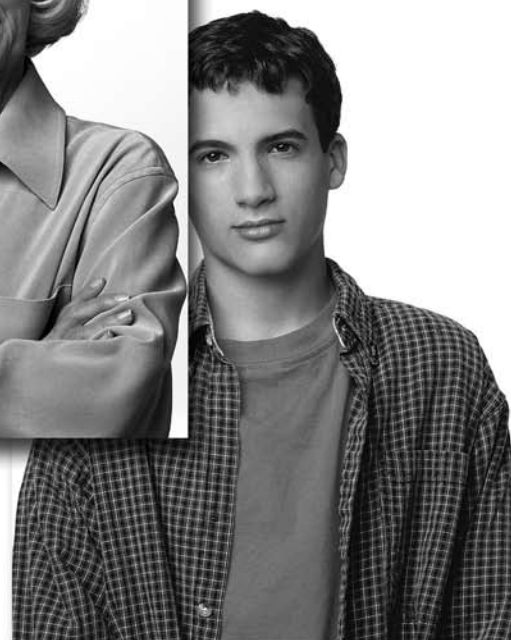
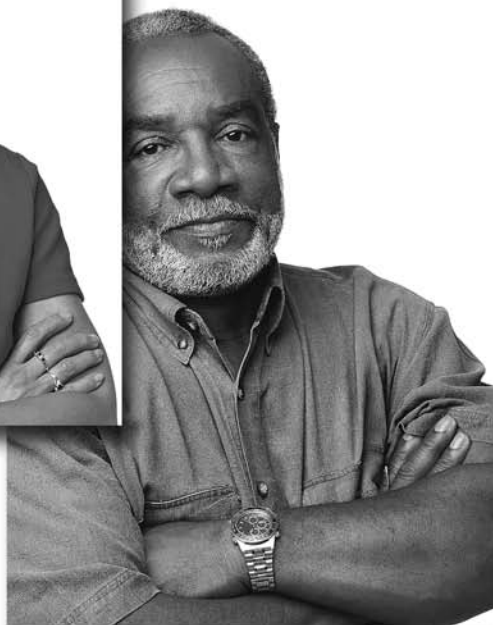


People With Amputation Speak Out

With the Amputee
Coalition of America (ACA)



Topics of Conversation

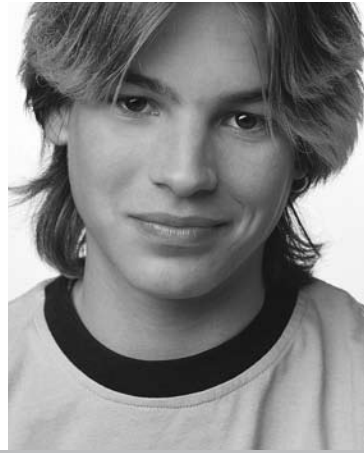
- Daily life and activities
- Feelings and concerns
- Services and support needed
- Barriers to health and well-being



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The Limb Loss Research & Statistics Program (LLR&SP)

The Limb Loss Research and Statistics Program (LLR&SP) is a collaboration of the ACA and Johns Hopkins Bloomberg School of Public Health. The overall mission of the LLR&SP is to:

- Improve the understanding of limb loss — how and where it occurs and how many people are living with limb loss
- Explore people's experiences living with limb loss
- Design programs aimed at improving function and quality of life after limb loss.

Acknowledgements

We would like to acknowledge the support and help provided by the staff of the Amputee Coalition of America (ACA) and the funding from the Centers for Disease Control and Prevention (CDC) and the National Center on Birth Defects and Developmental Disabilities (NCBDDD).

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Each year, approximately 185,000 Americans undergo amputation of a limb and about 1,000 children are born with a limb difference. In fact, it was estimated in 2005 that nearly 1.9 million people in this country are living with the loss of a limb. Limb loss may result from an injury, such as a fall or a motor vehicle crash, or may occur as a result of a disease such as diabetes mellitus, peripheral vascular disease, or cancer of a bone or joint. While there has been a marked decline in the number of injury-related or traumatic amputations in the U.S. due to innovations in treatment and injury prevention, there has been a sharp increase in the number of new cases of amputations in people with diabetes and vascular disease. Over half of all amputations in the U.S. are performed on people who have been diagnosed with diabetes. The risk of limb loss increases with age. Seniors age 65 and older have the greatest risk of amputation. As with diabetes and heart disease, smoking, poor nutrition and lack of exercise may also increase the risk of amputation. Certain racial and ethnic groups are at increased risk of amputation. African Americans are 1.5 to 3.5 times more likely to undergo amputation of a limb than non-Hispanic white Americans. Similarly, Hispanic Americans are 3.6 times more likely to undergo amputation than non-Hispanic white Americans. These differences are largely due to a higher number of people within the African American and Hispanic community living with diabetes and vascular disease.

Although we know a lot about the number of amputations that are performed each year, we know less about how an amputation impacts a person's everyday living and quality of life.

Missing from research studies about amputation was one important question: What is life like after an amputation? This question is key to exploring other questions, such as: What do people living with limb loss need to live the best life possible, and how do we meet those needs? From the beginning, it was clear that we needed to hear from the people who were the "experts" — those living with the loss of a limb or limbs, every day.

The purpose of the consumer survey was to determine how well people with limb loss were functioning in their everyday lives and what services they may need, but are not getting. This information is important for healthcare planners, policymakers and service providers to ensure that people with amputations receive what they need to live healthy and productive lives. With this in mind, survey questions were written to look at the following:

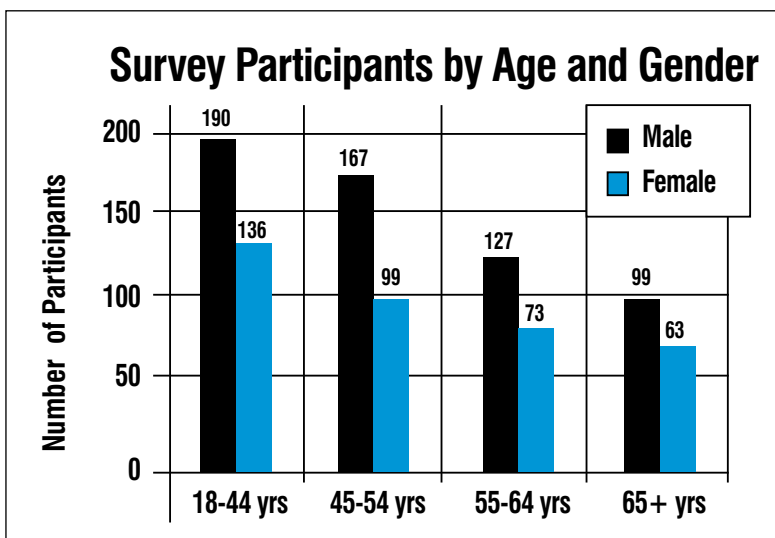
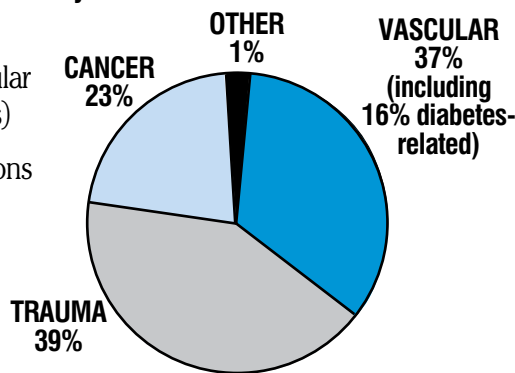
1. The overall health and well-being of people with limb loss
2. The need for services such as medical care and rehabilitation
3. The use of, and satisfaction with, prosthetic devices and related services
4. Environmental barriers and attitudes that impact overall well-being



The researchers at Johns Hopkins University, in collaboration with the Amputee Coalition of America, identified a group of individuals with amputations, age 18-84 years, from across the country. We selected people with amputations due to vascular disease, trauma, and cancer so that we could make comparisons across groups.

A total of 954 amputees completed the survey. They included:

- 357 with amputation because of vascular problems (152 of these were diabetics)
- 368 trauma- or injury related-amputations
- 220 cancer-related amputations
- 9 with amputation due to other reasons such as infection



Over half of the survey participants were male (61%). The average age was 50 years old and ranged from 18 to 84 years. People who lost their limb to cancer did so at a younger age (average 30 years) while those with diabetes and vascular problems experienced

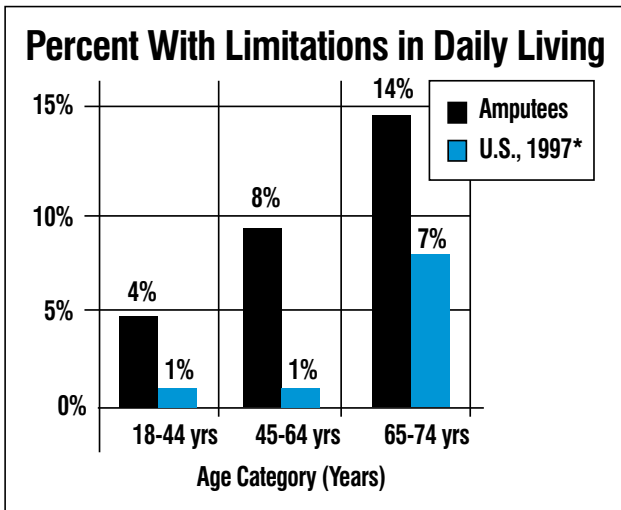
their amputations at an older age (average 52 years). The average time elapsed since amputation was 10 years (range 6 months to 66 years). The majority of amputees had graduated from high school (93%) and were living in households that were above the national poverty line (63%).



Level of Amputation

Upper Limb	Lower Limb
<i>Finger/Hand - 23</i>	<i>Toe/Foot/Ankle - 14</i>
<i>Below Elbow - 30</i>	<i>Below Knee - 370</i>
<i>Above Elbow - 48</i>	<i>Above Knee - 364</i>
<i>Bilateral Upper - 8</i>	<i>Bilateral Lower - 95</i>

The level of amputation varied by cause of amputation. The majority of vascular (52%) and traumatic (43%) amputees had a below-knee amputation, while 75% of cancer-related amputees had an above-knee amputation. Most of the upper-limb amputations were due to trauma or injury.



Activities of Daily Living

While most people said that they were independent, they also reported that they had some limitations in doing one or more activities. Bathing was the most difficult activity, with 30% saying that they experienced “a little” or “a lot” of difficulty.

Overall, a very small number of those surveyed (7%) reported that they required some help in performing the activities of daily living such as: bathing; eating;

dress; using the bathroom; and getting in and out of bed. However, this varied by age, with older amputees (14%) reporting needing more help than younger amputees (4%).

Compared to the general population in the U.S., amputees were more likely to report needing the help of another person in one or more activities of daily living.

While most people said that they were independent, they also reported that they had some limitations in doing one or more activities.

* SOURCE: National Health Interview Survey, 1997. Vital Health Stat 10(204). 2002. (FOR U.S. ONLY)

Daily Life

When asked about their major daily activity, overall nearly half of working-age amputees (18-64 years) were working full- or part-time or were going to school. Almost one-third (27.9%) reported being retired due to a disability, with the majority being in the 45-54 and 55-64 age groups. Participants with amputation due to diabetes or vascular-related causes were twice as likely to report being retired due to a disability than those with traumatic amputation, regardless of age or time since amputation.

Major Activity by Age Group (Years)

	Working	Unemployed	Student	Homemaker	Retired/ Disability	Retired
18-44	57%	10%	10%	8%	15%	Under 1%
45-54	48%	10%	2%	5%	33%	2%
55-64	35%	5%	0%	5%	42%	13%
65+	10%	1%	0%	6%	29%	54%

How Are You Feeling?



When asked to rate their quality of life from 1-10, with 1 being the lowest and 10 being the highest, the majority of amputees responded that their quality of life was good to excellent (5 and above on the scale).

Quality of Life

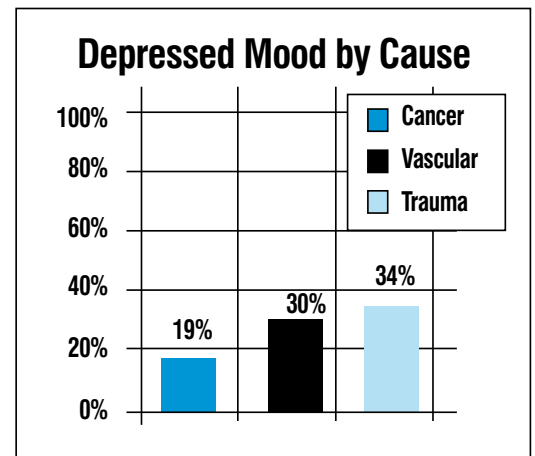
When asked to rate their quality of life from 1 to 10, with 1 being the lowest and 10 being the highest, the majority of amputees responded that their quality of life was good to excellent (5 and above on the scale). The average rating was 7 and did not vary by type or reason for amputation.

Emotional Well-Being

The survey also inquired about people's emotional states. The questions, which have been used in other studies to determine how people are feeling emotionally, asked how often each person experienced specific feelings such as loneliness, sadness, and happiness during the past month. Almost 30% of those surveyed were found to have a depressed mood.

By Cause

A higher proportion of people with traumatic amputation reported a depressed mood than those whose limb loss was from another cause.



By Age Group

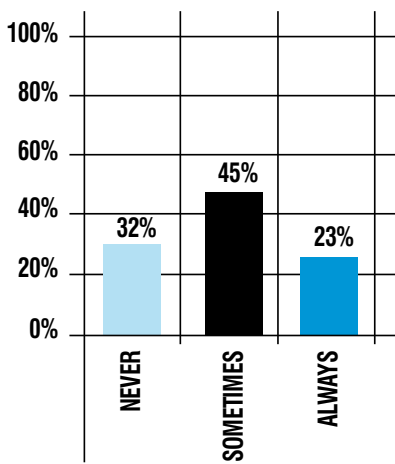
A depressed mood was more often reported by the younger people who took the survey (under 54 years of age). The chart below shows the percentage of people in each age group reporting a depressed mood.

	18-44 Years	45-64 Years	55-64 Years	65+ Years
Depressed Mood	32%	35%	24%	17%



Pain, whether in the amputated limb or in another area of the body such as the back or the nonamputated limb, can lead to limitations in activity and result in further disability. Most of those surveyed (91%) said they had some type of pain. Over three-fourths (83%) experienced pain in two or more body areas.

Residual Limb Pain

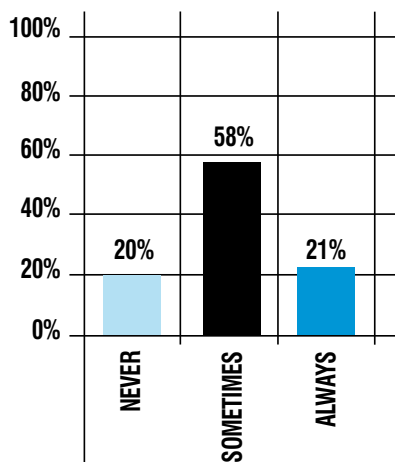


Residual Limb Pain

Almost 70% of all those surveyed said that they had residual limb pain (pain in the part of the limb that is still present). People with trauma related amputations were 1.5 times more likely to experience residual limb pain than those with vascular-related amputations, after adjusting for age, time since amputation, and chronic disease.

When asked to rate the intensity of their pain on a scale of 1 to 10, with 1 being extremely mild pain and 10 being extremely intense pain, the average intensity reported was 5.1. When asked if they were bothered by their pain, 86.5% reported being bothered, with one-third of those being “extremely” bothered.

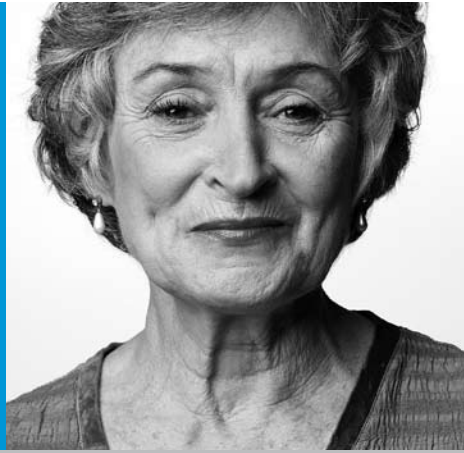
Phantom Limb Pain



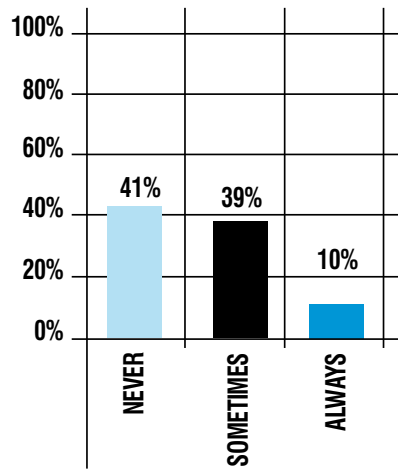
Phantom Pain

Phantom pain (pain in the part of the limb that is missing), was reported by 80% of amputees. Similar to residual limb pain, the likelihood of experiencing phantom pain did not vary by time since amputation. There was no difference in the number reporting phantom pain across cause after adjusting for age, time since amputation, and chronic disease.

When asked to rate the intensity of their pain on a scale of 1 to 10, with 1 being extremely mild pain and 10 being extremely intense pain, the average intensity reported was 5.5. When asked if they were bothered by their phantom pain, 81% reported being bothered, with one-third of those being “extremely” bothered.



Nonamputated Limb Pain

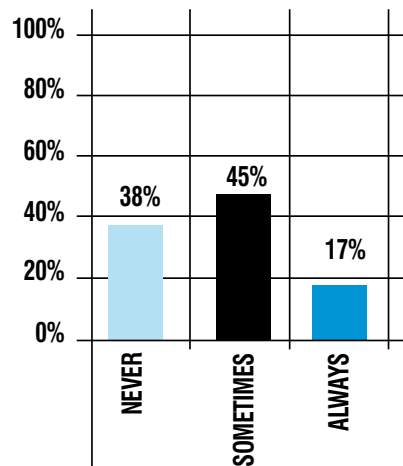


Nonamputated Limb Pain

Nearly half (49%) of all amputees surveyed reported experiencing pain in their nonamputated limb. The presence of nonamputated limb pain varied by cause of amputation, with cancer-related and traumatic amputees less likely to experience pain in the nonamputated limb than those who had vascular-related amputations, after adjusting for age and time since amputation.

When asked to rate the intensity of their pain on a scale of 1 to 10, with 1 being extremely mild pain and 10 being extremely intense pain, the average intensity reported was 4.6. When asked if they were bothered by their nonamputated limb pain, 88.3% reported being bothered, with just less than one-third of those being “extremely” bothered.

Back Pain



Back Pain

Back pain affected 62% of those surveyed. Back pain did not vary by the cause of the amputation nor by the time elapsed since the amputation. Nearly three-fourths of respondents were bothered by their back pain, with one-third of those reporting being “extremely” bothered.

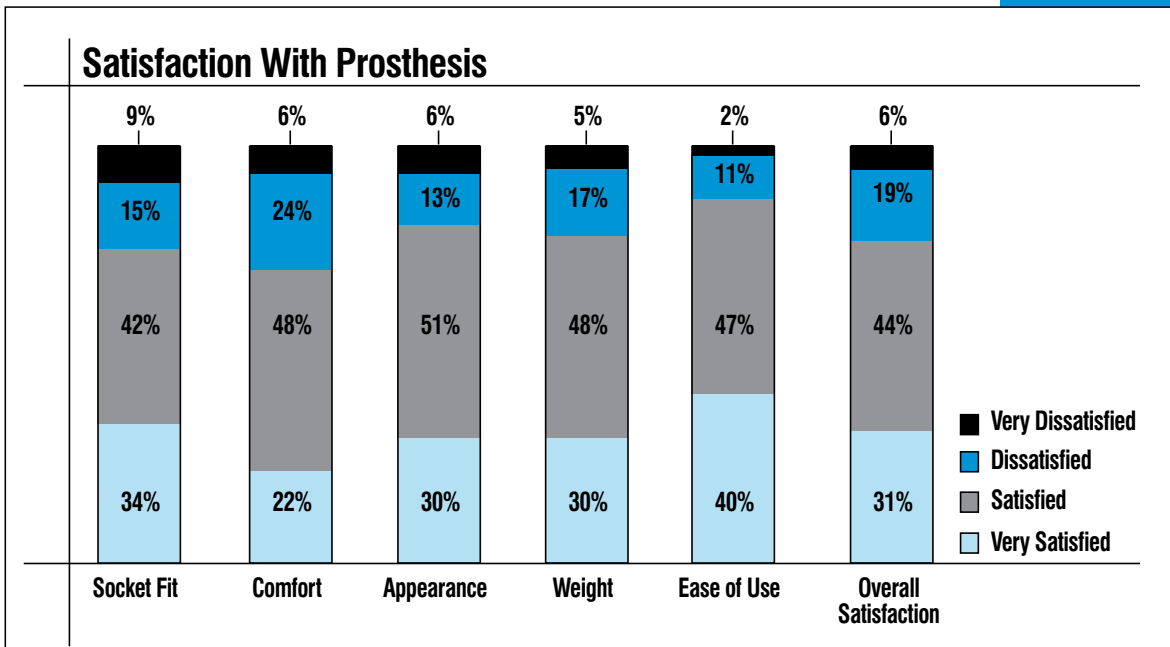


How Satisfied Are You With Your Prosthesis?

Satisfaction With Prosthesis

The majority of those surveyed (93%) reported owning a prosthesis but 12% said they did not wear their prosthesis on a regular basis. Among those who used their prosthesis, 83.7% reported that they wear their prosthesis 7 days a week. The average amount of daily use was 12 hours per day.

Overall, the majority of those surveyed reported being satisfied with their prosthetic device. However, one-third reported being dissatisfied with the comfort of their prosthesis.

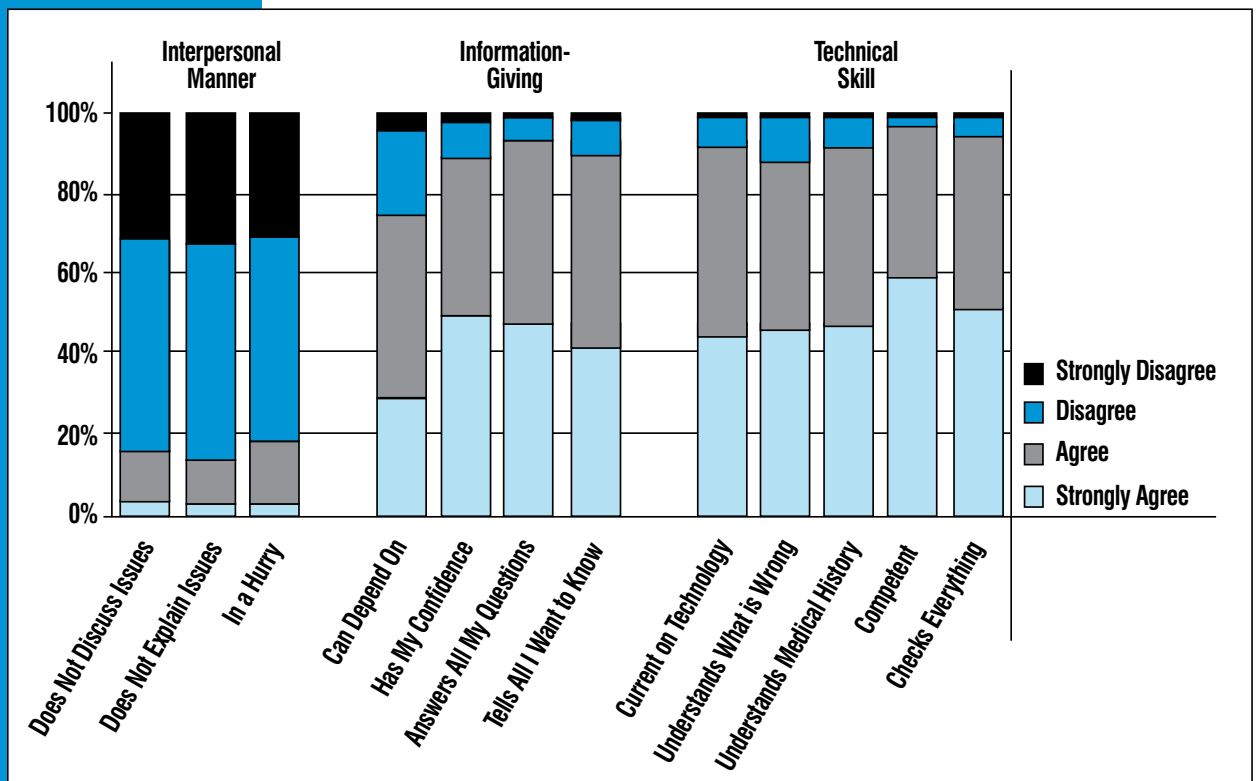


How Satisfied Are You With Your Prosthetist?



Satisfaction With Prosthetist

The average number of visits made to a prosthetist over the past year was 5 (range 0 to 200 visits). The majority of those surveyed were satisfied with their prosthetist in the areas of interpersonal manner, information-giving, and technical skill.



Other Assistive Technology

In addition to the use of a prosthesis, most of those surveyed (81%) reported using other assistive technology such as a cane, walker and/or wheelchair. Wheelchair use was associated with age, with older amputees (age 65 and older) being twice as likely to use a wheelchair than younger amputees (age 18 to 44), after adjusting for cause and time since amputation.



Medical Care

Over 80% of survey participants reported making one or more doctor visits in the past 12 months. One out of 10 reported not receiving medical care when they needed it. One-third of these were due to health insurance costing too much or not covering the cost of medical care.

Rehabilitation Services

One-fourth of survey participants reported receiving medical rehabilitation services, such as physical and occupational therapy, in the past year. The average number of visits per year to a rehabilitation specialist was 25, with more visits made by individuals with more recent amputation. Nearly 20% reported not receiving rehabilitation services when they needed it. Similar to medical care, the majority reported cost as the leading factor in preventing them from receiving rehabilitation services they needed.

Emotional Health Services

Nearly one-fourth (22%) of survey participants reported receiving emotional health services for an emotional problem during the past 12 months; only 9% reported needing it and not getting it. However, among those with depressed symptoms, half reported not receiving emotional health services. Among those receiving help, only 6% reported that they needed more help than they received. Reasons given for not receiving help included wanting to solve their own problems (27%) and not knowing where to go for help (19%).

Assistance in the Home

Nearly half (48%) reported needing help at home with activities such as personal care, meal preparation, and grocery shopping. One-fourth of those receiving help said they needed more help than they were currently receiving. Of those who were not receiving care, only 11% reported needing more help but not receiving it. The majority (66%) received help from a family or friend who lived in the same home with them, while 16% received help from a family member or friend who lived outside their home and 11% reported using a home health aide or a visiting nurse.

Peer Support Group

Current attendance at a peer support group was reported by 20% of the survey participants. Older amputees (age 45+) were more likely than those age 18-44 to report attending a peer support group, after adjusting for cause and time since amputation.

Environmental and Attitude Barriers

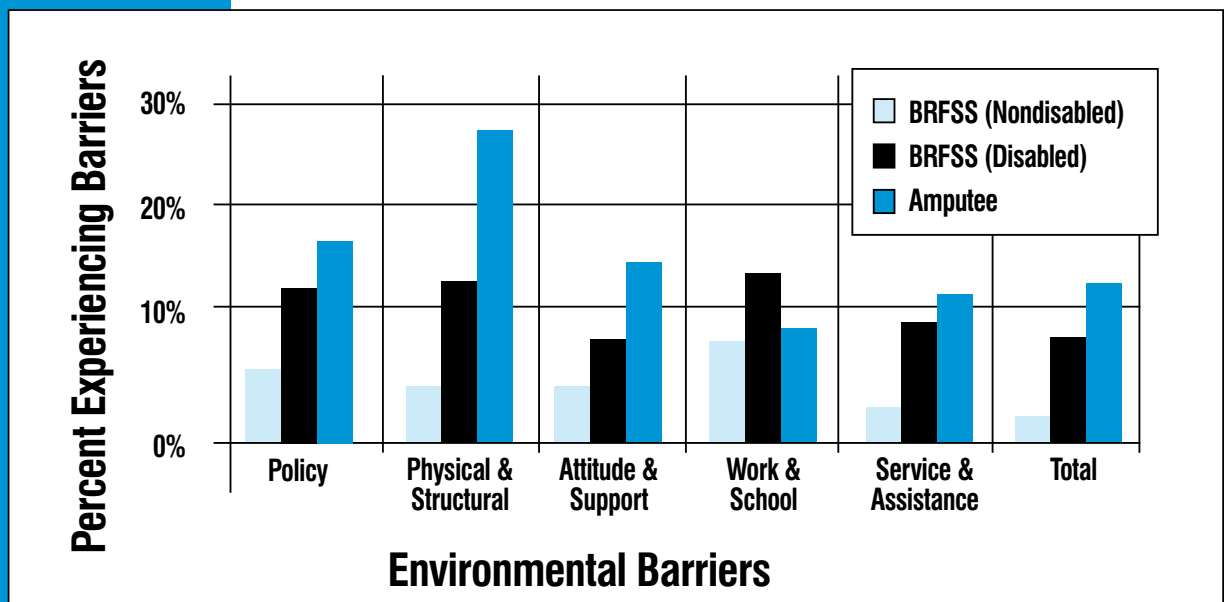


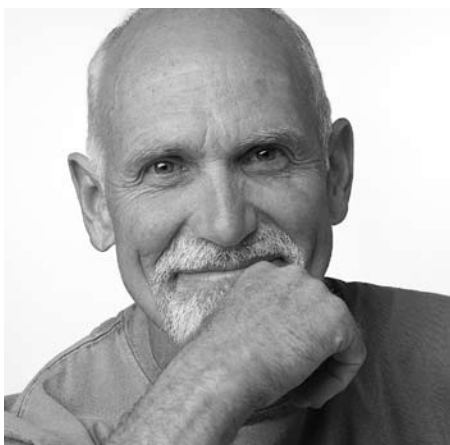
For people with limited mobility, potential environmental barriers include not only physical and structural barriers, such as uneven pavement or poorly lighted areas, but also societal and psychological barriers, such as discrimination and attitudes.

Environmental Barriers

For people with limited mobility, environmental barriers include not only physical and structural barriers, such as uneven pavement or poorly lighted areas, but also societal and psychological barriers, such as discrimination and attitudes, that limit a person's ability to do the things they want to do. We asked participants how often they experienced barriers in their day-to-day life and if they did, were they big problems or little problems. The five areas we asked about were: Policy, Physical and Structural, Attitude and Support, Work and School, and Service and Assistance.

When compared to a sample of people with and without disabilities who completed a survey (Behavior Risk Factor Surveillance Survey), amputees reported experiencing more barriers in all areas except Work and School. The difference was greatest in the area of Physical and Structural barriers.





Conclusions

- **Among community-dwelling amputees, the majority are living independently.** Only a few survey participants required assistance with daily activities such as bathing, dressing, eating, and getting in and out of bed. In spite of this, when compared to a national sample from the U.S., a larger proportion of amputees required assistance than their age-matched counterparts. The majority of amputees surveyed reported being employed, going to school full-time or working as a homemaker. However, a large number of working-age amputees (18-64 years) reported being retired due to a disability.
- **The most common secondary conditions associated with limb loss are pain and depressed mood.** Nearly all amputees surveyed reported experiencing some type of amputation-related pain in the past 4 weeks, with the most common pain type experienced being phantom limb pain. Depressed mood was also highly prevalent among people with limb loss. Nearly one-third of amputees surveyed were found to have depressed mood.
- **Among the sample of amputees surveyed, the majority reported wearing a prosthesis daily.** Most of those surveyed reported using other assistive devices such as canes, walkers and wheelchairs. Satisfaction with the fit of the prosthesis was high. However, nearly one-third of amputees were dissatisfied with the comfort of their prosthesis. The greatest satisfaction was reported in the ease of use of the prosthesis. Overall, amputees were satisfied with their prosthetist's skills. However, lower satisfaction ratings were found in the area of interpersonal manner and information-giving.
- **A significant number of amputees reported barriers to accessing physical and emotional healthcare during the past year.** One in 10 amputees did not receive medical care when they needed it and nearly half of all people with depressed symptoms reported not receiving the emotional health services they needed. Common barriers included cost and not knowing where to go for help.



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