DEMOGRAPHIC DIFFERENCES IN THE UPPER LIMB PROSTHETIC REHABILITATION EXPERIENCE

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ABSTRACT

This study aimed to evaluate trends in the prosthesis provision and training experience of individuals with upper limb absence and whether these trends were associated with any demographic factor. Furthermore, we evaluated whether the rehabilitation experience was associated with quality of life, health markers and other measures of rehabilitation success. Results of this study indicate demographic differences in upper limb prosthetic rehabilitation as well as trends in the effect of the prosthetic rehabilitation experience on patient outcomes.

INTRODUCTION

The loss of one hand can significantly affect the level of autonomy and the capability of performing daily living, working and social activities. [1] Degree of independence is one of the three indicators of Functioning, Disability and Health in the WHO International Classification [2] with maintenance of independence in activities of daily life being a key objective of post-amputation occupational therapy. [3] While determining the parameters which demonstrate "successful use" of an upper limb prosthesis is a complex topic, considering the myriad functions of the intact hand and the highly individual goals of potential users, [4] [5] degree of independence is a parameter in many functional performance measures. [6] This study aimed to identify demographic trends in individuals with upper limb absence associated with prosthesis use, rehabilitation and daily life. The results presented here indicate a strong association between gender and the prosthetic rehabilitation experience.

METHODS

Subjects

The study was recruited via email to the Amputee Coalition members database and displayed on the Amputee Coalition social media platforms. It is therefore assumed that the responses are majority North American in origin although respondent location or origin information was not recorded. Eligible participants were individuals over the age of 18 with unilateral or bilateral, acquired or congenital upper limb absence at any level. Subjects were eligible to participate in the study only once. Of a total n=309 individual responses, n=9 subjects did not complete the eligibility questions and were therefore not enrolled in the study. A further n=9 who were eligible to participate did not complete the study and were withdrawn due to incompleteness of the responses. A total of n=292 responses were included in the analysis.

Data Collection and Analysis

The study was a non-interventional, retrospective, cross-section design conducted with the approval of the NEIRB (#:120190122) consisting of a self-drafted online questionnaire and two validated outcome measures; Quick-Disability of the Shoulder Arm and Hand (QuickDASH), [7] and the EuroQol standardised measure of health status (EQ-5D-5L) [8]. Questions were grouped into categories as follows: personal demographics; prosthesis fitting and training history; current prosthesis use, activities and satisfaction; employment and activity trends. To evaluate differences in proportions, Pearson's Chi-squared significance test or the 2-sample significance test for equality of proportions were applied at a significance level alpha=0.05. Whenever needed, a continuity correction was applied for better approximations. All statistical analyses were conducted using R (version 3.6.2) software**.** [9]

RESULTS

Gender Demographics

A notable result of the study is the gender balance of respondents. It is generally accepted that the upper limb absence population trends to a male majority, [10] with females estimated to make up 20-30% of the total population. [10] [11] Conversely, in our study, female respondents were in the majority at 50.17% of the total population (46.49% male, 1.67% transgender or non-binary, 1.67% preferring not to answer). Acquired limb loss is understood to be more prevalent amongst males than females; [10] however, the prevalence of congenital limb deficiency (in the US) appears to be relatively equally distributed. [12]

In our study, 37.78% (n=57) of female respondents indicated their limb absence was congenital. Conversely only 11.85% (n=16) of male respondents indicated their limb absence was congenital. Although notable, this difference was not found to be statistically significant (p=0.06493). Congenital limb absence was indicated by 24.83% of the total respondent population.

Golden Period/First Fitting

The "golden period" in prosthetic rehabilitation is the concept that the earlier the prosthesis can be provided to a patient to use in training and therapy, the higher will be the rate of acceptance of the device and likelihood that the patient will become adept at using it as a helpful tool, [13] or be a "successful user". [5] The "golden period" is understood to be within 30 days of amputation [5] and was first introduced by Malone et al, 1984. [14] Despite this, it is known that achieving prosthetic fitment within 30 days of an upper limb amputation is challenging and is not achieved in many cases.

This was reflected in our study, in which only n=13 (4.51%) of respondents had their first prosthetic fitting within 30 days of their amputation. The most common duration between amputation and first prosthetic fitting was indicated to be ~6 months (n=59, 20.49%). In our study, those who indicated they were currently using a prosthesis were more likely to have had their prosthetic fitting at a time within six months of amputation (p=0.0008457).

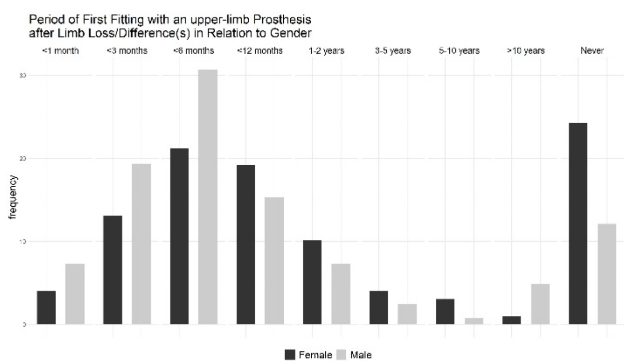

Figure 1: Time of First Fitting in relation to Gender

Females (n=38, 26.21%) were significantly less likely than males (n=71, 52.98%) to have received their first prosthetic fitting at a time within six months of amputation (p=4.646e-06). In fact, a greater frequency of females (n=24, 16.55%) than males (n=15, 11.1%) reported they had never been fit with a prosthesis, although a statistically significant difference (p=0.1973) was not found.

Reasons for Delay

Adjusting for those who perceived no delay in their prosthesis fitting (n=115. 40.49%), wound healing (n=72, 25.35%) and insurance coverage issues (n=64, 22.54%) were the most frequently indicated factors which had contributed to delay a prosthesis fitting. Interestingly, "no perceived delay" (40.49%) does not correlate with delay as reported by fitting period, if delay is considered as any fitting out-with the "golden window" (4.51%). Males were significantly more likely to report that "Physical readiness" (p=0.033) and "Wound healing" (p<0.001) caused a delay in their prosthetic fitting than females. Females were more likely to have their prosthetic fitting delayed by therapist availability issues than males (p=0.013).

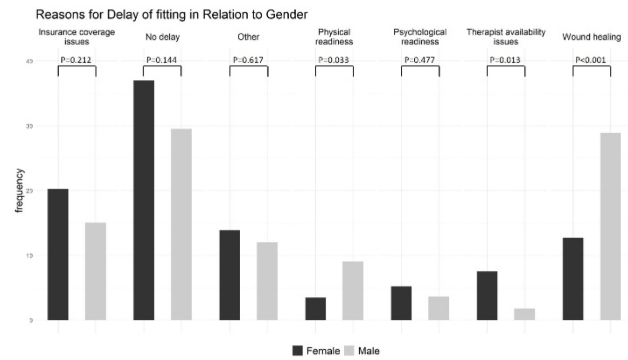

Figure 2: Reasons for fitting delay in relation to Gender

Training Received

In a systematic review, most included papers agreed that rehabilitation is vital to functional integration of upper-limb prostheses. [15] Despite the widespread agreement in the field there is a disparity between prosthesis provision and training. In our study only n=41 (14.24%) respondents reported they had never been fit with a prosthesis. However, n=102 (35.42%) of the total population reported they had never received training to use an upper-limb prosthesis, at a similar frequency to that reported by Ostlie et. al., 2012; 30.6% [16] and 31.1% [17]. In our study, those who had received prosthetic training were more likely to be currently using a prosthesis than those who had received no prosthetic training (p=4.053e-08).

Prosthesis Use

In our study, n=167 (58.80%) of respondents indicated they were currently using an upper limb prosthesis. A total of n=117, 41.20%, respondents indicated they were not currently using an upper limb prosthesis. In our study, although the frequency of males currently using any prosthetic device (n=85, 65.39%) was greater than the frequency of females currently using any prosthetic device, (n=76, 53.15%) this was not found to be statistically significant (p= 0.058).

There was a statistically significant difference in the types of prostheses currently used by male and females (p=0.000473). Evaluation of Pearson's standardised residuals indicate that the body-powered and passive functional prosthesis types had most influence on differences in gender. Body-powered prostheses are understood to be the most prevalently used type of device in the US. [18] It is believed that females have different requirements over their prostheses than males.[19] One study showed females to be more likely to use cosmetic devices and less likely to be users of actuated devices, as compared to males. [19]

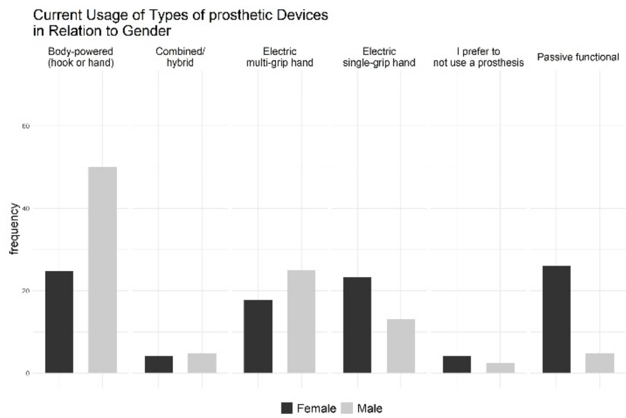

Figure 3: Current usage of types of prosthetic device used in relation to gender

Our study showed that the body-powered device was the most frequently used type of device by male respondents (n=42, 50.00%). In comparison female respondents used all device types relatively equally, body-powered (n=18, 24.66%), electric multi-grip and single grip combined (n=30, 41.10%); passive prostheses (n=19, 26.03%). Females used passive prostheses (n=19, 26.03%) at a greater frequency than males (n=4, 4.76%). Electric multi-grip and single-grip devices were used at an approximately equal frequency by both groups; females (n=30, 41.10%); males (n=32, 38.10%).

Differences in the rate of prosthesis use between males and females may be explained by a difference in the types of activities the prosthesis is required to be used for. This was not reflected in our study, in which there were no significant differences between males and females in terms of activities the prosthesis is used for.

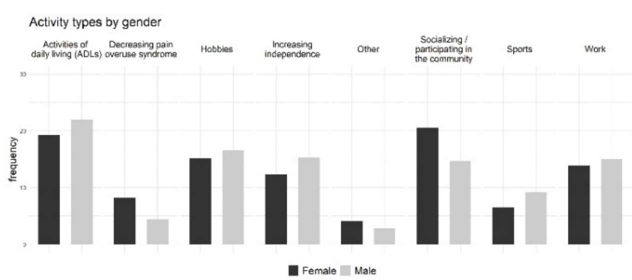

Figure 4: Activities prosthesis is used for in relation to Gender

Prosthesis Non-Use

Of the n=117 respondents who indicated they did not currently use a prosthesis, body-powered prostheses were the most frequently rejected type of device over-all (n=45, 38.46%) with electric multi-grip hands the least frequently rejected (n=14, 11.97%) over-all. There were no significant differences found in rejection rates by gender, which appear to approximately follow prescription rates.

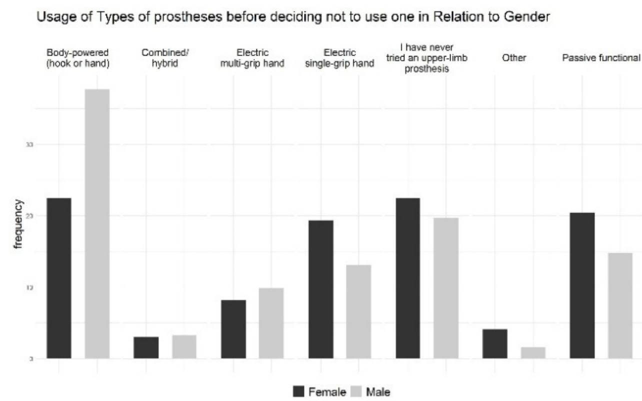

Figure 5: Usage of types of prostheses before deciding not to use one in relation to gender

Reasons for Non-Use of Prostheses

Some papers suggest that the higher rejection rate relates to a predisposition towards the aesthetics of the prosthesis in the female population, [12] inferring that prostheses do not provide aesthetic needs in females. In a further study, Biddiss & Chau reported that the type of prosthesis fitted (i.e. body-powered or myoelectric) did not appear to affect long-term use, but that passive devices were associated with higher rejection rates, [20] suggesting that insufficient functionality is also a key factor in cases of rejection.

In our study, reasons for not currently using a prosthesis were reported equally between genders in nine out of ten parameters. A significant difference was found for only one indicator, in that males were more likely than females (p= 0.014) to indicate they did not use a prosthesis because of insurance coverage issues.

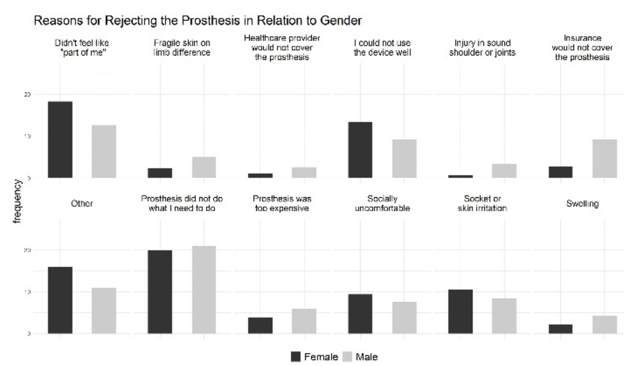

Figure 6: Reasons for rejecting prostheses in relation to Gender

In our study, the most frequently indicated reason for currently not using a prosthesis was functional. The reason “Prosthesis did not do what I need to do” was indicated by n=62 (52.99%) of our population not currently using prostheses.

DISCUSSION

The results of this study show that only 4.58% of respondents received a prosthesis within the “golden period” of 30 days from the time of amputation. Our study suggests that fitting within 6 months equates to a “better outcome” or greater likelihood of current prosthesis use, which supports current rehabilitation practices. Known challenges in the early fitting process were well represented in our study, with wound healing and insurance coverage issues being the most frequently reported. Interestingly, the most common response to this question was that “no delay to fitting” was perceived by the individual, which may be a result of expectation management by experienced clinical teams.

Our study revealed a statistically significant likelihood for those who had received prosthesis training to be currently using a prosthesis. This finding further cements the link between a thorough rehabilitation and training programme and a “better outcome” or greater likelihood of current prosthesis use. Further research is indicated to understand and alleviate specific barriers to fitting and training access.

Significant differences between genders were reported in the time to first fitting as well as perceived causes of fitting delay, however these barriers to treatment did not correlate to a significant difference in use of prostheses in daily life. These gender-associated differences in rehabilitation experience were surprising outcomes warranting further investigation. A further key observation in this study concerns the most common reason for rejection by both genders, “Prosthesis did not do what I need to do.” This finding may be linked to barriers to treatment including fitting delays and receipt of quality training, as well as a comment on the current availability of appropriate solutions for the entire upper limb absence population.

This study sets the stage for further investigation as it relates to the continuity of care of individuals with upper limb absence. The importance of the quality and expertise of prosthetic and rehabilitation providers cannot be overstated, meanwhile, routine collection of objective and subjective outcomes is essential for establishing evidence-based care pathways and solution development. Furthermore evidence-based decision making enhances both the ability of individuals with upper limb difference to make informed decisions relating to their prosthetic experience and rehabilitation care and hence informs third party reimbursement policy.

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