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**RURAL CAREGIVERS AND SOCIAL ISOLATION:
SOME PROPERTIES AND DIMENSIONS***

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ABSTRACT

There are an estimated 400,000 people with multiple sclerosis (MS) in the United States. Many rely on an informal caregiver for assistance. Caregivers are more likely than non-caregivers to report feelings of social isolation. Rural MS caregivers are especially prone to these feelings of isolation. We conducted in-depth interviews with rural caregivers of veterans with MS and used a grounded theory approach to data collection and analysis to illustrate some properties and dimensions of social isolation in a rural MS caregiving sample. These properties include: isolation and the rural environment; isolation from family; isolation from friends; and isolation from the person for whom they provide care.

Multiple sclerosis (MS) is an inflammatory disease of the central nervous system that results in progressive, chronic disability in both cognitive and physical function (Composton and Coles 2008). An estimated 400,000 people are living with MS in the United States (National MS Society 2013). The severity and persistence of physical and cognitive impairment means that many people with MS rely on a caregiver for help with activities of daily living (ADLs) and instrumental activities of daily living (IADLs). These activities include bathing, toileting, dressing, preparing meals, and other tasks associated with maintaining life and well-being (National Alliance for Caregiving 2012). Caregivers for those with MS are typically informal caregivers, or unpaid, nonprofessional caretakers, typically a spouse or family member who provides care as an expression of love and support (Watson

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2010). Multiple sclerosis is a progressively disabling disease that does not appear to shorten the lifespan significantly. This means that caregivers often continue in a caregiving role for many years (Gulick 1998).

Research on chronic illness suggests that caregivers of the chronically ill are negatively affected by the long-term provision of care (Erlingsson, Magnusson, and Hanson 2012). Compared with non-caregivers, caregivers have higher rates of depression and stress and have lower overall subjective well-being (Pinquart and Sorensen 2003). Caregiver burden speaks to the increased social and psychological weight of responsibility associated with providing long-term and intensive physical, psychological, social, and financial care and support (Buhse 2008). Caregiver burden has been linked to higher rates of anxiety and depression and an overall decrease in perceived quality of life (Argyriou et al. 2011; Opara, Jaracz, and Broła 2012). In addition, caregivers are more likely than non-caregivers to report feelings of loneliness and disconnection from others, a process called social isolation (Glozman 2004). Compared with those who provide care for other chronic medical conditions, MS caregivers are more likely to report feelings of social isolation. Social isolation is related to myriad poor health outcomes in caregivers *and patients*, ranging from elevated blood pressure to depression and early mortality (Cacioppo and Hawkey 2009; Pflieger, Flachs, and Koch-Henriksen 2010; Uchino, Cacioppo, and Kiecolt-Glaser 1996). Feelings of isolation may be partly attributable to the caregiving work required of MS caregivers, work that increases as the disease progresses (Arnett 2007; Figved et al. 2007).

The difficulties faced by caregivers can be exacerbated when they reside in rural areas where there are few community resources and people around to assist in times of need (Winterton and Warburton 2011). Rural dwelling MS caregivers are more likely to have lower health-related quality of life (Buchanan et al. 2008), and report higher levels of caregiver burden and strain compared with non-rural MS caregivers (National Alliance for Caregiving 2009, 2010, 2012). In addition, rural MS caregivers are more likely to experience greater health decline, higher levels of depression, and greater degrees of isolation from friends, family, and the community than those MS caregivers living in more urban population centers (Glozman 2004; Imes et al. 2011; National Alliance for Caregiving 2010). The research on rural caregivers strongly suggests that the physical environment in which they provide care is linked to more negative outcomes. Compared with knowledge on rural caregivers, the literature on rural caregivers of Veterans is thin.

To understand the challenges faced by rural dwelling caregivers of Veterans with MS better, we use a grounded theory approach to highlight some key

properties and dimensions of social isolation as discussed by caregivers. Social isolation properties include: isolation resulting from the rural environment; isolation from family; isolation from friends; and isolation from the person for whom they provide care. We also address the dimensions of social isolation within each of these properties. Our intent is to provide a descriptive, grounded analysis of social isolation as experienced by some rural caregivers of Veterans with MS. We follow with a brief discussion of how rural caregivers of Veterans with MS may differ from other caregivers.

METHODS

Program Description

The data presented here are derived from The Caregiver Assistance Program (CAP), a demonstration project supported by the Department of Veterans Affairs Office of Rural Health that explores innovative ways of providing institutional support to rural Veterans with MS and their caregivers. The CAP consisted of three components to improve caregiver self-efficacy and reduce caregiver strain and caregiver burden. These include: (1) problem-solving skills development; (2) resource education; and (3) supportive problem solving via videophone technology. To evaluate the effectiveness of the CAP, there were three interviews with the caregiver during the intervention: a baseline face-to-face interview, one mid-study telephone interview, and one post-intervention telephone interview. All calls with caregivers were recorded and transcribed. The CAP is described in detail elsewhere (Hinojosa and Hoffman 2012). In this article, we present qualitative data from the CAP to discuss the key properties and dimensions of social isolation for rural caregivers.

Participants

Six caregivers of rural Veterans with a diagnosis of relapsing remitting (RR), secondary progressive (SP), or primary progressive (PP) multiple sclerosis (MS) with a Kurtzke Expanded Disability Status Scale (EDSS) score of 5.5 and above (i.e., at least partially wheelchair bound) were recruited from a Veterans Administration Spinal Cord Injury and Disability (SCI/D) clinic in the Southeastern United States and *enrolled in the CAP program*. Caregivers were identified as potential participants for the CAP program by clinicians at the SCI/D clinic if they: were 18 years of age or older; provided primary caregiving assistance to a rural veteran for at least one activity of daily living (i.e., eating, grooming, walking, bathing); and lived in a rural area, defined as a Census statistical tract with fewer than 2,500 people, where

caregivers' addresses were matched by ZIP code to a Census-defined rural statistical tract. Eligible participants were contacted, and caregivers consented after Veterans provided consent for the caregivers to discuss caregiving. Data collection took place within the caregiver's home (for the baseline interview) or via videophone (for the clinical support calls made to caregivers at two weeks, four weeks, six weeks, and eight weeks). The analysis presented here consists largely of the data collected during the in-depth qualitative interviews conducted at the baseline because these interviews focused on the caregiver's perceptions of and experiences with providing care. Each interview lasted between 1.5 and 2.5 hours.

The average age of caregivers enrolled in this study was 56.3 years, with a range of 48 to 65 years. All caregivers were women, married to and living with the Veteran for whom they provided care. Only two of the six caregivers were employed, one full time and the other part time, with the remaining four caregivers unemployed at the time of the interview. Five participants considered themselves Caucasian and one was Hispanic/Latino. All spoke fluent English. Caregivers spent an average of 25 hours per week providing direct care to the veteran (i.e., dressing, feeding, bathing, etc.), with a range of 10 hours per week on the low end to 40 hours per week on the high end. These estimates are misleading in that they represent self-reported hands-on care; caregivers were available to the Veteran whenever they were in the home and may have underreported actual caregiving duties, omitting tasks like cleaning the home or doing laundry. All caregivers provided care as needed and remained on-call 24 hours a day, seven days a week.

All names and personally identifying information were removed from the data during transcription. We call the caregivers "CG" to designate their status, and with a unique number associated with the order in which they were enrolled (e.g., CG01, CG02, CG03, etc.). Veterans are called either CG01's Veteran or CG01's husband, and so forth.

Qualitative Interviews: Analytical Strategy

We used a grounded theory method (GTM) approach to data analysis because it is particularly effective for analyzing qualitative interview data (Glaser and Strauss 1967; LaRossa 2005; Strauss and Corbin 1998) and because it is rigorous (Charmaz 2006). A GTM approach is appropriate when there is little known about a substantive area (Glaser and Strauss 1967; Strauss and Corbin 1990, 1998), such as rural Veterans with multiple sclerosis and their caregivers. Analysis using a GTM approach starts with open coding, a process that entails a line-by-line analysis of data to identify phenomenological themes, or common participant

experiences. These are coded (labeled) as categories and subcategories when patterns are evident (Strauss and Corbin 1998). As themes emerge, a more focused coding process synthesizes these patterns into hierarchically organized themes that are then systematically coded around a core category, or central theme, that ties the data together. This process is called axial coding and allows researchers to identify common data properties (i.e., themes) and dimensions (i.e., variations within common themes). Data properties and dimensions are then systematically compared across thematic categories (Glaser and Strauss 1967). In this paper, social isolation is the core category.

Systematic data analysis starts early in the research with a process called the constant comparative method, the simultaneous collection and analysis of the data (Charmaz 2006; Glaser and Strauss 1967). As new cases provide new insights, previous cases are reviewed. Emergent themes are structured into a hierarchical ordering (Glaser and Strauss 1967).

Coding of the data was guided by four criteria: 1) the data (i.e., quote or statement) contained a key phrase that highlighted the thematic category (in this instance, social isolation); 2) the data were consistent with other responses in the coding category; 3) the quotation was clear and interpretable; and 4) the investigators agreed independently that the data fit the code. This approach strengthened the reliability of data coding (Lincoln and Guba 1985). These steps are discussed here as occurring sequentially. This is done for clarity. In reality, data analysis was an ongoing iterative process whereby new data were compared with previously collected data and data and codes were continually compared and revised throughout the analytic process. The result is a robust GTM analysis of social isolation for some rural MS caregivers.

FINDINGS

Social isolation was a common experience for the small group of rural caregivers of Veterans who were interviewed for this study. This finding is consistent with other work on MS caregivers (National Alliance for Caregiving 2010, 2012) and on caregivers in rural settings (Easter Seals 2007). Our work suggests that the caregiver experience of social isolation begins with the physical environment; providing care in geographic areas far from urban centers makes it difficult for caregivers to find time to maintain non-caregiving relationships. They experience social isolation as the result.

Using a grounded theory approach, we have identified the following as properties of that social isolation: isolation resulting from the rural environment;

isolation from family; isolation from friends; and isolation from the Veteran for whom they are providing care. We discuss each of these properties below.

Isolation Resulting from the Rural Environment

The MS caregivers in this study resided in rural areas, defined as a Census statistical tract with fewer than 2,500 people. To better understand the potential challenges faced by caregivers as they navigated and provided care within the rural physical environment, the study team took notes on the community and areas surrounding each caregiver's home. Rural living meant that two of the main responsibilities of these caregivers, managing the logistics of the household and providing medical care for their Veteran, were responsibilities that took time to accomplish. This is because the caregiver's home was far away from commercial and medical centers. The duties associated with home logistics and Veteran care consumed much of the caregivers' daily schedules and, as we illustrate in the sections that follow, meant that they had little time left for other activities, such as maintaining relationships with friends and family. In practical terms, social isolation followed partly from physical isolation.

Isolation related to household logistics. A memo made after the drive to CG03's initial interview notes that "the road leading into the community was flanked by burned pine forest for several dozen miles."

There were times on this stretch of 2-lane roadway in which [the interviewer] would not see another vehicle or person for 20 minutes or more. This is significant because [the interviewer] was travelling at the speed limit of 60 mph and the road was flat and largely straight for dozens of miles, providing clear visibility of the surrounding forest, fields, and roadway.

After emerging from the pine forest, the interviewer continued to the caregiver's home, a double-wide mobile home situated on approximately half an acre of land adjacent to undeveloped land. The home sat one mile off the main road. The nearest business was an independently owned store in an old gas station over a mile away.

To get to the house, [the interviewer] had to turn down an ungraded soft dirt road cut through the forest, and down another dirt-side road. There were no permanent structures other than the repurposed gas station. There were no visible commerce centers in the area. CG03 reported that the

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nearest gas station was 10 miles away; this was also the closest source for food. CG03 said that she often drove 40 minutes to the nearest grocery store.

As this excerpt suggests, rural living equals distance. Distance translates into time. It takes time to drive to the store, the bank, or the post office. Managing the daily needs of a modern household, such as grocery shopping, was an event that could take several hours to accomplish, leaving rural caregivers with fewer hours to engage in other activities, like direct caregiving. They also had little time for leisure. This may seem an obvious statement given that these are rural caregivers and rural, by definition, means being situated away from metropolitan commercial and residential developments. For the caregivers in this study, rural living meant an additional time burden that non-rural caregivers do not experience.

Isolation and the logistics of medical care. Rural living added to the daily time burden of managing the household. In similar fashion, rural living meant additional time required to attend to their Veteran's medical care needs. All of the caregivers in this study were responsible for the management of care transportation to and from their Veterans' medical appointments. The caregivers (and Veterans) enrolled in this study lived an average of 135.3 miles from their assigned VA Medical Center, where the Veteran received primary and specialty care for the treatment and management of multiple sclerosis. Distances ranged from 81 miles each way for the "shortest" trip, to 283 miles. Thus, the average distance for a round-trip visit to the VA was 270.6 miles, with a range of 162 miles to 566 miles. As with household management, covering such distances requires time. A round trip drive to the VA could take as few as three hours or as many as ten. In recent years the VA has established Community-Based Outpatient Clinics (CBOCs) for basic primary care needs to help rural Veterans avoid such lengthy drives. Even with these clinics available, Veterans in need of more complex specialty care, such as those with MS, must regularly visit the main VA medical centers. All the caregivers in this study said that making this trip twice or more per week was common, depending on the medical needs of their Veteran.

CG01 and her Veteran lived 283 miles from their assigned VA medical center. Fortunately, her Veteran had not had an exacerbation for some time and visits his neurologist once every six months. "Unless he's having issues, it's just not necessary for him to go any more often than that." Even so, the lengthy drive means a time-investment of a full-day or more. To help ameliorate the inconvenience of the lengthy trip, CG01 says that they have come to treat the travel as a mini-vacation.

We kind of enjoy it. We go sight-seeing. I usually try and take my camera and if we are early enough leaving from there, we try to take the back roads. So I can take pictures of old farm buildings and old things that are going to be gone in a few years. And we head back to [a small rural town] and places like that.

For other caregivers, the trip is less vacation and more part-time job. CG05 lives 85 miles from the VA in a home 30 miles from the nearest interstate highway. The actual distance belies the reality of their location; the home is located off the main road, down several country roads behind a field. To transport her Veteran to the medical center, they have a one-and-a-half hour drive each way. If we consider the time it takes her to drive to the VA, park, make it to the appointment, sit through an examination/intervention, return to the vehicle, and drive back home, a normal trip to the VA can take upwards of six hours. CG05 reports making this trip several times a month, sometimes as frequently as twice a week, depending on the medical needs of her Veteran.

That's a big issue with the VA. . . . I understand they have a lot of patients. And multiple times I've requested, "can we get all the appointments grouped together in one day?" And they say "No. We can't do that." When we were in [name of other city], they would actually make three or four appointments all in one day for us. It would be a long day, but when you're driving 170 miles round trip, I would rather have eight hours of appointments than to have to drive that [distance] four times in two weeks.

The rural location, coupled with Veteran medical needs, means that much of the caregiver's time is organized around driving; either driving to commerce centers for household supplies or driving to transport the Veteran to and from the VA medical center. Isolation related to rural living location is not only about the distances but also about the time it takes to traverse those miles. Generally, time spent on the road is time away from other activities, such as spending the time required to maintain relationships with other family members and friends.

Isolation from Family

A traditional source of social support for informal caregivers comes from family members. Some caregivers in this study expressed feelings of isolation from other

family members, especially when they lived in other towns or states. Rural living meant that face-to-face interaction with some family was possible only after traversing large distances. The daily care needs of the Veteran are a barrier to more regular family visits. Some avoided regular visits because long travel was hard on the Veteran. If the Veteran were not brought along, it meant arranging care for him, often at great financial cost. If the cost of care was too expensive, the caregiver might return the same day, but this meant a long, hard day of travel for the caregiver. On the other hand, when family members could visit the caregiver at the caregiver's home, the Veteran's MS symptoms, particularly mood lability (i.e., frequent or intense mood changes or shifts), made such visits stressful. Often, these visits were short. We identified two dimensions of isolation from family: care of the Veteran as a barrier to distant family travel, and the emotional needs of the Veteran as a barrier to more regular in-home family visits.

Care needs as a barrier to travel. For some caregivers, the distances required to visit other family members can prevent more regular family visits. Although technologies such as the videotelephone and computer have made face-to-face visibility over long distances possible, they can be poor substitutes for expressions of social support that physical proximity demonstrates. CG02 is an extreme example of travel distances to family; her parents live in another country. She recounted that when her father was dying she wanted to return home to be with him before he passed away. She had not seen him or other members of her family for several years because her Veteran was too ill to travel. His MS made the three-hour long trip from their rural home to the nearest major airport very uncomfortable for him. A difficult flight awaited the end of that drive, made so because of the logistics of loading and unloading him, and his wheelchair, from the plane. His MS-induced cognitive deficits and mood lability made the long flight extremely stressful for her and so she had largely avoided plane travel. The result was infrequent visits to her parents' home. She typically saw her other family members when they came to visit her, which, because of their lack of financial resources, was not often. To see her father for the last time, she decided not to travel with her Veteran. Asked why she did not take him, she noted the difficulties of travel mentioned above, but went on to state that she wanted to focus on her father rather than spending time addressing the care needs of the Veteran. "I can't focus on Papa when [Veteran] also needs me to do things."

To return to her family home without the Veteran, she had to find someone that could provide 24-hour care while she was away. "I am scared to leave him here alone because sometimes he falls on the floor two, three times a day." She eventually

enlisted the Veteran's mother who lived in another state. This meant arranging to fly her mother-in-law in while she was away. If the financial resources had not been available to pay for both her and her mother-in-law's travel expenses, then seeing her dying father alone one last time might not have been possible. Again, such travel is not typical of the rural caregivers in this study, but CG02's experience highlights how the management of the Veterans cognitive and physical MS symptoms can make traveling any distance a barrier to maintaining face-to-face relationships with other family members.

More typical is CG05. Her family lives in the same state, but her rural location means a several hour trip if she wants to visit. Asked why she does not see other family members more often, she cited the distance.

All my family lives on the east coast. I can't do that in a day anymore. In my younger days I could. But from here to there it's a three and a half hour drive . . . If I leave here at six in the morning and get there at nine or ten in the morning, then I have to leave at two or three in the afternoon to get back here at five or six in the afternoon, it makes for too long of a drive to do it in one day.

CG05 stated that although the distance makes for a long day, her concern for her Veteran is what prevents her from visiting family more. She notes her Veteran's attempts to walk without assistive devices as the reason "he falls all the time...if he falls when I'm [visiting family in another city], then he's on the ground all day." The distance between homes in her area makes it unlikely a neighbor would hear the Veteran ask for help. Her conscience makes it so she "could not forgive myself if something happened" while she was away. So she has scaled back visits to holidays and emergencies.

Not all the caregivers felt that maintaining family relationships was difficult. Advances in telecommunication have obviated the need to leave the Veteran alone while they visit with family. For instance, CG01 can stay in touch with her son and grandchildren who live several hours away. Providing regular care for her Veteran left her feeling like "I just could never seem to find the time" to see them. This changed when her son gave her a laptop "with a webcam and Skype." Now they can "talk to each other" and she can "see the kids. And that was one of the things. So now I can sit here and do it whenever [her Veteran] is sitting there watching the TV."

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Emotional needs of the veteran as barrier. Sometimes the Veteran's emotional needs are the barrier to more frequent visits by family members. Multiple sclerosis is neurodegenerative, affecting both physical and cognitive functioning. Mood lability is a common feature of cognitive dysfunction. Those with MS can be irritable, irrational, depressed, or angry. These moods sometimes come on with little notice and can be gone just as quickly. For those who do not fully understand the symptoms of MS, witnessing these symptoms, or being a target of them, can be an unsettling experience. CG06 told us that her son does not come home from college as much as she would like. In part, the son's infrequent home visits are related to his interactions with his father.

[The son] would come home and just drop his shoes wherever, just like before [he went off to live at college]. Now that sets [the Veteran] off. He can't stand a mess. With [the son] at school, things have to be just so. And that ain't a problem because it's just us two now. But when [the son] comes home, he just puts his stuff wherever. And so he yells at [the son]. It was like that with everything. And you know, [the son] isn't a baby anymore.

The son is aware of his father's MS, but the caregivers says "He's still just a kid" and is not sure if "he connects the yelling to [Veterans] MS. ... He don't say nothing, but he don't come home as much, either."

Recall CG05, who no longer took day trips to see her mother and sister because of concerns about leaving her Veteran alone. She feels that as her Veteran's MS has progressed, his mood has become increasingly unstable. His depression makes him irritable with others, and this is a personality trait that her mother and sister do not care for.

Mom used to come over once a month and spend the weekend here. But my mom has gotten very crotchety. So between crotchety mom and crotchety him, they don't mix well together. I just don't have her over anymore except for important holidays.

Caught between a daylong drive to visit her mother and sister and her husband's mood at home, CG05 does not see her family with the regularity she would wish. She stated that she contacts her mother and sister regularly by phone, but laments her increasing physical isolation from them.

Isolation from Friends

Caregivers' isolation from friends is related to living in a rural environment. The reality of physical isolation from others means that when the Veteran is in need of assistance, it must come from the caregiver or not at all. There are no friends around to help largely because there are no people around them in their rural locations. Yet social isolation resulting from physical location does not happen all at once; it is a process that occurs gradually over time. Isolation as a process means that friends initially rally around the caregiver (and Veteran), but as the Veteran's health declines over time, and the caregiver takes on the Veteran's increasing care needs, caregivers have less time to spend outside the home visiting with friends. Thus, isolation from friends has two dimensions: *physical isolation from others* and *isolation as a process*.

Physical isolation from others. Rural is a Census tract with fewer than 2,500 people living within the area. In practical effect, it means a sparse population with a relatively low number of homesteads. A unique feature of rural living is that there are few people around. Many Veterans (and caregivers) seek out rural areas for this reason. Fewer people means less traffic, less noise, fewer homes to break up the natural landscape, and more "space" to live. The upshot to a smaller number of neighbors is that there are fewer people to interact with, fewer people to befriend, and fewer friends available to provide help on short notice. In this way, physical isolation can lead to social isolation. Outside the occasional visit from other family members, rural caregivers were, for the most part, on their own. CG06 said that she was only able to take "a momentary break" when her son returns home from school. "He'll sit with his dad and I can go out with the girls for dinner. But that only happens when he's here for spring break or during the summer." Recall from above when CG06 noted her son came home to visit less than he used to because of his father's MS-related mood swings. This means fewer breaks from caregiving for CG06.

Rural living can present unique challenges to health in that there are fewer people around if a health emergency occurs. CG01 said that her Veteran likes to cut the grass with their riding lawn mower. "A lot of the times I go fuel it up and check it for him because he can't walk around to get around it and with the [wheel] chair it's too awkward for him." She recounted a situation in which impatience led her husband to start mowing the lawn without her assistance.

[I] didn't check the gas and he got to cutting the grass and he got stuck up there by the gate [an acre away from the house]. And of course, he

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couldn't come tell me. And the house is all closed up and he's out there yelling for me. Unfortunately, he didn't take the walkie-talkie with him that day and he sat out there for about an hour. And I got to wondering where he was at and went out to look for him ... and saw what had happened.

This situation was potentially deadly; MS patients can have difficulty regulating their internal body temperature. This couple lives in rural Florida where temperatures can soar more than 100 degrees in the afternoon sun. Without a way to contact his wife and no neighbors around to hear his cries for help, his situation could have easily led to dehydration, heat exhaustion, or even death. Rural living affords privacy via physical isolation, but that privacy also comes with its own unique risks and burdens, such as no friends in the immediate vicinity to help on short notice.

Isolation as process. Multiple sclerosis is a degenerative disease, with sufferers progressively losing physical function over time. As this occurs, MS patients require greater assistance with ADLs. Caregivers dedicate an increasing amount of time to bathing, dressing, feeding, and caring for their Veterans as MS ravages their physical and cognitive abilities. This means less time for maintaining other relationships. Losing friends as the result of the Veteran's MS was a common theme among rural caregivers.

The process begins because of time limitations brought on by MS care provision needs. Just as with family, physical distance is a barrier to maintaining face-to-face friendships because it takes time to drive anywhere and MS caregivers have increasingly less time as MS progresses.

CG05 described driving to and from medical appointments as a full-time job in its own right and spoke of an appointment-free day as "a day off." Asked about hobbies, she admitted that reading books in the evening is all she has time for. One distinct barrier to having a "vibrant social life" was "having to drive all that time."

CG04 told us that because of the care needs of her Veteran, social visits with her few remaining friends must be paired with her Veteran's medical visits. Otherwise, she does not have the time. Quick trips out with friends are simply not possible because of where she lives.

I can't afford to pay somebody every time I need to go to the store or to a doctor's appointment or even to go out to lunch with my girlfriends. I haven't been to a movie in years. And I haven't been to eat with my friends in a while unless it was on the way to a doctor's appointment.

Said CG04, her “friends have dwindled down to a very tiny core now because I can’t go anywhere so they quit calling and asking.”

Isolation as a process is also related to a breakdown in open communication between the caregiver and her friends. Research has shown that lasting relationships are built upon open communication, the process of sharing thoughts, feelings, opinions, daily activities, and information with others (Bauminger et al. 2008). Open communication helps establish, build, and maintain relationships and is linked to strong friendship relations (Stafford and Canary 1991). This can sometimes be a challenge for rural MS caregivers. CG04 finds that the daily-lived realities of providing care does not make for good conversations among her “core friends” of “three or four people.”

Because who wants to know that [Veteran] pooped all over the floor and the walls and the furniture. I’ll just say, “well, we had a rough morning.” Or something. Once in awhile I’ll say what happened. But mostly not. Their lives are totally different. Completely different.

CG04 continued to describe regular cleaning sessions, at least once a week, lasting an hour or more. Not that all events should be shared, but the sense that CG04 must protect her friends from the more unsavory aspects of caregiving has resulted in a gulf of understanding between what friends believe a caregiver has time for, such as social outings, and what the caregiver must do to provide care. This has strained her relationships even among her core group.

This process is also evident in CG06’s description of a shrinking circle of friends over the past few years “because many of them don’t understand MS. It’s like they are afraid of [Veteran]. He’s not contagious. But those aren’t the type of people I want around. So fine.”

Isolation from Each Other

Multiple sclerosis is a disease that is difficult for family members and friends to understand. This is true for caregivers as well. Despite their willingness to sacrifice time and effort providing care, caregivers may not fully understand the physical or cognitive decline the Veteran has suffered. Isolation from each other can occur when the caregiver does not, or cannot, understand the disease from the Veteran’s perspective.

CG05 said of her husband’s disability, “It’s not that he can’t do anything. It’s that he won’t. Because he has MS. It all circles back to ‘I have MS.’” She admits that

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he is angry over “what seems like my lack of empathy,” but defends her opinion because:

The doctor told him straight out ‘you have a very mild form of MS. You’re lucky’. And he didn’t want to hear that because he wants to go on with his pity party. But after a while, the pity party starts to get to me. I just want to [grrrrr, makes noise] ... Where can I go [indicates the field in front of the house]? It’s not like I can go to a friend’s [house] and blow off steam. So I have to sit here with him listening to him whine.... Sometimes I scream back at him and tell him to stop feeling so sorry for himself, that there are a lot of people out there worse off than he is.

She admits that these arguments have placed a strain on their marriage. With limited options for getting out of the home, they focus their anger on each other. Rural living means that there are few friends and family around who can deflect the growing irritation they feel toward each other. Their rural location means that there are few places to go within easy walking or driving distance when they really get upset with each other and need to get away.

DISCUSSION

A recent report on rural caregiving in America states that there are several unique areas of concern to rural caregivers. These include: the impact of caregiving on the rural workplace; the limited availability of services in rural areas; financial hardships on caregivers with low incomes; the stress of rural caregiving and related coping mechanisms; and access to and use of the internet (Easter Seals 2007). Our small sample limits our ability to make comparisons, but we note that many of these concerns were shared by our rural caregivers of Veterans with MS.

One way in which our sample differs, and more generally the population of rural caregivers of Veterans differ, is in their ability to access VA health care services for their Veteran. Veterans living in rural areas have access to primary and specialty care services at elevated levels compared with non-VA eligible civilians. Access to VA care ameliorates at least some financial burdens of care typical to rural caregivers. And while it does often lessen the financial strain for some, this may not be the case for all; some Veterans are not registered for VA services, or are unwilling or unable to access VA services because of mobility or financial concerns. Gasoline, auto insurance, and car payments still cost money. The Department of Veterans Affairs does offer travel stipends to assist with the costs of transportation,

but for those living in highly rural areas, that incentive may not be strong enough, either financially or as an inducement to endure long hours transporting in a vehicle. Yet despite these potential barriers, caregivers of Veterans living in rural areas are better positioned to access health care services for those for whom they care.

In addition, rural caregivers of Veterans have the added benefit of being able to access formal care support services not typical to rural caregivers generally. Depending on a Veterans disability rating, VA programs can provide in-home nursing care and some limited respite even in most highly rural areas. For the caregivers who participated in this study, there was regular contact with an occupational therapist that specialized in treating multiple sclerosis. The therapist contacted caregivers at home at two weeks after study enrollment, and again at four weeks, six weeks, and eight weeks to answer any questions caregivers might have related to therapies at home. We found that rather than relying on these calls to improve medical education related to MS, many caregivers used the calls to discuss their frustrations with caregiving. They simply needed someone to give them a supportive ear. Many caregivers of the non-VA eligible patient population do not have access to formal social support services.

Despite their ability to access care for their Veterans, and even with intensive clinical home support, rural Veteran caregivers still expressed the same frustrations noted among other rural caregivers; a lack of social support. We think this highlights the heavy psychosocial toll of intensive caregiving in rural areas; for if even those caregivers with high levels of access to and support from formal care services still feel socially isolated, one can only imagine the struggles of caregivers who do not enjoy such high levels of access. As we discussed above, providing informal caregiving services in remote locations meant limited contact with family and friends. The rural location does not *cause* social isolation, but rather, engagement with family and friends is restricted by the time it takes to traverse distances in rural locations.

Research elsewhere has connected social isolation to the intensive nature of caring for those with multiple sclerosis (Arnett 2007; Figved et al. 2007). Studies have also found that the unpredictable nature of the disease course of multiple sclerosis can present challenges to relationships, both in the family household and among other family and friends (National Alliance for Caregiving 2012). Challenges to relationships can result in social isolation. Research has also linked social isolation to increased morbidity and early mortality (Cacioppo and Hawkey 2009;

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Pfleger et al. 2010; Uchino et al. 1996). In our study, even when rural caregivers had clinical home support, social isolation was still a problem.

RECOMMENDATIONS

Clinical intervention to ameliorate social isolation requires attention to how rural Veteran caregivers develop feelings of social isolation. Social isolation results from the time burden of care or the distances traveled to manage the home, or exists as an emergent feature of their relationship with family, friends, and their Veteran. For instance, if isolation arises from rural living, then technological solutions may be available; Skype, FaceTime, and other real-time, face-to-face applications can reconnect caregivers to loved ones at a distance. The example of CG01 is instructive; recall she stayed in touch with her son via a laptop computer and Skype. The VA is using distance video technologies to provide physical and psychological therapies for rural Veterans. Where such technology is installed in a home, it could be made available to caregivers. Caregiver support groups via distance technology could be structured around MS (or other disorders). The technology used to connect the support group to clinicians and research experts who can provide information, answer questions, and connect caregivers with VA and community resources and with other caregivers of rural Veterans with MS. The associations between caregiver burden and social isolation, social isolation and depression, and depression and care provision make a caregiver distance support group an investment that could improve both the caregivers' and the Veterans' quality of life.

LIMITATIONS

The work presented here has limitations, the most obvious being the sample size. With an N=6 we do not suggest the themes noted in our caregivers' narratives are applicable to other caregivers. That said, sample size is less an issue in qualitative research where the goal is to conduct in-depth investigations. Phenomena like social isolation can be explored in this way to better understand their mechanisms (i.e., the properties and dimension). This knowledge can then be used to inform future research and theory. In particular, a grounded theory approach is aimed at building an experiential-level theory that can guide others as further investigation continues. This approach contrasts with quantitatively oriented work where the goal is to provide a broad overview of patterns within a particular set of phenomena. We can answer no questions regarding validity or reliability outside our small sample, but provide an informed discussion aimed at

furthering our understanding of social isolation as it relates to caring for Veterans with MS in a rural environment.

Another limitation is the use of personal narratives (i.e., self-reports). There is a difference between the lived reality of an experience and how those experiences are communicated (Polkinghorne 1996). Our participants' narratives are one possible narrative among many they might choose to communicate (Gubrium and Holstein 1997). For example, the narrative of rural-related social isolation may change depending on whether one is talking with one's spouse or with a stranger representing the Department of Veterans Affairs in an interview related to VA medical care. Narrative accounts are active, dynamic constructions that convey some aspects, but not others, of a person's sense of isolation within the contours of the time and space in which the narrative is told. Like personal experiences, narratives have a subjective nature. Then again, personal subjectivity is at the core of perceptions of isolation. Accepting these limitations should not distract from the clinical implications for how clinicians might better assist rural caregivers in overcoming social isolation.

SUMMARY

We have explored some properties and dimensions of social isolation as a way to better inform our understanding of why social isolation occurs for rural caregivers of Veterans with MS. Social isolation is a dynamic phenomenon with several factors that contribute to a caregiver's sense of disconnection from potential social support networks. Our work suggests a multilayered process that occurs over time and has origins in the rural environment. The time it takes to manage a household and to travel to medical appointments make it difficult to find time to visit with family and friends. Similarly, family and friends are not able to stop by to provide a few hours of respite unless their help is scheduled, often at a financial cost to the caregiver. The rural location makes it difficult to find minor forms of assistance, such a neighbor checking in on their Veteran. Rural living also makes it difficult to get out of the house to cool off during an argument, resulting in increased isolation from each other. The resulting combination leaves these caregivers feeling socially isolated.

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