet poignant cartoon. It says it all about Caregivers! The caregiver is lying on the therapist's couch and says, "Actually, I only come here to lie down. I can't get any rest at home!"

“Informal Caregivers” Defined

- › “An individual who cares for a friend or family member through helping the care recipient with activities of daily living or instrumental activities of daily living.” (Multiple Sclerosis Caregivers Report, 2012)
- › “An unpaid person who helps with the physical care or coping with the disease.” (Hileman, et al., 1992)
- › “With MS, it is often a family member, a partner, parent or adult child.” (CMSC website: www.ms-care.org/cm-sc/News/Web-Sights-Caregivers-Stress-2.html)
- › Informal caregivers are the primary resource allowing people with MS to remain in their homes. (Dunn, 2011)
- › CG = Informal Caregiver



Sloan, September 25, 2012

Slide 6

One definition of caregivers as it pertains to multiple sclerosis I found particularly powerful says:

“Informal caregivers are the primary resource allowing people with MS to remain in their homes.”

MS is a complex disease that affects the central nervous system (brain, spinal cord, and optic pathways). It is characterized by relapses (neurologic symptoms which appear rapidly over a few days and then improve to some extent over weeks or months), and remissions (periods of time that are without new symptoms). The disease is unpredictable and some people experience a variety of symptoms that might worsen (progress) over time. Because of the disabilities that can affect a person, the demands of caregiving can increase over time, increasing stress and burden.

Caregivers

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



(Courts, Newton, & McNeal, 2005)

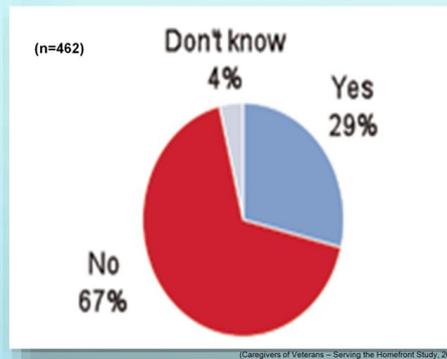
Sloan . September 25, 2012

7

(Read quote) This quote I found to be telling of how caregivers end up being caregivers.

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

Caregiving - Did We Have a Choice?

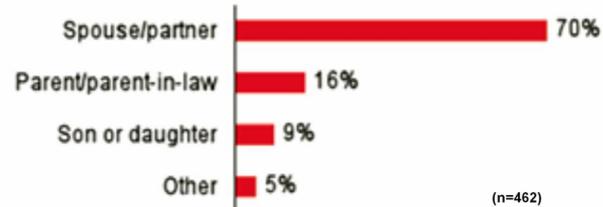


Sloan, September 25, 2012

8

So, to start with the general VA Caregiver study that many of you may know was the basis of starting the VA Caregiver program. I will go through some statistics that describe the VA Caregiver. The one statistic that struck me about caregivers of Veterans is that most caregivers at 67% reported not having a choice of being a caregiver.

Who are the Caregivers?



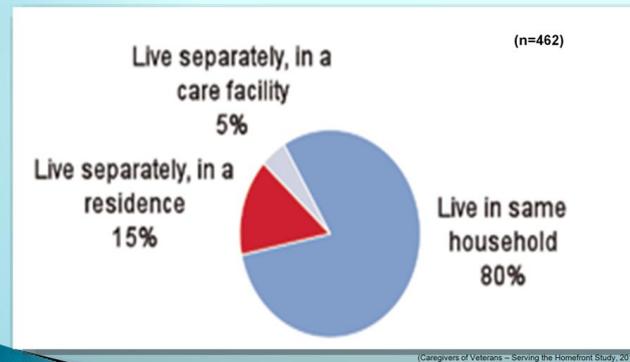
(n=462)
(Caregivers of Veterans – Serving the Homefront Study, 2010)

Sloan . September 25, 2012

9

The study showed that a large majority (70%) of Caregivers are Spouses or Partners. Only 16% are parents. And 9% are sons and daughters of Veterans.

Who are the Caregivers?



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

Sloan, September 25, 2012

10

Most 80% Caregivers live with the Veteran. 15% live outside the home. Only a small 5% care for a Veteran in a care facility. This tells me that most Veterans are staying home with their spouse or family member. Which is what we always hope to accomplish.

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)

Sloan , September 25, 2012

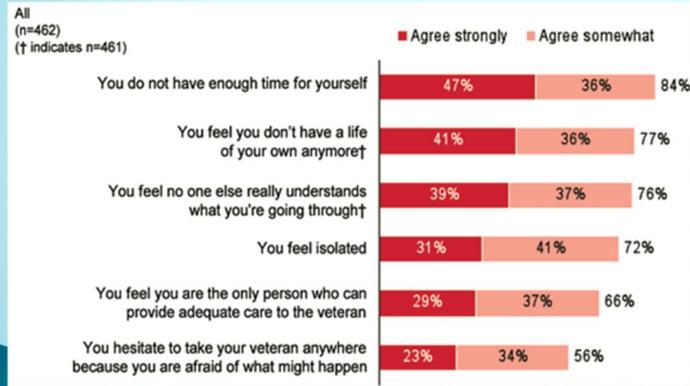
11

Most caregivers of Veterans, as we know, are women. It's interesting to compare it with the General population where a much lower percent at 65% are female caregivers vs. the 96% that are female caregivers of Veterans. More interesting and a bit surprising to me is the amazing difference between the spousal caregivers of Veterans at 70% versus only 6% in the general population.

Living with the Veteran, being the primary caregiver, and caregiving for more than 10 years is also significantly higher with Veteran Caregivers versus the general population.

This tells me that female spouse caregivers of Veterans stick around! This is pretty special and says a lot about the dedication our Veteran Caregivers.

Emotional Impact of Caregiving



(Caregivers of Veterans – Serving the Homefront Study, 2010)
Sloan, September 25, 2012

12

The emotional impact of caregiving of Veterans is very high. Most at 84% say they don't have time for themselves and 77% feel like they don't have a life of their own anymore. They also don't feel like no one else really understands what they are going through. They most often feel isolated. More than 50% hesitate to take their Veteran anywhere because they fear what might happen to the Veteran. And 65% feel they are the only one who can give the best care.

Top Challenges Faced by Caregivers of Veterans



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)

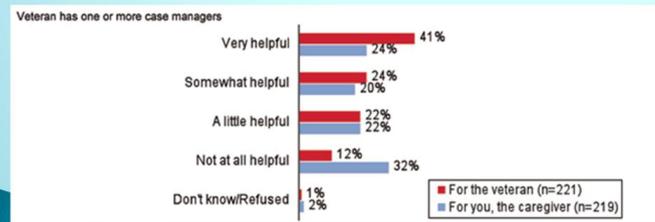
Sloan, September 25, 2012

13

The study revealed that at least 2 out of 3 caregivers had a list of challenges that they've had to face. The top challenges tell us that education about the Veteran's condition, connecting to resources and needing help navigating through the bureaucracies are what's needed the most. Where to go for a break for respite care was also a question.

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?”



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

Sloan, September 25, 2012

14

Now, let's take a look at how we as case managers and social workers have been doing with helping Caregivers. It's higher for helping the Veteran, although still less than 50%. I was a bit dismayed when I read this statistic. It would be interesting to see if we have improved since the VA Caregiver program has been implemented. What this tells me is that we have some work to do, which is why we are doing this presentation and continue to focus on Caregiver care.

Myth: The Caregiver isn't my client.



Adapted from Kris Frederickson & Adam Schug presentation, Seattle VA Puget Sound, 2011

Sloan, September 25, 2012

Slide 15

I'm wondering if any particular myths have affected our role as social workers with caregivers. This myth says "The Caregiver isn't my client."

Myth: The Caregiver isn't my client.

Reality

- ✓ Multiple Sclerosis is a "family affair." The best care you can give to the Caregiver means the best care you can give to your client with MS.
- ✓ Most Caregivers will appreciate the time you take to listen to their own needs and have their own situation taken seriously.



Adapted from: Kris Frederickson & Adam Schug presentation, Seattle VA Puget Sound, 2011

Sloan, September 25, 2012

Slide 16

And the reality is:

Multiple Sclerosis, or any chronic disease for that matter, is a "family affair." The best care you can give to the Caregiver means the best care you can give to your client with MS.

Most Caregivers will appreciate the time you take to listen to their own needs and have their own situation taken seriously.

Myth: I won't have time to help
the Caregiver.



Adapted from Frederickson & Schug presentation, Seattle VA Puget Sound, 2011

Sloan, September 25, 2012

Slide 17

Let's look at another MYTH:

If I help the Caregiver, I won't have time to complete my other responsibilities with my client.

Myth: I won't have time to help the Caregiver.

Reality:

- ☑ Caregivers may provide significant insights into the client's situation and identify important issues that are overlooked.



Adapted from Frederickson & Schug presentation, Seattle VA Puget Sound, 2011

Sloan, September 25, 2012

Slide 18

The myth is that you won't have time to help the Caregiver. But, what we find is that the caregiver can provide great insight and identify important issues that may be overlooked if we hadn't talked with the caregiver.

History of MS Caregiving Research

1980: General Caregiver Burden in chronic disease research began.

1997: First Quality of Life Study of people w/MS and their Caregivers – Aronson

- CG has a poorer QOL if...
 - ✓ A spouse.
 - ✓ Has longer duration of caregiving.
 - ✓ Moderate or worse MS symptoms in care recipient.
 - ✓ Care recipient has unstable MS disease course.



So, with these myths and realities in mind, we can start with looking at what other research says about caregivers. Giving a quick history, the timeline starts in 1980 when caregiver burden was first looked at in chronic disease research.

Later in 1997, the first quality of life study by Aronson looked at both people with MS and their caregivers and understanding their QOL issues. Aaronson hoped this research would lead to the support of home care versus going to a nursing home or assisted living.

History of MS Caregiving Research, con.

Dunn Lit Review (2011): Good review of MS Caregiver Research over 20 years.

- Reduces cost of outside paid caregiving.
- 'Hidden patient' – physical, emotional, psychological, social and economic burdens. (Buhse Study, 2008)
- 75% live with care recipient and 42% sole CG.
- Average duration = 9 years.
- Loss of mobility = greater burden for CG.
- May not be prepared for physical tasks. Recommends CG training.
- Health problems of MS patients mirrored in their CGs.
- › CG should be targeted for focused therapeutic strategies. (Pozzilli study 2004)



Quite a bit of research has been done with MS Caregivers. One Literature Review by a neurologist describes MS caregiver research over the span of 20 years. It points out MS caregiver's stress and burden, their unique challenges related to MS caregiving, and calls the caregiver "the hidden patient" since their problems may not be recognized.

History of MS Caregiving Research, con.

- **Respite/Palliative Care:** Reduces CG burden. (Edmonds, 2010)
- **Family Systems/Young CGs:** Young caregivers affected positively & negatively by parents w/MS. (Pakenham, 2007, 2012)

Latest on MS & CG:

- Multiple Sclerosis Caregivers Report, 2012.
 - ✓ Study by the National Alliance for Caregiving, NMSS, & Southeastern Institute of Research.



Other research lately has looked at respite care, reducing CG burden and how young caregivers can be impacted positively and negatively by caregiving their parent with MS.

The latest research has come out from the MS Caregivers Report this year done by the National Alliance for Caregiving, the National MS Society, and SE Institute of Research.

Who are MS Caregivers?

From 421 MS Caregiver Respondents:

- › Male 40%
- › Female 60%
- › Ave. Age 46 (range 25–86%)
- › 72% Married or living with a partner
- › 38% have Children under age 18 in the household
- › 2/3 have College or Graduate degrees
- › 70% Household Incomes were >\$50,000/year
- › Median Income for all respondents \$79,000
- › 58% Employed Full-Time

Multiple Sclerosis Caregivers Report 2012
from the National Alliance for Caregiving, NMSS, & Southeastern Institute of Research



Sloan . September 25, 2012

Slide 22

The 2012 MS Caregiver report surveyed 421 MS caregivers and describes them as being mostly female, age 46, married or living with partner, working full time. 38% have children, 2/3 have at least a college degree and a large majority make at least \$50,000.

Road to Caregiving

- ▶ 30% spouse/partner
- ▶ 26% son/daughter
- ▶ 10% sibling
- ▶ 7% friend or neighbor
- ▶ 5% parent
- ▶ 15% other relative (aunt/uncle, grandchild, cousin, in-law)
- ▶ 3% other



Multiple Sclerosis Caregivers Report 2012
from the National Alliance for Caregiving, NMSS, & Southeastern Institute of Research



Sloan, September 25, 2012

Slide 23

(skip) This slide describes the breakdown of caregivers. Many are sons and daughters and relatives.

Choice in Providing Care

- ▶ Almost half (48%) of respondents felt they did not have a choice in taking responsibility for caring for the person with MS.

Multiple Sclerosis Caregivers Report 2012
from the National Alliance for Caregiving, NMSS, & Southeastern Institute of Research



Sloan, September 25, 2012

Slide 24

Interestingly, this survey revealed 48% not having a choice of becoming a caregiver. Earlier, I said 67% of VA Caregivers said they didn't have a choice. Still a bit lower for the general population who answered this survey, but nonetheless, almost half of the caregivers didn't have a choice.

Time Spent Caregiving

- ▶ 24 hrs/wk average spent caregiving
- ▶ 13% spend > 40 hours/week caregiving
- ▶ Activities of Daily Living (ADLs) involved in caregiving: bathing, dressing, feeding, toileting, etc.
- ▶ Instrumental Activities of Daily Living (IADLs): shopping, housekeeping, transporting to doctor, cooking, handling finances, etc.

Multiple Sclerosis Caregivers Report 2012
from the National Alliance for Caregiving, NMSS, & Southeastern Institute of Research



Sloan . September 25, 2012

Slide 25

With MS Caregivers, the average amount of time per week spent caregiving is at least 24 hours, and 13% spent more than 40 hours/week caregiving – that’s a full-time job!

With MS, caregivers helped with bathing, dressing, feeding, toileting and other basic needs.

Also shopping, housekeeping, transportation, cooking, financial management, among other things.

External help for caregivers

- ▶ 27% of CGs are the only CG, but those who have supplemental paid in-home care support spend the same amount of time providing care as those who do not.

Multiple Sclerosis Caregivers Report 2012
from the National Alliance for Caregiving, NMSS, & Southeastern Institute of Research



Sloan | September 25, 2012

Slide 26

27% are the only caregiver, but even those who had help with paid caregiving, still spent the same amount of time caregiving as those who didn't have extra help.

MS Caregiver Burden

MS symptoms that increase burden on CGs

- Difficulty walking
- Cognitive Impairments
- Depression/anxiety
- Frequency of bladder dysfunction
- Instability of symptoms



CG Health Problems

- Tiredness
- Depression
- Back pain
- Insomnia
- Shortness of breath

✓ Notice how many mirror the care recipient's MS symptoms?

Dunn (2011), MS Caregivers Report (2012)



Sloan, September 25, 2012

Slide 27

Here are some of the MS symptoms that increase burden on caregivers: issues with walking, cognition, depression, bladder and bowel problems, and just not knowing what symptom will crop up or not.

Health problems that caregivers develop actually can mirror the care recipient's problems: fatigue, depression, back pain, insomnia, and shortness of breath.

MS Caregiver Burden, con.

- ▶ Most commonly reported emotional responses felt by caregivers in response to initial MS diagnosis: Compassion, followed closely by fear and anxiety.
- ▶ Negative impacts of caregiving reported:
 - overall financial situation (43%)
 - ability to participate in hobbies (39%)
 - mental health (38%)
- ▶ 1/3 suffer depression because of providing care.
- ▶ 1/2 are physically exhausted.
- ▶ Nearly 1/3 have experienced physical injury as a result of caregiving.
- ▶ 22% have lost a job due to caregiving.
- ▶ 17% report not being able to hold down a job due to caregiving.

Multiple Sclerosis Caregivers Report 2012
from the National Alliance for Caregiving, NMSS, & Southeastern Institute of Research



Sloan, September 25, 2012

Slide 28

When caregivers first find out about the MS diagnosis, they react with compassion, which is closely followed by fear and anxiety.

Then they feel the financial burden (may lose or not continue their job due to caregiving), decrease in their personal life (like hobbies) and their mental health suffers. 1/3 feel depressed, and 1/2 feel physically exhausted. 1/3 are physically injured from caregiving. So it has its physical toll.

Stages of Readiness of Support

Identified Phases in Caregiver's decision to seek and accept support:

1. Rejecting support
2. Resisting support
3. Seeking support
4. Accepting support



Source: McKeown, 2004.



Sloan, September 25, 2012

Slide 29

One study looked at different phases of caregivers decision making process of seeking and accepting support for their caregiving. It kind of looks like stages of grief, doesn't it? Rejecting, resisting, seeking and accepting support. It's our role as social workers to assist & support the caregiver through these phases.

Male MS Caregiver Burden

Buchanan Study

- National survey: Focused on MS male caregivers. (Buchanan, et al. 2011)

Results

- Greater burden assoc. greater hours per week providing assistance.
- Strong assoc. between perception of burden & mental health status of male CG



One MS Caregiver study looked at male caregivers. They found greater burden experienced as the number of caregiver hours increased for the male caregivers. They also found the perception of burden and the mental status were strongly related. It makes us want to pay particular attention to helping male caregivers.

Positive Impacts on Caregivers

- Positive impact on relationships with care recipient, children and other family members (74%)
- Health/in better shape (36%)
- Emotionally rewarding (25%)
- Better outlook on life (22%)
- Save more money (21%)
- Doing new hobbies with care recipient (19%)

Multiple Sclerosis Caregivers Report 2012

from the National Alliance for Caregiving, NMSS, & Southeastern Institute of Research

- Health of person w/MS associated w/caregiver perceptions that providing assistance strengthened caregiver/care recipient relationship. Nat'l NARCOMS survey: 530 CGs (Buchanan & Huang, 2011)



Sloan . September 25, 2012

Slide 31

Despite the negative impacts, there were positive impacts of caregiving of people with MS.

74% felt there was a positive impact on their relationship with the care recipient and other family members.

Some (36%) felt it improved their health and they were in better shape.

¼ found it emotionally rewarding.

22% felt they had a better outlook on life.

Some even felt they saved more money.

19% were doing new hobbies with care recipient.

Interestingly, the health of the person with MS was associated with the caregiver's perception that providing help strengthened their relationship.

Impacts on Relationships: Caregiver Challenges

Relationship/Family

- ▶ Frustration with care recipient (42%)
- ▶ Increased arguing with care recipient (14%)
- ▶ Doesn't have enough time to spend with other family members (27%)
- ▶ Argues with other family members about how to best provide care (20%)
- ▶ Can't spend enough time with children as would like (19%)

Multiple Sclerosis Caregivers Report 2012
from the National Alliance for Caregiving, NMSS, & Southeastern Institute of Research

Marriage

- ▶ Females more likely abandoned/divorced by husband after diagnosis. (Glantz, 2009)
- ▶ But...motivating factor for CGs – marriage vows and commitment to marriage important. (Mutch, 2010)



Sloan, September 25, 2012

Slide 32

MS caregiver stress and burden affects the family relationship, personal relationship with the care recipient and the put major stress on marriages. Frustration and arguing can escalate, other family members can be affected like not being able to spend enough time with children or other family members. Arguments with other family members about care can ensue. We talked earlier about male caregivers feeling more burden as the hours of caregiving increased; one statistic showed that females diagnosed with MS were more likely to be abandoned or divorced by their husband after being diagnosed. This tells me that as social workers we need to pay attention to male caregivers and reach out to assess their needs and caregiver burden as soon as possible.

On a more positive note, one study was done that identified the marriage vows and commitment as the motivating factor for caregivers.

Factors in Relationship Strength

Interviews w/ 8 (MS/CG) Couples (Starks, et al., 2009)

In-Sync	Out-of-Sync
MS Type: Relapsing/Remitting	MS Type: Progressive
Gradual onset of symptoms/impairments	Acute onset of symptoms/impairments
Slower progression of disease w/periods of remission	Faster progression of disease w/few (if any) remissions
Life roles/changes mostly 'on time'	Considerable disruptions to life roles & timing, including premature retirement
Share similar attitudes/approaches /strategies to problem-solving; frequently work as a team	Have different attitudes/approaches/ strategies to problem-solving; not always working as a team
Similar work/personality styles	Opposite work/personality styles previously complementary but in the context of increased demands become a source of conflict
	Adolescent children in the home



Sloan, September 25, 2012

Slide 33

This chart describes how the 2 different types of MS can affect how in-sync or out of sync couples can become in their relationship. The relapsing remitting type, where it may be a slower progression or shorter time periods of MS symptoms, may have less of an impact on the relationship than the more progressive type of MS, where symptoms may rapidly bring disability and impact daily functioning at a more intense rate.

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)

At the VA MS Center of Excellence, we've done some research with MS CGs in different studies. We've learned that the greater social support from the caregiver perceived by the Veteran with MS & the more affectionate support from the caregiver results in less depression in the Veteran. We also found out that the supportive qualities from the caregiver helps with adherence to their MS disease modifying medication. So, caregivers who are supportive and affectionate can help the Veteran feel less depression and improve adherence to their MS medication.

Myth: I don't have time to do a CG assessment.
...it will interrupt my flow and interfere with client trust.



Adapted from Kris Frederickson & Adam Schug presentation, Seattle VA Puget Sound, 2011

Sloan, September 25, 2012

Slide 35

Okay, going back to myths again. Let's look at another myth about assessing caregiver burden and stress:

The myth is I don't have time to do a caregiver assessment....it will interrupt my flow and interfere with client trust.

Myth: I don't have time to do a CG assessment...it will interrupt my flow and interfere with client trust.

Reality

- ✓ CG assessments are tools to guide the conversation and clinical practice.
- ✓ Assessments can pick up on issues concerning CG that may not be obvious.
- ✓ Assessments can be shortened, efficient and adapted for clinical use.
- ✓ Most importantly, the caregiver will feel listened to and acknowledged.



Adapted from Kris Frederickson & Adam Schug presentation, Seattle VA Puget Sound, 2011

Sloan, September 25, 2012

Slide 36

The reality is:

- Assessments can always be shortened and adapted for clinical use.
- Caregiver assessments can be used as tools to guide conversation and practice.
- Assessments can pick up on those possible “hidden” issues that may not be obvious. Reveal “the hidden patient”.
- Most important, the assessment may help the caregiver feel listened to and acknowledged.

Lisa later on will show us an example of how assessment can be used this way.

Myth: I won't have the answers or resources to deal with Caregiver issues



Adapted from Kris Frederickson & Adam Schug presentation, Seattle VA Puget Sound, 2011

Sloan, September 25, 2012

Slide 37

Let's look at this myth: I won't have the answers or resources to deal with caregiver issues.

Myth: I won't have the answers or resources to deal with Caregiver issues

Reality:

- ☑ Avoiding or excluding caregiver issues can lead to bigger problems with care.
- ☑ It is possible to work creatively with caregivers to tailor the use of limited resources.
- ☑ There are more resources than ever on the internet and accessible to caregivers.



Adapted from Kris Frederickson & Adam Schug presentation, Seattle VA Puget Sound, 2011

Sloan, September 25, 2012

Slide 38

The reality, if we avoid or exclude cg issues, it can lead to bigger problems with care. The other reality is, we have resources now, like the VA Caregiver website, that gives us a lot of tools to help caregivers. For specific diseases like MS, we are developing more and more web resources we can refer the caregiver to. Whenever I feel like I don't know where to turn, I say to the MS caregiver, I'm not sure, let's see if our website or if I "google" your question turns up an answer. They are much more responsive to me if I attempt to find the answer than if I don't assist at all. It is possible to work creatively with cg using limited resources, like using the internet.

Caregiver Assessments

- ❖ Sullivan Lit. review (2008) of 9 CG assessments.
 - Recommends CSI: short, easy, objective.
- ✓ Zarit Burden Scale (Zarit, 1980) (public domain)
- ✓ Caregiver Strain Index (CSI) (Robinson, 1983)
- ✓ Caregiving Tasks in MS Scale (CTiMSS) (Pakenham, 2007)
- ✓ Caregiver Reaction Assessment Scale (CRA) (Given et al., 1992)
 - w/SF-36 (Forbes, 2007) – 257 MS CGs survey
- ✓ CAREQOL-MS: Caregiver quality of life (Benito-Leon, 2011)
 - Specific to MS CGs. Will use examples of it later in Lisa's Case Studies presentation. Lisa found useful for her caregiver clients.



In looking at CG assessment tools, we found several useful standardized assessments that are available to use.

- You may already be familiar with these assessments & may already use them.
- Probably the most widely used is the Zarit Burden Scale and the Caregiver Strain Index. The CSI is short and easy to use and objective.
- Others have been developed for MS caregivers: CAREQOL-MS & Caregiving Tasks in MS Scale (CTiMSS).
- The CAREQol-ms Lisa will demonstrate its use in her case study presentation.

Caregiver Assessments

How many of you use these assessment tools?



Sloan, September 25, 2012

Slide 40

I'm wondering how many of you use any of the caregiver assessment tools with your Caregivers of Veterans?

Comprehensive Caregiver Assessments

- Context
- CG's perception of health and functional status of care recipient
- CG's values and preferences
- Well-being of the CG
- Consequences of Caregiving (perceived challenges & benefits)
- Skills/abilities/knowledge to provide care recipient with needed care
- Potential resources that caregiver could choose to use

Family Caregiver Alliance (2006). Caregiver Assessment Principles, Guidelines and Strategies for Change. Report from a National Consensus Development Conference (Vol. 1) San Francisco, CA.



Sloan, September 25, 2012

Slide 41

For those of you who have never used a CG tool or even those of you who do use them, there are some things to keep in mind when choosing a CG assessment:

- Think about the CG's context and perception of the care recipient's health and functioning.
- Also, keep in mind values and preferences of the CG.
- What are the challenges faced by the CG?
- What resources and other educational tools may be needed by the CG?

Critiques on Assessment Tools

- › Focus on burden rather than strengths.
- › Caregiver assessments often do not recognize multiple caregivers.
- › Many assessment tools not designed within a multicultural framework.
- › Length of questionnaires/time takes to give questionnaire.
- › There is not one that focuses on everything.
- › Specific questions direct to specific issue.

- › Others???

Adapted from Kris Frederickson & Adam Schug presentation, Seattle VA Puget Sound, 2011



Sloan, September 25, 2012

Slide 42

Some critiques of the current assessment tools are:

- There is more focus on burden rather than strengths.
- Hard to use for multiple CGs.
- They don't consider multicultural contexts.
- Length of time to do questionnaire.
- There is not one questionnaire that will do it all.
- The most useful way to use the assessments are to target for specific issues.

Models of MS CG Support

“Powerful Tools for Caregivers”

- Award winning national program supported by community-based organizations.
- 6 week educational series designed to provide family caregivers with tools needed to take care of themselves while caring for a loved one.
- Self management, skill building in stress management, communication, decision making.
- Based on study & program by Kate Lorig, et al. Stanford U.
- www.powerfultoolsforcaregivers.org



(skip) I just wanted to mention this caregiver model as a resource called “Powerful Tools for Caregivers” and it’s getting great reviews. It’s a 6 week course that trains caregivers and providers based on Kate Lorig’s research program. It’s being used all over the country.



▶ **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

▶ **MSCOE Website:** www.va.gov/MS

▶ **Stories:** www.va.gov/MS/Family_is_Everything.asp

▶ **Newsletter:** www.va.gov/MS/Newsletters.asp

Outreach we are doing with MS Caregivers at the VA MS Center of Excellence is a monthly caregiver support call led by me and another social worker, Maggie Kazmierski, from the Baltimore VA. This call offered to all VA MS caregivers nationally to give emotional support and share MS resources and learn about MS specific topics. This is a great example of how a VA caregiver in Seattle, WA can reach out to a caregiver in Gainesville, Florida, or Baltimore, MD, and discuss issues and support each other even across the country. Now, is this Macro level social work working well or what? We also have patient education calls that caregivers can participate in, access to our website, and the MS Veteran Newsletter. One anecdote I wanted to share with you all is what a caregiver told us in the last call. She said that she counted on the caregiver support call every month because it was the only thing that kept her going and that she could share what she is going through as a caregiver. It meant a lot to her. It made me want to offer the call every week! But, it also told me how important it is to offer a place where the caregiver can talk to others about issues, share resources and help each other with common problems.

Case Studies: MS Caregivers

Lisa Webb, MSW, LICSW
Virginia Mason Medical Center
Seattle, WA



Webb, September 25, 2012

Slide 45

Case Studies

- ▶ 3 Actual MS Client/Caregiver scenarios.
(names have been changed)
- ▶ Questions to think about.
- ▶ Application of CG Assessment
 - some CAREQOL-MS Questions.



Case Study #1 Phillip

- ✓ 33-yr single male, RRM-MS, onset 2003
- ✓ Symptoms mostly affect mobility, also has significant tremor
- ✓ Moved in with mother, home renovated to add downstairs apartment to accommodate Phillip
- ✓ Mother, primary caregiver, travels for work
- ✓ Phillip qualified for State program, COPES
- ✓ Phillip's care needs increased as MS progressed to total care, mother struggling to meet his needs
- ✓ Phillip once fell on his mother causing injury which prevented her ability to care for him for a week



Case Study #1 Phillip's Mom: Linda

- Linda needed knee surgery from arthritis so Phillip was placed in a skilled nursing facility.
- Even after surgery, she couldn't take care of him.
- Long-term plan is for him to remain at SNF.
- Linda still struggles emotionally and expressed desire to take Phillip back home.
- Linda still needs to be involved in Phillip's care as an advocate due to inadequate care he is receiving at the SNF.



Questions

- ▶ How can you support Linda with the decision to move Phillip to a nursing home?
- ▶ CAREQOL-MS Statements for Linda to Rate:
(1 =not at all, 2=a little, 3=sometimes, 4=quite a lot, 5=a lot)
 - I'm scared about the progress and consequences of MS.
 - My own health has worsened over the course of this year.
 - Ever since the person whom I care for started suffering from MS, I devote less time to my own personal appearance and well being.



Case Study #2 Candy

- ✓ 26-yr female with Primary Progressive MS, onset age 13.
- ✓ Symptoms: mobility, also has tremor, cognitive dysfunction & depression.
- ✓ Moved in with father upon college graduation.
- ✓ Father became primary caregiver, very supportive overall.
- ✓ Candy's care needs increased over couple of years at home.
- ✓ Qualified for assistance from State program COPES.



Case Study #2 Candy's Dad: Frank

- Frank became a paid caregiver.
- There has been tension in relationship given Frank's role as caregiver (blending between father/caregiver responsibilities).
- Candy now wants to move out of the house and live independently.
- Frank admits to struggling with caregiver burnout but very worried about Candy moving out.



Questions

- ▶ What resources would be helpful to Candy and Frank?
- ▶ CAREQOL-MS Statements for Frank to Rate:
(1 =not at all, 2=a little, 3=sometimes, 4=quite a lot, 5=a lot)
 - I reflect about the suffering that limited mobility brings to the person with MS whom I care for.
 - The attitude of the person with MS whom I care for elicits mood changes in me.
 - Taking care of a person with MS has meant a change in my lifestyle.



Case Study #3 Esther

- ✓ 49 yo married female w/Secondary Progressive MS since age 27.
- ✓ Baseline hemiplegia requires moderate assistance.
- ✓ Symptoms primarily physical w/some cognitive decline.
- ✓ Married 20+ years. Husband is primary caregiver.
- ✓ Esther's care needs continue to increase to the point where husband questions his ability to continue providing care.
- ✓ Paid caregivers assist when husband travels for work.
- ✓ Esther and her husband exploring care options as her needs increase.
- ✓ Esther wants to remain at home.



Case Study #3

Esther's Husband: Ted

- Ted has an out-of-town lover who Esther is aware of and permitting as a way to save her marriage.
- Ted admits difficulty watching Esther's MS progression; their relationship is based on intellectual activities now more challenging to Esther.
- Esther in a transitional care facility for a month recovering from multiple medical issues and will discharge to her home.
- Ted is concerned about Esther's return home with fear:
 - "Does she have enough care at home?"
- Ted has his own health issues that need to be addressed.
- Esther has expressed she feels Ted is "checked out" at times.



Questions

- ▶ What can the team do to help Ted reconnect with Esther emotionally and intimately?
- ▶ CAREQOL-MS Statements for Ted to Rate:
(1 =not at all, 2=a little, 3=sometimes, 4=quite a lot, 5=a lot)
 - Multiple sclerosis has affected my relationship with my partner either regarding our sexual or emotional relationship.
 - I believe some psychological aid would help me provide better care for the person with MS.
 - I have been suffering from sleep disturbances since I learned that the person whom I care for suffers from MS.



Resources

VHA Resources

- ❖ VA Caregiver support line: (855) 260-3274
- ❖ VA Caregiver Support: www.caregiver.va.gov
- 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 MS Centers of Excellence (MSCoE): www.va.gov/ms

Community Resources

- ❖ The National Alliance for Caregiving: www.caregiving.org
- ❖ Powerful Tools for Caregivers: www.powerfultoolsforcaregivers.org
- ❖ Today's Caregiver Magazine: www.caregiver.com
- ❖ National Family Caregivers Association: www.nfcares.org
- ❖ A caregiver managed website: www.caregiverscommunity.com

MS – Specific Resources:

- ❖ MS International Federation: www.msif.org/en/life_with_ms/family_friends_and_carers
 - ❖ CMSC: www.mscares.org/cmssc/News/Web-Sights-Caregivers-Stress-2.html
www.mscares.org/cmssc/News/Web-Sights-MS-Caregivers.html
 - ❖ National MS Society:
www.nationalmssociety.org/living-with-multiple-sclerosis/relationships/index.aspx
www.nationalmssociety.org/living-with-multiple-sclerosis/relationships/carepartners/index.aspx
- A Guide for Caregivers: <http://www.nationalmssociety.org/search-results/index.aspx?q=caregiver%2C+care+partner&start=0&num=20>



Thank you all for coming today!

I just want to point out online resources we used for the presentation.

Links to the cg assessments are also listed here.

Assessment Tools – References

- Zarit Burden Scale (Zarit, 1980) (public domain)
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



Caregiver Resources & Websites

Other Websites for Caregivers

- › American Academy of Family Physicians – A Practical Guide to Caring for Caregivers (with Zarit Burden Scale): www.aafp.org/aafp/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
- › Communication Tips & Assisting a Caregiver: www.familycaregiving101.org/assist
www.familycaregiving101.org/assist/communicating.cfm
- › Paralyzed Veterans of America: www.pva.org/site/c.a1Rk9NjLcJ2E/b.6306123/k.B389/Caregivers_Support.htm
- › Rosalynn Carter Institute for Caregiving: www.rosalynncarter.org
- › Website caregivers to other caregivers, personalized information, and local resources: www.agingcare.com/Caregiver_Support
- › The Family Caregiver Forum, National Family Caregiving Association: www.thefamilycaregiver.org/ed/bb/index.cfm
- › 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



Other websites for caregiver resources.

Caregiver “Sharing” Websites



Sloan & Webb, September 25, 2012

59

More websites to share with Caregivers for planning, sharing caregiving, and create a support system.