# Patient Perspectives

Real-world data that clinicians can use to inform prosthetic care and positively impact patient outcomes. Presented by The O&P EDGE in partnership with the Amputee Coalition.





# **Amputee Patient Comfort and Compliance**

# The O&P EDGE and the Amputee Coalition are proud to present the results of our inaugural amputee patient survey.

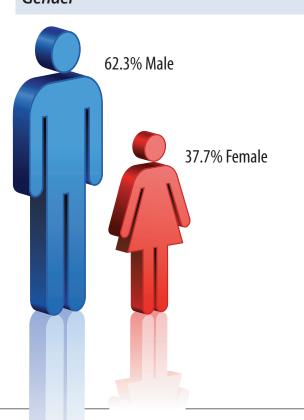
The purpose of this survey was to gain a better understanding of amputee behavior related to prosthesis wear. Specifically, we asked patients with limb loss and limb difference to report on their prosthesis wear habits, as well as their level of comfort when wearing a prosthetic device. For those who elect not to wear a prosthesis, we asked individuals why they made this choice.

In May 2011, the Amputee Coalition sent survey invitations to 8,000 individuals, who were selected randomly from its consumer database. More than 1,200 people completed the survey, for a response rate of 15 percent.

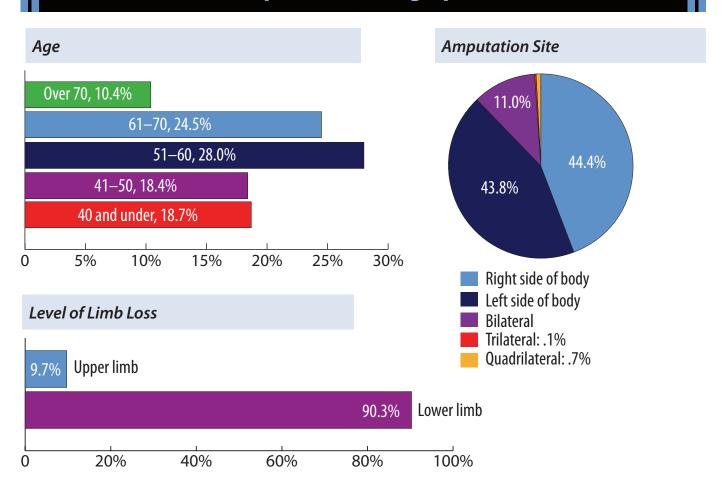
We hope the results, which appear on the following pages, will provide O&P practitioners useful information that they can use to help inform clinical care and improve patient outreach efforts.

This survey and summary were written jointly by The O&P EDGE and the Amputee Coalition.

#### Gender

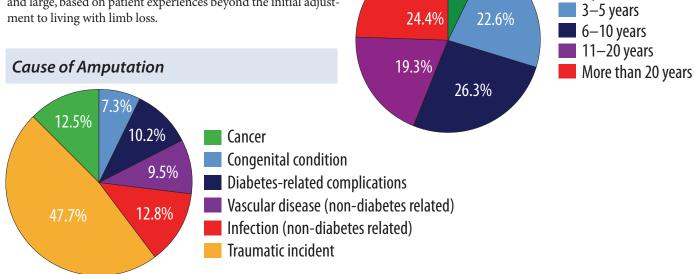


#### **Respondent Demographics**



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The majority of respondents—62.3 percent—were male, and 81 percent of all respondents were over the age of 40. Most had experienced a lower-limb loss. Suffering a traumatic incident was the most-cited cause of limb loss (47.7 percent), followed by non-diabetes-related infection (12.8 percent) and cancer (12.5 percent). Nearly 93 percent of respondents have been living with limb loss for more than two years, which indicates that the responses are, by and large, based on patient experiences beyond the initial adjustment to living with limb loss.



2 years or fewer

Number of Years with Limb Loss

7.3%

#### **Prosthetic Device Wearing Habits**

#### **Wearing Habits**

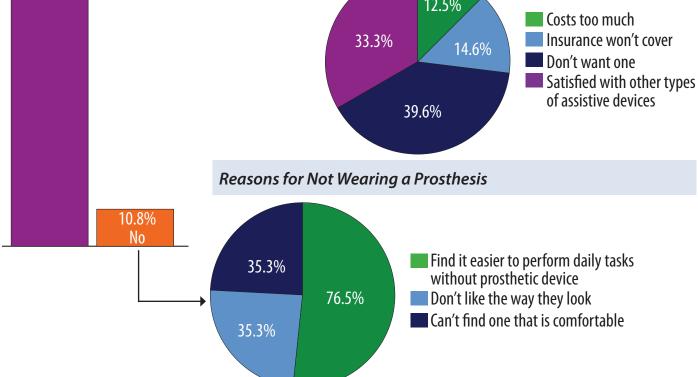
In answer to the first question, "Do you have a prosthetic device?", nearly all of the respondents—95 percent—have a prosthesis and 81 percent were either satisfied or very satisfied with it (see pie chart on pg. 36). Of the relatively small percentage of those who do not have a prosthesis, the primary reasons cited were that they either "didn't want one" or were "satisfied with other types of assistive devices." Other assistive devices that individuals reported using were manual wheelchair (57.1 percent), crutches (42.9 percent), and electric wheelchair or scooter (35.7 percent). When asked about other types of assistive devices they use, respondents were encouraged to check all that applied, thus the results represent the overall percentage of respondents who use each of these devices. Of the 5 percent (60 individuals) who said they do not have a prosthesis, 17 attributed it to cost or noted that their insurance won't cover it.

Respondents who have a prosthetic device tend to wear it regularly. Only 10.8 percent of those who have a prosthesis said that they do not wear it regularly, and of those, 76.5 percent indicated that they "found it easier to perform daily tasks without it." Reasons for not wearing a prosthesis were evenly split—35.3 percent said they don't like the way the prosthetic device looks, and 35.3 percent cited lack of comfort. (Editors note: In this question, participants were also encouraged to check all answers that applied to why they do not wear their device regularly and may have chosen more than one answer.)

Do You Wear Your Prosthetic Device Regularly?

# 94.8% Yes No 5.2%





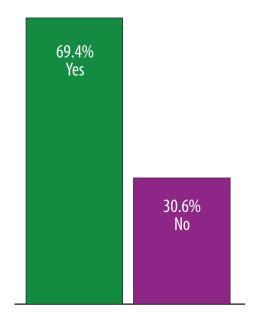
#### **Time Spent Wearing Prosthetic Device**

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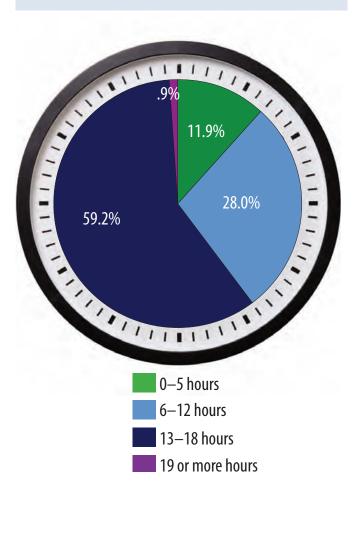
Of the respondents who report wearing their prosthesis regularly, 82.7 percent indicated that they wear it daily, and more than half of those wear the device at least 13 hours per day, indicating that for these users, wearing a prosthesis is an integral part of their daily lives. Of the 17.3 percent of respondents who report wearing their prosthesis fewer than seven days per week, responses were fairly evenly distributed between one through six days per week.

In terms of care provided, nearly 70 percent reported that they felt they had received sufficient training on using their prosthetic device, which may play a factor in time spent wearing the prosthetic device.

Did you receive a sufficient amount of training on using your prosthetic device?



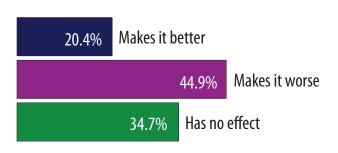
Average Number of Hours per Day Using a Prosthetic Device



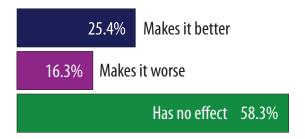
In terms of compliance, only 9.3 percent cited pain, and only 8.6 percent cited discomfort, as having "a lot" of impact on deciding whether or not to wear their prosthesis.

#### Wearing Habits, Comfort, and Pain

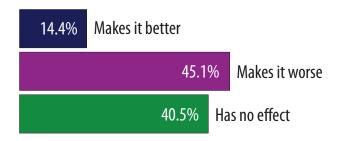
## Effect of Wearing Prosthesis on Residual Limb Pain



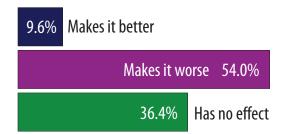
## Effect of Wearing Prosthesis on Phantom Limb Pain



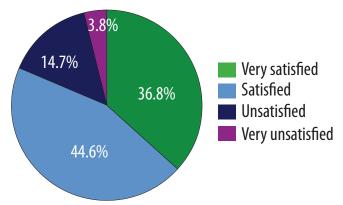
### Effect of Wearing Prosthesis on Joint Pain



# Effect of Wearing Prosthesis on Muscle Pain



#### **Overall Satisfaction with Prosthetic Device**



Although just over 80 percent of respondents who report wearing a prosthesis felt satisfied or very satisfied with their prosthetic device, some respondents reported that wearing a prosthesis increases joint and muscle pain.

# Impact of Pain and Discomfort on Wearing Habits

When asked about secondary conditions related to prosthesis wear, 82.4 percent of the individuals reported a secondary condition, with phantom pain being the most common. As shown in the series of graphs to the left, respondents thought that all of these conditions, with the exception of phantom pain, were made worse by wearing their prosthetic device. However, in terms of compliance, only 9.3 percent cited pain, and only 8.6 percent cited discomfort, as having "a lot" of impact on deciding whether or not to wear their prosthesis. Therefore, it appears that the effects of wear on secondary conditions and issues of pain and discomfort have little bearing on compliance.

#### **Next Steps**

*The O&P EDGE* and the Amputee Coalition hope that surveys such as this one provide O&P professionals information that will help them to improve the overall patient experience related to prosthetic device use. This information can be used to reach out to patients and facilitate patient-practitioner communication.

This survey is just a touchstone. As practitioners, what data would you like to see regarding patient care? More arms-, hands-, feet-, or knee-specific data? Clinically based data? Activity level versus prescribed prosthetic solution? Please send your feedback and comments to Karen Henry at karen@opedge.com

#### About the Survey

Survey results had a margin of error of  $\pm 3$  percent at a 95 percent confidence interval, meaning that 95 out of 100 times, these results are correct within 3 percentage points. The margin of error represents the degree of accuracy within the survey and for each question. Since this survey had a margin of error of  $\pm 3$  percent, items for which there is less than a 6 percent difference between responses fall within the margin of error and cannot be assumed to represent a true difference.