Evidence Note | Upper-Limb Prosthetic Outcome Measures

■ By F. Virginia Wright, PT, PhD, Senior Scientist, Bloorview Research Institute; Chair in Pediatric Rehabilitation, Bloorview Children's Hospital Foundation; Associate Professor, Department of Rehabilitation Medicine, University of Toronto

Key Points

- The use of standardized outcome measures for adults with upper-limb (UL) amputations is uncommon in the published literature. Future methods to assess impairment, activity level, participation, and quality of life (QOL) should address all aspects of measurement development and validation. The Jebsen-Taylor Test of Hand Function (JTHF), Box and Block Test (BBT), Assessment of Capacity of Myoelectric Control (ACMC), Upper Extremity Function Scale (UEFS), and Trinity Amputation and Prosthesis Experience Scales (TAPES) are the measures with greatest psychometric strength for adult UL prosthetic (ULP) users.
- Greater advances in development of clinical measures and validation have been made for pediatric patients with UL amputations. The most promising measures are the Assessment of Capacity for Myoelectric Control (ACMC), University of New Brunswick (UNB) Test, Assisting Hand Assessment (AHA), Prosthetic Upper Extremity Function Index (PUFI), and ABILHAND-Kids. Future work should emphasize test-retest reliability, responsiveness, and how best to assess participation and quality of life (QOL).
- The measurement of individualized goals for client-centered rehabilitation has become increasingly popular. Two internationally known goal-measurement tools, the Goal Attainment Scaling (GAS) and Canadian Occupational Performance Measure (COPM), have strong psychometric properties with adult and pediatric rehabilitation clients. Application to adult and pediatric ULP practice is recommended.

Scope of the Review

This Evidence Note summarizes outcome measurements in adult and pediatric ULP users, recommends clinical measures, and proposes future research. Building and implementing systems of outcome measures that address the diversity of rehabilitation clients is complex.[1] This update to Wright's 2009 systematic review[2] aims to enhance the knowledge of clinical teams selecting measures.

Application to Prosthetic Clinical Practice

There is international consensus that interventions and outcome indicators must take the International Classification of Function and Disability (ICF) framework[3] into account. This means assessing outcomes related to body structure and functions (impairment), activity (carrying out tasks), participation (involvement in life situations), and QOL, as well as considering characteristics of the client (adult or child), family, and environment in both intervention and evaluation decisions.[6]

Ramstrand and Brodtkorb[4] encouraged comprehensive use of outcome measures across R&D, clinical, and research arenas.[5] A review of ULP literature from 1980 to 2006[6] emphasized the adoption of standardized outcome measures to better understand the impact of age at fitting, technology, training protocols, prosthesis use and abandonment, and to allow international outcome comparisons.

Summarizing and Evaluating the Evidence

Wright's 2009 systematic review[2] and an updated search including data up to September 2012 on MEDLINE, Cummulative Index to Nursing and Allied Health Literature (CINAHL), and RECAL were the primary sources for this Evidence Note. The published papers reviewed had to address use of an ULP measure or a generic measure (i.e., across diagnoses) in a measurement validation, clinical outcomes, or cross-sectional prosthetic study. A search of musculoskeletal-related hand or UL dysfunction measures was also conducted.[7–9]

Wright's work[2] devised a quality-rating form based on published guidelines[10,11] to evaluate psychometric strength of reviewed measures. The form focused on content validity, internal consistency, reliability, criterion validity, construct validity, responsiveness, floor/ceiling effects, interpretability, and respondent/administrative burden. There was no attempt to calculate a quality summary score since the evaluated attributes had varied levels of clinical importance.[10,11] Summary charts with ratings of excellent, good, fair, and poor for measurement attributes gave a picture of validation results. Adult and pediatric hand function, UL functional abilities, overall functional abilities, and QOL results were shown separately.

Summary of Evidence

Table 1 includes full names of the measures and their acronyms, along with the focus of each measure. Table 2 offers a list of new research since 2008, measures used, and focus of the work.

Adults

Eleven outcome measures (five amputee-specific and six generic) were evaluated: ACMC, Southampton Hand Assessment Protocol (SHAP), UNB, JTHF, and BBT for hand function; UEFS and the Disabilities of the Arm, Shoulder, and Hand (DASH) for UL-focused functional abilities; Nottingham Health Profile (NHP), Short Form (SF)-36 Health Survey, and TAPES for quality of life; and Patient-Specific Functional Scale (PSFS) for individualized goals. These 11 measures were identified from 18 papers and two review papers.[5,12]

i) Five Measures of Hand Function

The ACMC observational assessment[13,14] shows psychometric promise, but is limited to myoelectric users. The SHAP observational test[15] was designed for UL amputees and several case studies recommend it,[16-19] but it has not been psychometrically tested. The UNB Test,[20] a similar measure, focuses on prosthetic use regardless of device type, but it has not been reworked for use with adults. The JTHF[21,22] and BBT[22–24] are hand-dexterity tests with evidence of ULP reliability, minimum detectable change, and concurrent validity when used with veterans.[25] This validation work needs to be replicated for civilian UL amputees.

ii) Two Measures of UL Functional Ability

The UEFS module[26] is the single prosthetic-specific, self-report questionnaire in this category. Burger et al.[27] suggested that UEFS should include more difficult skills like those in the ABILHAND, PUFI, or UNB Test. A UEFS revision[27] performed well in Rasch analysis work, but is still limited because of its focus on one-handed activities. Since unilateral tasks do not indicate how the affected hand is used in activities that require both hands, UEFS likely will not detect change related to prosthetic modifications or improved skill. The observed ceiling effect noted with the original and Rasch-scaled UEFS suggests limited applicability to young adults with higher functional demands.[28] A recent evaluation of the original UEFS[25] showed good test-retest reliability, but a large minimum detectable change estimate that might limit its responsiveness.

DASH,[29] a well-validated, generic self-report questionnaire used by many UL-dysfunction clinical populations, showed evidence of construct validity with UL amputees.[29] DASH's strength is its sports and performing arts modules, which can target active individuals' issues.

iii) No Measures of Participation

There are no specific measures in this category.

iv) Three Measures of QOL

TAPES[30] is a sound QOL measure for lower-limb amputees, but may fall short for UL amputees. It has undergone detailed work to establish internal consistency and factor structure, but generalizability is limited because the sample was primarily older veterans. Unfortunately, the TAPES UL subscale has not been included in recent validation work.[25]

Generic QOL scales SF-36[31] and NHP[32] are reliable and valid measures in general adult populations. Preliminary literature has shown that NHP has potential with UL amputees, but SF-36 suffers from a serious ceiling effect.

v) One Individualized Measure

In a validation paper[25] that appeared after Wright's systematic review,[2] an individualized measure known as PSFS[33] was introduced to prosthetic outcomes measurement. The PSFS goal-set and associated scores were not reported since the measure was not used at the retest session and there is no further conclusion for use in ULP.

Pediatrics

Nine outcome measures (five amputee-specific and four generic) were identified: ACMC, Unilateral Below Elbow Test (UBET), UNB, and AHA for hand function; ABILHAND-Kids, Child Amputee Prosthetics Project-Functional Status Inventory (CAPP-FSI), and PUFI for UL-focused functional abilities; Pediatric Orthopaedic Data Collection Instrument (PODCI) for participation; and Pediatric Quality of Life Questionnaire (PedsQL) for QOL. These measures were derived from 21 papers and two review papers.[5,12] Recent studies used AHA,[34] CAPP-FSI,[35,36] or PUFI[34–38] as outcome tools, leading to a greater understanding of the performance of each. One publication looked at measurement properties[37] while the rest evaluated prosthetic use patterns or outcomes.

i) Four Measures of Hand Function

ACMC, UNB Test, and UBET were evaluated as prosthetic-specific measures and AHA as the non-prosthetic measure. As noted earlier, ACMC[39] shows psychometrical promise, but is limited to users of myoelectric prostheses. Assessor training demands may limit clinical application and its ability to measure change is unknown. Although the UNB Test[20] suffers from a lack of validation efforts, it has achieved clinical acceptance because it was developed before extensive psychometric evaluation was considered a high priority[27,40] for an outcomes tool.[41] Shortcomings relate to a potential ceiling effect,[27,40] as well as a linked issue of the UNB Test's ability to evaluate change.

UBET[42] was the weakest measure in the quality evaluation by Wright[2] in terms of validity. The validation study methodological issues further weaken the conclusions on reliability. Linder et al.[12] also placed it as one of the weakest measures.

AHA[43,44] showed promising test-retest reliability and the ability to measure change. AHA and PUFI were moderately correlated, providing additive information about a child's hand function.[43,44] Children scored low on AHA compared to PUFI, perhaps due to its focus on quality of performance rather than difficulty. Researchers must determine whether there is additional value to AHA with a prosthetic-specific hand function measure (e.g., UNB, PUFI).[45,46] While there has been extensive work with the AHA since 2008, it has focused on children with neurologically-based hemiplegia; there is no further information on AHA's measurement properties in prosthetics.

ii) Three Measures of UL Functional Abilities

CAPP-FSI and PUFI are amputee-specific measures, while the ABILHAND-Kids is a non-prosthetic measure. CAPP-FSI[47] showed early promise in formal establishment of validity. There was a gap in published use of CAPP, but it was recently used by Korkmaz et al.[36] in a six-month follow-up study of children with acquired and congenital UL amputations. This paper reported that CAPP-FSI and PUFI detected large gains in both groups.

PUFI[40,48] has undergone further validation work following the developers' initial studies.[40] Buffart et al.[45,46] confirmed the construct validity results presented by PUFI's developers and offered estimates of detectable change. There are early indications of its responsiveness to change.[36–38] Refinement of PUFI continues. Use in clinical settings demonstrated the need for a subscale score to assess performance ability in tasks performed using the prosthesis.[45] The version of PUFI with this new subscale was tested[35,37] and clearly proved its interpretive value. The greatest criticism of PUFI is the number of items the respondent has to complete.

ABILHAND-Kids[49,50] showed promising test-retest reliability and minimum detectable change when used with amputees, but whether this parent-report questionnaire provides an advantage over prosthetic-specific functional questionnaires is unclear. Recent work has demonstrated utility with children and adults with neuromuscular disorders[51] and it is also being studied for obstetrical-related brachial plexus injury.[52]

iii) One Measure of Participation

PODCI[53] is a generic parent-report questionnaire that was used in two studies of children with UL amputation.[45,46] This work did not assess its psychometric properties in ULP, but its strength with other pediatric orthopedic groups suggests it might be a useful measure. CAPE may provide a fuller picture of the breadth of children's activities, environment, social interaction, and enjoyment of activities.[54] This cross-diagnosis child/parent-report questionnaire is gaining acceptance for use with children with cerebral palsy,[55] has been used with children with lower-limb amputation[56] or brachial plexus injury,[52] and is validated in several languages. CAPE

is helpful when it precedes use of an individualized measure (e.g., COPM,[57,58] GAS[59,60]). Validation in ULP is still required.

iv) One Measure of QOL

PedsQL[61] is the sole QOL measure reported in pediatric UL papers, but its single-study use is insufficient to support its application. While the PedsQL is used in other pediatric arenas, the KIDSCREEN[62] better reflects current QOL thinking and is available free from its developers. However, it has only been tested with children with pediatric lower-limb deficiency.[56]

Discussion

Outcome evaluations of adult prosthetic users have traditionally addressed satisfaction or functional questionnaires/surveys[63–66] or documentation of wear-time estimates. These are often used in place of validated functional or QOL measures.[67–71] There also has been a focus on biomechanical- or impairment-based measures when assessing prosthetic hand usage.[72–74] The complexity of these devices demands this, but it misses the important link to function. The recent interest in revision of UEFS reflects the importance of a life-context functional abilities measure.[28] In contrast, in the pediatric literature, there has been a 20-year effort to create and validate new outcome measures and refine existing measures. Participation and QOL still face serious measurement gaps.

What explains the scarcity of specific measures for adult UL prosthetic users? It may be a general lack of use of functional outcome measures in the adult hand-rehabilitation population, a problem affected by the absence of "good" measures that align with rehabilitation goals, and limited clinician time to perform detailed hand assessments.[77] In contrast, the international pediatric-rehabilitation community has encouraged validation of outcome measures.

In the adult studies, there appeared to be risky assumptions that measures imported from other rehabilitation areas maintain their psychometric properties when transferred to prosthetics. Similarly, in pediatrics, use of generic pediatric functional measures (e.g., PODCI and PedsQL) has not been accompanied by disclaimers about lack of validation work in UL prosthetics.

Recommendations for a Core Set of Outcome Measures

Both observational hand-function scales and self-report functional questionnaires offer a broad picture of abilities[27,80] and help to identify prosthetic use operation and integration issues that a child or adult might face. In forming a core set of measures for a particular clinical group,[1] it is essential to prioritize areas of the ICF and consider the fit/suitability of available measures.[81] What outcome questions are important? Should we specifically evaluate hand function (e.g., with the SHAP, BBT, JHFT, or ACMC) or assess the UL prosthetic user as a whole as DASH does? Is it important to differentiate and consider hand/arm outcomes as well as participation and QOL outcomes? How do individualized goals fit in? How do the impairment measures that clinicians use link with the core set? How can clinician- and client-respondent burden be minimized?

It is worth noting that changes in one area of the ICF may not be correlated with or predictive of other changes.[82] Thus, do not assume that large changes in an individual's manual dexterity skills will lead to changes in work activity participation or QOL. Rather, measure each area if all three are essential.

As discussed elsewhere,[83] one approach to core set development might be to use two or more prosthetic measures, a participation questionnaire, and a QOL measure. Measures must have strong psychometric properties and adequate content fit. For example, if one thinks of a core set for evaluation of adults, ACMC, UEFS, and TAPES give reasonable ICF coverage, are designed for use with adult amputees, and have undergone a reasonable degree of validation. For myoelectric users, ACMC should help to assess prosthetic use skill. However, it will not apply to individuals using a body-powered prosthesis. To learn more about underlying hand skills, SHAP—which requires further validation—or a redeveloped adult-based UNB Test might be suitable.

How should the work activity, sports, or hobby needs of adult amputees be measured?[84] Is it time to construct and validate a high-level arm-function questionnaire using ABILHAND or PUFI as a foundation? Could an individualized measure (e.g., PSFS, COPM, or GAS) tap into priorities of prosthetic prescription and rehabilitation programs? For QOL evaluation, TAPES could be used for prosthetic use experience. A broadly-based QOL measure (e.g., NHP) also might be valuable.

There are more prosthetic-specific measures and potentially suitable generic outcome measures of participation and QOL to choose from when building a core outcome set for children. The well-established UNB Test shows promise regarding hand skills and integration of prosthetic use, although test-retest and responsiveness to change must be further evaluated. It is still unclear if AHA as a non-prosthetic measure offers enough outcome information. With myoelectric users, as with the adult core set, ACMC should be strongly considered. PUFI appears to have the most psychometric support for use as a parent- or self-report measure of hand- and arm-focused functional skills. Length is its chief limitation. An individualized measure (e.g., COPM or GAS) could tap into individual functional priority areas. There is insufficient data on measurement of participation or QOL to comment, although CAPE and KIDSCREEN may work well.

Future Research

Emerging technologies will provide more possibilities to individuals with UL deficiency. We must measure outcomes associated with these technologies in a comprehensive manner, using well-validated and appropriately targeted measures. It is only with this approach that we can fully understand the impact our interventions have on our pediatric and adult patients. This is a critical foundation for patient- and family-centered care, and facilitating best practice.

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