## WELL-BEING AMONG INDIVIDUALS WITH UPPER LIMB AMPUTATION IS STRONGLY CORRELATED WITH BIMANUAL UPPER LIMB FUNCTION, ACTIVITY AND PARTICIPATION LEVELS, PROSTHETIC SATISFACTION AND LOWER RATES OF PAIN INTERFERENCE

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### ABSTRACT

A retrospective analysis of 250 individuals with upper limb amputation or limb deficiency was performed to better understand the relationships being well-being and upper extremity function, activity and participation, prosthesis satisfaction and wear times and pain interference. Well-being, as a cumulative construct of quality of life and satisfaction was found to strongly correlate with self-reported physical function in bimanual tasks, self-reported activity and participation levels, self-reported satisfaction with prostheses and reduced pain interference. By contrast, neither age, gender, time since amputation nor reported prosthesis wear times were found to correlate with well-being in this population. While causality between these closely related and overlapping constructs may prove difficult to establish, their close relationships suggest that well-being in this population may be pursued through the thoughtful provision of an appropriate prosthesis and training to enable the performance of bimanual tasks tailored to the unique activity and participation needs of the individual.

### INTRODUCTION

Upper limb amputation and congenital upper limb deficiencies are associated with a number of disabling characteristics. In addition to the obvious functional deficits attendant with the absence of the affected extremity, these individuals contend with a spectrum of pain experiences and social stigma, and in the case of acquired amputation, a dramatic alteration in self-image and vocation.

Well-Being has been described as a blended construct combining the elements of quality of life and satisfaction.<sup>1</sup> The restoration of well-being among individual with acquired upper limb amputation can be reasonably considered a primary objective of rehabilitation. Importantly, it may be influenced by a number of interconnected variables including an individual's functional upper limb capacity, their activity and participation amongst family, friends and society, and their daily pain levels and experiences.

Individuals who have undergone upper limb amputation have reported reduced scores with respect to the physical elements of their quality of life relative to both population norms<sup>2</sup> and individuals with lower limb amputation.<sup>3</sup> Similar findings have been observed with respect to the related construct of satisfaction with life even when controlling for a range of potentially confounding variables such as age, gender, marital status and educational level.<sup>4</sup>

With respect to limitations imposed upon activity, Gallagher et al identified frequently encountered broad activity limitations for this population. These included getting dressed (52.9%), taking care of household responsibilities (52.9%), and day-to-day work/school activities (40.0%).<sup>5</sup> Additionally, in consideration of restrictions to participation, the most frequently identified restrictions have been suggested in employment or job seeking (91.7%), family life (41.2%), leisure/cultural activities (41.2%), sports or physical recreation (38.5%), shopping (35.3%), living with dignity (35.3%) and socializing (23.5%).<sup>5</sup>

With respect to upper limb function, following upper limb amputation MacFarland et al found greater difficulty associated with bimanual activities such as washing and drying dishes, and food preparation and lesser difficulty

associated with tasks that lend themselves to one-handed performance such as driving, brushing ones teeth, and opening and closing doors.<sup>6</sup>

Beyond the described constraints to function, activity and participation, this population frequently contends with a number of often overlapping pain experiences. These include phantom limb pain, residual limb pain and overuse pains experienced in the sound side extremity or torso. One or more of these pain experiences has been reported by as much as 90% of those with upper limb deficiency, with most reporting multiple, overlapping pain experiences.<sup>2,7</sup> While phantom limb pain and residual limb pain appear to be more prevalent, overuse pains have been reported as both more severe and disruptive.<sup>7</sup>

The provision of an appropriate upper limb prosthesis may influence well-being in this population by restoring a measure of upper limb function and enabling improved activity and participation levels. While individuals with unilateral upper limb deficiency tend to rely heavily on their sound side limb for upper limb function, bimanual function is indicated for many daily tasks and may be enhanced with an appropriate prosthesis.<sup>8</sup>

Satisfaction with a prosthesis appears to be very user dependent, taking into consideration such elements as appearance, weight and reliability. Available evidence suggests that different upper limb prosthesis types (eg, body-powered, myoelectric and cosmetic) appear to address different areas of satisfaction with no consistently preferred device type.<sup>8-9</sup> Rather, prosthesis satisfaction appears most influenced by amputation level, with great satisfaction associated with more distal amputation levels.<sup>9</sup> Within the constraints imposed by amputation level, optimizing prosthetic satisfaction may be a product of matching device characteristics with user priorities.

The purpose of this retrospective analysis was to better understand the relationships observed between well-being and upper limb function during bimanual tasks, activity and participation levels, satisfaction with a prosthesis, and pain interference amongst a convenience sample of individuals with unilateral limb deficiency distal to the shoulder and proximal to the wrist who utilize and upper limb prosthesis

#### METHODS

Using the Prosthesis Evaluation Questionnaire-Well Being,<sup>1</sup> patients rated their satisfaction with life (SAT) and quality of life (QOL) over the prior 4 weeks. Scores range from 1 to 10, with higher scores indicating higher levels of well-being.

To evaluate upper limb physical function, a previously assessed custom 9-item short form derived from the PROMIS®-UE v2.0 item bank was administered (PROMIS-9 UE).<sup>10</sup> Patients were asked to report the level of difficulty associated with each item using a discrete, ordinal scale ranging from 1 (unable to do) to 5 (without any difficulty). Items included such tasks as opening and closing a zipper, cutting food using utensils and lifting or passing heavy items. All items within the PROMIS-9 UE are bimanual activities. Bimanual activities were intentionally chosen to attempt to isolate those activities where prostheses would be more likely to influence upper limb function. Raw scores were converted to t-scores using the healthmeasures.net scoring service such that a score of 50 corresponds to the average scores of the United States population.

Additional patient reported outcomes included the 4-item short form of the PROMIS-Ability to Participate in Social Roles and Activities (APSRA). This construct aligns well with the considerations of activity limitation and participation restriction proposed by the International Classification of Function, Disability and Health (ICF). Patients were additionally asked to report prosthesis satisfaction using the Trinity Amputation and Prosthesis Experience Scales- Revised (TAPES-R), a single item of pain interference (PROMIS-Pain Interference), number of months since amputation, hours of daily wear time per, age, and gender.

To analyse the data, a multivariate linear regression model was run (forward enter method) with patient wellbeing as the predicted variable. Secondarily, in addition to the multivariate model, each variable was separately analysed through a univariate linear regression to assess individual effects. This retrospective database review was approved by Western Investigational Review Board (Protocol #20170059).

#### RESULTS

There were 250 individuals with upper limb amputation that had an outcome of record for analysis. The majority had a transradial or wrist disarticulation amputation (73.2%), and reported amputation due to trauma (38.8%, or 66.4% of those with reported etiology). Slightly less than half reported having an electronic arm (46.0%).

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The overall regression model was statistically significant (R = 0.675,  $F_{(8,241)} = 25.162$ , p < 0.001; Table 1).

| R=0.675                         | В      | Standard<br>Error | β      | t     | Р      |
|---------------------------------|--------|-------------------|--------|-------|--------|
| (Constant)                      | 2.280  | 0.980             |        | 2.33  | 0.02*  |
| Activity/Participation (APSRA)  | 0.077  | 0.019             | 0.335  | 4.03  | <0.01* |
| Prosthesis Satisfaction (TAPES) | 0.200  | 0.051             | 0.240  | 3.90  | <0.01* |
| Pain Interference (PROMIS)      | -0.328 | 0.114             | -0.190 | -2.88 | <0.01* |
| Physical Function (PROMIS-9 UE) | 0.028  | 0.014             | 0.152  | 1.94  | 0.05*  |
| Daily wear time (hours)         | -0.023 | 0.024             | -0.059 | -0.97 | 0.34   |
| Time since amputation (months)  | 0.000  | 0.001             | -0.009 | -0.15 | 0.88   |
| Gender (male)                   | -0.040 | 0.301             | -0.008 | -0.13 | 0.90   |
| Age (years)                     | -0.001 | 0.008             | -0.004 | -0.08 | 0.94   |

Table 1: Correlates to Well-Being among Upper Limb Amputees

### DISCUSSION

This retrospective analysis provides some insight into those factors that appear to correlate most strongly with improved satisfaction and quality of life among individuals with major upper limb amputation or deficiency. While causality cannot be determined, the relationships between these various constructs provide a foundation for how the rehabilitation of this population may be best approached.

We assessed physical function through a custom short form of the PROMIS measure of physical function that has been validated within upper limb prosthesis users (PROMIS-9 UE).<sup>10</sup> Because of the tendency for prosthesis users to default to their sound side extremity to perform many unimanual activities, the items included in the custom PROMIS scale are bimanual tasks. A limitation of this measure is that it does not inquire as to whether an individual task is performed with or without the use of the prosthesis. It is possible that some users may employ alternate strategies to complete some of the items on the short form. However, the bimanual nature of these tasks suggests that the engagement of a prosthesis would have been more likely for many if not all of our respondents, especially given the overlapping correlations with higher reported rates of prosthesis satisfaction.

We observed a strong relationship between self-reported bimanual physical capacity and well-being. By contrast, the correlations between well-being and daily prosthetic wear times were only modest. This is consistent with prior published observation. Ostlie et al observed that despite good demonstrated prosthetic skills and high levels of prosthetic satisfaction and perceived usefulness, individuals with upper limb amputation reported engaging their prostheses to complete only about half of their ADLs with a stronger tendency towards prosthetic use observed in bimanual activities.<sup>8</sup> Chadwell et al also reported no correlation between prosthetic proficiency and daily prosthesis use.<sup>11</sup> Thus, it appears to be the user's ability to perform bimanual upper limb tasks when necessary, rather than their actual prosthesis wear times, that is more closely related to the overarching constructs of well-being and quality of life.

The relationship between well-being, upper limb function, activity and participation scores and prosthesis satisfaction warrant further study and consideration. It may be that those individuals with higher levels of physical function were more able to participate in their social roles and activities and, as a result, reported higher satisfaction and quality of life. Alternately, it may be that those individuals who were managed with prostheses more closely tailored to their activities and various roles reported both greater prosthesis satisfaction and higher levels of activity and participation, collectively culminating in higher satisfaction and quality of life scores. Causality between these

interrelated factors may be difficult to ultimately assign. Rather, their close associations should be seen as a strong rationale to pursue bimanual function with a prosthesis tailored to individual activity and participation requirements.

The correlation between reduced pain interference and increase well-being aligns with clinical observation. Individuals with upper limb amputation and deficiency often report a range of pain types and intensities.<sup>2,7</sup> These can include residual limb pain, phantom pain and pain related to over-use in the sound side extremity and through the upper back, neck and torso. Any of these pain types can ultimately have profound impacts upon well-being that would be difficult to overcome.

#### CONCLUSIONS

The constructs of QOL and SAT have been represented in the broader construct of Well-Being. Our data suggest that greater levels of Well-Being are correlated with higher levels of functional capacity with bimanual activity as measured with the PROMIS-9 UE, higher levels of activity and participation as measures with the PROMIS-APSRA, higher levels of satisfaction with prostheses as measured by the TAPES-R, and reduced levels of pain interference. By contrast, daily reported wear times, times since amputation, age and gender failed to correlate strongly with Well-Being. Prosthetic capacity in bilateral function, facilitation of activity and participation, satisfaction with prostheses and managing the complex pain experiences that can occur within this population appear to be key considerations in enhancing their overall well-being.

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