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Views on disclosing mistreatment: A focus group study of differences between people with MS and their caregivers

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Abstract

Both female and male persons with MS are at increased risk for various forms of physical, sexual, and disability-specific abuse. An ongoing study revealed a subset of respondents in which the caregiver acknowledged mistreatment of the person with MS, but that person either denied or minimized mistreatment

Methods: In an effort to understand this phenomenon, we conducted 4 focus groups of male caregivers, female caregivers, male persons with MS, and female persons with MS (total $n=15$). Data were analyzed using qualitative methodology

Results: Results included the surprising finding that, despite participants having been identified as recipients or perpetrators of mistreatment, all denied any form of abuse in the focus group setting. We concluded that attitudes toward mistreatment in these discrepant couples varied based on gender. Specifically, male caregivers may disclose abuse as a cry for help, whereas female caregivers may feel such behavior is justified because of the perceived “provocations” of the person with MS. Women with MS appeared reluctant to acknowledge abuse because they feared loss of their primary relationship; while men with MS calculated that putting up with a certain amount of mistreatment was worthwhile

Conclusion: More attention should be paid in identifying and understanding this subset of persons with MS and their informal caregivers.

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1. Introduction

Health professionals are increasingly concerned about the vulnerability of people with disabilities to various forms of mistreatment, especially intimate partner abuse and neglect. Published research favors the conclusion that women with disabilities are at greater risk for experiencing physical, emotional, and sexual violence than are women

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(or men) without disabilities (Plummer and Findley, 2012; Hague et al., 2011; Powers et al., 2002; Barrett et al., 2009; Casteel et al., 2008). Less is known about mistreatment risk factors among men with disabilities. One recent review article concluded that intimate partner violence occurs at elevated and disproportionate rates among women and men with disabilities, especially when assessed over the course of their lives (Hughes et al., 2011).

1.1. Factors associated with mistreatment

Characteristics of women with disabilities who are at greater risk for violence include greater ADL/IADL needs, greater social isolation, and higher depression rates (Nosek et al., 2006). The nature of the caregiving role itself may further contribute to mistreatment. Risk factors for abusive behavior in caregivers include whether they are married to their partners with disabilities, caregiver physical symptoms, and caregivers' clinical depression (Beach et al., 2005). One study found that caregiver resentment strongly predicted potentially harmful behavior (Shaffer et al., 2007), while a related study concluded that the caregiver feeling like a victim and blaming the person with disabilities were salient predictive variables (Williamson et al., 2005). The unpredictable and progressive nature of MS puts particular strain on caregiver partners (Buhse, 2008), and may increase the risk of mistreatment.

1.2. Purpose of this study

An ongoing larger study detected discrepancies between some participants with MS and their caregivers regarding acknowledgment of abuse. Specifically, even when the caregivers disclosed in a self-administered questionnaire that they had mistreated their partners with MS, some mistreated partners denied or minimized the mistreatment, a pattern opposite to what the literature shows (Simpson and Christensen, 2005). To investigate further this discrepant pattern in a disability-specific way (Freeborn and Curry, 2009), we interviewed willing couples using focus group methodology. Our institutional review board reviewed and approved the study.

2. Method

We conducted 4 focus groups: one each for male caregivers, female caregivers, men with MS, and women with MS. We believed caregivers and people with MS would have somewhat different perspectives. Because gender might influence participants' viewpoints, the focus groups kept role and gender homogeneous (Liamputtong, 2011).

Groups followed standard focus group procedures, including use of a question route developed by a multidisciplinary expert team, establishing a nonjudgmental atmosphere, and encouraging differences of opinion (Krueger, 2009; Malterud, 2001). Questions focused on what causes a caregiver to mistreat a person with MS; why persons with MS might not disclose mistreatment; whether focus group participants themselves had ever participated in or been the recipient of mistreatment; and how such situations

Table 1 Subject demographic information.

	Persons with MS	Caregivers
Gender	5 male, 3 female	4 male, 3 female
Age	44-85	34-76
Length of time w/MS/		
Length of time as caregiver	1-35 years	> 10 years
Assistive devices required for mobility	All	-
Nature of caregiver	5 spouse or spouse equivalents; 1 mother; 1 son	6 spouse or spouse equivalents; 1 daughter
Ethnicity	8 Caucasian	5 Caucasian; 1 African American; 1 native American
Years of education	12-17	14-17

should be handled. With participant permission, all focus groups were audiotaped and professionally transcribed.

All but one of the participants had been involved in the earlier phase of the study that included LEAD (Longitudinal, Experts, All Data) panel assessment or consensus decision about whether mistreatment had occurred.² Each focus group consisted of 4 members except for the group of female caregivers which consisted of 3 members. The expert panel confirmed 11 of the 15 participants (6 persons with MS and 5 caregivers, 4 of each from the same dyads) as having abusive relationships. Because it was difficult to recruit sufficient numbers from discrepant couples, one member of each group was not abused. Table 1 reports demographic information.

2.1. Data analysis

A qualitative method known as immersion-crystallization guided data analysis (Borkan, 1999). Statements of those not in abusive relationships were eliminated from the analyses. In the initial phase of this process, individual researchers noted keywords, phrases, and major themes (Table 2) (Liamputtong, 2011; Kelly, 2010). All members of the research team reviewed the transcripts. To detect core patterns and comments, we evaluated the transcripts for frequency of specific themes and intensity of comments. We resolved disagreements through face-to-face and email discussion and we established an audit trail of transcriptions, field notes, focus group summaries and interpretations (Brown, 1999).

²Because there is no published validated instrument or "gold standard" for mistreatment of adults with disabilities, the LEAD standard is the most rigorous strategy currently available and is the preferred standard for elder mistreatment to date (National Research Council, 2003; Wiglesworth et al., 2009,2010).

Table 2 Major themes by role and gender.

Role	Denial of abuse	Challenges of CG role	Explanations CG abuse	PwMS nondisclosure	Coping/avoid abuse
Male CG	yes	Extreme stress Isolation Burden Resentment	Blame PwMS Loss of partner	Dependence on CG Fear of alternative Male PwMS-pride	Independent life Physical activity Spirituality Emotional release
Female CG	yes	Denied extreme stress	Blame PwMS CG lack of preparation Resentment of PwMS	Hopeless Trapped Male PwMS-pride Protect abuser	Independent life Recognize warning signs Resources, training
Male PwMS	yes	Acknowledged extreme challenge of CG role	CG too busy PwMS blame	Shame/privacy Waste of time No one believes Make things worse Blame PwMS	Placate CG Independent life-CG
Female PwMS	Yes-strong	Acknowledged some challenge	CG lack of preparation	Blame PwMS Protect abuser	Leave relationship

3. Findings

3.1. Denial of mistreatment

In the focus group setting, all participants denied any form of mistreatment (defined by the facilitator as pushing, shoving, persistent shouting, raised voice, threats of abandonment, or neglect). **Male caregivers** who had been abusive thought in general it was more likely for male caregivers to leave or abuse the person with MS because, as caregivers, they were not as good as women and “could not handle” the burdens of the role. As the discussion progressed, a few male caregivers acknowledged minor mistreatment such as raised voice and expression of frustration, as well as thoughts that “it would be better for everyone if [the person with MS] died.” **Female caregivers** who had been abusive similarly denied engaging in any mistreatment, and expressed shock that caregivers could mistreat persons with MS. They agreed with male caregivers that women generally made better caregivers because women were more nurturing than men. Like their male counterparts, as the focus group continued, women caregivers acknowledged minor instances of mistreatment. One caregiver acknowledged not taking the person with MS to the ER after a stroke with the following justification: “It is very hard to tell what’s MS and... you get in the habit of okay we are not going to run to the doctor for every little thing. ...I didn’t take him to the hospital until finally the next day.”

Men with MS who had been mistreated denied mistreatment by their caregivers as well. “So I’m just very fortunate. I mean, [the caregiver] is wonderful.” One described caregivers in supernatural terms: “I just think, in some ways, they’re like an angel. They’re just, you know, floating around, always helping you.” **Women with MS** who had been mistreated also denied mistreatment and, like the female caregivers, 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 repeatedly to attestations of how caring their caregivers were: “My

husband likes it [taking care of her], he loves to be part of this. He loves to cook, he loves to do everything. So I let him.”

3.2. Challenges of the caregiver role

Male caregivers who were abusive all felt the caregiver 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 caregiver: the fear of worsening disease and what the future would bring, anger at the unfairness of life, and helplessness at having to watch the person with MS deteriorate. One participant described extreme isolation, with no one interested in or willing to listen to his struggles. Another described the “shattering of dreams” that occurred with his wife’s MS diagnosis, and later expressed passive suicidality: “I never contemplated suicide. But when I went to see a hepatologist about whether or not I had a liver disease... 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 always needing to be responsible and in charge was taxing for these male caregivers. “You got to always be anticipating... 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: “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.” **Female caregivers** who were abusive shared stories of “other” caregivers getting divorced due to the stress of the role, but on the whole they rejected the idea that MS had taken over their lives or that they felt overwhelmed.

Men with MS believed the level of care required by the person with MS could be burdensome, and perhaps too much for a caregiver. One admitted that if the roles were reversed, he didn’t know if he would stay in the relationship. This group frequently mentioned fear of the caregiver leaving. **Females with MS** expressed empathy for the

difficulty of the caregiver role, but with less intensity than their male counterparts: “I think you have to be understanding of what the person’s going through.”

3.3. Explanations for caregiver mistreatment

Two **male caregivers** stated that the person with MS was not appreciative of their efforts; and was not empathic to what the caregiver was going through. “Like, you know, he paid absolutely no attention, or, didn’t see, or saw and didn’t care. 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 she is. And she will tell me that.” These statements suggested a pattern of blaming the person with MS for lack of empathy and appreciation.

Another relevant theme among male caregivers was **loss of a partner**, sexually, intellectually, and emotionally. As the person with MS experienced loss of independence and increasing limitations, the relationship became more one-sided: “You know, [with babies] you have the diaper changing. 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.” Another male caregiver added, “You’re like, you’re on a team. 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.”

All abusive **female caregivers** reported the person with MS to be appreciative of their caregiving efforts. However, like the male caregivers, some female caregivers felt the person with MS didn’t have empathy for what they were going through, and was not sensitive to them: “I, I definitely noticed [the person with MS] is not as, um, sensitive to, not just me as her caregiver, but the people around her in general.” Some abusive female caregivers blamed the person with MS for possible caregiver mistreatment. One speculated that the caregiver might act out because “I think part of it might be if the, um, the person with MS is being unreasonable.” Other ideas from female caregivers about mistreatment included the possibility that the caregiver didn’t feel prepared to deal with the demands of care; the caregiver could feel helpless about his or her inability to influence the course of the disease (“taking it out on the patient, the fact that they can’t fix it or something...?”); or the caregiver might resent the person with MS for not getting better.

Men with MS speculated that the caregiver might ignore or neglect the person with MS because assistance seemed an interruption or unnecessary. “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.” Men with MS who had been abused tended to take responsibility for caregiver mistreatment by suggesting that their own behavior could provoke abuse: “I mean, I know whenever I screw up and get frustrated... I know I’ve screwed up. And I know I’ve lost my temper or said the dumb things I’ve said.” **Women with MS** who were abused, like men with MS, although they denied any mistreatment, were quick to take responsibility for problems between themselves and caregivers.

3.4. Why people with MS don’t disclose mistreatment

Male caregivers speculated that because people with MS were completely dependent on the caregiver they couldn’t afford to alienate this person. They suggested that the person with MS likely 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.” The person with MS also might fear change, and the possibility that a new caregiver 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 men with MS might be particularly reluctant to acknowledge mistreatment because it would violate their “macho” image and make them appear weak. “...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.”

Some **female caregivers** thought that the person with MS might feel hopeless and trapped, and not see any good alternatives. One female caregiver who was abusive suggested that men with MS might be especially unlikely to disclose mistreatment because of pride. Another abusive female caregiver suggested that the person with MS would feel guilty about reporting people who were family. “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.”

Abused **men with MS** speculated that persons with MS did not disclose mistreatment because they don’t want anyone to know what’s going on. “Sometimes we don’t want 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.” 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 men with MS also thought nondisclosure might be explained by the person with MS not wanting to make things worse.

Several **women with MS** engaged in blame of the person with MS to explain nondisclosure of mistreatment: “But for a person with MS, like I said, we’re very demanding a lot of days... It would be like, okay, well, they’re putting up with me maybe the best they can do and I’ll just deal with it.” Another guessed that people with MS might feel guilty: “Maybe I deserve it.” Like female caregivers, they imagined that keeping silent might be out of a desire to protect the caregiver: “Protecting the...the person out of love, maybe. I love this person, I can’t say anything...anything bad about them.” A few women agreed that it might be more difficult for a man with MS to ask for help than for a woman.

3.5. Coping strategies to avoid/manage mistreatment

Abusive male caregivers mentioned the importance of time to themselves and maintaining some sort of independent life as a way of heading off mistreatment. Other coping

strategies included physical activity and spirituality. One noted the importance, especially for male caregivers, of having an emotional outlet: “And if we don’t show those emotions and let ‘em out, then we’re really gonna go crazy”. 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.” Most **female caregivers** mentioned the importance of having an independent life, and being able to take time away from the person with MS. One abusive female caregiver talked about watching for warning signs, such as being so angry she would leave the person with MS without food or care, which would then trigger behaviors such as taking a break. Female caregivers agreed that the downfall of the caregiver was “trying to do it all.” They felt it would be helpful to have more resources that could assist the caregiver in knowing what to expect from MS.

Several **men with MS** expressed the need to mollify or pacify the caregiver to avoid conflict. One participant described routinely taking a “nap” on the floor after he fell down rather than bother his caregiver. Another man talked of having to manage his anger so he wouldn’t take it out on the caregiver: “You have to back off, and you have to realize that.” In a similar disclosure, another participant noted that if he lost his temper with his caregiver, he always apologized right away so that things wouldn’t escalate. Several recognized the importance of the caregivers 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?” All the **women with MS** agreed that if they were mistreated, they would get out of the relationship somehow. “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?” “I can’t imagine tolerating abuse.” Another woman who had been abused suggested that when dealing with an abusive caregiver spouse, the best solution was divorce.

4. Discussion

Among these participants, the majority of whom were in relationship with an abusive informal caregiver, we found two somewhat different configurations related to gender. First, **abusive male caregivers** felt extremely stressed and desperate, reflecting what one researcher called “chronic sorrow” (Hainsworth, 1996). They complained of significant difficulties in emotional adjustment, demands on their time, change in personal plans, disrupted sleep, constant worry and frustrations, and difficulty coping with the uncertainty of MS, all symptoms documented in existing literature (Khan et al., 2007; Waldron-Perrine et al., 2009; Mutch, 2010). Second, **female partners with MS** adamantly denied mistreatment, as if they feared that introducing any additional problems into the relational dynamic might push their caregivers over the edge. **Female caregivers** seemed less resentful or burdened than their male equivalents. **Male partners with MS**, while also denying mistreatment, reported placating and accommodating behaviors that seemed designed to defuse conflict. Male and female caregivers both indicated some resentment of the person

with MS, while participants in all groups tended to blame the person with MS for difficulties.

The pervasive stress and strain (Lim and Zebrack, 2004; Courts et al., 2005; Khan et al., 2007; Mutch, 2010), burn-out (Eriksson and Svedlund, 2006), and compassion fatigue (Lynch and Lobo, 2012) experienced by the male caregivers in our study likely made them more vulnerable to mistreating their partners with MS. Recent research on caregivers of patients with dementia (Takai et al., 2011) suggests that the subjective experience of the caregiver may be more important than patient-related variables in determining caregiver quality of life. We found the subjective experience of most of our male caregivers to be one of isolation, despair, frustration, and imprisonment. It is likely these feelings made them more susceptible to mistreating the person with MS, especially when caregivers’ stress exceeds their ability to cope (Copel, 2006).

4.1. Reasons for caregiver mistreatment.

Many participants tended to blame the person with MS for “provoking” caregiver upset. The literature documents that caregivers blame patients (Copel, 2006) and that people with MS blame themselves (Saxton et al., 2006) and our study showed evidence of both of these phenomena. Other explanations included caregiver frustration with the disease; deep-seated anger at the inability of the person with MS to improve; helplessness at not being able to make the person with MS better; the caregiver feeling shortchanged in life; and the caregiver feeling inadequate to fulfill their caregiving responsibilities. As in other studies (Courts et al., 2005), our participants agreed that women were better suited to the caregiver role than men. Male caregivers might therefore be more likely to mistreat their partners because they felt less prepared for the role. An early study concluded that male caregivers relied primarily on the person with MS herself for support (Good et al., 1995) which may help explain why changes in our male caregivers’ relationships with their partners were especially devastating.

4.2. Failure to disclose mistreatment.

To explain why people with MS do not disclose mistreatment, participants suggested that they might be afraid of the consequences, such as alienating the caregiver, who would then leave them. Other studies note people with MS expressing a similar fear of being abandoned (Courts et al., 2005). Several women (both caregivers and women with MS) noted that, if loved ones mistreat a person with MS, then what could they expect from a stranger? Hague et al. (2011) mentioned a similar phenomenon, observing that many of their female subjects with disabilities felt lucky to have any kind of relationship. Our participants also guessed that persons with MS would not want to “betray” their loved ones. Both men and women agreed that it might be particularly difficult for men with MS to disclose mistreatment because of the damage this admission would inflict on an already fragile self-esteem. Previous research suggests, however, that women have more trouble disclosing mistreatment than men (Saxton et al., 2006), which was the case in our research.

The Abuse Pathways Model (Hassouneh-Phillips, 2005) sheds further light on our investigation. This model notes the twin concepts of “Trade-Off and Stay-In”, in which women with disabilities make the choice to put up with a certain amount of abuse in exchange for perceived benefits. In other studies (Copel, 2006; Kearney, 2001), women with disabilities considered themselves different and inferior, made accommodations to placate their spouses, and saw no reason why their husbands should be remorseful, normalizing spousal aggression. Hassouneh-Phillips et al. (2005), describe this as a process of invalidation, in which the partner systematically discounts, objectifies, and hurts the woman with disabilities. Saxton and colleagues’ study of men with MS (2006) identified a similar psychological assessment process in which many felt abuse was a fact of life: their task was to determine the level they could handle.

In our study, women with MS denied mistreatment and asserted they would simply leave rather than tolerate an abusive relationship. These women were unwilling to acknowledge a threshold effect in their hypothetical black-and-white calculus. Male participants with MS, on the other hand, appeared to engage in a process that factored in trade-offs such as placating caregivers, restricting personal needs, trying to be more self-sufficient, and cutting anger off early in order to preserve the relationship. As in the Saxton et al. (2006) study, but in contrast to the work of Powers et al. (2008), we found men with MS to be *more* fatalistic than women in assuming nothing could be done about abuse. The moderate to severe physical dependency of all of our study’s participants with MS likely played an important role in the way they viewed the nature of mistreatment and even the extent to which they were willing to admit mistreatment (Casteel et al., 2008; Yoshida et al., 2009).

4.2.1. Coping strategies to avoid/manage mistreatment

Both male and female caregivers used similar coping approaches, such as cognitive strategies (downward comparison, positive reframing (Pakenham (2008), fatalism); maintaining some independence in their personal lives (DesRothier et al., 1992); and turning to a faith community to avoid abuse and mistreatment. Interestingly, male caregivers, but not female caregivers, mentioned the importance of emotional release. Participants with MS suggested educational and support groups for both caregivers and people with MS as a way of avoiding mistreatment. However, there are very few intervention programs and back-up services for adults with disabilities who have experienced interpersonal violence (Lund, 2011; Brownridge, 2006; Saxton et al., 2001); and little is known about promoting safety behaviors in personal assistance relationships (Powers et al., 2009). Both these factors make adequate training and preparation of caregivers difficult.

In our study, both caregivers and persons with MS indicated they believed support groups could be useful to reduce caregiver stress, as other studies have documented (McKeown et al., 2003; Saxton et al., 2001). Only one of our male caregivers reported participating in such a group, while another received regular informal support from his church. Both reported significant benefits from this

involvement in terms of sharing stories and coping strategies, and lessening feelings of isolation. Other caregivers stated that they had too many other responsibilities to attend a support group. Men with MS also endorsed the idea of caregiver support groups, although one felt his particular caregiver would not have time to attend. Women with MS, on the other hand, were more divided on the value of caregiver support, perhaps unwilling to acknowledge that such intervention was necessary.

4.3. Limitations of study

In terms of recruitment, some of the caregivers in abusive, discrepant dyads were indignant or angry at being contacted and declined to participate (or to allow the person with MS to participate), introducing a selection bias, and limiting the size and number of groups. This selection bias might also have had the effect of excluding the most serious instances of abuse from the study. That each focus group included one individual who had not directly experienced abuse created another unknown effect. These factors all restrict the strength of our conclusions.

5. Conclusion

Despite these limitations, this study raises provocative questions that deserve further investigation. To date, no study has examined this subpopulation of couples in which the caregiver reports more mistreatment than the person with MS acknowledges. Despite many similarities with other populations of abused people with disabilities, this study offers preliminary evidence that gender may affect attitudes toward mistreatment in these discrepant couples. Specifically, male caregivers may disclose abuse as a cry for help, whereas female caregivers may feel such behavior is justified because the person with MS somehow “provokes” it. Women with MS may be afraid to even contemplate that they are being abused because they fear threatening their primary relationship; while men with MS have calculated that putting up with a certain amount of mistreatment is worthwhile. Future studies should explore whether such differences place an important subset of the MS population at risk both for mistreatment and for its delayed detection.

Conflict of interest disclosure statement

The authors of this manuscript, Johanna Shapiro, Aileen Wigglesworth, and Elizabeth Morrison, attest that they have no conflict of interest with the topic or materials involved in this study; and did not receive payment for this work except in the course of their standard academic responsibilities.

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