A NATIONAL STUDY OF VETERANS AND SERVICE MEMBERS WITH UPPER LIMB AMPUTATION: SURVEY DEVELOPMENT AND PILOT TESTING

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BACKGROUND AND PURPOSE

Quality gaps in care to persons with upper limb amputation have been reported. Studies showing dissatisfaction amongst combat Veterans with upper limb loss led to calls for studies to understand needs and improve satisfaction. In 2016, a new longitudinal study was funded to address this gap. The new study includes both telephone surveys and in-person data collection. The purposes of this presentation are to describe the pilot work conducted to test and refine the survey for the new study and report preliminary results.

DESIGN AND METHODOLOGICAL PROCEDURES USED

The pilot study had two phases: survey development/cognitive testing to identify problematic items (Phase 1), and pilot testing of the full survey (Phase 2). The full survey was designed to assess demographics, amputation history, prosthesis use, function, quality of life, satisfaction with prosthesis and amputation care, quality of care, and included a risk-benefit assessment of technological advances requiring surgical intervention. The survey included new items, validated standardized measures, and items modified from a prior study. Cognitive testing and pilot testing resulted in refinements to the survey and a decision to administer by telephone only.

RESULTS

Phase 1 included 10 participants; 90% male, mean age 56 years, 30% with transradial (TR), 60% with transhumeral (TH), and 10% with shoulder level amputation (shoulder); 60 % were prosthesis users. Phase 2 included 13 participants; mean age 59 years, 92% male, 38% TR, 46% TH, and 15% shoulder; 77% were prosthesis users. Amongst Phase II prosthesis users, 60% used a bodypowered and 40% a myoelectric/hybrid. Seventy percent used two or more types of devices, and 60% used two or more types of terminal devices. Prosthesis users averaged

3.4 hours of use per day, and 40% were dissatisfied with their prostheses. Twenty three percent indicated that they would be willing to consider surgery for osseointegration, 54% for greater prosthesis control, and 31% for sensory restoration.

CONCLUSIONS/IMPLICATIONS

The refined survey is ready for use. Preliminary findings suggest that despite availability of multiple types of devices, there was a high prevalence of dissatisfaction with devices. At least half of pilot participants indicated their willingness to incur risk to obtain the benefits of a new or emerging prosthetic technology. Results of the full study will provide nationally representative data and ultimately may be used to improve the quality of care, provision of rehabilitation services and inform FDA regulatory approval.