

The Life Experiences of People with Multiple Sclerosis Who Practice Yoga: A Qualitative Case Study

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Abstract

Purpose: To examine the lives and experiences of people with Multiple Sclerosis (MS) who practice Yoga. If Yoga practitioners who have MS share their experiences, a deeper understanding of their lives and how Yoga affects those lives may be gained.

Study Design: Using case-study research methods, two women were interviewed to gain an understanding of their experiences of practicing Yoga and having MS. The theoretical framework for this study is based on Dorothea Orem's Self-Care Deficit Nursing Theory.

Findings: The findings showed that participants had affirming life philosophies, strong motivators, an ongoing development of body awareness, and the ability to think and act outside the norm.

Conclusions: This information could impact the development of meaningful client-driven information. Future research should include larger and more diverse populations, quantitative study, and in-depth qualitative evaluation.

AN's Story

AN's virtually lifeless body lay limp in her hospital bed; she could not speak, see, nor swallow. Her nurse chattered away asking questions of every nature while performing her care. AN repeatedly touched her finger to her nose. "No, honey," the nurse said, "you mustn't pull out your feeding tube."

The speech therapist entered the room and observed. Smiling, she placed her finger on her own nose. "She is

not trying to pull out her feeding tube; she is telling you in sign language that you are funny."

This is the retelling of a story that has become legend to those who know AN. Functioning in the present moment, in full awareness of the state of her body, she discovered a resource and delivered a heartfelt message to her caretaker. "I am in here. I hear you. I send my love."

AN is a *yoginî*, and her message to her nurse might be interpreted as Karma-Yoga, the Yoga of action, a practice that is the personification of AN. Beyond continued practice of Karma-Yoga she practices Hatha-Yoga, a practice encompassing many of the eight limbs of Yoga, including *âsana* (poses), *prânâyâma* (breath control), and *dhyâna* (meditation). After this very acute flare-up of relapsing-remitting MS, many of her symptoms have subsided. She walks with a choppy gait and her speech is mildly impaired, but nothing stops her. Her life is filled with a loving marriage, close friendships, Yoga classes, and the care of her service dog.

Multiple Sclerosis and Yoga

MS is an inflammatory demyelinating disease affecting the central nervous system. This chronic debilitating illness typically strikes between the ages of 20 and 40, affecting predominantly women.¹ One-third of a million people in the United States are affected; 200 people per week are newly diagnosed.² The disease is thought to be autoimmune, mediated by the activation of T-cells that cross the blood-brain barrier and destroy myelin.³ The most common form of MS is relapsing-remitting; this

type is characterized by partial or total recovery from symptoms of an exacerbation. There are also several types of progressive MS, including primary and secondary progressive.⁴

Symptoms of MS vary but often include weakness, visual disturbances, thermo-sensitivity, genitourinary dysfunction, general fatigue, memory impairment, paresthesia, anxiety, depression, and spasticity. Each individual experience with MS is unique. The course can range from mild to benign in some, while in others major progressive neurological impairment results.⁵

Over 50% of the respondents reported that Yoga practice had improved [their condition].

People with MS are currently choosing to practice Yoga,^{6, 7, 8} but the base of scientific research in this area is minimal. The literature reviewed for the purposes of this study had some connection to the therapeutic use of Yoga or healthful practices utilized by people with MS, but only one study looked specifically at the variables of Yoga and MS. No studies were found that examined the concepts of Yoga and MS utilizing case-study methodology.

One exploratory study of 59 subjects on Yoga as a therapeutic tool utilized a self-administered survey. Over 50% of the respondents reported that Yoga practice had improved coordination, circulation, fatigue, flexibility, and general mobility.⁹ Several studies on self-care, alternative therapies, and health promotion in MS reported the practice of Yoga. These findings suggest that people with MS are seeking

alternative therapies including Yoga.^{10, 11, 12}

The findings of one study reported that Yoga had a positive effect on the biopsychosocial needs of subjects with MS. This included decreased stress, an increased sense of well-being, calmness, and improved self-esteem.¹³ Studies report that people with MS exercise less¹⁴ and have a lower degree of physical activity,¹⁵ yet when they increase physical activity their quality of life and physical function improves.¹⁶ Another study reports that people with MS are seeking control over their physical symptoms.

A case study is often conducted when there is a lack of empirical information about a certain situation.¹⁷ The present study allowed individuals with MS who practice Yoga to convey information about their own life and worldview. Understanding these experiences can lead to the development and design of more in-depth studies and help health care providers and Yoga professionals to develop programs and interventions that meet the specific needs of clients.

Methods

Sample

Three women who identified themselves as Yoga practitioners with a diagnosis of MS were recruited for the study primarily through the Wisconsin MS Society. One woman was engaged in a pilot study that tested the interview tool; two were ultimately interviewed for the study. One had practiced Yoga for two years or more, and one had practiced a year or less. Two interviews were conducted in order to compare and contrast findings and identify possible emerging themes.

Other criteria included a current Yoga practice that began after the diagnosis of MS and a commitment to Yoga practice as evidenced by weekly classes or daily or weekly home practice.

Data Collection and Analysis

The theoretical framework for this study is based on Dorothea Orem's Self-Care Deficit Nursing Theory. Self-care is defined as care initiated by an individual on his or her own behalf to stay healthy and develop as a human being.¹⁸ The study was designed using guidelines on qualitative study from Boyd, Munhall, and Mariano.¹⁹ After receiving approval from the Institutional Review Board and obtaining informed consent, the investigator collected data using open-ended questions and an interview guideline. Each participant was asked to describe her experience completely. The grand tour research question was, "What is the life experience of someone with MS who practices Yoga?" Other questions included, "Has your life changed since the diagnosis of MS?" and "How does Yoga practice affect your MS?" As new subjects emerged, further questions were asked to allow for clarification and elaboration. Demographic questions were asked prior to the formal interview.

Each participant was interviewed twice. The first interview was approximately an hour and the second about 45 minutes. The interviews were audiotaped, professionally transcribed, and reviewed by the researcher for relevant concepts and clarification. Information from the first interview dictated the direction of the second interview.

The data were explored by listening to the tapes and reviewing the transcripts and the notes. Repeated

exploration brought to light new or varied data. The tapes elicited tone, and the transcripts elicited content. Repeated information supported data interpretation.^{20, 21} Reflection, comparison, and creativity were utilized throughout the data analysis to provide explanations, address the investigator's assumptions, and reduce bias. Trustworthiness, a means used in qualitative study to verify the quality of a conclusion, was established using confirmability, dependability, credibility, and transferability. Two expert readers also were engaged to review the study.

Through comparison and contrast, unique themes emerged. Putting together the components of gesture, intonation, and spoken word, a colorful picture emerged—a picture giving insight into the lives and experiences of people with MS who practice Yoga.

Findings

As the data were reviewed, a variety of themes emerged. Major themes related to life philosophy, motivators, diversified care, body awareness, deepening the relationship with God, and an ability to think and act outside the norm. GS and SR were random names assigned to the two women interviewed, each of whom had a unique story to tell.

Both participants have relapsing-remitting MS, both have had flare-ups since diagnosis, and both have symptoms that affect them on an ongoing basis. Both also saw Yoga as a positive life influence that aided their general state of well-being. GS had practiced Yoga under a year and had a dedicated home practice of four days a week. She practiced in her bathroom, stating that it was the only place her family left her alone. SR restarted her practice five years ago shortly after her

MS diagnosis. She studies with a certified Yoga teacher one to two times per week. She receives classes

Both [participants] saw Yoga as a positive life influence that aided their general state of well-being.

in exchange for cleaning services, a barter she relishes.

Life Philosophies

Both women described life philosophies that contribute to how they live their lives with MS. GS describes herself as a fighter, as someone willing to try anything that will improve her life. She moves her hands in a sweeping motion and smiles as she talks of her methods of living life with MS:

I am not willing to sit around and just assume that I will die and this illness is going to overtake me. I love life and I want to experience it to my fullest. [To] that end, I research everything to help me do better. If I can do things as far as exercise, I'll do them. If [there are] things I can eat that are better for me, I'll do it. Anything that I can do to improve myself, whether it's in or out of normal traditional medicine, I will explore it.

SR views MS as a small part of her life:

I don't address it as having a disease; I address it as the way I am. Because if I look at it as "I'm having a dis-

ease," then I look at [it as] "I'm being sick."

Shifts in Personality Style

Both GS and SR have described shifts in attitude and life focus. GS sees Yoga as a benefit of this shift, and SR sees it as a contributor to her change. GS describes herself as a reformed Type A personality who used to push herself in aerobics. She states that this shift in personality has made life, and life with MS, a lot better. She now prefers Yoga to aerobics because she feels it is less demanding and she can do it at her own pace.

She stated that this also has made life, and life with MS, much better:

Yoga is more or less private time by yourself, not in competition with others to make sure you have the perfect pose, you have the perfect flexibility range, and everything else. And that's totally different [from] my quote[/unquote] "former life."

SR describes herself as right-brained with just enough left brain mixed in to keep her from floating into the clouds. When she was younger she was very spontaneous, pushy, and attracted to fast city life, keeping her constantly stressed. She thinks this might have contributed to her getting MS. Now she prefers quiet small-town living. She attributes this shift to her Yoga practice:

Yoga has changed my life so much. I can't say MS has changed my life as much as Yoga has. I don't give in to the MS. It's not, not giving in to, but it's not acknowledging that I'm sick, and

that's why I'm doing what I'm doing.

Motivators

Motivation plays an important role in the lives of both these women. SR is strongly motivated by her Yoga practice and her desire to lead a happy life. She stated that before she started Yoga she did not realize she was unable to focus or relax. She is motivated to advance in her practice, and she loves the uniqueness and lack of competition. Her Yoga practice gives her a new perspective on things and is defined by her alone:

Yoga changed my life because it gave me a way of life, a way of dealing with things, a way of looking at things, which is so much different [from] what I did before.

GS is strongly motivated by being healthy and present for her family. Her face shines with excitement as she describes the new adventure of raising teenage boys. She has to be there as an active, vital parent. She recalls not liking the experience of relying on her sons and husband during an MS flare-up that left her with some paralysis:

I'm supposed to be . . . the person that holds the family together, and now it's just like, "Wait a minute, wait a minute, you guys have to do that for me." [And] that was the motivating factor, that I have got to get myself going because I'm not, quote [/unquote], "fulfilling my motherly role."

GS lost her mother at a young age. She spoke of having a lack of

role models growing up and wanting to be the best role model she could for her sons. This focus keeps her going every day. "I know what I missed and it would be unfair for me not to try for them." Now that she has MS, she is determined to stay healthy so she can be there for her children.

Diversified Care

Both participants go to great lengths to delve into alternative treatments that will keep them healthy and alleviate symptoms. Both have concerns about the medical system and how it exists today; they both desire more open-minded, inclusive care. Both also prefer herbs and supplements to pharmaceuticals, and both have altered their diets. GS has more of a focus on self-care. SR has more of a focus on alternative medicine. Yoga practice is a constant in the lives of both.

GS began her Yoga practice to increase range of motion in her joints. Beyond improved flexibility, she has developed a breathing and relaxation practice, as Yoga allows her to separate herself from the world. Yoga also represents prevention for her: "I don't have the pressure or stress that builds up that leads me to having symptoms of MS." And it allows her to breathe better and consciously:

You can feel through your toes all the way up that you're breathing, and you're exhaling, and all this junk is going out of your body. And, oh, it's just so renewing to me mentally and physically.

Yoga is a part of her treatment plan, and it allows her to take a time out and "unpeel" all the stress in her body and mind. She also does video

exercises, swims, and teaches water aerobics. She is focused on nutrition, eliminating certain foods and using supplements. She also gets plenty of rest.

Yoga is a way of life for SR. She is uncertain how Yoga has affected the MS and how it has simply helped

Both participants go to great lengths to delve into alternative treatments . . .

her personally. She does feel that Yoga helps prevent the crippling effects of the disease. She sees Yoga as being very personal; what she derives from her Yoga practice is unique to her:

I have to do it to keep myself from being crippled in a wheelchair, with a catheter in me, being totally mental. It teaches me how to focus on relaxing, how to do poses, which is stretching. It keeps my body lubricated. To me, Yoga has to be. It's my addiction to help my MS and myself.

After being diagnosed with MS, SR went directly to the library. She found a book about alternative therapy and MS that gave her hope. Although she was dissuaded from using such therapies, she persevered and tried many. She currently uses massage therapy, reflexology, aromatherapy, herbs, and Yoga, finding them all to be of benefit.

Both women have reservations about using Western medicine unless it is on their own terms. Neither woman takes the drugs cur-

rently in widespread use for relapsing-remitting MS, feeling uncertain about the safety of the drugs and preferring to find their own treatment modalities. GS fired her physician when he insisted she use them, feeling her needs as an individual were not addressed. She now seeks only physicians with a specialty in MS. SR sought out a doctor who supported the use of alternative medicine.

Body Awareness

Both GS and SR spoke of the development of body awareness, which enables them to tune in to bodily functioning on a day-to-day basis. GS has learned to listen to her body through Yoga and carries this into day-to-day life. SR sees Yoga as her medication. This allows each of them to live every day as effectively as they can regardless of the MS symptoms they may be experiencing. Yoga has taught them how to check in with their bodies and emotions, giving them a vehicle to recognize and potentially prevent problems.

GS has learned to pay attention to her body. Utilizing past experience with MS and her current knowledge of Yoga she has devised her own treatment modality. She may utilize breathing to refocus, or poses to evaluate how different parts of her body are feeling. When poses do not feel right, she realizes that she needs to pay more attention or perhaps get more sleep. She states that each day with MS is not the same as the day before. Inner dialog occurs, "What do I have to do today? What do I need to wear today? What do I have to change today?"

SR incorporates visualization, poses, meditation, and relaxation to work on problems as they occur in her body. She states that Yoga is her

medication—rather than take a pill she will do Yoga:

Let's say my feet hurt, or they're cramping up today. A lot of people would probably go get some medication to keep the cramps from happening. Well, Yoga does that for me. Yoga keeps me relaxed so I am aware of what's happening in my body.

Deepening Relationship with God

The spiritual nature of Yoga appeals to both participants. Both are practicing Christians and see Yoga as a vehicle to get closer to God. GS clears her mind with Yoga, making it more receptive to God. SR views the spiritual essence of Yoga as an entity unto itself, stating that Yoga has helped her find God within herself.

SR initially struggled with the concept of God being within, a belief she was introduced to through Yoga. This went against her traditional Roman Catholic upbringing, but she reconciled this by seeking her own truths. She now believes that if God is everywhere, then naturally God resides within her:

I was raised [to understand] that God is everywhere. He is there, and He is within you. And when I am going within, I am able to pray, relax, meditate, do all of that. I can combine [all of] it, just like Eastern and Western medicine needs to be combined so bad[ly].

GS often does Yoga before reading the Bible or doing anything. Yoga brings God into her life in a more serene way, "not just where you read the Bible and pray, but

internalize it more." Yoga helps clear her mind so that when she studies the Bible she is at peace with herself.

Discussion

Many common themes were found in this study. One theme woven throughout was the ability and desire of the participants to take active responsibility for their lives

The spiritual nature of Yoga appeals to both participants.

and make choices that impact their health in ways they deem positive. As Orem's theory suggests, both participants incorporate self-care measures into their day-to-day lives. Both feel successful in the outcome from these choices.

The findings of this study concur with much of the existing literature. They are consistent with many of the findings of previous studies on self-care, alternative therapies, health promotion, quality of life, physical activity, and Yoga and psychotherapy. Both participants actively engaged in the use of alternative therapies and self-care, both expressed awareness of positive quality-of-life changes, and both experienced positive physical and psychological effects from their practice of Yoga.

Findings by O'Hara et al. showed the use of complimentary therapies in MS populations as more prevalent than conventional therapies.²² One finding of a study by McLaughlin and Zeeberg was that self-care was used to gain control over uncertainty, dependence, and emotional and physical decline.²³ Studies on alternative therapies

mostly support the findings of this study. Two studies reported less severity in MS symptoms after using alternative therapies.^{24, 25} A participant in one study viewed alternative therapy as being life-giving, while traditional medicine was merely palliative.²⁶ Another study found that as health-promoting behaviors increase, quality of life increases.²⁷ Rehabilitative programs for people with MS

Both GS and SR reported improved physical and emotional functioning with the practice of Yoga.

also were found to improve quality of life.^{28, 29, 30}

Both GS and SR reported improved physical and emotional functioning with the practice of Yoga. This, too, was supported by the literature. Results of studies on group interaction and psychological effects showed that any supervised group activity improved the emotional state of the subject, provided positive health effects, and had an impact on disease-related stress.^{31, 32} Another study reported that Yoga had a positive effect on the biopsychosocial needs of the participant, including stress reduction, increased well-being, calmness, and improved self-esteem.³³ SR reported benefits from the group interaction provided by Yoga classes. GS found the stress-relieving properties of Yoga vital to her ability to be calmer and manage stress, which she feels prevents MS symptoms.

The lack of confidence in traditional Western medicine described by the participants suggests a need for further examination. Increasing the availability of centers that provide complementary medicine might

better serve the needs of the chronically ill.

Conclusions

Findings from this study indicate a strong need for future research, using both qualitative and quantitative means. More diverse populations and a larger number of participants also should be studied. This can only contribute to the enhancement of care offered to people with MS and other chronic illnesses.

The participants in this study live their lives in a gutsy way, with zeal and creativity. These women have taken charge of their lives, refuse to give in to the diagnosis of MS, and have designed and managed their own care. Although very different and individualistic, they have common threads from which a rich tapestry emerges. For them, self-awareness and body-awareness are paramount in living successfully with MS. They pay attention to trends in health care and choose care options that support their life choices. Communion and communication with God are seen as an important part of their being. Choosing to practice Yoga is not incidental—it is a purposeful choice taken to optimize wellness. Developing a greater understanding of these self-care choices in people with MS and other chronic illness is the first step in the creation of meaningful treatment options.

Endnotes

1. Ponichtera-Mulcare, J. Exercise and multiple sclerosis. *Medicine and Science in Sports and Exercise*, 1993, 25: 451–465.
2. National Multiple Sclerosis Society publications. Retrieved 6 Sep 2000 from URL: <http://www.nmss.org>.
3. Petjan, J., and A. White. Recommendations for physical activity in patients with

multiple sclerosis. *Sports Medicine*, 1999, 27(3):181–191.

4. National Multiple Sclerosis Society, op cit.

5. Stuifbergen, A., and G. Roberts. Health promotion practices of women with multiple sclerosis. *Archives of Physical Medical Rehabilitation*, 1997, 78:S3–S9.

6. Fawcett, J., M. J. Hanson, K. Riley-Lawless, and J. S. Sidney. Alternative therapies and multiple sclerosis: Two case reports. *Alternative Therapies*, 1996, 2(5):67–69.

7. Fawcett, J., J. S. Sidney, M. J. Hanson, and K. Riley-Lawless. (1994). Use of alternative health therapies by people with multiple sclerosis: An exploratory study. *Holistic Nurse Practitioner*, 1994, 8(2):36–42.

8. O'Hara, L., L. De Sousa, and L. Ide. A Delphi study of self-care in a community population of people with multiple sclerosis. *Clinical Rehabilitation*, 2000, 14: 62–71.

9. Rens, J. Yoga as a therapeutic tool in the treatment of multiple sclerosis: An exploratory study of patient perceptions. Unpublished master's thesis, California State University, Northridge, 1992.

10. O'Hara, De Sousa, and Ide, op. cit.

11. Fawcett, Sidney, Hanson, and Riley-Lawless, op cit.

12. Fawcett, J., J. S. Sidney, K. Riley-Lawless, and M. J. Hanson. An exploratory study of the relationships between alternative therapies, functional status, and symptom severity among people with multiple sclerosis. *Journal of Holistic Nursing*, 1996, 14(2):115–129.

13. Rens, op cit.

14. Stuifbergen, A. Physical activity and perceived health status in persons with multiple sclerosis. *Journal of Neuroscience Nursing*, 1997, 29:238–243.

15. Petjan, J., E. Gappmaier, A. White, M. Spencer, L. Mino, and R. Hicks. Impact of aerobic training on fitness and quality of life in multiple sclerosis. *Annals of Neurology*, 1996, 39:432–441.

16. Vercoulen, J., C. Swanink, J. Galama, J. Fennis, P. Jongen, O. Hommes, J. Van Der Meer, and G. Bleijenberg. The persistence of fatigue in chronic fatigue syndrome and multiple sclerosis: Development of a model. *Journal of Psychosomatic Research*, 1998, 45:507–517.

17. Mariano, C. Case study: The method. In P. Munhall and C. Boyd, eds., *Nursing Research: A Qualitative Perspective*. 2d ed. New York: National League for Nursing Press, 1993, pp. 311–337.
18. Tomey, A., and M. Alligood, eds. *Nursing Theorists and Their Work*. 4th ed. St. Louis, Mo.: Mosby, 1998.
19. Boyd, C., and P. Munhall. Qualitative research proposals and reports. In P. Munhall and C. Boyd, eds., *Nursing Research: A Qualitative Perspective*. 2d ed. New York: National League for Nursing Press, 1993, pp. 424–453.
20. Mariano, op cit.
21. Boyd and Munhall, op cit.
22. O'Hara, De Sousa, and Ide, op cit.
23. McLaughlin, J., and I. Zeeberg. Self-care and multiple sclerosis: A view from two cultures. *Social Science Medicine*, 1993, 37:315–329.
24. Fawcett, Sidney, Hanson, and Riley-Lawless, op cit.
25. Fawcett, Sidney, Riley-Lawless, and Hanson, op cit.
26. Fawcett, Hanson, Riley-Lawless, and Sidney, op cit.
27. Stuijbergen and Roberts, op cit.
28. Di Fabio, R., T. Choi, J. Soderberg, and C. Hansen. Health related quality of life for patients with progressive multiple sclerosis: Influence of rehabilitation. *Physical Therapy*, 1997, 77(12): 1704–1716.
29. Di Fabio, R., J. Soderberg, T. Choi, C. Hansen, and R. Shapiro. Extended outpatient rehabilitation: Its influence on symptom frequency, fatigue and functional status for persons with progressive multiple sclerosis. *Archives of Physical Medical Rehabilitation*, 1998, 79:141–146.
30. Stuijbergen, A., and S. Rogers. Health promotion: An essential component of rehabilitation for persons with chronic disabling conditions. *Advances in Nursing Science*, 1997, 19(4):1–20.
31. Crawford, J., and G. McIvor. Group psychotherapy: Benefits in multiple sclerosis. *Archives of Physical Medical Rehabilitation*, 1985, 66:810–813.
32. Trojan, A. Benefits of self-help groups: A survey of 232 members from 65 disease-related groups. *Social Science Medicine*, 1989, 29:225–235.
33. Rens, op cit.

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