SOCIAL WORK BEST PRACTICES FOR MS CAREGIVER SUPPORT

VA Social Work Career Development Call
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Agenda

1. Epidemiology, Assessment & Models of Treatment for the Informal Caregiver
   - Alicia Sloan

2. Group Discussion of Case Studies & Current Practice
   - Lisa Webb
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!”
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.
(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.”

(Courts, Newton, & McNeal, 2005)
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.
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.
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.
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.
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.
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.
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.
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.”
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.
Let’s look at another MYTH:

If I help the Caregiver, I won’t have time to complete my other responsibilities with my client.
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.
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.
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.
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.
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.
(skip) This slide describes the breakdown of caregivers. Many are sons and daughters and relatives.
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.
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.
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.
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.
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 ½ feel physically exhausted. 1/3 are physically injured from caregiving. So it has its physical toll.
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.
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.
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.
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.
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.
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.
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.
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.
Let’s look at this myth: I won’t have the answers or resources to deal with caregiver issues.
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.
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.
I’m wondering how many of you use any of the caregiver assessment tools with your Caregivers of Veterans?
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?
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.
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.
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

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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- yo 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-yo 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.
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.ug.edu.au
- Caregiver Reaction Assessment Scale (CRA) (Given et al., 1992)
  - Email Dr. Barbara Given, Michigan State University. barb.given@msu.edu
- CAREQOL-MS: Caregiver quality of life (Benito-Leon, 2011)
  www.sciencedirect.com/science/article/pii/S0895435610602866
Other websites for caregiver resources.

- University of Alabama at Birmingham – Caring for Caregivers – SCI InfoSheet #17: [www.spinalcord.uab.edu/sciasp/data/k-20479](http://www.spinalcord.uab.edu/sciasp/data/k-20479)
- Communication Tips & Assisting a Caregiver: [www.familycaring101.org/assist](http://www.familycaring101.org/assist)
- Communicating with Your Caregiver: [www.familycaring101.org/assist/communicating-with-your-caregiver](http://www.familycaring101.org/assist/communicating-with-your-caregiver)
- Paralyzed Veterans of America: [www.pva.org/caregivers/](http://www.pva.org/caregivers/)
- Rosalynn Carter Institute for Caregiving: [www.rosalynncarter.org](http://www.rosalynncarter.org)
- Website caregivers to other caregivers, personalized information, and local resources: [www.caregiver.com/Caregivers-Support](http://www.caregiver.com/Caregivers-Support)
- The Family Caregiver Forum, National Family Caregiving Association: [www.thefamilycaregiver.org/web/index.htm](http://www.thefamilycaregiver.org/web/index.htm)
- Caregiver planning diary: [www.e-caregiver.com](http://www.e-caregiver.com)
- Caregiver book: [www.e-caregiver.com](http://www.e-caregiver.com)
- Caregiver support and sharing: [www.familycaring101.org](http://www.familycaring101.org)
- Caregivers seeking information and support: [www.caring.com](http://www.caring.com)
More websites to share with Caregivers for planning, sharing caregiving, and create a support system.