National Stroke Association Stroke Perceptions Study

JUNE 2006

Prepared by:



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Introduction and Methodology

Background and Objectives

The purpose of this study was to examine barriers to rehabilitation following stroke and document any disconnects between survivors' and clinicians' perspectives on the need for and the effectiveness of post-stroke care. In addition, the study gathered perspectives from the general population in order to reveal "everyday" views on stroke and what actually happens after a stroke.

The data from this research will be used to enhance public relations, awareness and education materials and activities geared toward stroke survivors and caregivers, and to the medical community. The survey will also provide the NSA with other useful educational issues, such as key factors in seeking/obtaining effective treatment.

Methodology

A total of 1346 interviews were conducted using both telephone and online interviewing, as follows:

- <u>General Population Cell</u>: 523 interviews among online adults 18 and older. The sample was balanced by gender, age and census region to match the national population. Interviewing for this cell was conducted online at the Russell Research survey website. Interviewing was conducted April 17-26, 2006.
 - Online sample for the study was drawn from Survey Sampling International's SurveySpot online consumer panel. The panel currently has 2.3 million panel members who are recruited using a wide variety of online and offline methods, including website registrations, email invitations and telephone recruiting. For this study, invitations were e-mailed to potential respondents targeted by age, gender and census region.
 - In theory, with probability samples of this size, one could say with 95 percent certainty that the results have a statistical precision of plus or minus 4.3 percentage points of what they would be if the entire adult population had been polled with complete accuracy. Unfortunately, there are several other possible sources of error in all polls or surveys that are probably more serious than theoretical calculations of sampling error. They include refusals to be interviewed (non-response), question wording and question order, and weighting. It is impossible to quantify the errors that may result from these factors. This online survey is not a probability sample.



Introduction and Methodology (Cont'd.)

Methodology (Cont'd.)

- <u>Survivor/Caregiver Cell</u>: 504 interviews among adults who have suffered from a stroke and currently experience motor difficulties or limitations (or their primary caregiver). Interviewing for this cell was conducted by telephone. Interviewing was conducted March 27 - April 2, 2006 using lists provided by the National Stroke Association.
 - In theory, with probability samples of this size, one could say with 95 percent certainty that the results have a statistical precision of plus or minus 4.4 percentage points of what they would be if the entire population had been polled with complete accuracy. Unfortunately, there are several other possible sources of error in all polls or surveys that are probably more serious than theoretical calculations of sampling error. They include refusals to be interviewed (non-response), question wording and question order. It is impossible to quantify the errors that may result from these factors.
- <u>Clinicians Cell</u>: 319 interviews were conducted among the following clinician segments:

•	Primary Care Physicians	100 interviews
•	Neurologists	83 interviews
•	Physiatrists	20 interviews
•	Occupational Therapists	57 interviews
•	Physical Therapists	59 interviews

In order to qualify, clinicians must have been practicing medicine for a minimum of 1 year, actively see patients, regularly or occasionally see patients who have experienced a stroke, and whose average stroke patient is ages 18 or older. Interviewing for cell this was conducted using an Internet methodology. Interviewing was conducted from April xx – June xx, 2006 using lists provided by the National Stroke Association and Medtronic.

- In theory, with probability samples of this size, one could say with 95 percent certainty that the results have a statistical precision of plus or minus 5.5 percentage points of what they would be if the entire population had been polled with complete accuracy. Unfortunately, there are several other possible sources of error in all polls or surveys that are probably more serious than theoretical calculations of sampling error. They include refusals to be interviewed (non-response), question wording and question order. It is impossible to quantify the errors that may result from these factors.
- The sampling error by specialty is as follows: Primary Care Physicians, 9.8%; Neurologists, 10.8%; Physiatrists, 21.9%, Occupational/Physical Therapists, 9.1%.



Statistical Notation

The statistical significance of a result in this survey is the probability that the observed relationship (e.g., between variables) or a difference (e.g., between means) in a sample occurred by pure chance and that in the population from which the sample was drawn, no such relationship or differences exist. Using less technical terms, the statistical significance of a result indicates the degree that the result is "true." More technically, the value of the p-value represents a decreasing index of the reliability of a result. The higher the p-value, the less the observed relation between variables in the sample is a reliable indicator of the relation between the respective variables in the population. Specifically, the p-value represents the probability of error that is involved in accepting an observed result as valid or "representative of the population." For example, a p-value of .05 indicates that there is a five percent probability that the relation between the variables found in the sample is a "fluke."

The following statistical notations are used in the "General Population" section of the report:

- = Indicates figure is significantly higher than the other gender group at a 95 percent confidence level (i.e. p-value of .05 or less).
- O = Indicates figure is significantly higher than the other age group at a 95 percent confidence level (i.e. p-value of .05 or less).

The following statistical notations are used in the "Clinicians" section of the report:

- = Indicates figure is significantly higher than indicated group at a 95 percent confidence level (i.e. p-value of .05 or less).
 - B = PCPs
 - C = Neurologists
 - D = Physiatrists
 - E = Occupational/Physical Therapists



Summary - General Population

The vast majority of the U.S. population view stroke as a medical condition that causes long-term disability. They recognize that stroke survivors are often left with speech limitations, changes to their mobility and movement, and memory loss; as well as experiencing emotional/personality/behavioral changes. The primary warning signs of stroke (numbness on one side of the body, slurred speech, blurred vision, and confusion) are generally well known. A large proportion of Americans know someone who has suffered a stroke and many would be willing to provide assistance to someone recovering from a stroke.

- When presented with five alternative conditions, one-half of the adults surveyed most associated stroke with causing a long-term disability.
 - Most recognize that strokes are not fatal. Approximately half the adults surveyed believed that 75 percent of sufferers survived and an additional one-third indicated that 50 percent survive. Only one in ten respondents thought that only 25 percent of sufferers survive a stroke.
- Due to it being viewed as a disability and not necessarily life-threatening, it is not the most feared condition. Adults fear cancer most (65 percent place it among the top two feared out of the five alternative conditions included in the survey), followed by stroke (56 percent) and heart attack (55 percent). Men and older adults are significantly more likely than women to fear a stroke most (62 percent of men v. 51 percent of women / 66 percent of adults 55 or older v. 52 percent of adults 18-54), while females are significantly more likely to fear cancer most (71 percent v. 60 percent).
- Most adults associate speech limitations (87 percent) and loss of mobility (82 percent) with a stroke. A majority of respondents also believe it results in loss of memory (58 percent) and dependency on a caregiver (64 percent).
- Nearly all respondents indicated that movement issues (93 percent) and trouble communicating (88 percent) were common complications experienced by stroke survivors. Two thirds also mentioned that emotional changes or personality/behavioral changes were also common after a stroke. In addition, men were significantly more likely than women to believe that sexual issues were experienced after having a stroke (49 percent v. 37 percent).
- Numbness on one side of the body (86 percent) and slurred speech (84 percent) are widely believed to be the signs of stroke, and two-thirds of respondents also mentioned blurred vision and confusion.
- Two thirds of Americans know someone, be it family or friend, who has had a stroke. Almost half of these adults have provided some form of assistance to a person who has had a stroke (e.g. food delivery, help with errands). However, only two thirds of those who don't currently know someone who had a stroke claim they would be willing to help a stroke survivor.



Summary - Survivors

<u>The doctors who treated the stroke survivors</u>, mainly Neurologists and General Practitioners, <u>played an important part in their recovery</u>. More than half of the survivors attributed almost all or a lot of their recovery to the medical professionals they worked with during their rehabilitation. In addition, their doctors helped them feel optimistic about their chances of recovery.

The majority of stroke survivors received some form of therapy (physical, occupational, or speech) as part of their rehabilitation, lasting on average between twenty and thirty weeks. In addition, as part of their care, slightly less than half received orders for home therapy, which lasted an average of ten weeks. The main objectives of the rehabilitation therapy were to improve their ability to walk, talk, or improve movement of their arm and/or hand. More than one-half felt that the therapy they received was extremely or very successful in helping them reach their personal goals, and an additional one third felt the therapy was only somewhat successful. Only ten percent felt it was not successful at all.

Despite the success that is widely experienced in therapy, <u>one in eight stroke survivors</u> <u>did not receive therapy of any kind</u>. Among this group, over one half was not prescribed therapy and a small percentage could either not afford it or it was not covered by their health insurance. Additionally, <u>nearly three-fifths of survivors did</u> <u>not receive orders for home therapy</u>.

While therapy has helped survivors achieve some degree of recovery, the majority are still at least somewhat disabled. They want to be able to work, drive, and participate in daily activities; and they claim what has been most challenging to them since their stroke is coping with physical loss, getting around, not being able to communicate with others as well, and not being able to take care of themselves. Many of them still need assistance with daily tasks such as taking medication, toileting, bathing, doing laundry, shopping, and dressing.

Neurologists (44 percent) and General Practitioners (23 percent) were the primary types of doctors used by stroke survivors. <u>Only a small percentage primarily used Physiatrists</u> (15 percent), who are experts in the therapy field. Fifty six percent of the survivors felt their doctors were responsible for almost all/a lot of their recovery. An additional one fourth said they were responsible for about half. Approximately half of the survivors said that what their doctors told them made all the difference/gave them a lot of hope in terms of their ability to recover from their stroke. One fourth said their doctors gave them little or no hope in terms of their ability to recover from their stroke.



Summary - Survivors (cont'd.)

- After experiencing their last stroke, nine out of ten received some type of rehabilitation therapy, specifically physical therapy (93 percent), occupational therapy (80 percent) and speech therapy (68 percent). Two out of five survivors were also prescribed home therapy by their physician.
 - Spasticity was a fairly common experience among survivors, as three in five had symptoms. Among those experiencing tight-stiff muscles, one-half received treatment, which was most likely to include range of motion exercises (58 percent), gentle stretching (51 percent) and oral medications (47 percent). ITB therapy was used infrequently (3 percent).
- Being able to walk better was the primary goal of rehabilitation therapy (21 percent). Listed among their top two goals in recovery were walking (41 percent), better use of their arm (13 percent) or hand (12 percent), improving their speech (21 percent), being able to drive (10 percent) and going back to work (8 percent).
- Just over half the survivors involved in therapy (including home therapy) felt it was extremely or very successful in terms of helping them meet their personal goals of recovery.
 - However, one third felt their therapy was only somewhat successful and ten percent felt it was not at all successful. This lack of success was attributed to seeing a lack of progress (34 percent), money related issues (their insurance running out [18 percent] or running out of money to continue therapy [14 percent]), experiencing other health problems (15 percent), and spasticity (12 percent).
- There are several things survivors would most like to do but cannot due to their stroke, and most pertain to returning to their pre-stroke lives: working (17%), driving (16%), daily activities or tasks (14%), walking (13%) and hobbies or leisure activities (13%) were mentioned most often. Two-thirds of survivors indicated therapy has helped in accomplishing these tasks.
- The biggest challenges faced by stroke survivors overall are coping with physical loss (22 percent), getting around (13 percent), not being able to communicate as well (11 percent), and having trouble taking care of themselves (10 percent). More specifically, they face daily challenges in terms of walking (23 percent), dressing (13 percent), bathing (12 percent), cleaning house (12 percent), and preparing meals (11 percent).
 - Coping with these challenges includes receiving assistance with taking medicine, toileting, bathing, laundry, shopping, and dressing approximately half of the time. Slightly less often they also receive assistance with meal preparation and housekeeping.



Summary - Clinicians

Neurologists see the largest number of stroke patients each year and these patients represent approximately half of the doctors' practices. Their primary role is to coordinate patient care which they do by writing orders and getting reports, with some of them also meeting with therapists and others involved in the rehab treatment. Only one fourth of them have received specific training in rehab stroke care/therapy. Physiatrists and occupational/physical therapists have the most "hands on" contact with stroke patients, being personally involved in providing the treatment. As a result, most or all of them have received specific training in this area. The doctors and therapists involved with stroke rehabilitation believe that the most important goals (both from their standpoint and what the believe the patient wants) are to regain independence and gain back some/all of their motor skills. Physical and occupational therapists see patients' lack of progress, other health problems, depression and spasticity as the largest barriers to rehab goals. Doctors and patients often disagree on how to treat spasticity. The patients want oral medications and injections of Botoxolton, while the doctors are likely to prescribe range of motion and gentle stretching exercises as well. Half of the doctors wish there was more they could do to address the specific therapies used to help spasticity.

- Neurologist see an average of 169 stroke patients each year compared to 86 by the Physiatrists, 48 by Primary Care Providers, and 50 by the therapists.
 - These patients make up 47 percent of the Neurologist's practice compared to 24 percent of the Physiatrist's, one third of the therapist's, and only 7 percent of the PCPs.
- PCPs and Neurologists primarily coordinate patient care with 82 percent of the PCPs and two thirds of the Neurologists writing orders and getting reports. Close to one third of the Neurologists will also meet with a patient's therapist. By comparison virtually all of the therapists provide direct rehab treatment to the patients. The Physiatrists both provide direct treatment (35 percent) and meet with the therapists who provide it (40 percent).
- Independence is the main objective of rehab though the different clinicians describe it in various ways. Approximately one third of the doctors felt that the primary goal of rehabilitation is the get back a degree of independence. The therapists put more emphasis on regaining movement, with more than half saying that it is the most important goal of therapy. The Physiatrists also place high importance on a patient regaining movement (25 percent). All four groups of healthcare professionals also say it is important for the patient to get back to the activities of daily living and to be able to function daily (mentioned by approximately 2 out of 10 across all groups).



Summary - Clinicians (cont'd.)

- Three quarters of therapists involved in stroke rehabilitation see lack of progress as the largest barrier to meeting patient goals. At least sixty percent also saw other health issues, depression, and spasticity as impediments to meeting therapy goals. Cost was a barrier mentioned by at least half of the therapists (48 percent mentioned the patient's insurance running out and 28 percent that the patient did not have the money to continue).
- When patients request spasticity treatments (mainly of Neurologists and Physiatrists), the majority request oral medications (76 percent) and MYOBLOCK (60 percent). <u>Nearly half of patients will request ITB Therapy</u> when talking to their Physiatrist about specific spasticity treatments.
 - The majority of doctors and therapists will recommend range of motion and gentle stretching exercises to their patients with spasticity (80 percent or higher). Oral medication will also be prescribed by at least three quarters of the doctors. Neurologists and Physiatrists will give injections of Botoxolton (at least two thirds of them), while ITB Therapy is given by nearly half of the Physiatrists.



General Population



Half of adults believe that stroke is more likely to cause long-term disability than heart attacks, cancer, diabetes, or asthma.

 Older adults (55 or older) are more likely than younger adults (18 to 54) to believe that stroke is the condition most likely to cause long-term disability.

Condition Most Likely To Cause Long-Term Disability



■ Heart attack □ Stroke ■ Cancer □ Diabetes □ Asthma

Q.1 Which serious health condition do you think is most likely to cause long-term disability?



Men and older Americans are significantly more fearful of having a stroke.

- Men are significantly more likely than women to rank stroke as the condition they fear most or second most (62 percent v. 51 two percent).
- And, adults 55 or older are significantly more fearful of stroke than are younger adults (66 percent v. 52 percent).
- Women are significantly more afraid of cancer (71 percent fear most/second most) than they are of stroke (51 percent) or heart attack (53 percent), while the men have relatively comparable fear levels for all three conditions.

Top Two Conditions Fear Most



Q.2 Of the serious health conditions below, which do you fear most? Please rank the condition you fear most as "1", the one you fear second most as "2", etc. until all are ranked.



Changes to speech or mobility, or blindness caused by disease would have the most impact on daily routines.

- More than half of the adults felt that the most profound changes to their daily activities would occur if a disease were to limit their ability to speak or walk, or to cause blindness.
- Overall 90 percent of adults felt limited motor function would be the most disruptive to their life. Six out of ten felt that impaired vision would hamper them the most, while four out of ten would be most affected by changes in cognition.
- Women were significantly more likely than men to feel that sensory changes would have a large impact on their daily activities (25 percent v. 11 percent of the men).

Elements Of Present Daily Life That Would Most Hamper Daily Activities If They Were Limited By Disease



■ Motor ■ Vision ■ Cognition □ Sensory ■ Affect □ Language

Motor Elements (90%)		Vision (62%)		Cognition (43%)		Sensory (18%)	
Speech	53%	Blindness	54%	Memory	37%	Pain	17%
Walking	55%						



Q.3 What three elements of your present daily life would most hamper your daily activities if they were limited by disease?

Stroke is most strongly associated with speech limitations and loss of mobility.

- The vast majority expect that a stroke will cause speech limitations and loss of mobility.
- Two-thirds of adults assume that when you have a stroke you will become dependent on a caregiver for basic needs.
- Very few expect stroke survivors to have a full recovery or return to work.

Outcomes Associated With Stroke



Q.4 Which of the following outcomes do you associate with stroke?



Only one third of Americans know that 750,000 people suffer a stroke each year.

Half the adults underestimated the number of people who experience a stroke each year (39 percent thought it was 450,000 and 12 percent thought only 185,000).

Number Of People Experience A Stroke In United States Each Year



■ 185,000 □ 450,000 ■ 750,000 □ 1,000,000

Q.5 How many people do you think experience a stroke each year in the United States?



The majority of Americans know that suffering a stroke is not necessarily fatal.

- More than half the adults know that at least 75 percent of stroke sufferers will survive.
- Another one third believe 50% of stroke victims will survive.
- Only ten percent thought the survival rate was 25 percent.

Percentage Of Stroke Sufferers Who Survive



■ 25% □ 50% ■ 75% □ 100%



Q.6 Among the people who experience a stroke each year in the United States, what percentage do you believe survive?

Body numbness and slurred speech are widely recognized as signs of a stroke .

- The vast majority of adults know that numbress (especially on one side of the body) and slurred speech are signs of a stroke.
- Confusion and blurred vision were also mentioned as signs of stroke by two thirds of the adults.
- More than one-half know that a sudden headache for no reason could also be a sign of a stroke.
- Women and older adults are significantly more aware than men/younger adults that slurred speech and confusion are signs of stroke.





Q.7 To the best of your knowledge, which of the following are signs of a stroke?



It is well known that movement issues and trouble communicating are common complications experienced by stroke survivors.

- Most adults know that having a stroke can cause problems with movement and communication.
- Two thirds also recognize that emotional changes and personality/behavior changes are common complications experienced by stroke survivors.
- Less than half are aware that sexual issues can be a result of stroke, however men are significantly more aware of this problem than are women.

Common Complications Experienced By Stroke Survivors



Q.8 Which of the following do you think are common complications experienced by stroke survivors?



Two thirds of Americans know someone who has suffered from a stroke.

- Sixty six percent of adults know someone who has had a stroke. The person who suffered a stroke is just as likely to be a family member (immediate or otherwise) as a friend.
- Two percent of the general population has personally suffered from a stroke.

Whether Suffered A Stroke Or Known Someone Who Has







Stroke survivors are surrounded by people willing to help them.

- Forty five percent of adults have provided assistance (e.g. food delivery, help with errands) to someone they know who has suffered from a stroke.
- However, only two thirds of those who don't currently know a stroke survivor claim they would be willing to help someone with a stroke.



Q.10 Have you provided assistance (e.g., food delivery, help with errands) to a person who experienced a stroke?



Demogra	phics		
Total Respondents	<u>Total</u> (523) %	<u>Male</u> (248) %	<u>Female</u> (275) %
Gender			
Male Female	49 51	-	-
Age			
18 - 34 (net)	32	32	32
18 - 24	9	8	10
25 – 29	11	11	11
30 – 34	13	14	12
35 - 54 (net)	40	40	39
35 – 39	9	9	10
40 - 44	10	8	11
45 – 49	10	8	11
50 – 54	11	14	8
55 Or Older (net)	28	28	28
55 – 59	13	11	14
60 - 64	8	8	9
65 – 69	3	3	2
70 – 74	4	4	3
75 or older	1	2	-
Mean	44.3	44.9	43.7
Marital Status			
Married	51	48	54
Not Married (net)	<u>48</u>	<u>51</u>	<u>46</u>
Single (never married)	23	28	18
Divorced	12	13	11
Separated	3	3	_2_
Widowed	3	1	4
Living with someone	8	6	10
Rather not answer	1	1	0
Mean Household Size	2.7	2.4	2.9
Presence Of Children Under 18 In Household			_
Children Under 18 Present (net)	<u>35</u>	<u>29</u>	<u>41</u>
Under 2	8	6	10
2 to 5	12	7	16
6 to 9	11	8	14
10 to 11	9	7	11
12 to 14	10	8	12
15 to 17	9	ر گ م	11
No children under 18 present	65	L71J	59



Demographics				
Total Respondents	<u>Total</u> (523) %	<u>Male</u> (248) %	<u>Female</u> (275) %	
Education				
No College (net)	<u>27</u>	<u>20</u>	34	
Less than high school degree	3	3	4	
High school graduate	19	13	25	
Other technical school beyond high school	5	4	5	
<u>College (net)</u>	<u>72</u>	80	<u>64</u>	
Some college	24	22	25	
Completed 2-year college	10	11	9	
Completed 4-year college	19	21	16	
Some post-graduate	6	6	6	
Post-graduate degree	14	19	8	
Rather not answer	1	0	2	
Employment Status		_		
Employed (net)	<u>65</u>	<u>73</u>	<u>57</u>	
Work full-time	55	65	45	
Work part-time	10	8	12	
Not Employed (net)	<u>34</u>	<u>25</u>	<u>42</u>	
Homemaker	11	1	21	
Full-time student	3	3	3	
Part-time student	0	-	0	
Retired	14	15	12	
Unemployed	6	6	6	
Rather not answer	2	2	1	
Mean Annual Household Income	57.2	60.4	53.8	
Whether Of Hispanic Origin Or Descent				
Hispanic Origin Or Descent	13	13	13	
Not Hispanic Origin Or Descent	86	85	86	
Refused	1	2	1	
Ethnic Background				
African-American	12	10	13	
Asian/Pacific Islander	1	1	1	
Caucasian	72	73	71	
Native American	1	2	1	
Mixed Ethnic Background	4	4	5	
Other	4	3	4	
Refused	6	7	5	
Type Of Community Reside In				
Urban	30	31	30	
Suburban	49	50	47	
Rural	21	18	23	



Survivors



Stroke survivors interviewed for this survey are relatively independent and well past the initial recovery and rehabilitation stage.

- Three fourths of the stoke survivors interviewed for this research had suffered an ischemic stroke.
- The average number of strokes suffered by this group was 1.5.
- The mean number of years since they had their stroke was 3.3 years.
- Approximately two thirds of the survivors are in charge of their own care. Three out
 of ten have a family member who is the primary coordinator of their care.
- More than half the survivors do not need any type of assistance with their everyday activities. Overall, daily assistance is needed less than twenty percent of the time.

Total Respondents	<u>Total</u> (504) %
Stroke Type Suffered	
Ischemic (clot or blockage)	74
Hemorrhadic (bleeding kind of stroke)	24
Combination of Hemorrhadic and Ischemic	3
Transient Ischemic Attack or TIA	3
Number Of Strokes Suffered	
1	70
2	16
3	8
4 or more	6
Mean	15
mouri	1.0
Time Of Most Recent Stroke	
Less than 6 months ago	8
6 months to 1 year ago	11
1 - 2 years ago	19
3 - 4 years ago	24
5 or more years ago	39
Mean (years)	3.3
% of Time Need Assistance With Everyday Activities	
0%	58
1% - 24%	17
25% - 40%	6
50% - 74%	6
75% - 99%	5
100%	8
Mean	18.6
Weall	18.0
Primary Coordinator Of Care	
The stroke survivor	64
A family member	31
A hired caregiver	2
All Other Mentions	
	5

Stroke Related Information



Eight out of nine stroke survivors still experience motor limitations. In terms of these motor functions stroke has its greatest impact on walking, hand movement, and balance. Speech is the area least affected by stroke and also the area quickest to return to pre-stroke functioning.

- At least three fourth of the stroke survivors included in this study had problems with walking, hand movement, and balance as a result of their stroke. At the time the survey was conducted, approximately two thirds of them were still disabled in these areas.
- By comparison, stroke caused some type of speech impairment in two thirds of these survivors, however at the time of the survey half of them had recovered full functionality in this area.

Motor Limitations Experienced and Still Experience Since Stroke



Total Still Experience Motor Limitations = 87%



Q.J You indicated that you had experienced the following limitations as a result of your stroke. Which of the following limitations are you still experiencing??

Stroke survivors generally relied upon a Neurologist or General Practitioner for their post-stroke care.

- Forty four percent of stroke survivors used a Neurologist to handle their post-stroke recovery, while an additional 23 percent used a General Practitioner.
- At much lower levels were mentions of using a Physiatrist (15 percent) or Internist (8 percent).

Specialty Of Primary Doctor For Post-Stroke Recovery



Q.1 What was the specialty of the doctor who primarily handled your post-stroke recovery?



The majority of stroke survivors received some type of therapy as part of their poststroke care.

• Less than fifteen percent claimed not to have received physical, occupational, or speech therapy after their stroke.

Whether Received Physical, Occupational Or Speech Therapy After Stroke





Physical and occupational therapy were the primary therapies received by those involved in post-stroke therapy.

- The vast majority of stroke survivors who received some type of therapy were given physical therapy (93 percent), while eight out of ten needed occupational therapy.
- In addition, two thirds of those who suffered a stroke and received some type of therapy received speech therapy.

Types Of Therapy Received





Post-stroke physical therapy lasted an average of 29 weeks, significantly longer than either occupation therapy or speech therapy.

- Those who received physical therapy tended to remain with it an average of 29.3 weeks.
- By comparison, occupational therapy tended to last 21.5 weeks and speech therapy 19.9 weeks.
- Five to six out of ten stoke survivors received the different types of therapy for just eight weeks or less.

Number Of Weeks Received Therapy



Q.2d For approximately how many weeks did you receive (INSERT THERAPY)?



The top three goals of post-stroke therapy were to improve their ability to walk, improve their speech, and/or get better use of their arm or hand.

- Two out of three stroke survivors who received some form of therapy were looking to improve movement, mainly their ability to walk (44 percent). In addition they also hoped to get better use of their arm (15 percent) or hand (15 percent).
- One out of four were also looking to improve their speech.

Top Three Most Important Things Wanted Or Hoped To Achieve/Recover After Therapies

Total Received Therapy	<u>Total</u> (438) %
Movement (net)	<u>64</u>
Walking (subnet)	<u>44</u>
Ability to walk without assistance/on my own	3
Be able to walk without cane	3
Ability to walk/walk better (unspecified)	34
Miscellaneous Movement Mentions	
Be able to use my left/right side/left/right side was paralyzed/get movement in left/right	
side	3
Better use of left/right arm/get back use of left/right arm/use of arm/get arm	
working/movement in arm back	15
Better use of left/right hand/get back use of left/right hand/use of hand/get hand	
working/movement in hand back	15
Balance/get balance back/good balance	8
Restore abilities to use legs/use of legs	5
Be mobile/able to move/improve mobility/get back on feet (unspecified)	3
Speech (net)	<u>25</u>
Ability to talk/speak/talk better/better speech/get back speech (unspecified)	22
Cognitive Abilities (net)	<u>10</u>
Get my memory back/improve memory	4
Independence (net)	<u>13</u>
Activities (net)	<u>21</u>
Ability to drive/driving	15
Miscellaneous Mentions	
All that I had before/100% function I was at before/back to the way I was/my life back	6
Back to normal/be back to normal/self/life	8
Be able to work/get back to my job	11
Want to write better/write/ability to write	6

Q.3a To you, what are/were the three most important things that you wanted or hoped to achieve/ recover after therapies?



By far the most important rehabilitation goal of post-stroke therapy was to be able to walk better.

- Twenty one percent of the stroke survivors who received some form of therapy indicated that their most important goal was to be able to walk/walk better.
- All other specific goals were mentioned by fewer than 10 percent of those receiving therapy -- improving their speech (9 percent), better use of their arm (6 percent) or hand (5 percent), get back to normal (7 percent)/the way I was before (5 percent), and to be able to work (4 percent) or drive (4 percent).

Most Important Rehabilitation Goal

Total Received Therapy	<u>Total</u> (438) %
Movement (net) Walking (subnet)	<u>42</u> 26
Ability to walk/walk better (unspecified)	21
Miscellaneous Movement Mentions	
Better use of left/right arm/get back use of left/right arm/use of arm/get arm	
working/movement in arm back	6
Better use of left/right hand/get back use of left/right hand/use of hand/get hand	_
working/movement in hand back	5
Speech (net)	<u>11</u>
Ability to talk/speak/talk better/better speech/get back speech (unspecified)	9
Cognitive Abilities (net)	<u>4</u>
Independence (net)	<u>6</u>
Be independent/independence (unspecified)	3
Activities (net)	<u>8</u>
Ability to drive/driving	4
All that I had before/100% function I was at before/back to the way I was/my life back	5
Back to normal/be back to normal/self/life	7
Be able to work/get back to my job	4
Better vision/good eyesight/get vision restored	2
Want to get better/get well/recover/recuperate	2

Q.3b And of these three, what was your most important rehabilitation goal?



The majority of stroke survivors felt they were at least somewhat successful in meeting their rehabilitation goals.

- Ninety percent of stroke survivors who received some form of therapy felt they were at least somewhat successful in meeting their own rehabilitation goals.
- More than half felt they were extremely or very successful.
- Only ten percent felt they were not successful in meeting their goals.

Success Rating For Meeting Rehabilitation Goals





Q.4a Overall, how successful would you say you were in meeting your rehabilitation goals? Would you say you were...

Not seeing progress and lacking the funding to continue with therapy were the primary reasons stroke survivors considered themselves not very successful in meeting their rehabilitation goals.

- One third of the stroke survivors who received therapy but felt they were somewhat or not successful in meeting their own rehabilitation goals mentioned a lack of progress as the reason for not meeting their goals.
- One third also mentioned that they could not continue the therapy because of cost related issues and this is why they had not met their goals (18 percent that their insurance ran out and 14 percent that they did not have the money to continue).
- Experiencing other health problems (15 percent) and spasticity or tight-stiff muscles (12 percent) were the other main reasons given by respondents who did not feel they had been extremely or very successful in meeting their therapy goals.

Reasons Therapy Was Less Than Very Successful





Q.4b Why do you say that you were (Insert Answer)?

More than half of the stoke survivors who received some form of therapy attributed a lot or almost all of their recovery to the medical professionals that treated them during their rehabilitation.

- Twenty seven percent attributed almost all of their recovery to their doctors while an additional 29% said a lot of their recovery was due to the doctors.
- Approximately one fourth thought that half of their recovery was due to the medical professionals that helped them after their stroke.
- Two out of ten only felt that only some or little/none of it was due to the help received from their medical professionals.

Amount Of Recovery Attributed To Medical Professionals That Treated During Rehabilitation



Q.4c Using the following scale, how much of your recovery from stroke do you attribute to the medical professionals that treated you during your rehabilitation?



The majority of those who did not receive some type of post-stroke therapy did not need it.

- Half the stroke survivors who did not receive some type of therapy as part of their care were not prescribed it by their doctor (presumably because they did not need it).
- In addition, 14 percent indicated that they did not need physical, occupation, or speed therapy after they had suffered their stroke.
- Cost was a minor factor in why stroke survivors did not receive therapy, with only 5 percent mentioning that their insurance did not cover it and 2 percent saying they could not afford it.

Reasons Did Not Receive Therapy




Healthcare professionals helped stroke survivors feel optimistic about their ability to recover from their stroke.

- Half the stroke survivors mentioned that whatever their healthcare professionals said to them about their odds of recovery either made all the difference or gave them a lot of hope.
- An additional one fourth felt that their doctors gave them some hope.
- And, approximately one fourth mentioned that their doctors gave them little or no hope that recovery was possible.

Amount Of Hope Given By Healthcare Professionals



■ Made all the difference □ A lot of hope □ Some hope □ A little hope ■ No hope

Q.5 How much hope did your healthcare professionals give you in your ability to recover from your stroke?



Less than half the stroke survivors received orders for home therapy given by a visiting professional such as a PT, OT, or SLP.

Whether Received Orders For Home Therapy



■ Received Orders For Home Therapy □ Did Not Receive Orders For Home Therapy





Q.6a Did you receive orders for home therapy, that is receiving rehabilitation services in one's home from a visiting professional, such as a PT, OT or SLP?

Stroke survivors received home therapy for an average of ten weeks.

• Two thirds of the stroke survivors received home therapy for eight weeks or less, almost equally divided among those who received it for one to four weeks (35 percent) and those who received it for five to eight weeks (30 percent).

Number Of Weeks Expected To Continue Home Therapy



Q.6b For approximately how many weeks were you expected to continue home therapy?



A large proportion of the stroke survivors with orders for home therapy were able to maintain their recommended schedule.

Whether Able To Maintain Recommended Home Therapy Schedule



Unable To Maintain Recommended Home Therapy Schedule
 Able To Maintain Recommended Home Therapy Schedule

Total Received Orders For Home Therapy (n=219)

Q.6c Were you able to maintain this recommended home therapy schedule?



The majority of stroke survivors felt they were at least somewhat successful in meeting their home therapy goals.

- Eighty nine percent of stroke survivors who received some form of home therapy felt they were at least somewhat successful in meeting their home therapy goals.
- More than half felt they were extremely or very successful.
- Only eleven percent felt they were not successful in meeting their goals.

Success Rating For Meeting Home Therapy Goals



Extremely Successful
 Very Successful
 Somewhat Successful
 Not Very Successful
 Not At All Successful

Q.6e Overall, how successful would you say you were in meeting your home therapy goals?



Three out of five stroke survivors have experienced spasticity since their stroke.

57% of respondents (58% of stroke survivors) indicated they have experienced spasticity.

Whether Experienced Tight-Stiff Muscles/"Spasticity" Since Stroke

■ Experienced Tight-Stiff Muscles □ Have Not Experienced Tight-Stiff Muscles





Q.7a Since your stroke, have you experienced tight-stiff muscles, which may have been referred to as "spasticity"?

Half the stroke survivors experiencing spasticity have received treatment for the condition; mainly range of motion exercises, gentle stretching and oral medications.

- Six out of ten adults who received treatment for their tight-stiff muscles were treated using range of motion exercises.
- Approximately half of them were also treated using gentle stretching or given oral medications.
- Injections of Botox were given to one-third of these patients.
- Surgery (7 percent) and ITB Therapy (3 percent) were not used very often to treat spasticity.

Treatments Received For Tight-Stiff Muscles



Q.7b Have you received treatment for this?

Q.7c Which, if any, of the following treatments have you received?



Coping with physical loss and not being able to do things for themselves were the most challenging aspects of having survived their stroke.

- Twenty two percent of stroke survivors mentioned that coping with physical loss has been the biggest challenge for them.
- Going places/getting around (13 percent), not being able to communicate as well (11 percent), and not being able to take care of themselves by bathing, dressing, or grooming (10 percent) were mentioned next most frequently as challenges faced by these survivors.
- Also mentioned as major challenges were coping with changes in their ability to think and remember (9 percent) and not being able to drive (9 percent).

Most Challenging Circumstances As A Stroke Survivor (table only shows items mentioned at a 3% level or higher)

Total Respondents	<u>Total</u> (504) %
Coping with physical loss	22
Going places/getting around	13
Not being able to communicate as well	11
Self-Care Tasks (bathing, dressing, grooming, etc.)	10
Coping with changes in my ability to think and remember	9
Not being able to drive	9
Loss/change in job	5
Walking	4
Loss of income	4
Changing to a healthier lifestyle	4
Being able to do things myself	3



Working and driving are the two most important things stroke survivors wish they could do, followed closely by participating in daily activities, walking, and hobbies.

- Working (17 percent) and driving (16 percent) are mentioned most frequently when asked what is the most important thing that they would like to do, but cannot now because of their stroke.
- Mentioned next most frequently were participation in daily activities or tasks (14 percent), walking (13 percent) and hobbies or leisure activities (13 percent).
- Seven percent of these survivors said they could do everything/they have no limitations.

Most Important Thing Would Like To Do But Cannot Due To Stroke



Q.9 Which of the following is the most important thing that you would like to do, but cannot now because of your stroke?



A large percentage of the stroke survivors involved in physical, occupational, or speech therapy believe it has helped or will help them achieve the thing they most want to do, but can't because of their stroke.

- Two thirds of stroke survivors who have participated in rehabilitation therapy believe it
 will help them accomplish their most important goal (i.e. working, driving, being able
 to do their daily activities/tasks, walking, or being involved with hobbies/leisure
 activities).
- One fourth are not optimistic that it will help.

Whether Therapy Helped Or Will Help In Accomplishing Most Important Thing Would Like To Do But Cannot Due To Stroke

Don't Know

□ Therapy Has Not Helped/Will Not Help In Accomplishing Goal



■ Therapy Has Helped/Will Help In Accomplishing Goal

Total Received Therapy (n=438)

Q.10 Do you feel that your therapy goals helped or will help you in accomplishing this goal?



Walking presents the greatest daily challenge. Other activities that have become major challenges and which limit their independence are dressing, bathing, cleaning their home, and preparing meals.

- Nearly one fourth of stroke survivors indicated that walking has become the most challenging activity of their daily lives.
- They also find it challenging to dress themselves (13 percent), bathe (12 percent), clean the house (12 percent), and prepare meals (11 percent).
- Other issues mentioned as problematic (and which also impede on their independence) are grooming (7 percent), toileting (6 percent), shopping (5 percent), eating (4 percent), and doing laundry (4 percent).

Daily Activities Find Most Challenging

(table only shows items mentioned at a 3% level or higher)

	<u>Total</u>
Total Respondents	(504)
	%
Walking	23
Dressing	13
Bathing	12
Cleaning the house	12
Preparing meals	11
Moving around	9
Writing	8
Grooming	7
Toileting	6
Shopping	5
Eating	4
Doing laundry	4
Taking medicine	3

Q.11a What activities of daily living do you find to be most challenging?



Stroke survivors are most likely to need assistance with taking medication, tending to their hygiene needs, and household maintenance.

- On average stroke survivors need help in talking their medication and attending to their toileting needs more than half of the time.
- Approximately half of the time they need help with bathing, dressing, laundry, shopping.
- They are least likely to receive assistance with eating, requiring help on average one fourth of the time.

Mean Percentage Of Time Need Assistance With Activity

	Total
Total Find Activity Challenging	%
	(14)
Taking medicine	53.6
	(32)
Toileting	53.1
	(58)
Bathing	51.5
	(18)
Doing laundry	50.8
	(23)
Shopping	50.8
	(65)
Dressing	49.9
	(57)
Preparing meals	47.9
	(58)
Cleaning the house	45.4
	(37)
Grooming	39.1
	(38)
Writing	35.3
	(116)
Walking	33.3
	(43)
Moving around	31.4
	(20)
Eating	26.5

Q.11b What percentage of the time do you need assistance for (Insert activity)?



There was tremendous interest in a program that would coordinate friends, family, colleagues, neighbors and others who expressed interest in helping support stroke survivors during their rehabilitation and recovery.

- The vast majority of stroke survivors would have accepted help from a program that would have coordinated receiving help from others for such things as bringing meals, helping with household chores, helping with yard work, running errands, filling out forms, etc.
- Only one in ten would not have accepted help from this type of group.

Whether Would Have Accepted Help From Rehabilitation/Recovery Support Group



Q.12a If a program had been available for you and your family caregiver to coordinate friends, family, colleagues, neighbors and others who expressed an interest in helping support you during your rehabilitation and recovery, would you have accepted the help?



Those who would have accepted help from a program to coordinate support from family and friends believe it would be an extremely helpful program.

- Eight out of ten stroke survivors who expressed interest in the support services coordination program think it would have been extremely or very helpful to them during their rehabilitation and recovery period.
- An additional sixteen percent thought a program of this type would have been at least somewhat helpful to them.

Program Helpfulness Rating



Q.12b How helpful would it have been for you and your family caregiver to have had a program available to coordinate friends, family, colleagues, neighbors and others who expressed an interest in helping support you during your rehabilitation and recovery?



Those who would have not have accepted help from a program to coordinate support services either have family members who are helpful or else they are independent and prefer to help themselves.

- One third of the stroke survivors who would not have been interested in the support services coordination program mentioned that they already have family members who help them, primarily their husband (10 percent) or wife (10 percent). They also said that their family helped (10 percent).
- One quarter of them said that they are independent and prefer to do things on their own.
- An additional twenty percent didn't feel they needed a program of this type.

Reasons Would Not Have Accepted Help

	Total
Total Would Not Have Accepted Help	(60)
	%
Family Members Helped (net)	<u>35</u>
My husband helped	10
My wife helped	10
Family helped/family support (unspecified)	10
Kids helped/son	3
Sister helped	2
All other family members mentions	3
Miscellaneous Mentions	
Prefer to do it myself/independent/think I should be able to do things on my own	25
Didn't need it	20
Friends helped	7
Never accepted help	2
All other miscellaneous mentions	17
Nothing/Don't Know/No Answer	5



Magazine articles are the primary source for learning about new treatments.

- Half of the stroke survivors indicated that they learn about new treatments that are available from magazine articles.
- Nearly one quarter mentioned that they get new information from the Internet.
- Physicians, newspaper articles, support groups, and television were the next most frequently mentioned sources for new information (between 11 and 16 percent mentioning each of these sources).

Means By Which Generally Hear Or Learn About New Treatments That Are Available

	<u>Total</u>
Total Respondents	(504)
	%
Magazine articles	52
Internet	23
Physicians	16
Newspaper articles	13
Support group	11
Television programming	11
Therapists	6
Family members	5
Friends	4
Hospital	3
Advertising	1
All Other Mentions	9
Don't Know	6



Two out of five stroke survivors feel they do not have enough information about stroke rehabilitation and recovery.

- 38% of respondents indicated they lack information.
- Three out of five respondents (62%) believe they have enough information.

Whether Have Enough Information About Stroke Rehabilitation & Recovery

■ Have Enough Information □ Lack Information



Q.D6 Finally, do you feel you have all the information you need about stroke rehabilitation and recovery?



Demographics		
Total Respondents	<u>Total</u> (504) %	
<u>Gender</u> Male	42	
Female	58	
<u>Age</u> 30 – 34 35 – 39	2 3	
40 - 44	5	
45 - 49	8	
50 - 54 55 - 59	13	
60 - 64	12	
65 - 69	12	
70 – 74	14	
75 – 79	10	
80 - 85	5	
85 or older	1	
Mean	61.1	
Employment Status		
Do Not Work (total)	<u>84</u>	
Retired	59	
Unemployed	12	
Homemaker	9	
Volunteer	3	
	1	
Work Full-/Part-Time (net)	<u>16</u>	
Work full-time (more than 30 hours per week)	11	
work part-time (so hours of less per week)	8	
<u>Ethnicity</u>		
Caucasian	85	
African-American	9	
Hispanic Nativo American	2	
Refused	3	
Trofused	5	
Whether Have Internet Access		
Have Internet Access (net)	<u>76</u>	
At home only	61	
At home and work	10	
At work only	1	
At the library	2	
Do not have access to the Internet	2	
	<u> </u>	
Type Of Community Reside In		
Urban	29	
Suburban	46	
Kurai	25	



Clinicians



Neurologists and Physiatrists see significantly more stroke patients than primary care physicians and occupational or physical therapists.

- Overall, the doctors included in this study see an average of 84 stroke patients per year.
- Neurologists see an average of 169 stroke patients each year, significantly more than the other three classifications of clinicians.
- The Physiatrists see significantly more stroke patients than do the primary care physicians and the therapists (87 compared to 48/50 respectively).

Number Of Stroke Patients See Per Year



^{*} Caution, small base size.

Q.1a In an average 12 month time period, how many stroke patients you see?



Stroke patients represent nearly half of a Neurologist's total patient load.

- On average, approximately one fourth of the patients seen by the doctors included in this study are stroke patients.
- By comparison they make up nearly one half of the Neurologists' practices, significantly higher than for any of the other clinician types.
- One third of the patients being rehabilitated by occupational or Physical Therapists are stroke patients.
- Only seven percent of a Primary Care Physician's practice are stroke patients, significantly less than the other medical professionals.

Percentage Of Complete Patient Base That Are Stroke Patents



^{*} Caution, small base size.

Q.1b And what percentage of your complete patient base are stroke patients?



Occupational and physical therapists work with stroke victims significantly more often on an in-patient basis.

• Occupational and physical therapists work with six out of ten of their stroke patients on an in-patient basis.

Share Of In-Patient/Out-Patient Stroke Patients



Q.2 What percentage of your stroke patients are in-patient versus out-patient?



While PCP's deal with all issues related to stroke, Neurologists and Physiatrists are more likely to address specific concerns related to language, vision, movement, and spasticity.

- The majority of Primary Care Physicians address all of a stoke patient's general concerns, ranging from risk factors (97 percent) to depression (90 percent), cognitive issues (84 percent), speech problems (77percent), movement disorders (77 percent), and language (65 percent). Less than half of them deal with vision problems.
- Neurologists, on the other hand, are significantly more likely to be dealing with language and vision problems than are the PCPs. They are also somewhat more likely to be addressing speech problems.
- The Physiatrists are the most likely of the three types of doctors to be dealing with language, movement, and spasticity issues and the least likely to be addressing the risk factors.



Stroke-Related Issues Address

* Caution, small base size.

Q.3 What types of stroke-related issues do you address?



Virtually all Primary Care Physicians claim to talk to their patients about stroke prevention.

• Only four percent say that they do not typically talk about stroke prevention before a patients has had a stroke.

Whether Typically Talk About Stroke Prevention Before A Stroke





Giving stroke survivors back their independence and helping them improve their movement and mobility are the primary goals of the doctors and therapists who treat them.

- At least one third of the doctors and 45 percent of the therapists consider regaining some measure of independence to be the most important rehabilitation goal for their stroke patients.
- Helping patients improve their mobility and motor skills is of utmost importance to the therapists, with more than half of them saying this is the most important treatment goal for their stroke patients.
 - The doctors don't put quite as much importance in improving patient's movement skills, with only two out of ten considering this a primary goal for their patients.
- Between twenty and twenty five percent of the clinicians who treat stroke patients believe that it is important to help them regain their ability to function daily and be able to participate in activities related to daily living.
- The doctors, much more so than the therapists, believe it is important to help their patients improve their speech (17-20 percent v. 3 percent of the therapists).
- Related to independence, the Physiatrists and therapists see safety and being well enough to go home as important goals for their patients (10-15 percent v. 4-6 percent of the PCPs and Neurologists).

(Table follows on next page)



Most Important Rehab Treatment Goals For Stroke Patients

(table only shows items mentioned at a 3% level or higher)

Total Respondents	<u>Total</u> (319) %	<u>PCP</u> (100) %	<u>Neurologist</u> (83) %	<u>Physiatrist</u> (20)* %	Occ./Phys <u>.</u> <u>Therapist</u> (116) %
Independence (net) Be independent/independence/independent living Functional independence Be able to take care of themselves Independence going to the bathroom	<u>39</u> 23 7 5 4	<u>36</u> 24 3 5 1	<u>36</u> 25 10 1	<u>30</u> 25 5 5	<u>45</u> 21 10 9 10
Movement (net) Be mobile/able to move/improve mobility/get back on feet Walking (subnet) Regain motor skills/motor recovery/regain motor function Functional mobility Better use of arm/get back use of arm/movement in arm back Independent mobility Getting out of bed/bed mobility	31 7 4 4 3 3 3	<u>19</u> 11 4 2 - 1 -	<u>18</u> 5 1 7 1 2 1 -	25 10 5 5 - - 5	53 4 6 2 10 7 9 7
Activities (net) Activities of daily living/improve/regain/do as much as possible	<u>28</u> 23	<u>29</u> 23	<u>30</u> 24	<u>25</u> 20	<u>27</u> 22
Able to function daily/function/functionality	20	20	22	25	17
Speech (net) Ability to talk/speak/talk better/better speech/get back speech Communication/communicate better	<u>13</u> 6 4	<u>20</u> 14 3	<u>17</u> 2 6	<u>20</u> 5 10	<u>3</u> - 3
Safety All that they had before/back to the way they were/their life back Ambulation Be well enough to go home/allow them to live at home Transfers/ability to transfer/improve transfer Not have another stroke/prevention of reoccurrence Regain cognitive abilities/impaired cognitive abilities	9 6 6 5 4 4	4 12 5 4 - 7 6	6 5 2 4 - 2 5	10 - 5 15 - 5 5	15 2 9 10 16 2 3
Be less depressed/get rid of depression Community access/support Improve gait/gait Be able to eat/learn to eat Swallow/being able to swallow	4 4 4 3 3	4 1 1 4 5	3 7 2 4 - 1	5 - 5 - - 5	2 7 9 4 2
Independence with ambulation Patient education	3 3	- 1	4 1	5 -	4 6

* Caution, small base size.

Q.5 In your opinion, what are the most important rehab treatment goals for stroke patients?



The doctors and therapists also believe that their stroke patients consider getting back their independence and improving their movement and mobility to be the primary goals of their rehabilitation.

- Between one quarter and one third of the clinicians think that their patients view gaining independence as one of their most important rehabilitation goals.
- The therapists and Physiatrists think their patients view the ability to improve their movements (mainly walking) as their most important goal, much more so than do the PCPs and Neurologists (59 and 25 percent vs. 6-8 percent respectively).

Most Important Rehab Treatment Goals To Stroke Patients

Total Respondents	<u>Total</u> (319) %	<u>PCP</u> (100) %	<u>Neurologist</u> (83) %	Physiatrist (20)* %	Occ./Phys <u>.</u> <u>Therapist</u> (116) %
Independence (net)	28	30	<u>33</u>	<u>15</u>	25
Be independent/independence/independent living (unspecified)	19	25	24	10	12
Be able to take care of themselves	4	-	2	-	9
Functional independence	3	2	6	5	1
<u>Movement (net)</u>	<u>26</u>	<u>8</u>	<u>6</u>	<u>25</u>	<u>59</u>
Walking (subnet)	14	3	-	5	37
Be mobile/able to move/improve mobility/get back on feet	3	1	1	10	5
Activities (net)	<u>14</u>	<u>11</u>	<u>18</u>	<u>30</u>	<u>10</u>
Activities of daily living/improve/regain/do as much as possible	11	10	16	20	5
Able to function daily/function/functionality All that they had before/back to the way they were/their life back Be well enough to go home/allow them to live at home Back to normal/be back to normal/self/life Speech (net) Ambulation Fulfill patient's quality of life goals/improve quality of life	10 8 5 5 3 3	12 11 4 5 2 - 5	13 5 4 6 5 4	10 5 15 - 15 5 -	5 8 7 6 5 4 1
Don't know/no answer	13	14	16	5	10

* Caution, small base size.

Q.6 And what do you perceive to be the most important rehab treatment goal to stroke patients?



The majority of Physiatrists and Neurologists have stroke patients who ask for specific spasticity treatments.

- Virtually all of the Physiatrists (note that there are only 20 included in this study) have had stroke patients ask them for specific spasticity treatments.
- Six out of ten Neurologists have had specific spasticity treatments requested of them.
- By comparison, between thirty and forty percent of the other two groups of medical professionals have had similar requests made of them.

Whether Stroke Patients Request Certain Spasticity Treatments



^{*} Caution, small base size.

Q.7a Do you have stroke patients requesting certain spasticity treatments from you?



Oral medications and injections of Botoxolton are the primary spasticity treatments requested by patients.

- PCPs are asked primarily for oral medications by their patients suffering with spasticity.
- Both oral medications and Botoxolton are requested by the majority of patients seeing Neurologists.
- Physiatrists and occupational/physical therapists are asked for a much wider range of specific treatments, with Botoxolton being requested most frequently.
- ITB therapy is requested most often of the Physiatrists, with one in four of their patients requesting it.



Base = *Total who have had patients request specific spasticity treatments from them* * *Caution, small base size.*

Q.7b Which spasticity treatments do stroke patients request from you?



Regardless of a spasticity patient's request, the majority of clinicians will recommend range of motion and gentle stretching exercises to their patients. The doctors will also recommend oral medications. Splinting or casting is highly recommended by the Physiatrists and therapists. Surgery is recommended in about one quarter of the cases.

- Between eighty and ninety percent of the doctors and therapists recommend range of motion and gentle stretching to help their stoke patients who are experiencing spasticity. At least eighty percent of the MD's will also recommend oral medications.
- Splinting or casting is a major recommendation of the Physiatrists (80 percent) and therapists (73 percent).
- MYOBLOCK is highly recommended by both Neurologists (65 percent) and Physiatrists (85 percent). Nearly half of the Physiatrists will recommend ITB therapy (45 percent).





^{*} Caution, small base size.



Q.10 What spasticity treatment/therapy regimens do you typically/commonly recommend for stroke patients?

PCPs will refer spasticity treatments to a specialist more often than the other two types of doctors.

Physiatrists are the most likely of the three types of doctors to work directly with their
patients with stretching and range of motion exercises, as well as to provide them with
MYOBLOCK and splinting or casting.

Therapy Regimens Typically/Commonly Refer To A Specialist



* Caution, small base size.

Q.11 What therapy regimens do you typically/commonly refer to a specialist?



Half of the clinicians wished there was more they could do to address the specific therapies used to help their stroke patients with spasticity.

- One third of the PCPs and Neurologists would be interested in giving injections of Botoxolton.
- Physiatrists were most interested in learning more about ITB therapy (25 percent).
- Overall, 17 percent of clinicians were interested in learning more about ITB therapy.
- Therapists wanted to be better able to address splinting and casting therapies.



Clinical Issues Wish Could Do More To Address



Q.13 Are there any clinical issues listed below that you wish you could do more to address?

While the majority of professionals treating stroke patients claim to have the resources needed to treat or direct their rehabilitation, the PCPs are the least likely to have these funds available.

- Over ninety percent of the Physiatrists and occupational/physical therapists claim to have the funds needed to appropriately direct the care of their stroke patients.
- By comparison, one fourth of the PCPs and one fifth of the Neurologists claim not to have the necessary funds.

Whether Have Resources To Treat/Direct Rehab Treatment/Therapy For Patients



^{*} Caution, small base size.



Q.8 Do you feel you have the resources to treat and/or direct rehab treatment/therapy for your patients?

PCPs and Neurologists primarily write orders and get reports for their stroke patients' rehabilitation. The Physiatrists both provide direct treatment and meet with therapists involved in the rehab, while the occupational and physical therapists primarily provide the treatments.

- The majority of PCPs write orders and get reports related to their stroke patients' rehabilitation. 17 percent also claim to meet with their patient's therapists.
- Two thirds of the Neurologists write orders and get reports. Three in ten will meet with their patients' therapists.
- More than one third of the Physiatrists either provide direct treatment to their patients or else meet with the therapists that do. One fourth of them also write orders and get reports.
- The vast majority of physical and occupational therapists provide direct services to their patients. A small percentage will also meet with other therapists providing care.



Involvement With Patients' Rehabilitation

Q.9 How involved are you with your patients' rehabilitation?



^{*} Caution, small base size.

According to physical and occupational therapists the most common barriers to accomplishing therapy goals are lack of progress, other health problems, depression, and spasticity.

- Seven out of ten therapists mentioned that a patient's lack of progress or other health problems they may have are the major reasons why stroke survivors do not accomplish their rehabilitation goals.
- Six out of ten also mentioned that their patients experienced depression or spasticity and that became a barrier to their success.
- Money related issues were also a problem (53 percent mentioned that their patient's insurance ran out and 28% that their patient did not have money to continue with therapy).

Barriers That Typically Get In The Way Of A Stroke Survivor Accomplishing Their Therapy Goals



Q.12 What barriers do you typically see get in the way of a stroke survivor accomplishing their therapy goals?



Very few PCPs and Neurologists have received specific training in rehab stroke care/therapy.

- All the Physiatrists and the majority of therapists have received specialized stroke rehabilitation training.
- Approximately one quarter of the Neurologists have received stroke care training.
- Only one in ten of the PCPs have received this training.

Whether Received Specific Training In Rehab Stroke Care/Therapy



^{*} Caution, small base size.

Q.14 Have you received specific training in rehab stroke care/therapy?


Doctor/Patient Information Occ./Phys. PCP Total Neurologist Physiatrist Therapist А В С D Е **Total Respondents** (319)(100)(83)(20*) (116)% % % % % Years in Practice 10 3 or less 8 7 7 5 11 4-5 10 10 14 -6-7 15 9 13 11 11 8-9 9 8 10 12 10 10-11 10 12 11 10 8 12-14 6 8 13 9 10 15-17 12 13 11 10 12 16 E 18-20 10 9 10 7 15 E 9 E 21-24 6 5 2 25 or more 13 11 15 11 16 15.0 E 13.3 16.1 12.2 Mean 13.7 Patients' Conditions 100 CE 98 CE Chronic Pain 76 54 67 70 80 E 81 C Parkinson's 74 74 67 100 CDE Headache 68 75 E 28 79 DE 73 DE Epilepsy 56 15 27 Stroke 100 100 100 100 100 Average Age Of Stroke Patients 18 – 29 0 1 --5 BC 30 - 392 1 _ _ 40 - 49 1 1 2 1 50 - 59 11 9 13 15 9 45 60 - 6942 44 35 40 70 – 79 42 43 41 40 42 С 5 2 80 - 842 -4 85 or older 0 1 66.4 67.5 68.3 67.0 67.3 Mean Primary Work Location 59 BE 50 B 42 B Hospital 36 80 CDE 36 E 30 E Private Practice 40 10 BC 18 BC Out patient Rehab 7 -5 С 15 SNF; LTAC (Long Term Acute Care) 6 2 _ Assisted Living facility 2 1 _ _ Community Health Center 3 1 1 -5 BC Inpatient Center 3 1 _ Outpatient 2 12C 1 1 1 All Other Mentions 7 5 4 **Professional Affiliation** 67 E 60 45 C JCAHO-certified stroke center 54 na CARF-certified stroke center 22 11 26 C na None of the Above 30 40 na 28

* Caution, small base size.



	Demographics				
Total Respondents	<u>Total</u> A (319)	<u>PCP</u> B (100)	Neurologist C (83)	<u>Physiatrist</u> D (20*)	Occ./Phys. <u>Therapist</u> E (116)
	%	`% ´	%	`% ´	`% ´
Gender		_			
Male	54	74 E	78 E	65 E	11
Female	46	26	22	35	89BCD
Age					
Under 30	6	-	2	-	17 BCD
30 – 34	13	10	6	10	<u>22</u> BC
35 – 39	22	22	22	20	23
40 – 44	18	17	27 E	25	11
45 – 49	15	15	16	25	14
50 – 54	14	22 E	<u>12</u>	5	9
55 – 59	5	3	11 BE	5	3
60 - 64	3	4 E	4 E	<u>5</u> E	-
65 or older	3	7 CE	-	<u>5</u> C	1
Rather Not Answer	1		1	<u> </u>	1
Mean	42.9	45.9 E	44.3 E	44.8 E	38.4

* Caution, small base size.

