

**ORIGINAL RESEARCH**

# Self-Reported Cognitive Concerns in People With Lower Limb Loss



Sara J. Morgan, CPO, PhD, Valerie E. Kelly, PT, PhD, Dagmar Amtmann, PhD, Rana Salem, MA, Brian J. Hafner, PhD

*From the Department of Rehabilitation Medicine, University of Washington, Seattle, WA.*

**Abstract**

**Objectives:** To investigate differences between self-reported cognitive concerns in people with lower limb loss (LLL) and normative data derived from the U.S. general population, and secondarily to determine whether there were cognitive differences based on amputation etiology or age.

**Design:** Survey.

**Setting:** General community.

**Participants:** A volunteer sample of persons with LLL (N=1086) resulting from trauma or dysvascular complications who regularly use a prosthetic limb.

**Interventions:** Not applicable.

**Main Outcome Measure:** The Quality of Life in Neurological Disorders Applied Cognition—General Concerns Short Form version 1.0 (Neuro-QoL ACGC), an 8-item self-report measure of general cognitive concerns.

**Results:** People with LLL reported significantly more cognitive concerns than the Quality of Life in Neurological Disorders normative sample. Mean Neuro-QoL ACGC scores were significantly lower than normative values ( $P<.001$ ) across subgroups defined by age (ie, <40, 40–49, 50–59, 60–69, and 70+ years) and subgroups defined by etiology (ie, traumatic and dysvascular LLL). However, there were no significant differences in cognitive concerns among age subgroups ( $P=.84$ ) or between the etiology subgroups ( $P=.58$ ).

**Conclusions:** When compared with the Quality of Life in Neurological Disorders normative sample, individuals with LLL report greater concerns with cognitive health. Cognitive concerns were not differentially affected by age or cause of amputation. The presence of cognitive concerns in people with LLL suggests a need to assess perceived cognitive function in order to tailor education and training in prosthetic use and care.

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Limb loss profoundly affects an individual's physical health and often requires the provision of complex rehabilitation services such as prosthetic care and physical therapy.<sup>1</sup> Common causes of lower limb loss (LLL) include dysvascular conditions (eg, peripheral vascular disease) and traumatic events (eg, motor vehicle collisions).<sup>2</sup> Although LLL has been traditionally viewed as a focused musculoskeletal condition, research suggests that people with LLL experience greater cognitive impairment (CI) than the general population.<sup>3,4</sup> In a review by Coffey et al,<sup>3</sup> CI in people

with LLL was attributed to 2 primary factors: the typical age of people with LLL and the common presence of comorbid conditions such as diabetes or dysvascular disease. In the United States, an estimated 54% of people with LLL experience amputation because of vascular conditions, and 42% of people with LLL are older than 65 years.<sup>2</sup> Older age,<sup>5</sup> diagnosis of diabetes,<sup>6</sup> and comorbid dysvascular conditions<sup>7</sup> have each been associated with a decline in cognitive function. Because previous research of cognitive function in people with LLL primarily involved older participants with LLL from dysvascular conditions,<sup>3</sup> little is known about cognitive functioning in people with LLL from nondysvascular conditions or in younger people with LLL. It is sometimes assumed that these individuals do not experience CI, but its presence in these subpopulations could have significant impacts on rehabilitative care.

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CI may manifest as deficits in learning, memory, and executive functions,<sup>8,9</sup> thereby increasing challenges with prosthetic rehabilitation. In addition to walking with a prosthesis, people with LLL need to properly don and clean their prosthesis, maintain prosthetic components, accommodate limb volume changes, address wounds, and manage pain. These activities require the cognitive ability to acquire, remember, and adapt new information.<sup>10</sup> The presence of CI is also associated with undesirable functional outcomes (eg, poor mobility, decreased prosthesis use, and loss of independence) among people with LLL.<sup>3,11-14</sup> As such, identifying and understanding cognitive issues in people with LLL may be critical to optimizing treatment and promoting long-term health outcomes. It is also important to know whether CI differentially affects people of different ages or LLL etiologies so as to inform which individuals may be candidates for cognitive assessment.

The aim of this study was therefore to compare self-reported cognitive concerns between persons with LLL and the general population. A secondary aim was to determine whether there were differences in cognitive concerns based on etiology or age. We hypothesized that people with LLL would experience greater cognitive concerns than a normative sample based on the U.S. general population. In addition, we hypothesized that people with traumatic LLL would experience fewer cognitive concerns than people with dysvascular LLL and that young people with LLL would experience fewer concerns than older people with LLL.

## Methods

### Participants

Volunteers with LLL were recruited using magazine advertisements, mailings, internet postings, and flyers located in clinics across the United States. Eligibility criteria were as follows: (1) age  $\geq 18$  years; (2) unilateral LLL below the hip and at or above the ankle; (3) no other amputations; (4) traumatic or dysvascular amputation etiology; (5) use of a prosthesis to walk; and (6) ability to read, write, and understand English. The enrollment target was 500 people with traumatic amputation and 500 people with dysvascular amputation. Study procedures were reviewed and approved by an institutional review board, and all participants provided informed consent.

### Procedure

Self-reported cognitive concerns were measured in a cross-sectional study conducted between December 2011 and November 2012. Data were collected during large-scale testing of candidate items for the Prosthetic Limb Users Survey of Mobility, a self-report measure of prosthetic mobility.<sup>15,16</sup>

Candidate participants were directed to a website for study information and self-screened by answering nonidentifiable

questions about the stated inclusion/exclusion criteria. Eligible participants were directed to the Assessment Center website (Northwestern University, Chicago, IL)<sup>17</sup> to complete the survey. Alternatively, candidates could contact research staff to be screened and, if eligible, receive a paper survey. Paper surveys were double-entered by research staff to minimize data entry errors.<sup>18</sup> Both paper and electronic surveys were reviewed by research staff for completeness and consistency. Respondents were contacted about missing data or potentially invalid responses.

### Survey

Participants' health outcomes were assessed with a self-report survey. The 8-item Quality of Life in Neurological Disorders Applied Cognition—General Concerns Short Form version 1.0 (Neuro-QoL ACGC) was included to evaluate perceived concerns with cognitive abilities, including memory, attention, and decision-making.<sup>19</sup> The Neuro-QoL ACGC includes items such as "I had to read something several times to understand it," and "I had trouble keeping track of what I was doing if I was interrupted." The Neuro-QoL ACGC solicits information from respondents about the frequency with which they experience cognitive concerns over the prior 7 days. Quality of Life in Neurological Disorders (Neuro-QoL) instruments (including Neuro-QoL ACGC) were developed using item response theory and have been tested in people without health concerns and in people with neurologic conditions, including multiple sclerosis, epilepsy, stroke, and Parkinson disease.<sup>20</sup> The Neuro-QoL ACGC is brief, has normative scores, and has demonstrated evidence of reliability and validity across a range of clinical populations.<sup>20</sup>

The Neuro-QoL ACGC was scored according to the developers' instructions.<sup>21</sup> Neuro-QoL T scores are centered on a normative sample mean  $\pm$  SD of  $50 \pm 10$ . A higher T score indicates that the respondent reports fewer cognitive concerns. Normative T scores for the Neuro-QoL ACGC item bank are based on a general population sample ( $n = 533$ ).<sup>19</sup>

In addition to cognitive health, participants answered questions about demographic (eg, age, sex, race, ethnicity) and clinical (eg, coexisting medical conditions, amputation etiology, amputation level) characteristics. Respondent age at survey completion was classified into 5 age categories (ie,  $<40$ ,  $40-49$ ,  $50-59$ ,  $60-69$ , and  $70+$  years) to assess the effect of age on cognitive concerns.

### Analysis

Demographic and clinical characteristics for the study sample were summarized using descriptive statistics. Neuro-QoL ACGC T score distributions were evaluated for normality using the Shapiro-Wilk test, and visual inspection of the histogram and quantile-quantile plot. Student *t* tests and chi-square tests were performed to assess differences in continuous and categorical characteristics between subgroups based on amputation etiology. To test the hypothesis that individuals with LLL report greater cognitive concerns than the Neuro-QoL normative sample, 1-sample *t* tests were used to compare the normative sample mean T score (ie, 50) to means of the overall sample and age and etiology subgroups. To test the hypothesis that individuals with dysvascular LLL report greater cognitive concerns than individuals with traumatic LLL, T scores were compared between etiology groups using Student *t* tests. Analysis of variance was similarly used to compare scores among the 5 age groups. An alpha level of .05 was used as the level of significance for all tests and was adjusted

#### List of abbreviations:

CI	cognitive impairment
LLL	lower limb loss
Neuro-QoL	Quality of Life in Neurological Disorders
Neuro-QoL ACGC	Quality of Life in Neurological Disorders Applied Cognition—General Concerns Short Form version 1.0
TBI	traumatic brain injury

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