Can Caregiver Burden in Stroke Patients with Muscle Spasticity be Alleviated Based on the Course of Treatment Selected?

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Stroke survivors often experience spasticity; the inability to move their muscles freely, as a lasting disability after their event. Patients with muscle spasticity are unable to dress, bathe, and feed themselves because of this. Some patients’ muscles are so spastic that they are permanently pinned to their bodies. Caregiver burden is commonly experienced in family members who are taking on more responsibility than ever before, especially in the lives of caregivers for stroke survivors with spasticity. Family members feel added stress because they have to juggle the care of the stroke survivor and their own family. The patients’ loved ones are at risk for physical and psychological harm. They can also lose their jobs and their family in the process. Muscle spasticity can be alleviated to some extent with physical therapy or injections of botulinum toxin A, commonly known as Botox. This study is proposed to determine if a specific course of treatment can alleviate caregiver burden over time. Stroke patients and their caregivers will be tracked for 6 months, 1, 2 and 3 years after their initial stroke to determine if there is a correlation between course of treatment for spasticity and the alleviation of caregiver burden.

*Keywords*: caregiver burden, stroke, and muscle spasticity

Strokes affect approximately 800,000 people every year and is the leading cause of disability (Jones, Adams, & Brown, 2010). Stroke is defined as “a cerebral vascular accident resulting in an interruption of blood flow to an area of the brain from either a blood clot or the rupture of a blood vessel (Camak, 2015). Some common side effects from strokes are “visual disturbances, dysphasia, foot drop, balance issues, muscle spasticity and post stroke seizures” (American Stroke Association, n.d). Most stroke victims are unable to care for themselves fully and need a caregiver of some type. Caregivers experience caregiver burden because they are now taking on responsibilities that they hadn’t before.

Caregiver burden is defined as, “the type of stress or strain that caregivers experience related to the problems and challenges that they now face” (Buhse, 2008).

Caregivers spend a great amount of time helping their loved ones to do simple tasks such as providing proper hygiene and dressing them. The caregivers now have to feed, dress, bathe, and drive their loved ones to their doctors’ appointments. Each week the amount of hours caregivers spend helping their loved ones increases. Zorowitz, Gillard and Brainin, (2013) reported that caregivers increased their hygiene hours of care from 9.0 hours to 28.2 hours and their dressing hours from 3.3 to 32.1 hours per week.

As time goes on, more adult daughters are starting to become the main caregivers of their parents who have suffered a stroke. (Bastawrous, Gignac, Kapral, & Cameron. 2014). They are spending less time with their children and husbands just so they can take care of their loved one. Adult daughters with stroke parents experience role overload and are unable to keep the successful jobs they had which puts added financial burden on top of their emotional burden (Bastawroud et al., 2014). Caregiver burden is not only harmful to the caregiver, this burden...
can negatively affect the patient also. Patients who see their caregivers being burdened are at risk for cognitive decline (Cramm, Straing, & Nieboer, 2012). The cognitive decline that they can experience has a more negative effect on caregiver burden than any physical problems they have (Cramm et al., 2012).

Muscle spasticity is “one of the most common and incapacitating complications” that can arise from having a stroke (Galvao, Dos Santos, Dos Santos, Cabral, & Monte Silva, 2014). Spasticity can be defined as an intense “charley horse” and is seen in 30% of patients who have strokes (American Stroke Association, n.d.; Thibaut et al., 2013). With the use of brain imaging scans, scientists have been able to find an association with brain lesion locations in stroke patients and muscle spasticity. “Damage to the insula, thalamus, basal ganglia and many white matter tracts can cause upper limb muscle spasticity” (Picelli et al., 2014). Muscle spasticity is painful for a patient because his or her muscles tighten and freeze. The muscles become difficult to move without causing extreme pain. These patients’ muscles are permanently in a contracture, which requires intense physical therapy to alleviate. These contractures affect “patients abilities to perform activities of daily living and prevents them from traveling outside their homes” (Esquenazi, 2011).

Most of these patients with muscle spasticity need constant care because they are unable to dress themselves or provide basic hygiene. A great number of patients with muscle spasticity are “unable to work as a result of their spasticity which causes financial burden” (Esquenazi, 2011). Not only do these patients experience financial burden, they are “at an increased risk for falls and hip fractures” (Esquenazi, 2011). Caregivers also feel a financial burden because most have to quit their jobs to be able to work around the clock to help their loved one. Most caregivers get thrown into this new role without any preparation or knowledge of how to cope with the financial burden. Caregiver burden scales can capture general burden but not the in-depth experience of these burdens. Muscle spasticity carries a great financial issue because of the expense of treatment. On average a patient with muscle spasticity in 2003 paid over $84,195 in health care costs compared to $21,842 for a stroke patient without muscle spasticity (Esquenazi, 2011).

The two most common treatments for muscle spasticity are physical therapy and botulinum toxin A injections. Patients can choose either one of the treatments or a combination of both. Physical therapy programs commonly called P.T consist of activities to improve range of motion, strength, balance and coordination (Galvao et al., 2014). P.T. can be used to help reduce the spasticity in the affected limb. Physical therapists can use the Modified Ashworth Scale to access the amount of spasticity based on a scale from 0-4. A score of zero on the Modified Ashworth Scale indicates no increase in muscle tone and a score of four indicates rigidity in flexion and extension. Based on the patients score, the physical therapist can tailor their exercises to achieve better movement. If these exercises are successful the patient can have a better quality of life and be able to relieve some stress from their caregiver (Galvao et al., 2014). Patients should perform exercises that are slow and rhythmic. Most of these exercises use passive movement but help to decrease muscle tone (Blomberg, 2012). Patients can also have their upper arms splinted or casted to provide support and to improve function (Zorowitz et al., 2013).

Another effective treatment is injections of botulinum toxin A in the affected area. Botulinum Toxin in nature is “produced by a bacterium named clostridium botulinum” (Isoyama & Takeuchi, 2013). The toxin is able to “block vesicular acetylcholine release at neuromuscular junctions and reduces focal muscle contracture” (Isoyama & Takeuchi, 2013). Blocking these muscular junctions would provide the patient with less pain so that they can work more on improving their range of motion. Improving range of motion could lead to the decrease in spasticity in these patients and they could return to some of the function they had before their stroke. Depending on the degree of spasticity the amount of toxin can be adjusted. For spasticity in the upper limbs, each patient could have between 25 to 100 units injected (Isoyama & Takeuchi, 2013). The only adverse effects that have been seen are pain, rash, edema or muscle weakness. All effects were noted at the injection site and are similar to the effects that can occur from other injections (Isoyama & Takeuchi, 2013).

Furthermore, a case can be made that a combination of both botulinum toxin A and physical therapy would be better than just one or the other. Overtime, the combination of botulinum toxin and physical therapy has been suggested to decrease Modified Ashworth scale scores (Isoyama & Takeuchi, 2013). The combination is found to help range of motion in patients that have extremities that are splinted (Isoyama & Takeuchi, 2013). The ability of the toxin to decrease pain helps the patient to focus more on the exercises they need to perform to help their range of motion. This combination was studied at a long-term care facility in Hong Kong, which had patients suffering from severe limb spasticity (Lam et al., 2012). These patients were suffering from such severe limb spasticity that they needed caregivers around the clock. Most patients were bed or wheelchair bound and had splits on their extremities. All were on a physical therapy routine, which consisted of passive limb stretching exercises twice a week and splitting for three hours a day. All patients were given injections of botulinum toxin A that were based on the clinical judgments of the injection team. In that particular study, botulinum toxin A and physical therapy improved ratings on the caregiver burden scale for these patients (Lam et al., 2012). If muscle spasticity could be reduced or controlled to a point where caregivers are not needed, then caregiver
burden could be decreased. Decreasing muscle spasticity could lead to a decrease in severity of symptoms, which would allow patients to be more independent. If patients were able to do more tasks on their own, then caregivers would be needed less. This research could impact insurance companies because they would be able to cover a treatment that would be most effective for the patient. This study will further explore if a specific course of treatment such as botulinum toxin A or physical therapy, or a combination of both can help to alleviate caregiver burden over time.

**PROPOSED METHOD**

**Study Design**

I will conduct an experimental study, which will evaluate the different treatments available for muscle spasticity in stroke victims. This will allow us to find the most effective treatment, which will help to alleviate caregiver burden the most.

**Participants**

Approximately 100 stroke survivors and their primary caregivers will be recruited from three specific stroke hospitals in New York. All participants will be volunteers who have given consent to be a part of the study. In order to be a part of the study, the patients must have had a stroke within the last three to six months and have muscle spasticity. Their caregiver must spend at least 20 hours or five days a week caring for them, must be a family member, and not a professional staff member. The researcher will continue to recruit until there are twenty-five patients choosing physical therapy, twenty-five choosing botulinum toxin A, twenty-five choosing both physical therapy (pt) and botulinum toxin A, and a final group of twenty-five who will be the control group. The designated groups are a physical therapy group, which will be group 1, a botulinum toxin A group which will be group 2. A physical therapy and botulinum toxin A group which will be group 3, and last will be group 4 the control group that decided to not have treatment. Participants will be studied for the initial three years following their stroke.

**Materials**

The materials that would be used for this experiment would be the Modified Ashworth Scale, Caregiver Burden Scale and a Caregiver Satisfaction Questionnaire. The Modified Ashworth Scale is used to access muscle spasticity in stroke patients. It is a scale from zero to four. Zero is no increase in tone, one is slight increase in muscle tone and two is more marked increase in muscle tone. In between 1 and 2, there is a one plus category that is used in some cases. One plus indicates a slight increase in muscle tone that is followed by minimal resistance. A three on the scale indicates a considerable increase in muscle tone and a four indicates that the affected part is rigid in flexion and extension. The Modified Ashworth scale is given by the physical therapist and is based on their evaluation of the patient. The physical therapist assesses the patients' muscle tone and their range of motion. Based on both of those criteria, the physical therapist comes up with a score from zero to four. The patients in this study will have a Modified Ashworth score of a two (Bohannon & Smith, 1987). A sample of a Modified Ashworth Scale can be found in Appendix A.

The Caregiver Burden Scale has multiple questions that assess how the caregiver feels about the person they are taking care of. All questions have a four point Likert scale, which range from never to nearly always. Some examples of questions are, “Do you feel that your relative asks for more help than he or she needs?, Do you feel stressed between caring for your relative and trying to meet other responsibilities for your family or work?” More examples of these questions can be accessed in Appendix B. After the caregiver is done taking the scale, their scores will be tallied and recorded as a baseline (Zarit, Reever, & Bach–Peterson, 2002).

The Caregiver Satisfaction Questionnaire was adapted from the Caregiver Burden Scale and is answered by the patient and assesses how he or she feels about his or her care. All questions have a four point Likert Scale, which ranged from never to nearly always. Caregivers will be instructed to keep a weekly journal of any observable changes in their loved one. A sample of the caregiver satisfaction questionnaire can be found in the Appendix C.

**Procedure**

Stroke survivors that volunteer for the study will be given an informed consent prior to the start of the study. Stroke survivors and their caregiver will be asked if they want to participate in a 3-year study and then will be brought in for a preliminary checkup where they will be assessed by a physical therapist. The physical therapist will administer the Modified Ashworth Scale so that the researcher will have a baseline score. Caregivers will be given the Caregiver Burden Scale by the researcher. All participants will retrieve treatments for free and will be compensated by their insurance company for transportation fees. Group one will be given a variety of range of motion exercises that will need to be completed twice a day every day. These exercises will be monitored by a physical therapist to ensure that the exercises are done correctly.

Group two will receive a physical therapy routine that is the same as the physical therapy group. In addition to the physical therapy, this group will receive 50 units of botulinum toxin in their wrist and another 50 units in their
bicep. These injections will be administered by the primary physician and will be given once every 12 weeks for a year in combination with the physical therapy exercises. Group three will receive 50 units of botulinum toxin in their wrist and another 50 units in their bicep. Their primary physician will administer the injections and they will be given the drug once every 12 weeks for a year. Group four will not receive any treatment because they refused treatment. A physical therapist, primary doctor, and the researcher will closely monitor each group. Some participants will have home visits, but these will be selected randomly by the researcher. All participants will have to come back to the stroke hospital for an assessment at six months, a year, two and then three years after their stroke. At each follow up, the caregivers and the stroke victims will be assessed on their progress and will be given new Ashworth Scales, Caregiver Burden Scales and Caregiver Satisfaction Questionnaires. At each interval of time, data will be collected and analyzed. The data will be analyzed through SPSS. Participants are allowed at any time to withdraw from the study with permission from their doctor.

CONCLUDING REMARKS

Significance

Caregiver burden needs to be alleviated in some way because of its physical and financial demands. If this burden were eliminated caregivers would be able to juggle all that their life demands and be able to care for their loved one as well. This study is attempting to fix a problem that many families face each day, which is rising financial cost and family breakdown. This study is designed to definitively determine the best therapy for these patients. The combination of botulinum toxin A and physical therapy could help these patients to be able to do one or two of the tasks they never thought they would ever be able to do again. This in turn would take some of the burden off of their caregivers. The study may take a long time to produce proper results, but after the three years are completed, we will be able to help many families. This study could help to reunite families and help caregivers to rejoin society. This research could change the way stroke victims with muscle spasticity are treated and can help families to continue to function in a healthy way.

Limitations

This study presents several limitations. One limitation to this study is that participants may want to quit the study before the three years is completed. Another limitation is that patients could pass away during the duration of the study from other illnesses that they may have. Since patients are volunteering for the study, not all patients will have the exact same spasticity. Each case of spasticity is unique and cannot be generalized. Some patients may have a higher pain tolerance and may not be affected as much by the spasticity. A higher pain tolerance may cause patients to perform more tasks before they feel pain and have to stop. The physical therapy exercises may not be able to alleviate the spasticity and may be viewed as unsuccessful. Patients who are only receiving the toxin may build up a tolerance to the drug, and not be able to benefit from the drug. The study lacks random assignment because participants were recruited for specific groups based on the treatment they chose. Participants may not be as honest as possible when they have to fill out the questionnaires, and may only give answers that they think the researcher wants. If a patient were to drop out in any of the groups, another patient would not be able to join the study because of the timeline provided. In this case, the results would have to be analyzed by the researcher and adjusted properly.

REFERENCES

CAREGIVER BURDEN IN STROKE PATIENTS

Rehabilitation, 95, 222-9.  
http://dx.doi.org/10.1016/j.apmr.2013.10.023


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APPENDIX A

Modified Ashworth Scale

Modified Ashworth Scale Instructions

General Information (derived Bohannon and Smith, 1987):
- Place the patient in a supine position
- If testing a muscle that primarily flexes a joint, place the joint in a maximally flexed position and move to a position of maximal extension over one second (count "one thousand one")
- If testing a muscle that primarily extends a joint, place the joint in a maximally extended position and move to a position of maximal flexion over one second (count "one thousand one")
- Score based on the classification below

Scoring (taken from Bohannon and Smith, 1987):
0  No increase in muscle tone
1  Slight increase in muscle tone, manifested by a catch and release or by minimal resistance at the end of the range of motion when the affected part(s) is moved in flexion or extension
1+ Slight increase in muscle tone, manifested by a catch, followed by minimal resistance throughout the remainder (less than half) of the ROM
2  More marked increase in muscle tone through most of the ROM, but affected part(s) easily moved
3  Considerable increase in muscle tone, passive movement difficult
4  Affected part(s) rigid in flexion or extension

Patient Instructions:
The patient should be instructed to relax.

Downloaded from www.rehabmeasures.org
Test instructions provided courtesy of Richard Bohannon PT, PhD and Melissa Smith, PT
# APPENDIX B

## Caregiver Burden Scale

<table>
<thead>
<tr>
<th>The following questions reflect how people sometimes feel when they are taking care of another person. After each question, circle how often you feel that way: never, rarely, sometimes, frequently, or nearly always. There are no right or wrong answers.</th>
<th>Never</th>
<th>Rarely</th>
<th>Sometimes</th>
<th>Frequently</th>
<th>Nearly always</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Do you feel that your relative asks for more help than he or she needs?</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>2. Do you feel that because of the time you spend with your relative, you do not have enough time for yourself?</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>3. Do you feel stressed between caring for your relative and trying to meet other responsibilities for your family or work?</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>4. Do you feel embarrassed over your relative’s behavior?</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>5. Do you feel angry when you are around your relative?</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>6. Do you feel that your relative currently affects your relationship with other family members or friends in a negative way?</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>7. Are you afraid about what the future holds for your relative?</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>8. Do you feel your relative is dependent on you?</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>9. Do you feel strained when you are around your relative?</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>10. Do you feel your health has suffered because of your involvement with your relative?</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>11. Do you feel that you do not have as much privacy as you would like, because of your relative?</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>12. Do you feel that your social life has suffered because you are caring for your relative?</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>13. Do you feel uncomfortable about having friends over, because of your relative?</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>14. Do you feel that your relative seems to expect you to take care of him or her, as if you were the only one he or she could depend on?</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>15. Do you feel that you do not have enough money to care for your relative, in addition to the rest of your expenses?</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>16. Do you feel that you will be unable to take care of your relative much longer?</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>17. Do you feel that you have lost control of your life since your relative’s illness?</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>18. Do you wish you could just leave the care of your relative to someone else?</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>19. Do you feel uncertain about what to do about your relative?</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>20. Do you feel you should be doing more for your relative?</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>21. Do you feel you could do a better job in caring for your relative?</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>22. Overall, how burdened do you feel in caring for your relative?</td>
<td>0</td>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
</tbody>
</table>

**Total score:**

**SCORING KEY:**

0 to 20 = little or no burden; 21 to 40 = mild to moderate burden; 41 to 60 = moderate to severe burden; 61 to 88 = severe burden.

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**FIGURE 4.** Caregiver Burden Scale. This self-administered 22-item questionnaire assesses the “experience of burden.” Adapted with permission from Zawit SH, Reeve KE, Bach-Peterson J. Relatives of the impaired elderly: correlates of feelings of burden. Gerontologist 1986;20:649-55.
APPENDIX C

Caregiver Satisfaction Scale

Caregiver Satisfaction Scale:

Patients Name: Date:

The following questions reflect how you feel about your caregiver and the care they provide for you. After each question, circle how often you feel that specific way: never, rarely, sometimes, frequently, or nearly always. Please be truthful in your answers.

1. Do you feel that your caregiver provides the proper care for you?

<table>
<thead>
<tr>
<th>Never (0)</th>
<th>Rarely (1)</th>
<th>Sometimes (2)</th>
<th>Frequently (3)</th>
<th>Nearly Always (4)</th>
</tr>
</thead>
</table>

2. Do you feel like a burden to your caregiver?

<table>
<thead>
<tr>
<th>Never (0)</th>
<th>Rarely (1)</th>
<th>Sometimes (2)</th>
<th>Frequently (3)</th>
<th>Nearly Always (4)</th>
</tr>
</thead>
</table>

3. Do you feel embarrassed about the extent of care that your caregiver has to provide?

<table>
<thead>
<tr>
<th>Never (0)</th>
<th>Rarely (1)</th>
<th>Sometimes (2)</th>
<th>Frequently (3)</th>
<th>Nearly Always (4)</th>
</tr>
</thead>
</table>

4. Do you ever feel angry with your caregiver?

<table>
<thead>
<tr>
<th>Never (0)</th>
<th>Rarely (1)</th>
<th>Sometimes (2)</th>
<th>Frequently (3)</th>
<th>Nearly Always (4)</th>
</tr>
</thead>
</table>

5. Do you and your caregiver fight more than three times a week over your care?

<table>
<thead>
<tr>
<th>Never (0)</th>
<th>Rarely (1)</th>
<th>Sometimes (2)</th>
<th>Frequently (3)</th>
<th>Nearly Always (4)</th>
</tr>
</thead>
</table>

6. Do you feel a strain between your caregiver and yourself because of your disability?

<table>
<thead>
<tr>
<th>Never (0)</th>
<th>Rarely (1)</th>
<th>Sometimes (2)</th>
<th>Frequently (3)</th>
<th>Nearly Always (4)</th>
</tr>
</thead>
</table>
7. Do you feel that your caregiver only spends time with you because of your disability and not because they want to?

<table>
<thead>
<tr>
<th>Never (0)</th>
<th>Rarely (1)</th>
<th>Sometimes (2)</th>
<th>Frequently (3)</th>
<th>Nearly Always (4)</th>
</tr>
</thead>
</table>

8. Do you feel uncertain about your future?

<table>
<thead>
<tr>
<th>Never (0)</th>
<th>Rarely (1)</th>
<th>Sometimes (2)</th>
<th>Frequently (3)</th>
<th>Nearly Always (4)</th>
</tr>
</thead>
</table>

9. Do you wish you could do more to help your caregiver?

<table>
<thead>
<tr>
<th>Never (0)</th>
<th>Rarely (1)</th>
<th>Sometimes (2)</th>
<th>Frequently (3)</th>
<th>Nearly Always (4)</th>
</tr>
</thead>
</table>

10. Do you feel as if you have lost your sense of independence and no longer enjoy life?

<table>
<thead>
<tr>
<th>Never (0)</th>
<th>Rarely (1)</th>
<th>Sometimes (2)</th>
<th>Frequently (3)</th>
<th>Nearly Always (4)</th>
</tr>
</thead>
</table>

Scoring Key:

- 0-10 = Satisfied with care
- 11-20 = Somewhat satisfied with care
- 21-30 = Moderately Satisfaction with care
- 31-40 = Not satisfied with care.