

MS FOCUS GROUP THEMES * NARRATIVE SUMMARY

Description of Groups

We conducted four focus groups, one each for male caregivers (CGs), female CGs, male persons with MS (PwMS), and female PwMS. We divided the groups in this way because we believed caregivers and persons with MS have somewhat different perspectives. We also felt that gender might influence viewpoints of participants. Role and gender were also made homogeneous to ensure similarity within each group. Between 3 or 4 individuals participated in each group. The PwMS were somewhat harder to engage than the CGs, and this was particularly true of the female PwMS group. We speculated that this was in part attributable to some cognitive deficits that made tracking the conversation and organizing responses somewhat more limited.

Description of sample

All but one of the participants had been a participant in the earlier phase of the study the survey validation stage that included LEAD panel assessment of whether mistreatment had occurred. The other participant, a male caregiver, participated in the field study of phase 1 and no evidence of mistreatment was collected in that assessment. Each group consisted of 4 members except for the group of female caregivers which consisted of 3 members.

Recruitment was by priority based on the results of the survey study.

1. Those PwMS whose CGs reported mistreatment (usually psychological abuse), while they reported either less or no mistreatment (from 5 dyads: 2 female PwMS, 3 male PwMS, 1 female CG and 3 male CGs.)
2. Others who participated as a dyad were contacted after the first subgroup was exhausted (one dyad: male pwMS and female CG, no abuse; one female PwMS, no abuse; one female caregiver who had been abusive).
3. Others who participated in the survey study without a caregiver were recruited (one female PwMS who had been abused)
4. One participant from the field study (a male CG, assumed not abusive).

Some of the abusive caregivers and dyads were indignant or angry at being contacted and this certainly represents a selection bias. Nevertheless, 11 (6 PwMS and 5 CGs , 4 of each from the same dyad) of the 15 participants were confirmed as having abusive relationships (that is the expert panel considered all evidence and assessed that abuse had occurred). Participants not in abusive relationships included one participant in each of the four groups.

The age range for the eight PwMS was from 44 to 85; and they had been diagnosed with MS for from 1 to 35 years. All required the use of assistive devices for mobility. Their caregivers included five spouses (one of these a spouse equivalent), one mother and two other relatives. Sexes of caregivers were five female and three male, and two were Hispanic caregivers. Caregiver ages ranged from 26-76 years and duration of caregiving from between 1 and 2 years to 35 years.

The age range for the four male and three female CGs was from 34 to 76. Six were spouses (one spouse equivalent) and all had known their care recipient with MS for more than 10 years. None were Hispanic, one reported indigenous (native American or Alaska native) race and another was African American. Only one worked full-time and one part-time. Years of education ranged from 14-17. Their four female and three male care recipients ages ranged from 55-68. None were Hispanic and one was African American. The care recipients had been diagnosed from 4 to 35 years, and all required assistive devices for mobility.

In addition to the focus group discussions, All PwMS were asked to complete the 16 item Spann-Fischer Codependency scale ($M \pm SD = 46.75 \pm 13.30$). Based on preliminary norms, two participants (25%) scored within the low range < 37.3 indicating unlikely codependency and the other eight scored higher, in the midrange (< 67.2), but none over that level, which was highly sensitive for codependency. {{3684 Fischer, Judith 1991}} There was no difference of means for male and female participants (Mann-Whitney U nonparametric test) either with or without the non-abused participant scores included. Scores trended lower for the males, and this difference is documented in the literature.

Denial of Mistreatment

All participants in all groups (CGs and PwMS) denied that they either administered or received mistreatment (defined by the facilitator as persistent shouting, raised voice, threats of abandonment, or neglect).

Male CGs who had been abusive acknowledged that “other” CGs couldn’t cope, and empathized with their situation. “Statistically, you hear about the number of spouses that, who are the caregivers, say, I can’t deal with this.” One male CG stated that he thought mistreatment must be prevalent because it is so hard to watch the PwMS deteriorate and the CGs could not manage their helplessness. Male CGs thought it was more likely for male CGs to leave PwMS because in general, as caregivers, they were not as good as women and “couldn’t handle” the burdens of the CG role. For themselves, the male CGs mostly denied any mistreatment: “...and it does get frustrating, and sometimes what I do is I take a walk, go outside and scream, I’m sure the neighbors have heard me scream, but I just scream at myself, I never scream at [the PwMS] because it’s, it’s not [the PwMS], it’s the disease.” One male CGs stated that his self-worth came from being able to take care of the PwMS, and would take it as a personal failure if the PwMS went to a nursing home. “I went through a range of emotions I’ve never experienced in my life [when [the PwMS] had to go to a nursing home when the CG needed surgery]. I would, I cried for 2 or 3 hours, I got extremely angry, I wouldn’t talk to anyone, I wouldn’t do anything. Because it seemed like I had become such a failure, that I couldn’t keep [the PwMS] out.” In an interesting turn of phrase, another male CG stated it was his devotion that stood between him and leaving or hurting the PwMS. “And that, that’s why, if I didn’t love [the PwMS] as much as I do, I can easily, easily, easily understand why somebody would say, I can’t take anymore of this, because I’m gonna hurt [the PwMS]. And walk out the door.” As the discussion progressed, a couple of male CGs acknowledged minor mistreatment such as raised voice and expression of frustration, as well as thoughts that “it would be better for everyone if the PwMS died.”

Female CGs who had been abusive similarly denied engaging in any mistreatment, and expressed shock that CGs could mistreat PwMS. Like the male CGs, they were quick to say they would never leave the PwMS. They agreed with male CGs that women generally made better CGs, because they were more nurturing than men. Also like their male counterparts, as the focus group continued, they acknowledged minor instances of mistreatment: One admitted that “outsiders” might view her as “hard,” and overly anxious about the PwMS; another acknowledged “yelling.” One said that it was hard to know when it was “appropriate” to get angry at the PwMS: “What and who can say, what’s an appropriate thing to get mad at for them?” One CG acknowledged not taking the PwMS to the ER after a stroke with the following justification: “It is very hard to tell what’s M.S. and... I quit thinking, you know, you get in the habit of okay we’re not going to run to the Doctor for every little thing. It is probably aspiration and [the PwMS] had a stroke in August and I thought it was M.S. I didn’t take [the PwMS] to the hospital until finally the next day.” On the whole, female CGs tended to minimize conflicts and one participant denied ever raising her voice in anger toward [the PwMS]. Female CGs seemed to define mistreatment as physical violence; or if PwMS was neglected or their safety was threatened in any way. They did not seem to feel shouting or raised voices really qualified as mistreatment.

Male PwMS who had been mistreated denied mistreatment by their CGs as well. “So I’m just very fortunate. I mean, [the CG] is wonderful.” One described CGs as angels: “I just think, in some ways, they’re like an angel. They’re just, you know, floating around, always helping you.” The abused participants agreed with the statement that their CG understood their perspective and was empathetic toward them. They also seemed to agree that it was up to the PwMS to let the CG know if there were problems: “You know, when it (CG neglecting, not responding to PwMS) happens a lot, you should let your caregiver know.”

Female PwMS who had been mistreated also denied mistreatment and, like the female CGs, expressed disbelief that such a thing could happen. In fact, throughout the session, although the facilitator attempted to move on to other topics, the participants returned again and again to attestations of how caring their particular CGs were. One CG echoed another woman’s praise of her (abusive) [CG]: “My [CG] is very caring, very loving, very giving to me, just like your [CG] sounds like. And uh, from the very beginning you [the facilitator] were talking about problems that I had never had.” Another stated, “Boy, [her CG] really does care. You know, [the CG] looks into a lot of different things for me. And, uh, [the CG] is now very, very happy [taking care of speaker].” A third concurred: “I know my [CG]... [the CG] likes it, [the CG] loves to be part of this. [the CG]e loves to cook, [the CG] loves to do everything. So I let [the CG].” These women went to great lengths to convey an image of loving, willing devotion in their caregivers.

Blaming PwMS for Lack of Empathy toward CG

A couple of abusive **male CGs** stated that the PwMS was not appreciative of their efforts; and was not empathic to what the CG was going through. “Like, you know, [the

PwMS] paid absolutely no attention, or, didn't see, or saw, and didn't care. I don't know. But you know, I end up going, 'Didn't you just see what in the hell I was going through?'" Another complained, "And no matter how sick I get, I'm never as bad as [thePwMS] is. And [thePwMS] reminds me of that. And [the PwMS] will tell me that." However, another abusivemale CGs disagreed, saying the PwMS indeed was appreciative of CG's efforts.

While some abusive male CGs felt PwMS was unappreciative and unempathic, all abusive **female CGs** reported the PwMS to be appreciative of their caregiving efforts, although some noted the PwMS was also apologetic for the demands made on the CG. However, some female CGs felt the PwMS didn't have empathy for what the CG was going through, and was not sensitive to the CG. One woman explained this by speculating that all the PwMS' energy went into just making it through moment-by-moment, so they aren't aware when they have frustrated the CG. "And a lot of it's being used in just maintaining themselves. I, I definitely noticed [the PwMS] is not as, um, sensitive to, not just me as her caregiver, but the people around [the PwMS] in general. Um, I don't think [the PwMS] notices when she's exasperated you, as easily as [the PwMS] used to."

Challenges of the CG Role

Male CGs who were abusive all felt the CG role was extremely challenging. "You gotta be a super human being to deal with this." Some of the problems they identified were the emotional cost of being a CG; the fear of worsening disease and what the future would bring; anger at the unfairness of life; and helplessness at having to watch the PwMS deteriorate. They expressed frustration that the CG always had to be "the strong one," to be "in control," and to anticipate accidents and problems. They pointed out that the CG can never get sick because no matter how sick they are, the PwMS is always worse off. One participant also described extreme isolation, with no one interested or willing to listen to his struggles as a CG. The same CG said he felt like a second-class citizen because of how being a caregiver had constrained his life. Another described the "shattering of dreams" that occurred with the diagnosis of his wife, and later expressed passive suicidality, hoping for a terminal illness to end his suffering. "I never contemplated suicide. But when I went to see a hepatologist about whether or not I had a liver disease at UCLA, I was praying I had it. Because I said, 'It's gonna be over. Yeah. I'm gonna die. I want cancer.'"

The pressure of, in their eyes, always needing to be responsible and in charge was very taxing to these male CGs. "You got to always be anticipating. My wife [indiscernible] finishes drinking something. Yeah. And then she takes her hand off... I got a, a Golden Retriever that is a service animal, for her. And he's got this tail that's wild, okay? [laugh] If it's anything with a dye in it, it's going to end up o the rug. I know it's gonna end up on the rug. [indiscernible] So whenever she drinks anything, I gotta watch her. Going out to dinner, same thing. Gotta watch her. Again you get frustrated." Another speaker echoed this sentiment: "But it's the anticipation. You've got to anticipate a threshold that high. It stops the wheelchair, and flips it, you know? Um, things like that. And you're, you're

always... on. Even when you're asleep, you're on. The switch never goes off.” Another told a similar story: “You know the way I, I describe it to people. If you watch Star Trek. And the Captain, sometimes he'll be on yellow alert. [indiscernible] red alert, they're full mode. I said, we're always on yellow alert. We never go off. So that even if the person doesn't have an immediate need, you're still primed for what you know is gonna happen. Something is gonna happen.”

Female CGs who were abused did not address this issue in depth. While they appeared to empathize with the challenges of the CG role, notably by sharing stories of “other” CGs getting divorced due to the stress of being the caregiver, there was a fair amount of rejection of the idea that MS had taken over their lives, or that they felt overwhelmed, or that they felt fear about the future.

Male PwMS sympathized with the CG role, and thought it was very difficult to stay in a relationship with a PwMS. One PwMS described the CG as a “sponge” who had to absorb all the PwMS frustrations. Several men in this group believed the level of care required by the PwMS could be burdensome, and perhaps too much for a CG. One admitted that if the roles were reversed, he didn't know if he would stay in the relationship because of the burden. Another CG said that although in a long-term relationship, the CG had the advantage of really knowing the PwMS (in contrast to a professional caregiver), this didn't make the task of caregiving any easier. Several expressed the belief that many of the long-term relationships with a PwMS ended in divorce, although one normalized the prevalence of divorce, and implied that MS was not necessarily relevant. These men were quick to take the perspective of the CG. Several expressed the need to mollify or pacify the CG (one participant described taking a “nap” on the floor after he fell down rather than bother the CG):

Speaker: “But it's difficult. Like, I can't get up, like you said. But it's, uh, it takes a good...”

Facilitator: “It's a matter of time. It takes longer for you. Or if you're tired, you, if you fall down, and you want to get up right away. It's, a lot of times, that's not going to happen.”

Speaker: “No. I don't mind sleeping, you know. Have to wake up a half hour later, [laugh], I mean, [laugh],

Facilitator: “So you're, you're a little flexible, but still somebody needs to come and, and, and help you.”

Speaker: “Sure, it would be nice.”

Another member of this group talked of having to manage his anger so he wouldn't take it out on the CG: “You have to back off, and you have to realize.that, that does,'cause [otherwise] you're gonna have to take it out on something or somebody.” In a similar

disclosure, someone else noted that, if he lost his temper with his CG, he always apologized right away so that things wouldn't escalate. Along these same lines, a different speaker mentioned the importance of developing patience until the CG was ready to help him. One participant noted that he just "tried to be as quiet" as possible, so as not to irritate the CG.

Female PwMS did not speak much on this topic. However, like the female CGs, they too expressed empathy for the difficulty of the CG role: "I think you have to be understanding. of what the person's going through."

Challenges of the PwMS Role

Male and female CGs both acknowledged the frustrations of having MS, but did not discuss this issue in depth.

A couple of abused **male PwMS** admitted that sometimes they felt ignored or neglected by their CG, and had to make special efforts to get attention. Loss of independence, and especially loss of driving and loss of work, were reported as particularly difficult aspects of MS.

These men felt very vulnerable, initially not wishing to disclose their disease for fear they would lose their employment; and now fearing the government would not provide adequate support or that they would end up alone and dependent. The fear of the CG leaving was pervasive in this group:

Facilitator: "Is that a fear that any of rest of you had? That your partner would leave, you know, and just throw up his or her hands, and say, enough is enough?"

Speaker 1: "I think that's a fear. Out of my frustration that I blow it...Uh, go too far."

Speaker 2: "Could be. [Caretaker] and I have had disagreements. Um, but, I don't think he actually would leave..."

One participant shared his awareness of other PswMS who had committed suicide, and admitted that this scared him: "I think what scares me the most is out of those three people [speaker knew with MS], two have committed suicide." One participant explicitly denied suicidality. He stated that he had accepted his disease although he didn't like it.

Female PwMS who had been abusive did not focus on this topic.

Particularly Stressful Aspects of MS

Several **male CGs** who had been abusive mentioned the "**unpredictability**" of the disease, noting that it was impossible to know what to expect. One CG stated, "But no matter what happens, the next day I wake up thinking that it's gonna be better today when in fact I don't know if the [MS] demons are gonna come out of the closet again or not."

This same individual talked about the “curse of MS,” having to watch someone you love “being tortured” every day.

The **chronicity and progressiveness** of the disease also seemed to be a special burden. Even as the CGs wore down over time due to the demands of caregiving, their caregiving burdens increased as the disease progressed. One male CG who had been abusive complained that MS takes over not only the PwMS life, but the CG’s life as well. Further, with MS, there was “**no end in sight**,” unlike caring for someone with a terminal illness. The PwMS would not die of their disease, so it seemed endless, and sometimes death appeared as the only relief. “And I sometimes say to myself. Why? Why do we have to live this existence? At least, with cancer, you die.”

Another theme was the **loss of a partner** – first sexually, then intellectually, and finally emotionally. As the PwMS experienced loss of independence and increasing limitations, the relationship became more one-sided, more like a parent-child than like partners. “You know, [with babies] you have the diaper changing. You have the messes that are made every day and everything else. With the knowledge of that as they get older, they become more independent, and your responsibility diminishes. But in the case of a progressive disease like the MS patient, it’s just the opposite.” “You’re like, you’re on a team. And, and one year, instead of having 11 on the team, you have 10. And you’ve got 9. And then you reach a point where you’re the only person on the team. But you’re gonna still play. Because you have no choice.” “Over the years, when we first met, we were lovers. And we couldn’t keep our hands off each other. And then that transitioned into being partners and trying to solve problems. Helping each other out. And then that transitioned into being intellectual partners in terms of solving the world’s problems. And what’s wrong with politics and so forth. And now it’s involved into I’m no longer her lover. The intimacy isn’t there. It’s not that I didn’t want it there. But it’s just not there. She can’t feel it.”

A particular source of stress was the **tension between the PwMS perception of their abilities and capabilities, and the CG’s need to keep the PwMS safe.**

Speaker 1: “She does stuff because she wants to feel like she’s normal. And she’ll do stuff way beyond her, you know, way beyond her, what she should be doing. And she knows it’s wrong, but she does it, and there’s always consequences. Always consequences.”

Speaker 2: I um, my wife there’s not a lot she can do anymore but she still tries to do things and so for me there’s a fine line between trying to step back and let her do as much as she can versus stepping in when I need to and if I step in too quickly then she gets frustrated because she wants to she still wants to do.”

Male CGs also resented the “**shrinking world**” of the PwMS, because that meant their world was shrinking as well. “I’ve tried to encourage him to get interested in absolutely anything. Painting. Uh, you know? Anything. And he. The only thing he wants to do is sit there and watch TV.”

Several mentioned the stress of coping with the **cognitive deficits** of the PwMS, particularly short-term memory loss. One male CG described in detail his distress at

trying to figure out whether the PwMS had taken too much or too little medication: “But the frustrating part for me is she'll take pills. And then she'll ask me five minutes later if she took her pills. And that's scary because some of those pills can be very damaging. So, um, so I have to watch her that way. And I created my job close enough to my home, so I can check on her every 2 hours or 4 hours, or whatever it had to be.” A different participant highlighted general communication problems that resulted: “...so it's like talking more and more to someone who really doesn't understand you anymore, and, um, really, there's a real comprehension problem that I have to deal with.”

Like male CGs, **female abusive CGs** mentioned the frustrations of the **uncertainty of the disease**: One participant was particularly distraught that she could not discriminate what in her mother's behavior was attributable to MS (which she found easier to accept); and what was simply interpersonal conflict. In a similar point to the male CGs, the female CGs were burdened by the **progressive nature** of the disease, leading to greater impairment and greater need in the PwMS; and they similarly mentioned the phenomenon of “**no end in sight**.”

Like the male CGs, a particular source of tension was the **control struggles** between CG and PwMS. One abusive CG acknowledged: “I now do all the driving. But, he wants to tell me how to get there, and where to turn. And he's not right. And I sometimes, I do have to yell at him. Let me do it my way, I know what I'm doing.”

The female CGs agreed the loss of sexual dimension was difficult, but only when this issue was specifically asked about by the facilitator: “I've talked with someone [laugh], my gynecologist about this and she said to, when you're caring from him put on your, your nurse Hilda hat and then when you're not being the lover. But it seems like I am constantly caring for him. I walk in the house, and he'll say to me, I need to go to the bathroom, rather than, hello, how are you?” Facilitator: “Uh-huh. So then it's more and more wearing the nurse Hilda hat.” “Exactly.” Facilitator: “And less and less being the lover.” “Yeah.”

Like male CGs, female CGs found **cognitive changes** and memory issues particularly frustrating, especially the fact that the PwMS often did not see the extent of their impairment: “I don't, I personally don't think she sees how, I think intellectually she recognizes that she's like not as sharp as she used to but I don't think she really sees how much she's declined really. Yeah, I think she thinks it's better than it is.” Another commented how frustrating it was to try to get their point across to the PwMS in conversation because of cognitive deficits.

Female CGs, unlike male CGs, also complained about the **financial burden** of the disease; as well as the **administrative burden** of handling insurance and Medicare issues. In contrast to the male CGs, female CGs complained of both **explosive and depressive behavior in the PwMS**.

Male PwMS who had been abused frequently described their disease as very frustrating. The progressive nature of the disease also raised fears in the PwMS that they would require professional care-giving or a nursing home down the road. They noted that, because MS is not fatal, both PwMS and CG had to cope with other illnesses as well. In terms of their **relationships**, they noted the frustration of increasing dependence, in the words of one, a regression to a child-like state: “I feel like I’m a little kid again, but I’m not.” Another man stated, “You wanna do things yourself, and you know you can't. And you mentally know you can, which you used to do. So you're, you're aware of what's going on, but you know you can't do it. And, um, and you hate to become dependent upon on everybody else and you have to lose your temper.” The loss of independence was galling, and not being able to drive was seen as a major blow: “... it can be a blow to one’s self-image not to be able to drive.” Another man commented, “Yeah, you're a mature adult, and you've done these things for many years. And even though I've had MS, from, what, since '79, it's still, you know, very frustrating to talk about driving. Yeah, I wanna keep driving. And it's, it's horrendous when I went to get it renewed a couple years ago, and I had to go through all hell to get everyone....Yeah, it was horrible, and, uh, very demeaning, I thought.”

A different PwMS, whose mother was his CG, felt it was a completely unequal relationship, and denied that there was any way in which he gave anything to the CG. Another, however, did feel as though his relationship still had elements of mutuality (“**I can still go out to dinner. And go in some nice places, and certainly picking up the tab and all.**”).

Female PwMS who were abused said comparatively little on this topic. They did discuss the **tension between their need for independence and the CG’s need to protect them and do things** for them: “I see it in my daughter's face sometimes where she, um, wants to do more for me and I do, I'll admit, I get a little agitated where it's like, let me do it.” The same speaker at a later point added, “: I think my daughter is anxious, more anxious about things involving my life than I am. And I simply refuse to be anxious. And this annoys her. She wants me to be more intense with some of these things than she is. I said. No. I. I'm not gonna do that.” The female PwMS mentioned the **unpredictability** of MS as a stressor as well.

Explanation for CG mistreatment

Male CGs did not address this issue.

Female CGs who had been abusive sometimes blamed the PwMS. One speculated that the CG might act out because “I think part of it might be if the, um, the person with MS is being unreasonable.” Later, one female CG acknowledged “not signing up for this.” She talked about the PwMS as not appreciating how difficult it can be for her: “**In our case, our, he has just, in the last couple of months, realized that I need help. He's a very large**

man and I have been trying to get him into bed and get him up in the morning. And I don't have the physical strength and my body has really taken, has really taken a toll on my body.” Other ideas about mistreatment included the possibility that the CG didn't feel prepared to deal with all the demands that care of the PwMS entailed; that the CG could feel helpless about their inability to influence the course of the disease (“Taking it out on the patient, the fact that they can't fix it or something maybe, you know?”); and that the CG might resent the PwMS for not getting better. Someone else commented that it could be frustrating to the CG to try to get their point across to PwMS (because of cognitive deficits).

Male PwMS speculated that the CG might ignore or neglect PwMS because they were busy, didn't want to be bothered, or thought the PwMS was capable of doing the task themselves. “Well, or they're doing something, and they don't want to be bothered at that time, or they want you to try and do it yourself.” In a rather convoluted argument, one PwMS offered the idea that CGs loved the PwMS so much and wanted them to get better so badly that when they didn't, the CG would lash out of a sense of helplessness.

Male PwMS tended to take responsibility for CG mistreatment. A couple admitted taking out their frustration with their disease on their CG: “You know. I mean, I know whenever I screw up and get frustrated, I. The first thing I want to do is embarrass. I mean, apologize. Cuz I know I've screwed up. And I know I've lost my temper or said the dumb things I've said. Why the hell I do that?” They suggested that sometimes the PwMS could behave in ways out of frustration that would provoke mistreatment from the CG. One participant admitted to feeling guilty for his dependence on his CG, and the way in which his disability limited her life: “And I feel bad that it's in the situation I'm in, and, you know, I have to depend on her a lot, and take me places and everything.” Several suggested that it was up to the PwMS to point out to the CG when they felt neglected (as opposed to the CG's responsibility).

Female PwMS who were abused

Had very little to say on this topic. One participant thought that perhaps it had to do with excusing their behavior and feeling inadequate to the challenge of caregiving: “Making excuses for themselves. Maybe making excuses...And have feelings of inadequacy to the job.”

Why CGs disclose mistreatment

Male CGs were not asked this question.

Abusive Female CGs thought it might be because the CG was looking for a way to give up the caregiving role; or that they felt justified in mistreatment, didn't perceive it as wrong, and were asking for sympathy for how hard their lot was. “Either, they want out, and they want to, someone else to be forced to take care of them. Or maybe they feel justified. Maybe they are looking for sympathy for [their] struggle.” A final speculation was the disclosing treatment was a cry for help.

Male and Female PwMS who had been abused did not respond to this question.

Why PwMS Don't Disclose Mistreatment

Male CGs speculated that PwMS were completely dependent on the CG, so they couldn't afford to alienate this person. The PwMS feared being abandoned and ending up alone. "Part of the fear may be if that gets back to that person. That may trigger the person leaving." They also might fear change, and the possibility that a new CG could be even worse. "Is it gonna be better than what she has? What is replacing me? Is it gonna be better? It might be worse." They thought that male PwMS might be particularly reluctant to acknowledge mistreatment because it would violate the macho image and make them appear weak. "And if you're the one who's now sick I think that just tears away at your self esteem just because you're sick, uh, to... to begin with and then if you have a case where uh, whoever the caregiver if they're doing abuse or something you really don't want to admit to that because that just knocks you down even more than you know." One male CG thought the reasons for nondisclosure would be similar to abuse victims in general, rejecting the idea that there was anything unique about the situation for PwMS.

An abusive Female CG suggested that the PwMS would feel bad about "telling on" people who loved her. "She would probably feel bad, because she's kind of telling on the people who love her, or, and are the only ones there, sort of daily, caring for her. Even though she's being mistreated, she would feel bad. And then she would say, well now who, you know? These people, this is my husband and my daughter, and they're supposed to love me. And how, is there really gonna be someone that takes care of me better than these people that are supposed to love me?"

Others thought that the PwMS might feel hopeless and trapped, and not see any good alternative. Upon questioning, one female CG who abused a male CG suggested that male PwMS might be especially unlikely to disclose mistreatment because of pride.

Abused Male PwMS speculated that PwMS did not disclose mistreatment because they don't want anyone to know what's going on. "Sometimes we don't wanna, the outside people to know that what, what's really going, at the house or with our caregivers, and whatever. We just keep it quiet. We don't really say." **The face that one shows to the world he described as "oh yeah, everything's perfect, everything's good, and I'm gonna go on."** Keeping quiet seemed like the best strategy. There was also concern expressed that "outsiders" don't really understand the situation. "You take everybody else on the outside they don't know nothing. They don't know you, me, you know?" Therefore explaining would be a waste of time.

The abused male PwMS also thought nondisclosure might be explained by the PwMS not wanting to stir things up, or make things worse. They also suggested that the PwMS might be embarrassed by his own behavior of yelling or losing his temper, which were

perceived as unmanly, and this would come out if the subject were opened up. “And you're kind of embarrassed for your own behavior. I mean you don't want, you don't want yell at someone or loose temper. That's embarrassing. It's unmanly, maybe. [laugh].”

Female PwMS who had been abused like female CGs, had very little to say about this. One imagined that it might be out of a desire to protect the CG: “Protecting the, the person with MS out of love, maybe. I love this person, I can't say anything, anything bad about them.” The female PwMS agreed that it might be more difficult for a man with MS to ask for help than for a woman. Regarding getting out of an abusive situation, one abused female PwMS said “You, you have to be able to get along, first of all. Let alone have them not be good to you. Why would you put up with it?” Another abused female PwMS did not respond to the idea of disclosing to a physician, but when questioned, said she would talk to a friend or a social worker.

Care-Giver Coping

Male CGs who were abusively mentioned the importance of time to themselves and maintaining some sort of independent life. Other coping strategies mentioned included physical activity, spirituality (and the support community provided through religious affiliation), One noted the importance, especially for male CGs, of having an outlet for their emotions “And if we don't show those emotions and let 'em out, then we're really gonna go crazy.”; but another noted the difficulty of finding people who would listen: “If you share it with anybody, they don't want to be around you. Because you're such a negative person.”

An abusive Female CG talked about watching for warning signs, such as being so angry they would leave the PwMS without food or care; neglecting providing “necessities of life” to the PwMS; and feelings of frustration and annoyance. These warning signs would trigger behaviors such as taking a break, or doing a task/project away from the PwMS. Another, after prompting, stated that she recognized the importance of empathy toward the PwMS: “Sometimes, I put myself in his shoes. Because, God knows, he's doesn't wanna be that way. And, if I had to sit around all day long, and, uh, and he drops things, and it's so frustrating picking things up. I have to look at that side of it too.”

One CG had consulted with priest who had family experience of MS. Most mentioned the importance of having an independent life, and being able to take some space from the PwMS. They noted that the downfall of the CG was “trying to do it all.” A couple said they would consider getting help if physically caregiving got to be too much for them; or if they couldn't meet the standards of care set by the PwMS. They felt it would be helpful to have more resources that could assist the CG in knowing what to expect from MS, including guidelines for managing common MS problems; and help with deciding about medications. Another desirable resource that several thought would help with coping was back-up care.

One **male PwMS** noted that his CG coped by attending church and socializing with friends. Several recognized the importance of the CG having an independent life: “She can have her own life and get away from me sometimes, you know? [laugh] Because I think I become a pain in the ass a lot, you know?” One abused PwMS noted that his CG probably wouldn’t have time to attend a support group.

One Female PwMS who had been abused suggested that for an impaired CG, the best solution was divorce. When a class for CGs was suggested, one participant agreed and another participant disagreed that anything valuable could be learned through a class: “I don't think there can be better training except living with us.” They also suggested being more empathetic to the PwMS: “: I think that you have to rely on... the person being most sympathetic to the person who's in need.”

PwMS Coping

Male and female CGs and females PwMS who had been abused did not comment on this topic.

One **abused male PwMS** said that some degree of independence and privacy was important to his ability to cope with his disease. Two mentioned a kind of fatalism – they had no choice but to keep going: “And you know, what is the, what's the alternative? [laugh]. And so you just have to go on.” He stated “I have to be so careful that I don't feel sorry for myself. You know, because there's some other poor sucker that's a lot worse off than I am.” Another agreed: “Right away I, I gave that up. I never asked myself why me.”

SUMMARY

The picture that emerges from the focus groups on the whole is one of stressed individuals at the edge of their coping, especially men, both CGs and PwMS (there were exceptions to this conclusion in all groups). Male CGs were outspoken about the overwhelming stress of their role; while male PwMS seemed to find the ravages of the disease particularly distressing.

Focus groups were perhaps not the best methodology to elicit admissions of mistreatment, as both CGs and PwMS vociferously denied even mild mistreatment. Female PwMS were almost obsessive on this topic, returning throughout the discussion to reiterate the devotion of their CGs. PwMS seemed to feel very invested in the idea that CGs provided care out of love, not duty; and that caregiving was a choice, not an obligation. Female PwMS were especially quick to take responsibility for aggravating or otherwise upsetting CGs, while male PwMS emphasized the importance of mollifying and not upsetting CGs. As the discussion progressed, both male and female CGs acknowledged minor mistreatment, such as raised voices.

Most participants acknowledged specific aspects of MS that made it a particularly hard disease to deal with for caregivers. These included the unpredictability of the disease, its

variable but progressive nature, and ironically the fact that it is *not* usually a terminal condition. Other issues of major concern were the effects that increasing PwMS dependency had on the nature of the relationship itself; and the control struggles between the PwMS trying to maintain as much independence as possible and the CG wanting to take over many tasks of daily living for the PwMS. Other especially aggravating issues were cognitive deficits and short-term memory problems and the progressively “shrinking world” of both PwMS and CG.

When asked to speculate about reasons for CG mistreatment of PwMS, most participants (CGs and PwMS) tended to blame the PwMS for “provoking” CG upsetness. Other answers included CG frustration with the disease; deep-seated anger at the PwMS’ inability to improve; and helplessness at not being able to make the PwMS better. Other possibilities offered by participants included the CG feeling shortchanged in life; and feeling inadequate to fulfill their caregiving responsibilities. Similarly, participants who responded to queries about why CGs might disclose mistreatment thought it might be a cry for help; a way of justifying their behavior; or a preemptive strike against the PwMS independently making a disclosure.

In terms of why PwMS do *not* disclose mistreatment, participants offered many ideas. They suggested that the PwMS might be afraid of the consequences. PwMS might be afraid of alienating their CG, with the result of being abandoned and ending up alone. Several women (both CGs and PwMS) noted that, if loved ones mistreat a PwMS, then what could they expect from a stranger? They also guessed that the PwMS would not want to “betray” their loved ones. Another possibility was that PwMS rationalized and minimized mistreatment. Empathy for the CG (“their lot is so hard”) and PwMS self-blame (PwMS thinking they “deserved” such treatment) also appeared to play a role in participants’ thinking. Both males and females agreed that it might be particularly difficult for male PwMS to disclose mistreatment because of the damage this admission would do to their self-esteem and pride.

Both male and female CGs used coping approaches, such as cognitive strategies (downward comparison, positive thinking, fatalism), maintaining some independence in their personal lives, and turning for support to a faith community. Interestingly, male CGs mentioned the importance of emotional release, whereas female CGs did not. PwMS were aware that CGs needed help in coping, and suggested educational and support groups. They also recognized the importance of some separate time for the CG. Female PwMS stressed that CGs needed to be giving people to be effective caregivers.

Powerlessness – male CG’s – anger at that.

Is this more about why caregivers tell us what they're doing than why PwMS don't tell what's happening to them?

Gender effects. Cite stuff on males.

Taking out the pronoun for "the other" to increase confidentiality.

Abused Male PwMS: Being a man myself it's, it's hard to do you know