PATIENT REPORTED OUTCOME MEASUREMENT INFORMATION SYSTEM PROFILES OF PERSONS WITH LOWER LIMB LOSS

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INTRODUCTION

In this modern era of evidence-based practice, clinicians are increasingly encouraged, expected, or required to use standardized instruments to document patient outcomes. The National Institutes of Health's (NIH's) Patient Reported Outcomes Measurement Information System (PROMIS) is a suite of reliable, precise, and clinically meaningful self-report instruments designed to measure varying aspects of physical, mental, and social health.[1] PROMIS instruments are freely available to orthotic and prosthetic (O&P) practitioners as item banks, short forms, or computer adaptive tests (CATs).[2] PROMIS instruments provide T-scores that are centered on US general population (mean=50, standard deviation=10). PROMIS scores for persons with various health conditions (e.g., cancer, traumatic brain injury, postpolio syndrome) have been reported, but PROMIS scores for persons with lower limb loss have not been published. This information is needed to put health symptoms and quality-of-life (QoL) indicators of persons with limb loss in context with the general US population and may guide use of PROMIS instruments in O&P care.

METHOD

The PROMIS-29 instrument, which includes items pertaining to physical function, anxiety, depression, fatigue, sleep disturbance, social role participation, and pain interference was administered as part of an NIH-funded study to develop the Prosthetic Limb Users Survey (PLUS). Respondents were recruited via clinic flyers, magazine advertisements, list-serv postings, consumer websites, and social networks. Selection criteria included 18 years of age or older, the ability to read and write English, unilateral amputation at or above the ankle and below the hip, traumatic or dysvascular etiology, and use of a prosthesis to ambulate. Surveys were administered online and on paper. Surveys also collected information related to respondents' general health, amputation, prosthesis, physical health, living environment, activity, assistive device use, mobility, balance, concentration, and demographics.

RESULTS

The PROMIS-29 instrument was administered to 942 persons with limb loss. Participants' mean age and time since amputation were 54 (SD=14) and 12 (SD=14) years, respectively. Participants were mostly male (70.9%) and Caucasian (80.1%). Participants reported using their prostheses 12 (SD=5) hours per day, on average. Survey respondents reported anxiety, sleep disturbance, and depression similar to the general US population. They reported significantly higher pain, increased cognitive concerns, and lower physical function, fatigue, and social role satisfaction (all p<0.0001) than the national norm (Figure 1).
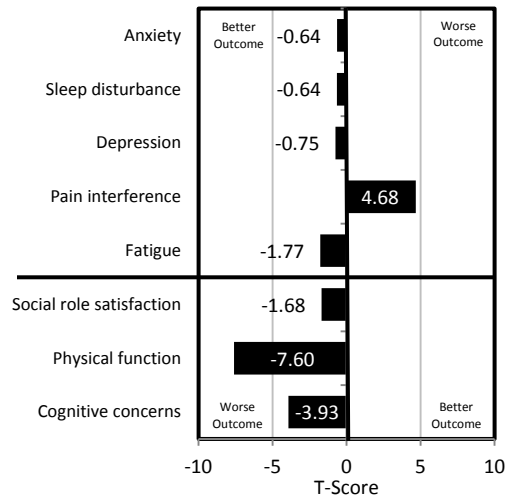

Figure 1. PROMIS profiles of symptoms and quality of life indicators of persons with lower limb loss relative to US general population.

DISCUSSION

Worse physical function, more pain, and reduced satisfaction with social roles would be expected in a population of users of lower limb prosthetics. Lower fatigue than the general population was not anticipated. We hypothesize that reduced capacity for physical activity and increased pain associated with limb loss lead to limited physical activity and, by extension, lower fatigue.

CONCLUSION

PROMIS-29 is an efficient tool for describing patterns of symptoms and QoL indicators for patients with limb loss. Comparisons to the US general population norms provide helpful context for interpretation of the scores of individuals with limb loss.

CLINICAL APPLICATIONS

Use of brief, standardized instruments like PROMIS-29 can inform clinical practice in O&P by measuring and documenting patients' perceptions of health and may serve to facilitate evidence-based care.

REFERENCES

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