

Care by a Caregiver: The Use of Self in Qualitative Research

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Abstract: This narrative, reflective paper discusses a qualitative research study on multiple sclerosis (MS) caregiving in which the author/researcher utilized her own caregiving experiences and shared with the study participants in open dialogues. It examines the choice to research a topic with a close personal connection, i.e., the use of self in research. Moreover, this paper discusses the use of reflective journaling to gain greater awareness during the research process, and to assist with data analysis. Intimate passages from the journal are shared throughout the narrative concerning shared experiences, self-care, and topic analysis. Discussions are framed chronologically as before, during, and after the qualitative study was completed. The experience of caring for a partner with MS is central to this reflection, and the paper provides insight into that experience along with a discussion of the practice of using oneself in research.

Keywords: use of self in research, multiple sclerosis, caregiving, reflective journaling

Introduction

My involvement with qualitative research has been a remarkable journey both professionally and personally. As part of my dissertation research, I chose a topic with which I have a close personal connection. I am a female multiple sclerosis (MS) care partner, and my husband has had the diagnosis of MS for more than 20 years. During that time, I have provided varying levels of care for him. MS is a disease that primarily affects women, and women traditionally provide the majority of unpaid family care; thus, the MS caregiving experience is a unique situation for exploring gender roles in caregiving (Nodder et al., 2000). This illness has caused great personal loss to my husband, John, our four children and me. MS, however, also provided me with an opportunity to return to academia, complete a PhD in social work and conduct research involving MS caregivers.

I am certainly not the only qualitative researcher who has chosen a research topic that hits close to home; many others have done the same. In this paper, I will explore the use of self in research and reflect on my dual role as both researcher and caregiver. Further, I will explore my choice to research a topic with such close personal connections. My situation allowed me shared access to the MS caregiver experience during the research process. My original intent was to use my experience and knowledge about MS and caregiving as an advantage in connecting with the participants in my research. In the end, my research and its results became a source of personal growth and inspiration to me. In my research, I was able to transcend the role of researcher and fact-finder by

sharing the lived experience with my participants, thereby deepening my perceptions of care as I identified with caregivers and care receivers alike. During this journey, I developed a substantially deeper understanding of my research topic and myself simultaneously.

Understanding Multiple Sclerosis and Family Caregiving

MS is a progressive, degenerative neurological condition that is unpredictable and results in a wide array of symptoms and disabilities. It affects more than 2.3 million people worldwide. MS is an immune-mediated disease in which the body's immune system attacks the protective lining (myelin sheath) of the central nervous system, thereby forming "sclerosis," or scar tissue. This impairment results in damaged or destroyed nerve impulses (National Multiple Sclerosis Society [NMSS], 2016a). The course of the disease places a burden not only on those with MS, but on their caregivers as well. The severity and symptoms of MS vary greatly from patient to patient and include fatigue, numbness, walking difficulties, balance and coordination problems, bladder and vision problems, dizziness, vertigo, sexual dysfunction, pain, impaired cognitive function, emotional changes, depression and spasticity (NMSS, 2014). With recent advances in medication management, individuals with MS are having fewer and less severe exacerbations of symptoms than in the past. Further, medications delay the onset of significant disability, thus allowing MS patients to continue living in their own homes longer and require less institutional care (NMSS, 2010). These advancements are good news for the patient; however, they place additional responsibilities on care providers.

Care for MS patients may be informal and unpaid or professional and compensated. 80% of informal home care is provided by live-in relatives, primarily the patient's partner (Carton, Loos, Pacolet, Versieck, & Vlietinck, 2000). In other words, the bulk of the responsibility of in-home care falls to the patient's loved ones. Patients without such a relative to provide in-home care must utilize other forms of support on the MS care continuum, such as friends and family who do not live in their home, personal care services, homemaker and chore services, skilled nursing, or rehabilitation services (NMSS, 2016b). Individuals who require professional care assistance must rely on private income, health insurance, or government-funded insurance programs for payment of these medical-related services. In-home care remains much more cost-effective and desirable for both cost and other reasons than out-of-home care.

In general, MS is a costly disease, especially with the recent addition of self-injectable drugs. The cost of care increased by more than 35% per patient over a 10-year period, from \$9,515 per patient in 1995 to \$12,879 per patient in 2004 (Kunze, Gunderson, Gleason, Heaton, & Johnson, 2007). Disease-modifying therapies in the United States can cost upwards of \$48,000 annually, per MS patient (Goodman, 2012). These costs have contributed to the ongoing conversation about health care cost concerns in the United States. Some other nations have had a form of nationalized health care for some time now; therefore, their costs are lower than in the U.S. (Russo et al., 2004). The National Multiple Sclerosis Society (NMSS) supports continued overhaul of the U.S. health care system and provision of health care cost assistance to individuals with MS. The NMSS estimated the cost of MS to be around \$70,000 annually per patient (NMSS, 2016c). It is financially devastating to many families not only because of the direct costs of the illness but also because of the indirect costs, namely loss of potential earnings for both the patient and the caregiver.

Aside from the financial burdens, the lack of predictability in onset of symptoms make MS an extra challenging disease for patients and loved ones alike. Because the disease's process and symptoms vary significantly from one individual to another, it is difficult to predict the individual's course of MS. Although rare, some individuals with severe

disability may experience infections and die prematurely. The NMSS reported that the overall life expectancy for a patient with MS is 95% of normal life expectancy (NMSS, 2014). However, the effects of MS are more insidious than this rate implies. For example, MS generally impairs the individual's ability to complete many of the activities of daily living.

Family care partnerships are vital for patients with chronic illnesses and for keeping patients with MS in their own home as long as achievable. Prior research has been conducted on caregiver stress (Pearlin, Mullan, Semple, & Skaff, 1990; Robertson, Zarit, Duncan, Rovine, & Femia, 2007; McKeown, Porter-Armstrong, & Baxter, 2003), caregiver assistance (Dobrof, Ebenstein, Dodd, & Epstein, 2006), and caregiver burden and stress (Phillips, Gallagher, Hunt, Der, & Carroll, 2009). This past research has shown that providing care for a chronically ill individual is generally viewed as a stressful situation for caregivers and has a profound impact on not only the patient's social roles, but his or her family's well-being (Robertson et al., 2007). These caregivers are at risk of increased stress and depression as well as poorer quality of life (Khan, Pallant, & Brand, 2007). Providing care for someone, especially over a long period, can be overwhelming, and caregivers who encounter competing demands (e.g., work/career demands on top of full-time caregiving) are especially prone to depression (Wang, Shyu, Chen, & Yang, 2011).

Schwartz and Frohner (2005) and Pakenham (2005) addressed the importance of informal care specific to MS caregivers and agreed that providing assistance to the family caregiver benefits both the patient and the caregiver. Caregivers find themselves in a position for which they are ill-prepared, but their willingness to take on this role offers multiple advantages to the patient. Unlike individuals with the disease, however, caregivers do not view themselves as a focus for treatment, yet they, too, could benefit from assistance and support. Caregivers of patients with any disease (not only MS) face a difficult task and typically have a range of emotions associated with the care they provide. Additionally, providing a support system for the caregiver ultimately benefits both the patients and society because patients prefer the assistance of their loved ones, and such in-home care is also at a lower cost and reduces the expense to society (Dobrof et al., 2006).

Family caregivers do not always utilize available social support when they need it. O'Hara, De Souza, and Ide (2004) concluded that although MS patients receive considerable amounts of care from family members, those caregivers are not receiving social support from professionals in return. Moreover, these caregivers report clinically significant levels of psychological stress related to the care of a partner with MS (Pakenham, 2001). Providing greater support to caregivers is likely to reduce their feelings of burden, stress, and isolation. Such support will allow the caregiver to continue with his or her caregiving responsibilities, thus reducing the potential for the patient to require more costly, professional care assistance.

The availability of community resources and social support vary by location. Various online support networks are also available for individuals with MS, their loved ones, and their caregivers. Current services are typically accessed via the patient's treating physician, who provides information and referral services. Organizations such as the NMSS also have information and linkage services (NMSS, n.d.). The NMSS reports that 432,526 individuals with MS had registered with it as of the organization's last census in April 2014 (M. Nadvornik, personal communication, April 7, 2016). Exact numbers of individuals with MS are only estimated because individuals are not required to report their illness, but the NMSS estimates that 2.3 million individuals worldwide are living with MS (NMSS 2016d).

Understanding how many care partners of MS patients identify themselves as needing services or utilizing outside assistance is difficult. Currently, NMSS does not keep census numbers on care partners. It provides services to caregivers, including financial planning, referrals to health care professionals and community agencies, financial assistance, emotional support, education programs, self-help groups, and an online discussion forum for care partners (MSConnection.org). Other organizations, like Can Do Multiple Sclerosis (n.d.), offer lifestyle empowerment programs for people with MS and their care partners (Kalb, personal communication, April 7, 2016).

Although these services for MS caregivers exist, it remains difficult for caregivers to see themselves as

an identified focus of treatment and support, and to therefore seek out needed assistance. Services to caregivers are provided more as an afterthought and not as a primary focus during treatment. These caregivers struggle with the demanding role of providing care to another and often go underserved and under-supported in the process. (Family Caregiving Alliance, n.d.).

My MS Story

My husband, John, a board certified internal medicine physician and a licensed pharmacist, has this life-changing disease. John received his MS diagnosis in November of 1993, just after our engagement. We married the following March. MS episodes occurred several times during the early years of our marriage. Those episodes were unplanned and random, and they changed our life plans.

We took the minor exacerbations of the illness in stride. For example, on one occasion we had to leave a function early, and on several occasions, John had to wear an eye patch for intense vertigo. It was an annoyance that we handled. However, our lives changed drastically during our fourth pregnancy. John suffered his most significant exacerbation, which resulted in extensive vision impairment in his left eye. During previous episodes, John had experienced vision problems that had left him with central vision loss in his right eye. Now, John was totally blind in his left eye. The lack of vision in both eyes required him to leave his job as an emergency room physician. I was seven months pregnant at the time and worried how I would drive myself to the hospital when our fourth child arrived.

John was unable to complete tasks required of a primary care physician, like suturing or looking in a patient's throat or ears. He spent three years not working and received disability insurance. It was during that time that I was able to attend the University of Utah to pursue my Ph.D. studies in social work. The opportunity to return to school was a direct result of my husband not working, as it allowed my family to both relocate and remain economically stable. My husband provided care for our children and support to me; without his care, I would have remained a master's degree-level social work clinician.

Although I believed our situation with MS was less

severe than that of others, I still felt a unique connection with spouses and caregivers of individuals with MS. I understood, personally, the random attacks that strike when no one is watching. Like many others, I lived the experience of compartmentalizing MS, tucking the disease away in a box while I tried to move on with living life and take care of my family. That strategy always worked for a time, until the disease ripped the box open and showed its ugly self again in some bold manner. I had firsthand understanding of how MS attacked the flow of a family, forcing members to stop and respect the power of the disease. In many ways, it was not just John who lived with MS, but all of us in his immediate family. And we each knew that, at any moment, the courses of our lives could change, and we would be forced to proceed in a new direction at the disease's command. The rhythm of our lives went something like this: recover, move on, forget and repeat. I felt defenseless against the disease, and I hated the loss of control inherent in MS.

At one point, someone close to me suggested that I must be happy that my husband lost his eyesight because it allowed me the opportunity to work toward my PhD. I told that person that I would never be happy that my husband lost his eyesight, but that I could truly understand that sometimes people find the strength to make something good come out of something bad. My life was a swirl of intense, personal emotions as I began thinking about possible research topics for my dissertation. For obvious reasons, I was drawn to the topic of MS, and focusing my research on unpaid-nonprofessional caregivers seemed fitting—these were people with whom I had a shared experience.

It is important to note that while no MS experience is typical—every case differs from one another—my husband's experience has not been nearly as devastating as others'. John has a strain of MS that has not been as progressive or as debilitating as many patients experience. His disease attacked his vision significantly, but he remains able to walk, move, and meet the demands of daily living with minimal assistance. Those with a more aggressive form of MS are less fortunate in terms of the impact on their daily lives. Of course, some experience fewer symptoms than my husband.

Before the Research

When my husband had to abruptly stop working due to the extreme exacerbation of his illness (causing the vision loss in not only one but now both eyes). He found himself at home, spending large amounts of time in isolation, and miserable. In focusing my dissertation research on MS, I hoped my husband might become interested in my research and write about his personal experience with the disease. I thought this opportunity might engage his brain and draw him out of his sense of isolation.

I began looking at peer-reviewed journals on MS. The articles that most fascinated me were the ones on caregiving. I became drawn to studies that focused on the family caregiving experience, but I noticed a gap in the existing research. Although research on general care and caring for patients with other illnesses was available, research focused on MS caregivers' experiences was generally lacking. Therefore, my questions for this research arose directly from my personal experience and my review of the literature.

I designed a qualitative study that looked at perceptions of MS care from both the caregiver's and the care receiver's viewpoint, to see if traditional gender roles affected the care experience, especially given that MS affects women more frequently than men. I interviewed 20 participants individually first; then I interviewed each care receiver/giver dyad in a follow-up, joint interview in which I examined perceptions of the care experience. I looked at the caregiving experience, care roles and responsibilities, and the role of social support among the dyads (Hughes, 2016). Prior to beginning my research, I thought carefully about sharing my own situation with the participants and, in the end, determined I would be transparent and identify as a caregiver.

To Share or Not to Share

I struggled with whether to share my personal experience with my research study participants, but after much thought and deliberation, along with a review of relevant research, I decided that doing so was the best decision. I am a fairly transparent person in general, and I believe a small amount of self-disclosure can be useful. As a clinical social worker, I had developed over time the skill of minimal self-disclosure. But still I needed to determine any

prior precedence and insights regarding choosing a research subject with a close personal connection, so I turned to other researchers.

Padgett (2008) discussed studying the familiar versus the unfamiliar, and identified two advantages of sticking with a familiar topic for a qualitative research study. The first advantage is easier and faster development of rapport with the participants. The second is the jump-start in knowledge acquisition. Padgett also noted that a disadvantage of researching a familiar subject is the risk of being too close to the subject matter. Knowing too much about a subject matter can create blinders and lead to premature assumptions and conclusions.

I found several examples of excellent qualitative studies that were conducted by researchers with a close personal connection to their subject that supported my desire to research MS caregivers. These included research on disability conducted by Zola (1983); on divorce, by Riessman (1990); and on working parents, by Hochschild and Machung (1989). Perhaps the best example of such a study is that of anthropologist Robert Murphy, who suffered from a neurological condition that gradually restricted his movement and resulted in his death. He made tremendous contributions to disability studies with his book *The Body Silent* (1990). Toward the end of his life, he “used his own intimate experience of disability and his intellectual acumen as an anthropologist to broaden our understanding of human behavior” (Goldin & Scheer, 1995, p. 1443).

I believed participants in my study would be more severely ill than my husband, so I felt there was less potential to assume that we would share a mutual understanding of the care experience. I also believed the use of my close connection to MS and caregiving would facilitate transparency. My status as a caregiver and an insider to the disease, I believed, would allow participants to feel a connection with me as the researcher and therefore more comfortable sharing their experiences. This shared experience of similar burdens, I thought, would strengthen the research.

To be clear, there are also limitations to a study in which the researcher discloses personal information with participants. In this study, the most probable challenge posed by personal sharing was that

participants may have assumed a shared understanding and thus not offered as complete an explanation to the phenomena being studied. During the participant interviews, I was willing to answer questions about my experience with MS. However, I used my clinical skills to bring the discussion back to participants’ own experiences. My goal in using personal disclosure was to make the participant feel comfortable in the interview. I was a caregiver and an interviewer focusing on a participant’s experience. I set limits to what I shared with the participants and professional boundaries within the interview if the participant became overly concerned with my experience. For example, I told one participant, “I am interested in hearing about your experience with caregiving. I can answer questions about my situation but I really want to hear about yours.” One way I kept the interview focused on a participant was to probe more deeply in order to elicit rich explanations. My background as a clinical social worker undoubtedly assisted me in conducting research interviews. While developing empathy and understanding of a participant’s experience, I was able to use my clinical skills to encourage a deep exploration of that experience. For example, I explored comments made by a female patient, who I will call Carol for the purposes of this paper. The question began with my inquiring about support groups:

Jennifer (Researcher): Have you ever participated in a support group?

Carol (Participant): No. I’m afraid.

Jennifer: What are you afraid of?

Carol: It seems like the more you know about it, the more it eats away at your life. You know? I’m ignoring it. I’m ignoring it.

Jennifer: So keeping some distance from it . . .

Carol: Yeah.

Jennifer: Is that what’s keeping you safe?

Carol: I hear from people that I haven’t talked to in eons that’ll call me and say, “I just had an aunt or a sister or a friend or somebody who was diagnosed with MS, blah blah blah.” Why are you calling me?

Jennifer: How does that make you feel?

Carol: Well, I guess it makes me feel I’m glad that I can be there for them, to have someone to call.

Jennifer: Mm-hmm.

Carol: But I can’t tell them anything any different than, you know, a doctor or anybody else will tell them.

This excerpt is rich with emotion, authenticity, and expression that goes beyond the initial question.

I was also able to ask questions for clarification. For example, in the following exchange, the caregiver, Ralph, was asked if he was dependent on or independent of his wife. Ralph responded that he was dependent. I wanted to know more than that, so I followed up with a question for deeper expression by the participant:

Jennifer: Do you think that you're dependent on or independent of one another?

Ralph: I'd say dependent.

Jennifer: And tell me how you're dependent on each other.

Ralph: Well, you know, I love her to death and I need her. You know, I want her. You know, I miss her when she's, you know, at work or gone during the day and I'm just sitting there with the cats, you know.

Exploring deeper and providing opportunity for clarification is one benefit of the use of self in research. The researcher can say, "I understand your situation; now tell me more, because I know there is more to tell." For example an exchange with a female caregiver named Sarah:

Sarah: He has weakness in his hands. He's not real good at opening hard stuff anymore or lifting, you know, just the grasp. It just depends on the day though. That's not always but we never know if it's the MS causing the problem.

Jennifer: Okay.

Sarah: Just, if he's having a bad day or a good day. And he limps just a little, but nobody else would notice that. And he has a lot of cramps like during the night.

Jennifer: In my experience, whatever happens to my husband, I instantly think it's the MS. But physical symptoms happens to other people too.

Sarah: Right! But you immediately think MS and it might not be. I mean, the cramps, I'm like, 'Maybe you should just take calcium.' You know, because you read that.

Jennifer: Right.

Sarah: Or maybe you're dehydrated. Which, the cramps could be from the MS, or they could not be. I mean, I get them sometimes too.

Use of Self in Research

I made a decision early in my dissertation process to explore a situation that was personally meaningful and significant. I believe this, in turn, made for a richer research experience. The participants' stories were especially heart-wrenching for me because I shared a similar experience with the caregivers. I believe the participants divulged more of their experience knowing that we had this commonality. In addition, because of my experience, I was able to use language the participants understood. Consequently, participants may have felt safer and a greater sense of connection with me as the researcher.

One specific way I was able to relate to the participants was through our common knowledge of the available medications and the systems for delivering them. My husband has taken four different types of MS medication, so I am familiar with all of them as well as their side effects. For example, he suffered difficult side effects from interferon beta-1a medications. He experienced flu-like symptoms after each injection that lasted until it was time for the next injection. I also immediately recognized when a patient talked about taking Tysabri® (natalizumab), which my husband also takes. I knew that Tysabri®, a monoclonal antibody, requires an IV infusion every 28 days and must be administered at a medical facility (MS Lifelines, 2012).

Participants were interested in which medicine my husband took and how it was working. Some participants asked if my husband had a particular symptom that they experienced. In these instances, I carefully reminded myself to not assume understanding and instead allowed the participants to direct the conversation and share their experience. When asked, I answered questions and used my experience as a way to establish a connection with the participants. If asked, I was able to share some knowledge of the illness and my personal experience. During the individual interviews, 9 of the 20 individual participants asked me questions or discussed my experience and knowledge of MS. For example, here is an excerpt from an exchange with one male patient:

George: My wife said your husband has MS too?

Jennifer: He does, yes.

George: How long has he had it?

Jennifer: He has had it [for] 18 years.

George: 18?

Jennifer: Yes. How long have you had it?

George: I've had it—well, I think I [have] had it longer. I was diagnosed in 2005, so I've had it for 6 years that I've been diagnosed with. But I knew something was happening back in 2002. My legs, my feet were getting heavy. Like when you step in mud and it sucks up your feet and you've got to pull them out, you know? So I knew something was up, but I was just—it was like 2003, I'm sorry—and my work was just downsizing so my job got eliminated. And I wanted to get back into education. And I knew something was wrong—I don't want to say [I] knew, I just felt something was wrong. Something was different. I didn't know if it was a nerve in my back or something. I had this really outrageous insurance that we had to pay on our own. So I thought, "Well I'm not going to mess with that." And then when I got my school job about a year later, I knew something was up.

Another female patient said, "But you know all about this because your husband has MS." The participants who did inquire did so about practicalities such as my husband's medication regime or the use of assistance in our home. Family caregiving can be an isolating experience; I believe some saw this as an opportunity to share and connect. I allowed the participants the opportunity to inquire and direct the conversation if they so desired.

During the Research

In order for me to adequately process this experience, my dissertation committee suggested I keep a self-reflective journal. Self-reflective journals provide an opportunity to bring mindfulness to a situation, develop insights and explore repeating themes. Researcher Ortlipp (2008) discussed their use and advocated using of such exploratory processes in qualitative research. I personally found the journal to be a way to investigate my intense emotions after completing an interview. I even viewed it as another piece of the information I was gathering for my research.

I thematically coded my journal entries, and the content that I most frequently coded had an emotion

of sadness. Conducting the interviews was far more emotionally intense than I anticipated. Writing in the journal gave me an outlet to process these emotions and provided an important sense of closure to each interview.

My self-reflection began after my first set of interviews with a male caregiver and a female patient. I interviewed the female patient first while the caregiver waited. At one point during the interview, we had to stop so the caregiver could lift his wife from the wheelchair and carry her to the restroom. She appeared so frail and damaged. During his interview he rationalized:

Her symptoms are not that bad. I feel that we're not as bad off as the other people that you're interviewing maybe. Some of them have more serious issues than what we have. Just from what I've read, from what I've heard and so forth.

I was shocked because he seemed completely unaware of how seriously ill his wife appeared. I couldn't wait to journal about my feelings. That journal entry read:

That person's disease is so severe she needs assistance transferring from her wheelchair to the restroom and yet she is still telling me her MS isn't as bad as others who have it worse. Really, her disease is pretty bad. I do that myself. I rationalize this experience by telling myself that my husband's illness isn't as bad as some. I feel sad for the woman who can't use the bathroom on her own and sad for myself because someday that might be me, transferring my husband from wheelchair to toilet.

Later, I referred back to and reflected on my own journal notes in conjunction with my analysis of the interview transcripts. I was able to use my journal as an opportunity to identify themes in the interviews and to make a connection between MS caregiving and the process of grieving and loss. Grieving was not one of my original theoretical frameworks. This theme only emerged through the journaling process. In reading my entries, I noticed I recorded emotions that are embedded in Kübler-Ross's stages of grief (Kübler-Ross, 1969). Kübler-Ross's theoretical explanation describes grief as manifesting itself in stages that include denial, anger, bargaining, depression and acceptance. Noticing the use of the word "denial" over and over again in my journal

illuminated a connection between grief and caregiving that I had not previously considered. Upon realizing this connection, I wrote about it, noting that the participant spoke of anger, denial and acceptance. This discovery raised new questions and observations for me. I wrote:

Is the process of providing care interwoven with the process of the loss associated with death and dying? Are caregivers grieving? I need to keep track of this and see if other participants discuss these emotions. I guess it's not that much of a leap to think of caregivers as grieving. They are probably grieving what used to be. Providing care is a type of loss. The patient has lost the ability to do something and the caregiver has lost what used to be.

Connecting this theme of grief with the interviews, I noted that denial was discussed as a coping skill by 4 of the 5 male patients in my study. For example, Kyle said, "I was in denial for like the first 6 months," and another man named Mike said that denial is like a self-defense mechanism.

Incidentally, Kübler-Ross (1969) discussed the concept of denial as a temporary defense that is later replaced by some feelings of acceptance.

Journaling helped me maintain focus on the participants' experiences and not get lost in my own reactions because I knew that after every interview, I would take an opportunity to write about my own thoughts. Reflective journaling gave me a concrete forum for expressing and processing my emotions, which in turn helped me maintain an emphasis on participants' experiences during interviews. The purpose of my research was not to process my own experience, and the structured outlet of a journal helped me keep this focus.

My prior clinical experience brought an additional layer of richness and depth to the situation. I used the journaling process not only as a personal outlet but as a prompt for developing additional questions to ask participants during follow-up interviews. After one set of interviews I wrote:

This patient minimizes the significance of her illness. I am interacting with a woman with severe illness, and she is telling me how her

illness isn't really that bad. She is almost in denial of the seriousness of her health problems. Is this a coping technique? Could this be denial? On the other hand, her husband has an acute understanding of the significance of his wife's condition. There appears to be a disconnection between the caregiver and care receiver in this particular couple. Is the couple aware of this difference? I will explore further in the joint interview.

At times I felt drained. I was emotionally exhausted after some interviews in particular and had to force myself to journal. I had a long car ride home, and I was grateful for the time to shut off my brain during that drive home. One time, I remember sitting in the parking lot forcing myself to my notepad. During that session I wrote:

I feel immensely sad. This is a horrible disease. I feel badly for the patients and the caregivers. Everyone is just waiting for the next shoe to fall, and meanwhile they are all playing the same game that some other guy has it worse, so that makes them somehow lucky. No wonder MS patients isolate themselves. I feel so bad for these patients and their caregivers.

By the time I was several interviews into the research, I had moved to a place of personal fear. The interviews were hitting close to home. I wrote:

What if John's illness gets worse? What if he's in a wheelchair like this participant? How will I manage my kids, my work and caregiving? I am so afraid this will be me in the future. I could be burdened with these same responsibilities, and how will I ever find the strength to do it all alone? This is not what I bargained for.

After the Research

When I began this research, I thought my husband's illness was well contained. I, like so many of the participants I interviewed, believed others "had it worse," that we were one of the "lucky ones." I felt we coped with our situation quite well. I now know that caregivers and patients learn to adapt to the challenges using a variety of available resources. I learned that many people with MS and caregivers describe themselves this way. It is an adaptive coping strategy used by many. Even those who are greatly affected by

the disease describe themselves as one of the lucky ones. I used exactly the same coping skill I observed in many of my study participants. When I coded the interview transcripts, I categorized this observation under the theme “Some other guy has it worse.” I discussed this theme as either part of the grief stage of bargaining or as a sort of “magical thinking.” Bargaining is seen by Kübler-Ross as an attempt to postpone the worsening of the situation by living right (Kübler-Ross, 1969). This is a form of magical thinking or casual reasoning, in which a person looks for a connection between potentially random events (Zusne & Jones, 1989). In my journal I wrote of my own thoughts and experience with this type of thinking:

This feels like this participant is coping with the experience by using magical thinking, like they can somehow ward off the disease by living a good life and being a good person. As if some higher power has the ability to keep them healthy because they had good behavior. Is this superstitious, magical thinking or merely a strong faith perspective? I am reminded about the time people from our church told me to pray for John’s vision to return. John as a medical provider told me he was pretty sure the damage to his eyes was so extensive he would not get his vision back, but there we were on Sunday and a do-gooder was trying to instruct me on the power of prayer. It didn’t work. John didn’t get his sight back, so does that mean I totally suck at prayer? Or are we not good enough? I see this as a coping technique that many participants are using, but I worry about the danger in magical thinking or bargaining. What if it doesn’t work? MS is a progressive degenerative illness, so patients get worse. It is the very nature of the disease.

Over the course of my research, my husband’s symptoms worsened. The interview conversations hit me hard when they involved discussion about experiences similar to mine. My research forced me to process my own emotions surrounding the illness, and led to a range of emotions, from overwhelming sadness to inspiration. For example, I became acutely aware that MS is an isolating disease. During an interview, a female patient stated:

I used to go places and see my friends...but I can’t drive or anything anymore, so I don’t see

much of them anymore. They’re working, and they [have] family and stuff too. We just don’t do things anymore.

In response, I wrote in my journal:

MS is such an isolating disease. This couple stopped socializing. They are probably unaware that they have isolated themselves, which is the very same thing we did when things got worse. We stopped hanging out with friends and going places. It wasn’t the friends that pulled away from us, it was us pulling away from socialization.

Many people with whom I spoke did not know others with MS or have the opportunity to speak with another patient or caregiver. I was in that same situation. With MS, the mere act of living with the illness forces people to isolate. As the participants spoke of isolation, I realized that we, too, had isolated ourselves as a way to cope and survive. I reflected on our situation and realized the drastic changes that occurred in our life following several of John’s MS attacks. Making this connection between the participants’ description of inaccessibility and loneliness, and my personal experience with isolation, provided me another area for exploration and for future research.

When I started my research project, I was looking for a topic that was of interest to me, but honestly I wanted to get the work done so I could graduate. I told myself that the best dissertation was a finished dissertation. I was not striving for perfection, just completion. Somewhere along the line, I realized that I had gathered important information both about the MS care experience and the use of self in research. I felt a huge sense of accomplishment and pride. My family traveled to Utah with me for classes, and they came with me to my graduation ceremony. I felt as if the entire family earned the degree because of the sacrifices everyone made. Our children saw their dad cooking dinner, doing laundry, and handling other housework while Mom learned statistics. My Ph.D. was our collective accomplishment. The illness drew us together in our shared burden, but is also drew us together in pride of this achievement.

I am not unlike the care partners I interviewed for my research. Like them, I did not identify myself as a target for treatment. After all, I did not have the disease—my husband did. I’m healthy, I thought; I

don't need treatment. And so I sat on the sidelines, listening to my husband's physician tell us about medications and treatments, never once thinking that I should seek assistance. In one journal entry closer to the end of my data gathering process, I wrote:

I continue to question why these caregivers are not seeking any type of formal assistance, but today it hit me like a giant "ah-ha" moment. I have never sought formal assistance either. Am I not just like them? Wouldn't I benefit from some type of programming? I rationalize that I am a high-functioning individual and I can do this without assistance, but isn't that what all the caregivers are thinking too? What makes me resistant to services? Probably some of the same things that make the participants resistant to services. I also believe because I am in a helping profession I am not sure how good I would be at receiving treatment. It's hard for me to turn that off and . . . find myself in the place of healer rather than taker. It would be like more work after work and the thought just overwhelms me.

Care partners have an enormous burden, but in our current system of care, we do not identify caregivers as a focus of treatment or concern. If caregivers do manage to seek out services, it is as an afterthought to the service demanded by the person with the illness.

We are providing a disservice to family care providers by not making them a focus of support and treatment. We also should examine the complex reasons behind why caregivers may not seek out such services. In my situation, despite my background in a health-related field (social work), I didn't see myself as a patient. Like other clinicians, I had a misled belief that mental health providers should have a "high level of psychological wellness," (Norman & Rosvall, 1994, p. 450) and that seeking treatment would be an admission of inadequacy.

Use of Self-Disclosure in Research

Personal experience with MS may be both a strength and limitation of a qualitative study design. As I was careful to keep in mind that I was not the center of my research, my intent was to use myself and my experiences to add a richness and depth to my study.

I believe that enhancement occurred. For example, self-reflection and journaling provided an opportunity to explore the use of myself freely. The strength of my experience allowed me to gain wider access to information in order to co-construct the reality of this particular social situation. Results of qualitative research are open to the researcher's personal biases; therefore, member checking was extremely important and a deliberate part of my research process. Fortunately, that step of checking for bias yielded minimal results besides strengthening the overall process.

This research forced me to face the reality of my personal situation. I attempted to use the technique of intellectualizing, whereby a person deals with emotions using facts and data (Arnold, 2014). Some participants wanted more than mere information. They wanted me to answer the same questions I was asking of them. One female caregiver asked: "How do you do this? How do you handle having a husband with MS plus being a mom of four kids?" At first I wanted to answer with knowledge about the disease, but I quickly realized her question wasn't about gaining facts; it was about the shared experience of both of us living as care partners to husbands with the same illness. Resisting the urge to rattle off data, I answered with authenticity, telling her, "Some days it's harder than others. Today was a good day. Last week, not so much. It's day by day. How do you handle these responsibilities?"

If I were to repeat this study, I would do it in the same manner—choosing to self-disclose. The use of self in this research brought about deeper conversations and emotions. My research and understanding were stronger because of using myself in the research process. For example, the decision to remain hidden and unknown in social work research has merit in many instances. However, the decision to share is beneficial to researcher and participants alike, and in my research in particular, this decision led to much greater insight and development of understanding about the caregiving experience. The use of self in this research on MS caregiving led to transparency, authenticity, genuineness and substance in the interviews.

My Story, Continued

John went back to work part-time in July 2008, three

years after he stopped his clinical work and just after I took my competency exams. He is a preceptor at a residency clinic, where he supervises medical residents and provided treatment in a federally-qualified health care setting where his vision is not required. This university is a leader in providing necessary accommodations to assist people with disabilities with gaining employment.

This week John received his 100th dose of Tysabri. The clinic made him a sign and gave him a brownie. He holds the record for the longest time on this infusion medication at this clinic, which is something to celebrate. Today, he is well, which is also something to celebrate. So many others have it worse-really.

In the fall of 2014, I took a tenure-track position as an assistant professor of social work at the same university where John works. We now commute to work together. His MS remains stable. My daughter, an English major, just text-messaged me this week with questions about her father's MS. She is writing about MS caregiving for a literature assignment. I guess writing about it runs in the family. How could we not take an interest in this topic, whatever our professional context? MS is a disease that, even when well contained, dominates life; it's always lurking in the background with the potential to rear its head and interrupt life. Caregiving, too, is draining and all consuming as the disease; just in different ways. For now, we are thankful for this period of stability.

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