



**United Spinal
Association**

Status of Persons with
Spinal Cord Injury/Disease:
Highlights

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Mission Statement

United Spinal Association is dedicated to enhancing the lives of all individuals with spinal cord injury or disease by ensuring quality health care, promoting research, advocating for civil rights and independence, educating the public about these issues, and enlisting its help to achieve these fundamental goals.

About Us

United Spinal Association was founded in 1946 by veterans with spinal cord injuries, to enable members, as well as others with disabilities, to lead full and productive lives. We participated in drafting the Americans with Disabilities Act and other civil rights laws, and continue to promote their enforcement. Our programs, including advocacy, sports and recreation, medical research, and accessibility services, are supported by your donations.

The purpose of this study is to generate a better understanding of life with a spinal cord injury (SCI), multiple sclerosis (MS) or post-polio syndrome. To this end, findings will be publicly released to generate a platform of discussion regarding issues faced by those with these conditions.

To meet this objective, Russell Research, an independent survey research provider (www.russellresearch.com), conducted interviews with 290 adults who have been diagnosed with one of the three conditions (132 with SCI, 104 with MS, and 54 with post-polio). For those with MS and Post-Polio, additional screening criteria were applied to ensure that these respondents use a wheelchair all the time, most of the time or sometimes. With relatively homogenous groups such as these, the somewhat small samples reported herein are generally acceptable for the purposes of survey research.

In terms of sampling, a multi-mode approach was utilized to maximize the opportunity for respondent participation. After being screened for participation via telephone, potential respondents were offered three possible methods for completing the survey: completing the survey on the telephone at the time of screening, completing the survey via a paper questionnaire sent through the mail, or completing the survey on a secure Web site via a provided link.

The survey was administered on a national basis from April 20 through May 7, 2004. Respondents were screened randomly from lists of telephone numbers where it was reported that there was a household member with one of the conditions. The list of telephone numbers for those with MS was additionally cross-referenced against a list of households where it was indicated that a member had a wheelchair to improve the likelihood of reaching someone who experiences some degree of physical immobility.

The total sample is weighted to reflect the actual proportion of the three subgroups relative to each—in other words, the universe of those with an SCI or a related disability (i.e., those with MS or post-polio who, to some degree, need the use of a wheelchair). For the purposes of this report, in total, the three segments make up the SCI/D universe.

All samples are subject to some degree of sampling “error”—that is, statistical results obtained from a sample can be expected to differ somewhat from results that would be obtained if every member of the target population were interviewed. At a 95 percent confidence level, a margin of sample error of +/- 6.2 percent applies to the total sample. For the three specific subgroups, the margins of sample error are: +/- 9.8 percent for those with SCI, +/- 9.8 percent for those with MS, and +/- 13.3 percent for those with Post-Polio.

The following statistical notations are used throughout the report: □ Indicates figure is significantly higher than the indicated sub-group at a 95 percent confidence level (S = SCI, M = MS, P = post-polio).

Key Findings

The results of this survey indicate that despite significant challenges, persons with spinal cord injuries (SCIs), multiple sclerosis (MS), and Post-Polio Syndrome display strength of character and positive outlooks. Unfortunately, the clear need they have for community support and advocacy is currently unmet either because it is lacking or there is ineffective outreach.

The personal impact of SCI, MS, and post-polio is substantial. Pain, loss of employment and relationships, and severe physical incapacities are very common results of these conditions.

Although respondents consider condition-related organizations valuable sources of information, unaided awareness of SCI, post-polio and, to a lesser degree, MS-related organizations is extremely limited. In addition, the vast majority of those surveyed have never received assistance from a condition-related organization.

The majority of respondents (70 percent) feel that the concept of a United Spinal Association would be extremely or very helpful. Nearly 80 percent of persons with SCI feel that this is the case, and about 60% of respondents with MS or post-polio see a United Spinal Association as an extremely or very helpful resource.

As many as two-thirds of the respondents surveyed had experienced moderate to excruciating pain during the prior seven days. More than four out of ten had experienced severe or excruciating pain.

The majority of respondents (77 percent) agree that the Federal Government should pursue stem cell research. By comparison, however, only 25 percent feel the Federal Government should pursue therapeutic cloning.

In terms of mental health, over half of those surveyed with a SCI have been diagnosed with and treated for depression. Just one-third of post-polio respondents have received mental health counseling.

Employment among respondents dropped from 80 percent prior to disability to only 20 percent at the time of the study. Among those who are no longer employed, at least part of the blame is placed on transportation difficulties (48 percent). Most persons surveyed have made some changes to their residence to make it more accessible, yet persons with spinal cord injuries are less likely to do so.

Despite the impact of their injuries or conditions, many respondents still maintain remarkably positive outlooks on life, have a clear sense of self-worth and tend to feel satisfied with personal relationships and activities. The vast majority of respondents (88 percent) indicate that they can still laugh and see the funny side of things. Roughly three out of four disagree strongly that they are no longer interested in their appearance (76 percent), that their lives are empty (69 percent), that people don't enjoy spending time with them (68 percent) or that they have difficulty communicating with people (67 percent).

Despite their ability to maintain a positive outlook, respondents are realistic about the challenges faced by those with their conditions. Almost nine out of ten agree that people with disabilities can be unfairly discriminated against at times. Six out of ten indicate that it is difficult for people with their condition to raise children. And, nearly half feel they will never be as successful or happy as they were before the injury or onset of the condition.

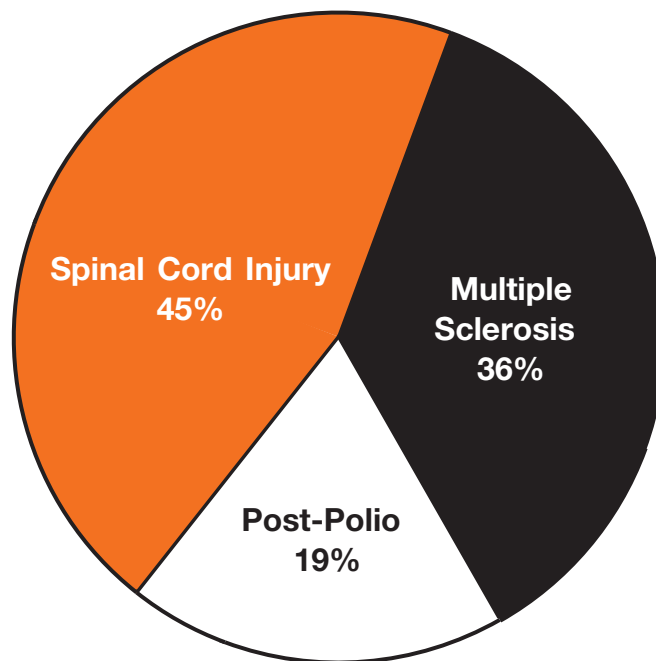
Among those surveyed with a SCI or related disability who are currently in a relationship, the vast majority (86 percent) consider their current relationship with a spouse or partner to be good or excellent. At least half of these respondents participate frequently in activities with that person.

Based on their relative distributions versus each other in the general population, the interviews completed for this study were weighted to the following proportions:

- Forty-five percent have a spinal cord injury (SCI).
- Thirty-six percent have multiple sclerosis (MS) and use a wheelchair at least sometimes.
- Nineteen percent have post-polio and use a wheelchair at least sometimes.

Please note, the total sample is weighted to reflect the actual proportion of the three subgroups relative to each —in other words, the universe of those with SCI or a related disability. For the purposes of this study, related disabilities are defined as those with MS or post-polio who, to some degree, need the use of a wheelchair. In total, the three segments make up the Spinal Cord Injury/Disease (SCI/D) universe.

Conditions (Weighted Distribution)



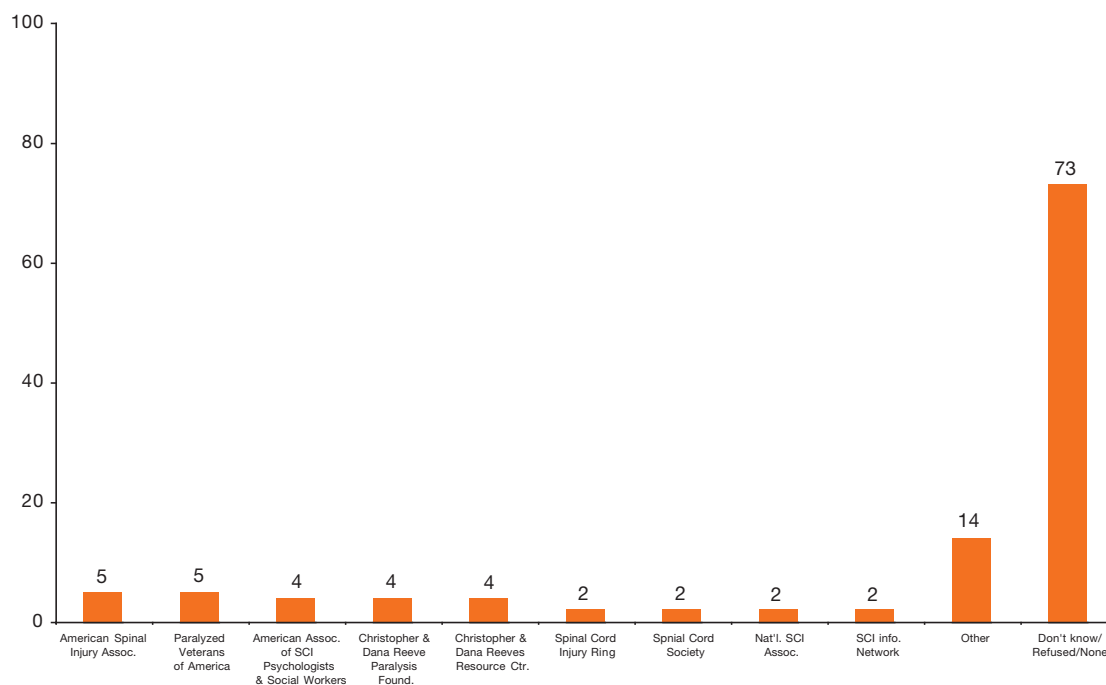
Utilization of Condition-Related Resources

For those with SCI, awareness of resources available to provide help and/or information regarding their condition is appallingly low.

- On an unprompted basis, the majority of respondents (73%) could not name even one organization that focuses on improving the lives of people with SCI.
- Of the many organizations that exist, unaided recall was very limited. The associations with the highest recall were American Spinal Injury Association, Paralyzed Veterans of America, the American Association of SCI Psychologists and Social Workers, and the two organizations sponsored by Christopher and Dana Reeve (all with unprompted recall levels of only 4 to 5 percent).

Unaided Awareness of Spinal Cord-Related Organizations

Base: Total Who Have/Care for Someone with a Spinal Cord Injury (n = 132)



Question: What organizations that focus on improving the lives of people with SCI are you aware of?

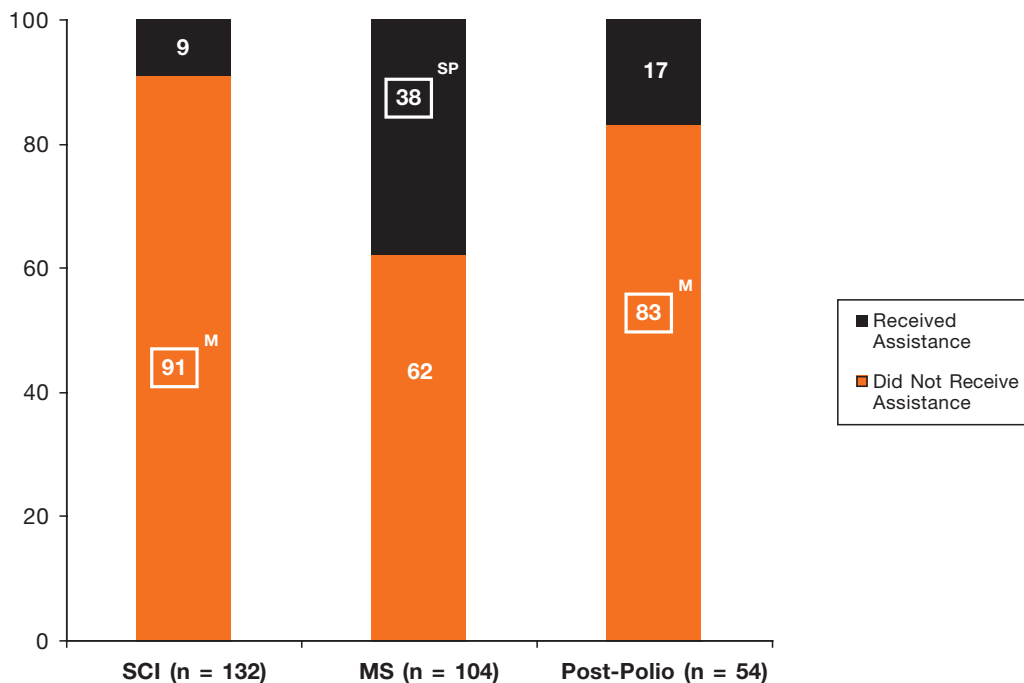
Utilization of Condition-Related Resources

Those surveyed with MS are significantly more likely to have received assistance or services from an organization dedicated to their condition than people with SCI or post-polio.

- Approximately four out of ten people with MS have received some type of assistance from an MS-related organization.
- The large majority of those with post-polio (83%) have not used any services provided by organizations available to help them.
- Very few individuals with SCI (9%) have utilized the services offered by organizations geared towards helping those with their condition.

Whether or Not Have Received Assistance or Services From a Condition-Related Organization

Base: Total Who Have/Care for Someone with Condition



Question: Have you received any assistance or services from a [SCI/MS/post-polio] related organization?

United Spinal Association Concept Evaluation

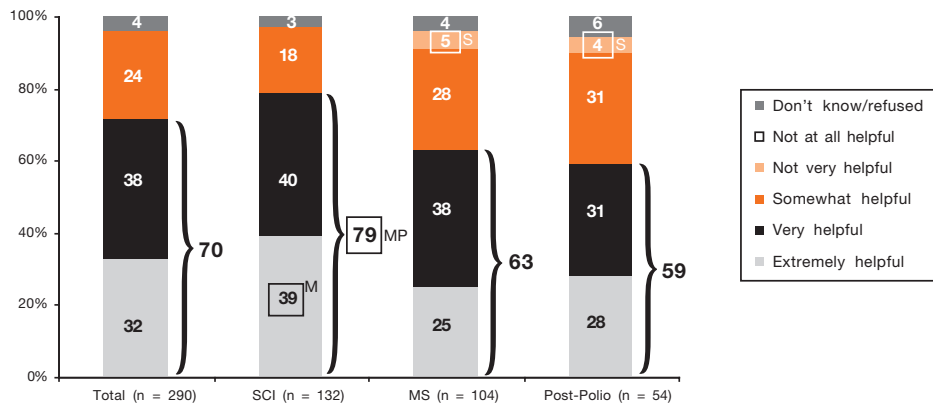
“Arising from our belief in the inalienable right of all individuals to enjoy freedom, United Spinal Association offers programs and services that enable people with spinal cord disabilities to lead richer, more fulfilling lives. We are committed to reaching this fundamental objective by helping to assure quality health care, promoting research, advocating for civil rights and independence, educating the public about these issues and enlisting their help.”

Based on the above description, the large majority of respondents with SCI indicate they think this new organization could help them; only one-third however report they would be interested in becoming a member.

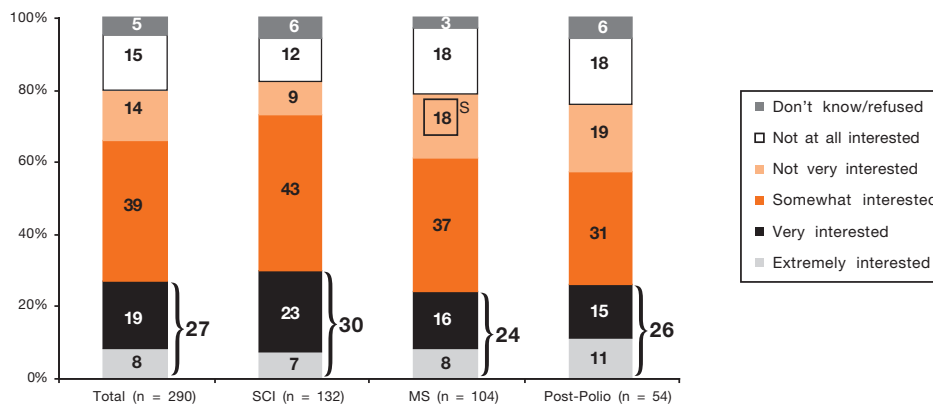
- Seventy-nine percent of those with SCI thought this new organization could help them, significantly higher than those with MS (63%) or post-polio (59%).
- Only two or three out of ten respondents, however, would be interested in membership.

Helpfulness of Organization and Interest in Membership

Base: Total Who Have/Care for Someone with Condition



Question: How helpful do you think this organization would be to someone with [a SCI/MS/post-polio]?



Question: How interested would you be in becoming a member of United Spinal Association?

Joining United Spinal Association is driven by a desire for information.

- Half of those respondents who indicated interest in joining this new organization are looking for information. Specifically, when asked why they were interested, respondents stated they are hoping for information that might help improve their lives (23%) or just be helpful (12%).
- One out of ten (11%) also mentioned the organization could potentially help them help other people.

Reasons for Interest In Membership

	Total	SCI	MS	Post-Polio
Total Extremely/Very Interested in United Spinal Association	(78) %	(39)* %	(25)* %	(14)* %
POSITIVE (GRAND NET)	83	82	84	86
Information Provided (Net)	49	52	36	64
Might help me improve my life	23	25	20	21
Helpful information/might help me	12	11	12	14
Want/need any information I can get	5	3	4	14
Might be informative/educational	3	3	0	7
Want to know new treatments	3	5	0	0
All other information provided mentioned	4	7	0	0
Positive Miscellaneous				
I can help people/want to help other people	11	13	12	0
Need more research on it	4	0	8	7
Have spinal related problems/injuries	3	3	4	0
Like to keep up with people things	2	0	8	0
Would meet my needs	2	0	4	7
All other positive miscellaneous mentioned	8	1	0	4

Question: Why are you interested in joining the United Spinal Association?

* Caution: Small base size.

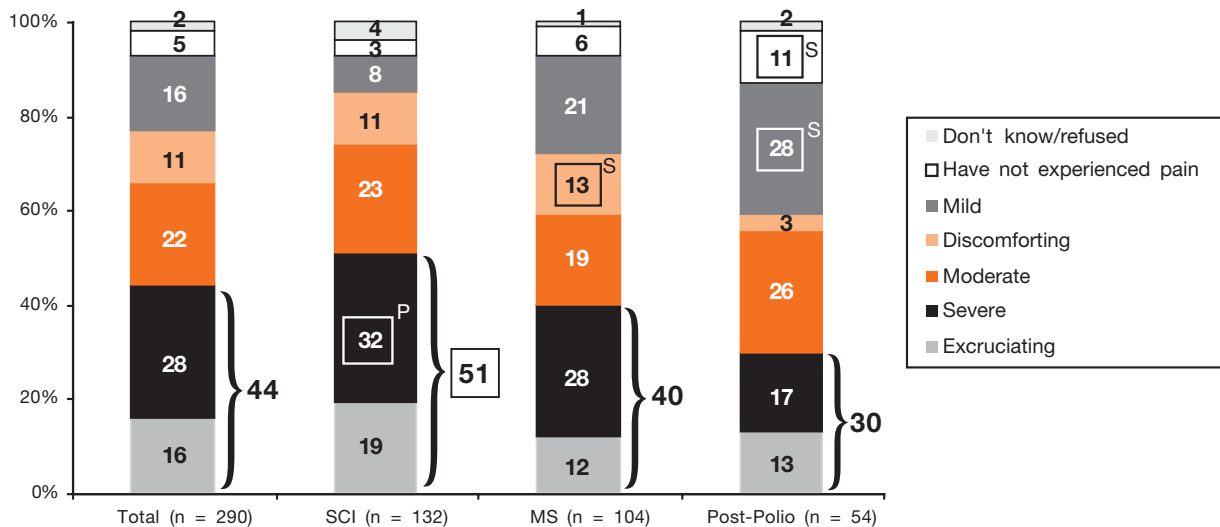
Treatment

More than four out of ten respondents in this study had severe or excruciating pain in the seven days prior to being interviewed.

- Two-thirds of the respondents had at least moderate pain during the past week.
- Respondents with SCI have the most pain, with as many as half indicating that they were in severe or excruciating pain during the week prior to being interviewed.

Severity of Pain Experienced

Base: Total Who Have/Care for Someone with Condition



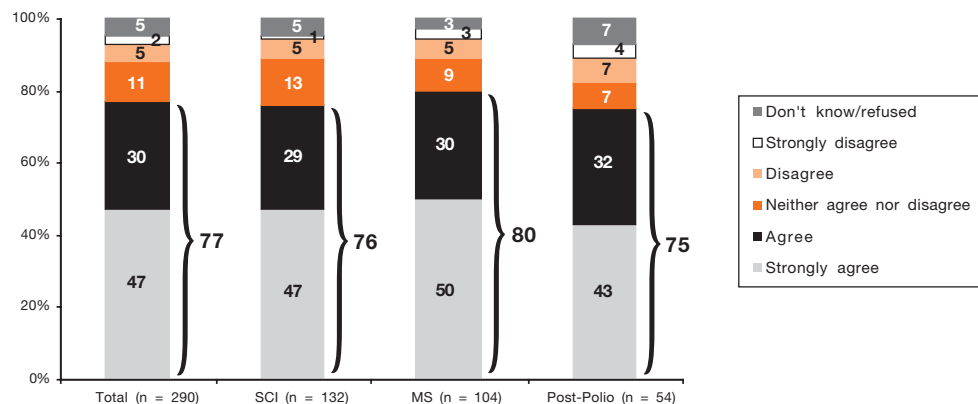
Question: How would you rate the severity of any pain you have experienced during the last seven days?

A large majority of respondents agree that stem cell research is a good idea; this is not true, however, when it comes to therapeutic cloning.

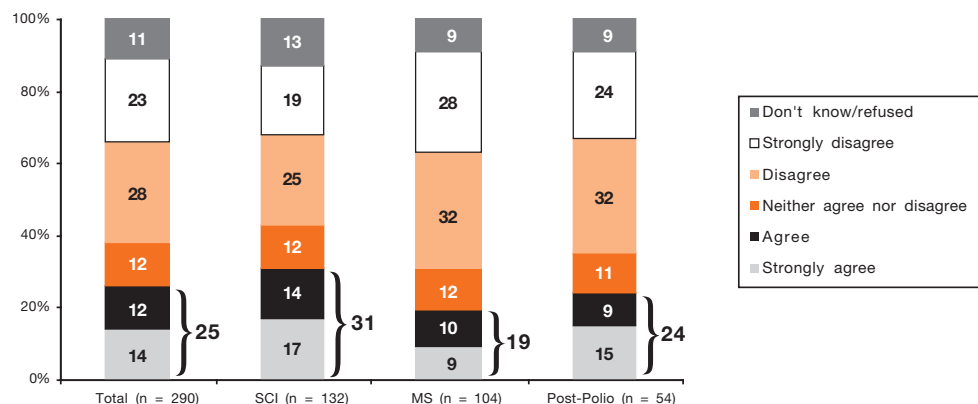
- About eight out of ten respondents agree that the Federal Government should pursue stem cell research.
- Only one quarter of those interviewed feel the Federal Government should pursue therapeutic cloning.

Reaction Toward Stem Cell Research and Therapeutic Cloning

Base: Total Who Have/Care for Someone with Condition



Question: How strongly do you agree or disagree that the Federal Government should pursue stem cell research?



Question: And how strongly do you agree or disagree that the Federal Government should pursue therapeutic cloning?

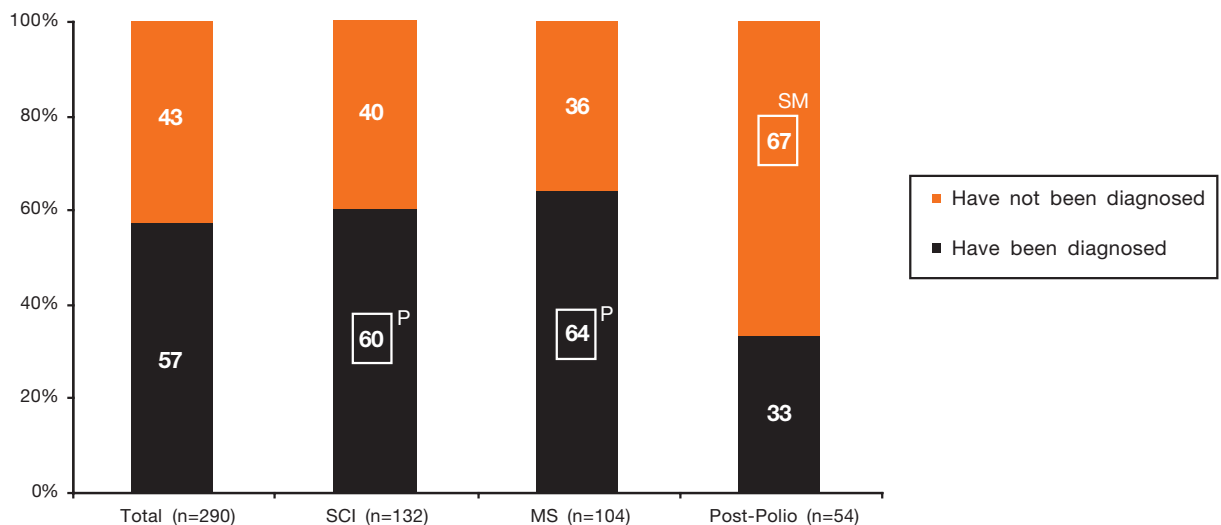
Effect of Condition

Nearly two-thirds of respondents with SCI or MS have been diagnosed with depression.

- Compared to those with post-polio (33%), about twice as many respondents with SCI (60%) or MS (64%) have been diagnosed with depression.

Depression Diagnosis

Base: Total Who Have/Care for Someone with Condition



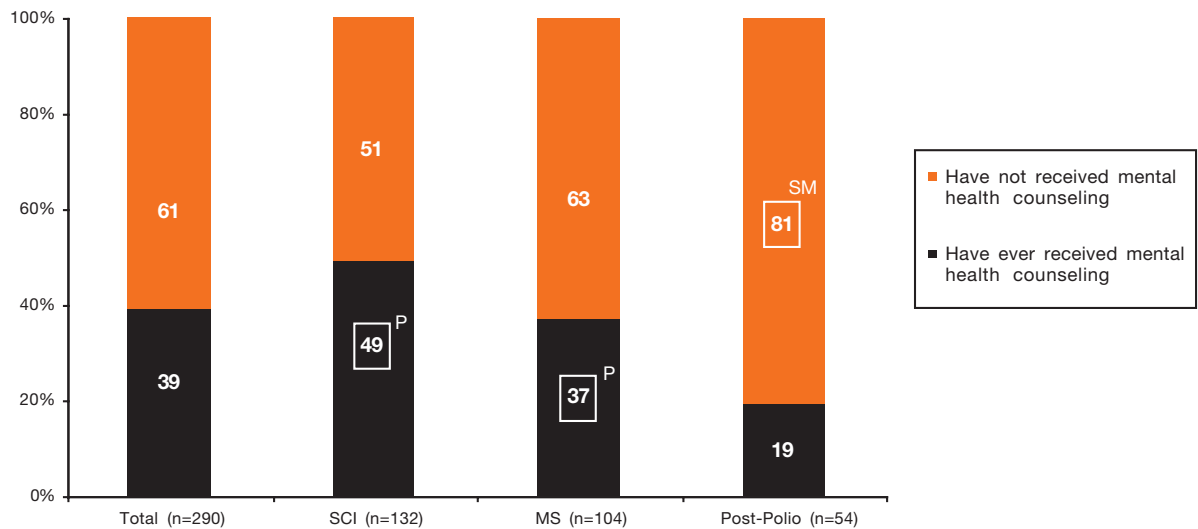
Question: Have you been diagnosed with depression at any time since [your SCI/the onset of your MS/the onset of your post-polio]?

Compared to the proportion diagnosed with depression, fewer respondents have actually received mental health counseling.

- While half of those respondents with SCI (49%) have received mental health counseling, a minority of those with MS (37%) report that they have, while fewer of those with post-polio (19%) indicate this is the case.

Mental Health Counseling

Base: Total Who Have/Care for Someone with Condition



Question: *Have you ever received mental health counseling because of your [SCI/MS/post-polio]?*

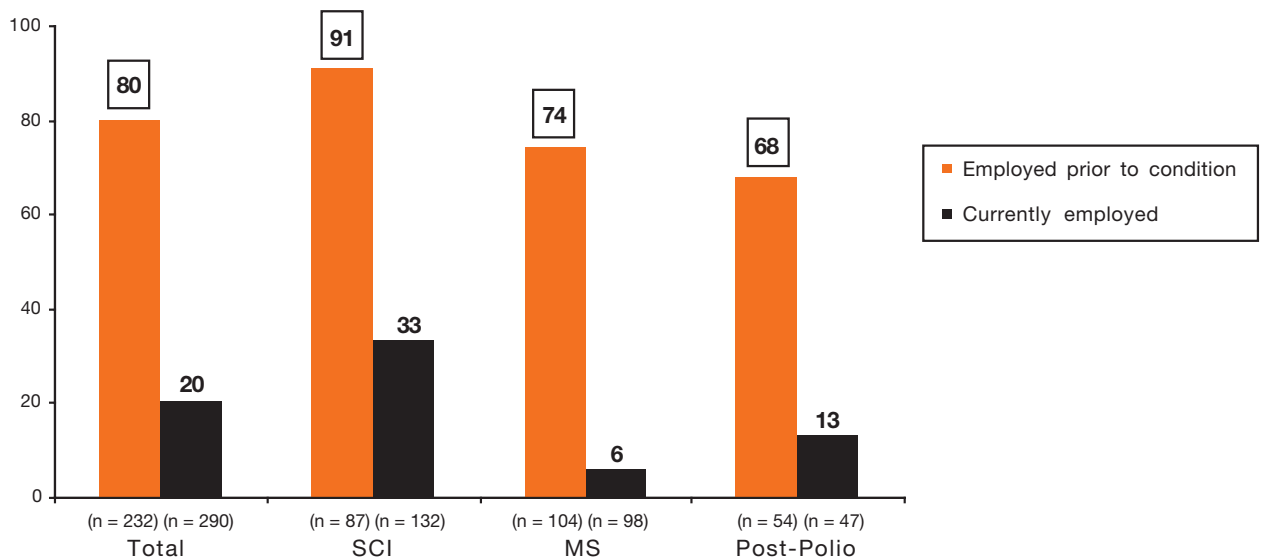
Effect of Condition

Respondents with SCI, MS or post-polio are significantly less likely to be employed since their injuries or the onset of their conditions.

- The vast majority of respondents with SCI (91%) report that they were employed at least part time prior to their injury. At the time of the survey, only one-third report being currently employed.
- Approximately seven out of ten of those surveyed with MS or post-polio were employed prior to using a wheelchair. Less than 15% of either group indicated they were currently employed at the time of the survey.

Employment: Currently and Prior to Condition

Base: Total Who Have/Care for Someone with Condition



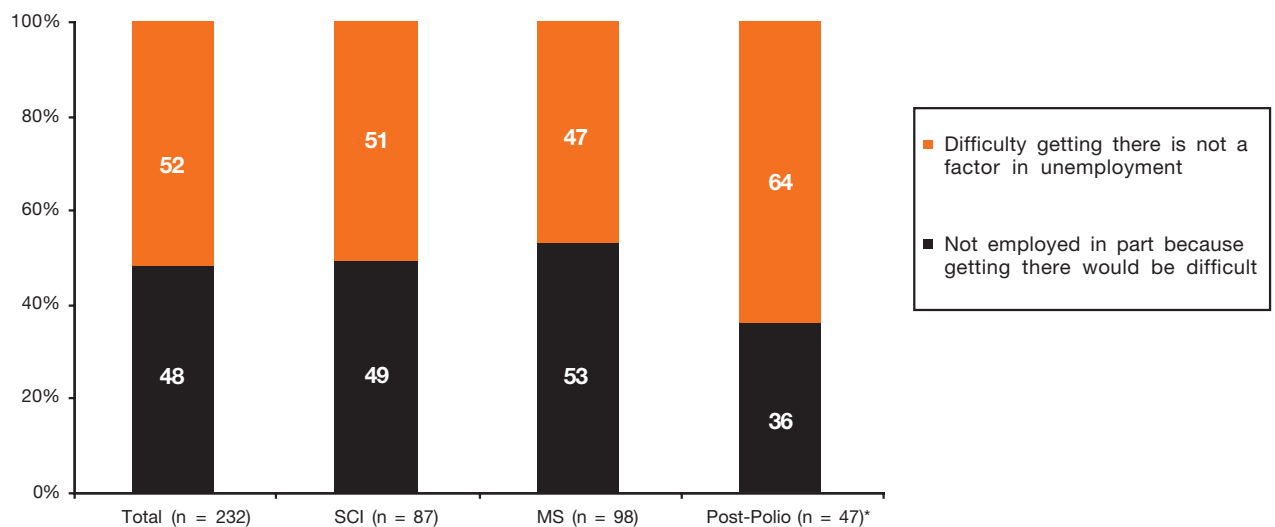
Questions: *What is your current employment status?
Were you employed before [your SCI/the symptoms of your "MS"/"Post-Polio"] reached a point where you needed the use of a wheelchair?*

Approximately half of the unemployed respondents with SCI and MS indicated that transportation issues have contributed to their lack of employment.

- Transportation is less of an issue for those surveyed with post-polio, with only one-third indicating that their unemployment is due, at least in part, to difficulties in getting from their home to a place of employment.

Unemployment Related to Transportation Difficulties

Base: Total Who Are Unemployed



Question: *Would you say that you are currently unemployed at least in some part because getting from where you live to a place of employment would be difficult for you?*

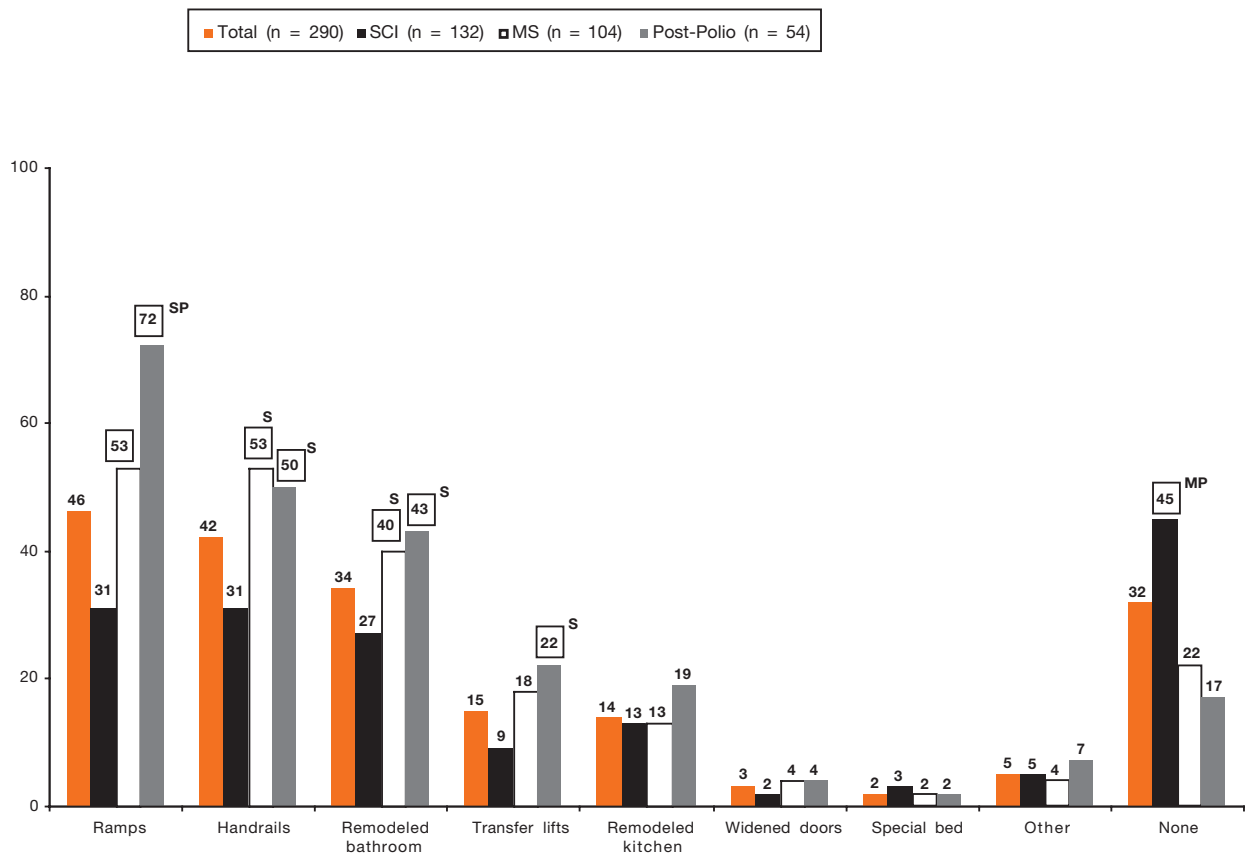
Home Life

Many respondents with SCI, MS or post-polio have had to add ramps and handrails or remodel bathrooms in order to make their homes more accessible.

- Those with post-polio or MS are most likely to have added ramps or handrails in their homes or remodeled their bathrooms. Those with SCI are comparatively less likely to report having made permanent renovations to their homes versus respondents from the other subgroups.

Changes Made to Home

Base: Total Who Have/Care for Someone with Condition



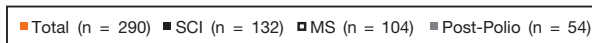
Question: Which of the following types of changes or additions did you make to your home to make it more accessible [because of your SCI/because your MS/post-polio reached a point where you needed the use of a wheelchair]?

Respondents maintain positive outlooks on life.

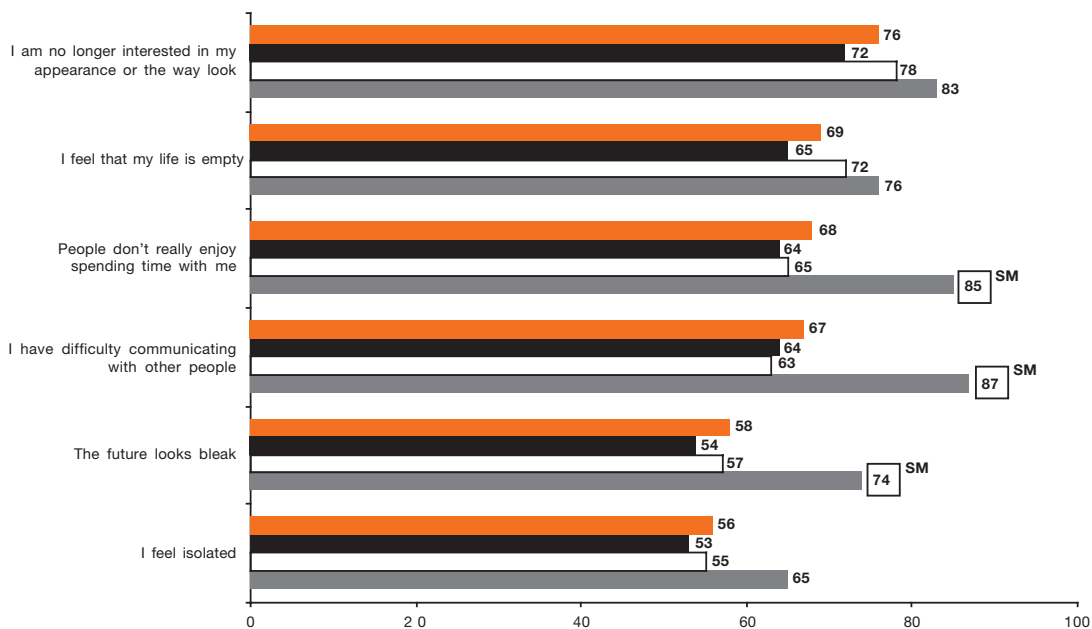
- More than half the respondents disagree or strongly disagree that they are no longer interested in their appearance, that their lives are empty, that people don't enjoy spending time with them, that they have difficulty communicating with others, that the future looks bleak, and that they feel isolated.
- Those with post-polio have a significantly more positive outlook on three of the below dimensions.

General Attitudinal Profile

Base: Total Who Have/Care for Someone with Condition



Percentage of Those Who Disagree/Strongly Disagree with Following Statements



Question: Please tell me whether you agree, strongly agree, disagree, strongly disagree or neither agree nor disagree that each of following statements describes your personal experiences or feelings during the past 30 days.

Respondent Outlook

Even though they maintain positive outlooks, respondents are realistic about the challenges they face.

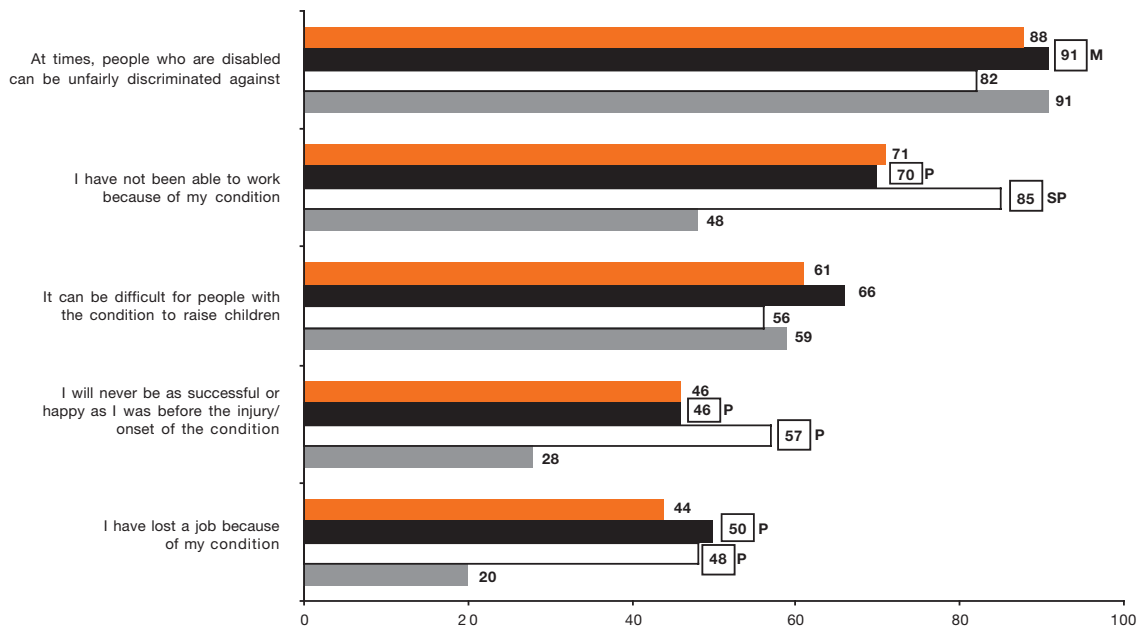
- The vast majority agree that people with disabilities can be unfairly discriminated against.
- Respondents also largely recognize that their condition makes it hard for them to work and could make it difficult for them to raise children.
- As many as one half of those with MS or SCI report they have lost a job because of their conditions. Similarly, it is at least somewhat common for respondents from these subgroups to indicate feeling that they will never feel as successful or happy as they were before the injury or the onset of their conditions.

Condition-Related Attitudes

Base: Total Who Have/Care for Someone with Condition

■ Total (n = 290) ■ SCI (n = 132) ■ MS (n = 104) ■ Post-Polio (n = 54)

Percentage of Those Who Agree/Strongly Agree with Following Statements



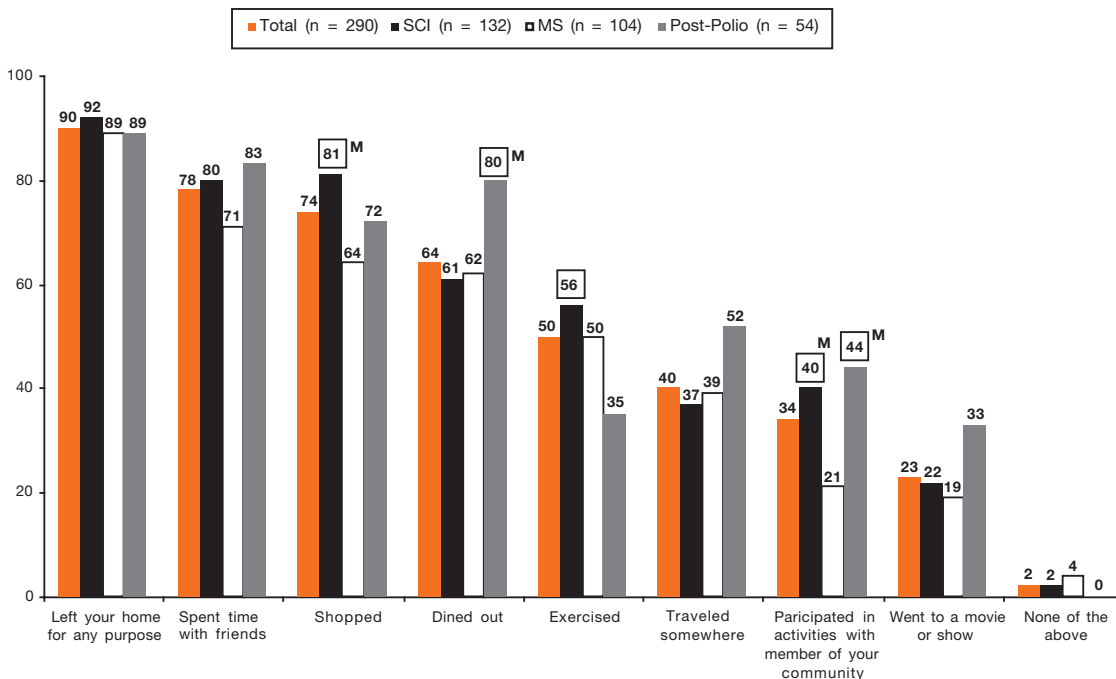
Question: Please tell me whether you agree, strongly agree, disagree, strongly disagree or neither agree nor disagree with each of the following statements.

Respondents engage in a wide variety of social activities. There does, however, appear to be some degree of isolation present in terms of their relationships with members of their communities.

- Nine out of ten left their home within the past month.
- Seven or eight out of ten spent some time with their friends.
- Shopping and dining out were also enjoyed by a majority of respondents.
- To a lesser degree, respondents also spent time exercising and traveling.
- Only a minority (34%) indicate they participate in activities with members of their communities.

Activities Participated in During the Past 30 Days

Base: Total Who Have/Care for Someone with Condition



Question: Which of the following choices describe activities that you have participated in during the past 30 days?

Respondent Outlook

Among those with a spouse or partner, respondents are generally very happy with their relationships and the support they receive and can provide in return.

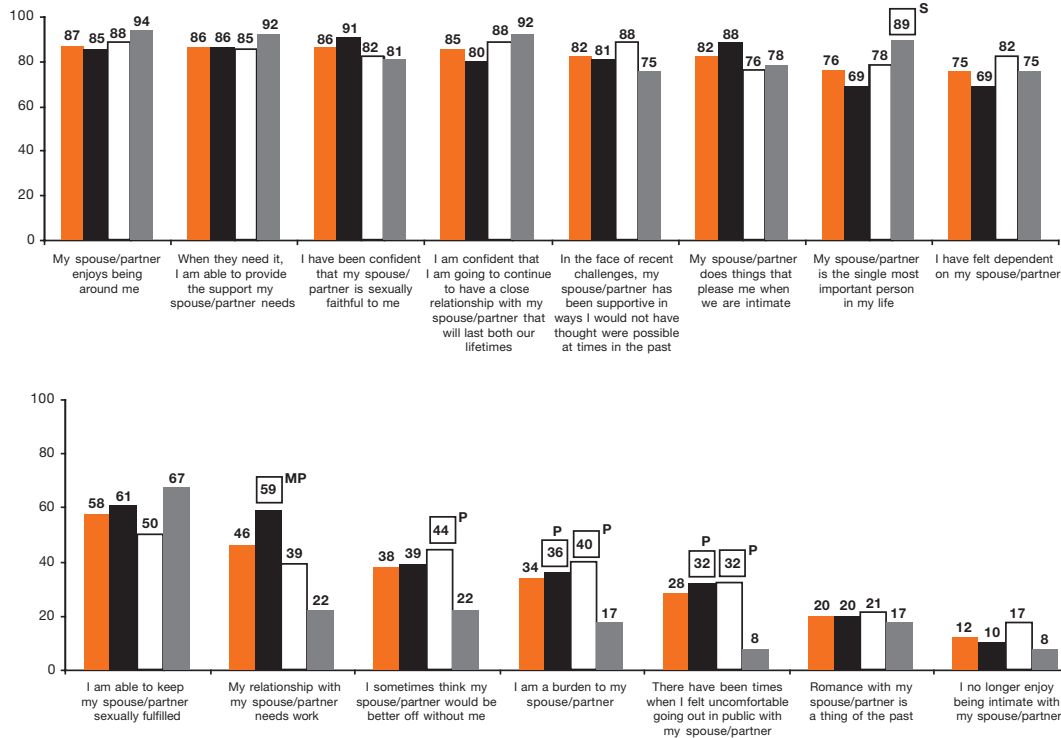
- Those surveyed with post-polio are most likely to feel that their partner is the most important person in their life (89%) and the least likely to feel any problems exist between them and their significant other (my relationship with my partner needs work—22%, I sometimes think my partner would be better off without me—22%; I am a burden to my partner—17%, there have been times when I felt uncomfortable going out in public with my partner—8%).
- Six out of ten (59%) of those with SCI report their relationships with their spouses or partners need work—a proportion significantly higher than what was found among the other two respondent cells.

Perceptions of Relationships

Base: Total Who Are Currently in a Relationship

■ Total (n=193) ■ SCI (n=85) □ MS (n=72) ■ Post-Polio (n=36)*

Percentage of Those Who Agree/Strongly Agree with Following Statements



Question: Please tell me whether you strongly agree, agree, disagree, strongly disagree or neither agree nor disagree that each of the following statements describes your current relationship with your spouse or partner during the past 30 days.

* Caution: Small base size.

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Expanding Opportunities for Veterans and All Paralyzed Americans