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ORIGINAL RESEARCH

# Health-Related Profiles of People With Lower Limb Loss

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**Abstract**

**Objectives:** To construct profiles of self-reported health indicators to examine differences and similarities between people with lower limb loss and a normative sample (hereafter called the norm) and to compare health indicators between subgroups based on level and etiology of limb loss.

**Design:** Survey.

**Setting:** General community.

**Participants:** Adults with unilateral lower limb loss ($N=1091$) participated in this study. Eligibility criteria included lower limb loss due to trauma or dysvascular complications and regular use of a prosthesis.

**Interventions:** Not applicable.

**Main Outcome Measures:** The Patient-Reported Outcomes Measurement Information System 29-item Health Profile version 1.0 measures physical function, pain interference, fatigue, sleep disturbance, anxiety, depression, and satisfaction with participation in social roles. The norm includes 5239 individuals representative of the U.S. general population in sex, age, race, ethnicity, and education.

**Results:** People with lower limb loss reported statistically significantly worse physical function, pain interference, and satisfaction with participation in social roles and significantly less fatigue than did the norm. People with transfemoral (ie, above-knee) amputation significantly differed in physical function from people with transtibial (ie, below-knee) amputation. Similarly, people with amputation due to trauma and dysvascular etiology significantly differed in physical function and satisfaction with social roles after adjusting for relevant clinical characteristics.

**Conclusions:** People with lower limb loss generally report worse physical function, pain interference, and satisfaction with social roles than do the norm. People with dysvascular amputation reported worse physical function and satisfaction with social roles than did people with traumatic amputation. Health indicator profiles are an efficient way of providing clinically meaningful information about numerous aspects of self-reported health in people with lower limb loss.

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Loss of a limb has a profound impact on health indicators, including physical, mental, and emotional health. Associations between lower limb loss and impaired functional mobility, an aspect of physical health, have been well documented.[1-8] Limited mobility often persists in the months and years after limb amputation.[2-4,9] Lower limb loss is also associated with other physical and mental health problems, such as pain (eg, phantom limb,[10,11] residuum,[10,11] and back pain[12,13]) and depression.[10] Health indicators for people with lower limb loss also differ by factors such as level of amputation and etiology.[5,10,14]

Worse health outcomes are often associated with poor rehabilitation results in people with lower limb loss.[10] For example, people with lower limb loss who experience depression also more commonly report less use of a prosthetic limb, higher perceived vulnerability, and lower self-rated overall health.[10] Conversely, greater participation in social experiences is positively associated with mobility outcomes, such as walking distance.[3] Assessment of health indicators in clinics is important because monitoring and addressing physical, mental, and social function may improve rehabilitation outcomes in people with lower limb loss.[1] Despite the recognized importance of physical, mental, and social issues related to the rehabilitation of people with lower limb loss,[15] health providers typically focus rehabilitation efforts on patients' physical health and may not adequately assess psychosocial functioning.[16] This tendency to focus on physical recovery may be reinforced by challenges related to availability of brief and psychometrically sound health assessment instruments that are easy

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for clinicians to administer, score, and interpret.[17,18] New measurement tools developed with funding from the National Institutes of Health, such as Patient-Reported Outcomes Measurement Information System (PROMIS) instruments, allow for an efficient assessment of multiple self-reported health indicators.[19] Because PROMIS instruments are brief and the scores are on the same metric, they lend themselves to the construction of profiles that include aspects of physical, mental, and social health.[19] Well-established instruments, such as Medical Outcomes Study 36-Item Short-Form Health Survey, could also be used to examine profiles of health indicators, and the studies[20,21] using such instruments have described worse health indicators for people with lower limb loss than for those without lower limb loss. However, some domains of Medical Outcomes Study 36-Item Short-Form Health Survey and related instruments (eg, SF-12) are different from those of the Patient-Reported Outcomes Measurement Information System 29-item Health Profile (PROMIS-29). In addition, PROMIS-29 domains can be administered using computer adaptive testing, which increases the precision of the score while minimizing respondents' burden.[22] To date, no studies used PROMIS measures to examine health indicators for people with lower limb loss.

This study aimed to examine health indicator profiles for a large sample of people with lower limb loss by comparing scores of physical function, pain interference, anxiety, depression, fatigue, sleep disturbance, and satisfaction with participation in social roles (1) between the overall sample and PROMIS normative sample (hereafter called the norm) and (2) between subgroups with different levels of limb loss and etiologies of amputation. We hypothesized that (1) individuals with lower limb loss would generally report worse health than the general U.S. population, especially on physical function, and (2) individuals with higher amputation levels and dysvascular etiology of amputation would report worse health than their peers with lower amputation levels and traumatic etiology of amputation.

# Methods

## Study design

Data for this study were obtained from a cross-sectional, self-reported health survey administered to lower limb prosthesis users in the process of developing an instrument to measure mobility in people with lower limb loss (ie, the Prosthetic Limb Users Survey of Mobility [PLUS-M], available at: www.plus-m.org). Surveys were administered to study participants by computer, paper, or phone, according to their preferences, and included the PROMIS-29 as well as self-reported demographic and clinical characteristics.

***List of abbreviations:***

| | |
|---|---|
| **MID** | **minimal important difference** |
| **PLUS-M** | **Prosthetic Limb Users Survey of Mobility** |
| **PROMIS** | **Patient-Reported Outcomes Measurement Information System** |
| **PROMIS-29** | **Patient-Reported Outcomes Measurement Information System 29-item Health Profile** |
| **TFA** | **transfemoral amputation** |
| **TTA** | **transtibial amputation** |

## Participants

Participants were recruited across the United States using flyers posted in 133 private, 4 hospital, and 7 institutional clinics. Magazine advertisements, Listserv postings, targeted mailings from a national clinical provider, and postings on journal, clinic, and patient organization websites were also used. All study participants were required to report that they (1) are 18 years or older; (2) have a unilateral amputation below the hip and at or above the ankle resulting from trauma or dysvascular complications; (3) have no other amputations; (4) regularly use a lower limb prosthesis to walk; and (5) are able to read, write, and understand English. Amputations at or above the knee were categorized as transfemoral amputations (TFAs), and amputations at or above the ankle and below the knee were categorized as transtibial amputations (TTAs).

For the purpose of PLUS-M development, recruitment targets were set to include a minimum of 500 people from each of the following subgroups of people with lower limb loss: (1) those with TTA from either traumatic or dysvascular etiologies; (2) those with TFA from either traumatic or dysvascular etiologies; (3) those with dysvascular lower limb loss at the TTA or TFA level; and (4) those with traumatic lower limb loss at the TTA or TFA level. All participants belonged to 2 of these 4 subgroups. The subgroups were chosen as they represent the most prevalent etiologies and levels of amputation among people with lower limb loss.[23,24]

All study procedures were reviewed and approved by the University of Washington Institutional Review Board.

## Measures

### Demographic and amputation-specific measures

Participants were asked to provide basic demographic information including age, sex, race and ethnicity, employment status, veteran status, education, and income level. In addition, participants provided information on amputation level and etiology, comorbid health conditions, time since amputation (in years), daily prosthesis use (in hours), and average pain intensity.

### Health indicators

The PROMIS domain framework organizes the instruments into physical, mental, and social health.[19] The PROMIS-29 version 1.0 was administered to measure aspects of physical health (physical function, pain interference, fatigue, sleep disturbance), mental health (anxiety, depression), and social health (satisfaction with participation in social roles). The PROMIS item banks, on which the short forms included in the PROMIS-29 are based, were developed using rigorous methodology including item response theory.[19] All PROMIS instruments provide an item response theory–based score on the T-metric, with a mean of 50 and SD of 10. The norm scores for each of the PROMIS-29 health domains are based on samples representative of the U.S. general population in sex, age, race, ethnicity, and education.[25] A higher score indicates higher levels of the trait that is being measured. For instance, a higher score of depression indicates worse health, whereas a higher score of physical function indicates better health. With one exception, the score of 50 represents the mean of the norm that is representative of the general U.S. population. The sleep disturbance instrument is centered on a population who had a greater percentage of clinical populations than was present in the