

The Stigma of Digital Amputation: A Survey of Amputees with Analysis of Risk Factors

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Abstract

Purpose: We aimed to quantify the stigma associated with digital amputation using the Neuro-QOL Stigma patient-reported outcomes instrument and examine the patient and injury factors associated with a more severe amputation stigma experience.

Methods: This descriptive retrospective cohort study analyzed 164 patients who underwent digital amputation. Records were reviewed for age at amputation, sex, indication, laterality, level, number of amputated digits, and a diagnosis of depression that preceded amputation. Enrolled patients remotely completed the Neuro-QOL stigma computer adaptive test, a battery of PROMIS instruments, and a questionnaire clarifying personal/injury details. Multivariable analysis was used to identify factors associated with a more severe stigma experience.

Results: Among 164 digital amputees enrolled, the observed mean Neuro-QOL Stigma score of 47.2 +/- 8 is slightly below the population mean of 50. Younger age, a worker's compensation claim, and a diagnosis of depression at the time of amputation are each independently associated with a more severe stigma experience after digital amputation. Neither socioeconomic variables, anatomic details of the injury, nor mechanism were independently associated with Neuro-QOL Stigma.

Conclusions: While we have previously targeted patients with more severe injuries for discussion of coping with physical stigma, our findings suggest that attention should perhaps instead be focused on digital amputees who are young, depressed, and/or involved with worker's compensation. A surgeon may be of service to the at-risk patient by offering referral to a mental health provider who can offer depression treatment and/or support the patient's process of coping and adjustment.

Introduction

Stigma is defined as "the situation of the individual who is disqualified from full social acceptance" [1, 2] and it involves both enacted and internalized components.[3] Enacted stigma refers to negative attitudes expressed by a community towards a person with a devalued characteristic, and may result in negative consequences like fear, avoidance, and/or discrimination. This enacted experience may result in internalized stigma, which is when this person comes to personally endorse the negative public attitudes such that they self-stigmatize.[3] This is associated with a variety of negative outcomes such as self-isolation, low self-esteem, poor self-efficacy, low quality of life, and failure to pursue employment and independence.[3]

Stigma may result from a variety of potentially devalued conditions including but not limited to behaviors, race/ethnicity, social status, and mental or physical disabilities.[4] Limb conditions including scarring, congenital differences, and amputations are known to carry stigma,[4-6] and there is evidence supporting the possibility of stigma associated with digital amputation.[7-9] In fact, the expectation of stigma for digital amputees has been cited as justification for noncritical replantation[7-11] and advanced prosthetic digit fabrication.[12-14]

Surveys of patients with stigmatizing conditions are an important part of understanding their stigma experience.[15-17] However, previous studies of digital amputation stigma have been limited to surveys of surgeons and the general non-amputee public regarding expectations and assumptions surrounding a theoretical amputee's experience. Given the potential implications for indicating replantation/digit preservation, or simply for counseling new amputees in an evidence-based manner, this absence of patient-reported data from digital amputees represents a meaningful deficit in the literature.

The primary objective of this study is to quantify the stigma associated with digital amputation using information gathered directly from digital amputees using the Neurology Quality of Life (Neuro-QOL) Stigma patient-reported outcomes (PRO) instrument. This is a computer adaptive test (CAT) which has been designed to measure the combination of both enacted and internalized stigma.[3] Although it was designed and validated in patients with neurological diseases,[3] it has been broadly applied including among patients with upper extremity conditions.[7-9] Furthermore, recognizing that digital amputees are a heterogeneous population, we aimed to examine the patient and injury factors (present at the time of amputation) associated with an individual's stigma experience. We also sought to evaluate how stigma correlates with other psychosocial and functional outcomes. Our primary hypothesis was that digital amputees would report stigma in excess of the population mean, and that age, mental health conditions, and injury severity would meaningfully impact the degree of stigma experienced.

Materials And Methods

This is a descriptive retrospective cohort study of digital amputees. After receiving approval from the Washington University School of Medicine institutional review board, CPT and ICD-9/10 databases were queried for all patients undergoing digital amputation or revision amputation between April 2010 and April 2020. Medical records were reviewed for age at amputation, sex, indication for amputation, laterality, level, and number of amputated digits. Depression that preceded the amputation (as evidenced by a formal diagnosis or documentation of a prescription for that indication) were recorded from the chart. The patient's home address was used to determine their area deprivation index (ADI), [18, 19] a measure of socioeconomic disadvantage and deprivation that has been used in several upper extremity outcomes studies (higher score represent greater deprivation).[20-23]

Inclusion criteria for study enrollment were one or more digital amputations sustained within the study period and age ≥ 18 years at the time of injury. Eligible patients were contacted by telephone. After a scripted explanation of the study it was requested that each patient complete a battery of electronically administered PRO questionnaires. Patients who were deceased, unable to be contacted, unwilling/unable to receive the PRO questionnaires, unable to provide informed consent, and those unable to comfortably communicate in English were excluded. Consenting patients provided an email or cellular phone number where they could receive a personalized and secure link to the study PROs instruments, which were administered remotely. The CAT questionnaires administered in this study were: Neuro-QOL Stigma v1.0 (CAT item bank available in **Appendix 1**), Patient Reported Outcome Measurement System (PROMIS) Anger v1.1, PROMIS Anxiety v1.0, PROMIS Depression v1.0, PROMIS Upper Extremity Function v2.0 (UE),

PROMIS Ability to Participate in Social Roles and Activities v2.0, and PROMIS Pain Interference v1.1, in addition to a short questionnaire clarifying handedness, ethnicity, education level, and worker's compensation (WC) status. All PRO instruments in this study have a reference population mean of 50 and standard deviation of 10, with higher scores indicating more of the concept being measured. For example, a Neuro-QOL Stigma score of 60 represents a high-stigma experience, which is one standard deviation in excess of the reference population mean.

Statistical methods

Explanatory variables were treated as dichotomous, interval, or continuous. Education was dichotomized (0=less educated, 1=more educated) based upon whether or not the patient had completed an Associate's degree or higher. The most proximal amputation level was dichotomized (0=distal, 1=proximal) based upon preservation (or loss) of the proximal interphalangeal joint in non-thumb digits and/or preservation (or loss) the proximal phalangeal head in thumbs. Comparison of means was accomplished using a two-tailed student's t-test. Intergroup comparison of proportions was accomplished using a chi-squared test. Bivariate relationships between all explanatory variables and the primary outcome variable (Neuro-QOL Stigma) were assessed using linear regression. Explanatory variables with bivariate p values ≤ 0.2 were entered into the multivariable regression. Multivariable analysis was achieved using stepwise regression. Correlation between primary and secondary outcome variables was assessed using Pearson's r. Statistical significance was defined as $p < 0.05$.

Conservative a priori power calculation revealed that in order to obtain 80% power for detection of a moderate effect size ($f^2 = 0.15$) [24, 25] in a multivariable model with up to 10 entrant explanatory variables, a minimum sample of 118 subjects would be required.

Results

Database query yielded 1109 patients with qualifying amputations. Exclusion for deceased status, unable to contact, unwilling/unable to consent, and failure to return questionnaires is detailed in **Figure 1**. 164 patients ultimately completed follow-up questionnaires. Demographic and injury details for the entire digital amputee cohort and the follow-up study cohort are compared in **Tables 1 and 2**. Compared to all qualifying digital amputees, the surveyed group is older, more likely to be white, less deprived, and more recently amputated. Furthermore, females and non-WC cases were over-represented in the follow-up group. 15/164 (9%) patients had a diagnosis of depression at the time of amputation. Mean Neuro-QOL stigma score in the follow-up cohort was 47.2 +/- 8. A histogram of Neuro-QOL Stigma scores for the sample is shown in **Figure 2**.

Patient and Injury Factors Associated with Stigma Experience

Bivariate analysis (**Table 3**) revealed that among all explanatory variables, younger age at amputation, higher ADI, less education, WC status, and a diagnosis of depression at the time of amputation are

associated with a significantly worse stigma experience after digital amputation. Neither sex, number of amputated digits, thumb involvement, amputation level, dominance of the injured side, nor a traumatic mechanism were associated with Neuro-QOL Stigma. Because the responding population was overwhelmingly (89%) White, the impact of ethnicity could not appropriately be analyzed.

Seven explanatory variables (age at amputation, ADI, education, depression, number of amputated digits, dominance of the injured side, WC status) had bivariate p-values <0.20 and thus met criteria for entrance into the multivariable model. Multivariable analysis (**Table 4**) revealed that among the seven explanatory variables entered into the stepwise regression, only three have independent associations with stigma experience, while the remaining variables do not have significant associations in the model. Specifically, younger age, a WC claim, and a diagnosis of depression at the time of amputation are each independently associated with a more severe stigma experience after digital amputation. The R² for this model is 0.15.

Relationship between Neuro-QOL Stigma and Secondary Outcome Measures

The primary outcome variable (Neuro-QOL Stigma) was found to have statistically significant relationships with other measures of patient outcome (**Table 5**). Unfavorable scores on PROMIS UE, PROMIS Depression, PROMIS Anxiety, PROMIS Anger, PROMIS Ability to Participate in Social Roles, and PROMIS Pain Interference, were all correlated with higher/worse degrees of stigma.

Discussion

This study reports the patient-reported stigma experience of digital amputees measured using the Neuro-QOL instrument. While the mean Neuro-QOL stigma score was slightly below the population mean, substantial variability was observed and a more severe stigma experience was found to be associated with older patient age, pre-existing depression, and a worker's compensation claim. Notably, neither socioeconomic variables nor injury characteristics were independently associated with stigma.

In a 2016 survey of both surgeons and the general public, Maroukis et al. [7] confirmed that non-surgeon American respondents had a strong preference for attempted replantation. Hand surgeons generally did not share this preference, and the reasons for this discrepancy were investigated. While both parties had similar expectations for the outcome of a successful replantation, there were striking differences in surgeon and non-surgeon expectations surrounding the patient experience after digital amputation. In addition to expecting greater functional impairment, the American public estimated that digital amputees experience substantial stigmatization. Specifically, 40.8% of the public agreed that digital amputees would be treated unkindly, and 18.4% agreed that they would be avoided by others, while less than 10% of surgeons agreed with either of these assertions.

This anticipation by the American general public that digital amputation is a stigmatizing injury has been substantiated by other authors,[8] and the avoidance of this stigma has been used to justify both non-critical replantation[26] and advanced digital prosthetics.[12, 14] Despite this, the only evidence

supporting the existence of digital amputation stigma comes from the suppositions of lay public and surgeons who have never had a digital amputation. The absence of information surrounding the stigma experience of actual digital amputees is a substantial gap in the literature.

In this population of 164 digital amputees, the observed mean Neuro-QOL stigma score of 47.2 +/- 8 is slightly below (indicating less stigma than) the population mean of 50. While the absence of pre-injury PRO data makes it impossible to definitively measure the impact of amputation upon stigma, this result can be reasonably interpreted as evidence that digital amputation is not highly stigmatizing to the average patient in our sample. However, as evidenced by the histogram in **Figure 2**, there was considerable variability in Neuro-QOL Stigma with scores ranging as high as two standard deviations above the observed mean. This inter-patient variability of stigma severity motivated our analysis of patient and injury factors that might predict an individual amputee's experience. Specifically, we focused on factors present and known at the time of injury such that this information could be used to identify at-risk patients who might benefit from anticipatory supportive measures.

Among the demographic, social, psychiatric, and injury variables examined, only younger age, social deprivation, low education, pre-existing depression, and a WC claim were found to have significant bivariate association with higher stigma. Multivariable regression clarified that among these, only younger age, a WC claim, and depression prior to the amputation were found to have significant independent association with Neuro-QOL Stigma. Using the unstandardized beta coefficients in **Table 4**, it can be approximated that an age decrease of 16 years is associated with a 2 unit increase in Neuro-QOL stigma, while worker's compensation involvement and prior depression are each associated with separate 4-point increases in Neuro-QOL stigma. Though the minimal clinically important difference for the Neuro-QOL stigma scale is not known, the combination of the factors above would be expected to influence a Neuro-QOL stigma score by an amount that approximates one standard deviation.

The finding that younger age is associated an increased perception of stigma is consistent with existing literature on the topic. In a study of 1,216 participants in the National Survey for Midlife Development in the United States, a significant interaction between greater stigma and younger age was observed.[27] The authors explained that with age, individuals are more strongly motivated to regulate their emotional well-being.[28] Thus, older adult may deemphasize stigma-based experiences and show greater emotional resilience relative to younger individuals.[27]

While we are unaware of previous studies examining the impact of depression on the stigma associated with amputation or other readily apparent physical differences, there is precedent for a relationship between these two factors in the chronic pain literature. Naushad et al observed that patients with chronic pain and depression reported greater chronic-pain related stigma than patients with depression alone, and concluded that "the presence of depression appears to be associated with greater experience of non-depression related stigma". [29] This observation is in agreement with the findings of the current study, wherein pre-existing comorbid depression was independently associated with increased patient-reported stigma. While the reason for this association is incompletely understood, analysis of stigma subscale

data in the study by Naushad et al found that depression was associated a greater need to hide their condition, and made patients more likely to perceive experiences as stigmatizing.[29] While the CAT data in our study are not suited to this type of sub-analysis, it is plausible that these effects might extend to the digital amputee population and cause depressed persons to conceal their amputation and/or perceive daily experiences as stigmatizing.

Given that WC cases have been associated with poor patient reported-outcomes in a wide variety of upper extremity conditions,[30, 31] it is not surprising that this factor is also independently associated with increased stigma after digital amputation. It has previously been argued that when an outside agency is playing such a large role in the administration of care, that patients are encouraged to remain in the sick role,[32] which could certainly include a perception (and/or over-reporting) of stigma.

Contrary to our hypothesis that functionally and aesthetically more severe injuries would be associated with increased stigma, we detected no impact of the number of amputated digits, level of amputation, involvement of the thumb, mechanism, or dominance of the injured side. Because concealability, disruptiveness, and aesthetic qualities are among the factors known to exacerbate stigma,[2] this finding was unexpected. We interpret this finding to mean that in digital amputees, patient factors rather than the anatomy/injury factors are the primary drivers of the stigma experience.

While this study was focused on the stigma experience of digital amputees, it is important to recognize that stigma as an outcome does not occur in isolation. In this sample, stigma was significantly correlated with other negative PROs including PROMIS measures of pain interference, depression, anxiety, anger, ability to participate in social roles and activities, and upper extremity function. While a detailed analysis of factors contributing to these specific PRO measures is beyond the scope of this paper, these moderate correlations ($r=0.54-0.69$) imply that in many cases, negative outcomes co-occur and likely share similar risk factors. This is consistent with existing evidence that stigma is associated with other negative outcomes,[3] and underscores the clinical relevance of this study.

The most substantial limitation of this study is incomplete follow-up and resultant response bias which was primarily due to inability to contact 54% of eligible patients, with refusal to participate (11%), and failure to complete a questionnaire after agreeing to do so (11%) as secondary contributors. The modest rate of patient enrollment (164/1109, 15%) is likely related to the 10-year range of eligibility for inclusion, which increases the likelihood that patients' contact information will be out of date. Compared to the entire eligible population, study participants were more likely to be female, white, older, less socioeconomically deprived, recently amputated, and involved in a WC case. This is generally in line with the findings of previous studies which indicate that younger age, male sex, and low income are predictive of survey non-response.[33, 34] The fact that 89% of respondents were white indicates that that conclusions should not be confidently generalized beyond this group. Furthermore, this single center study has not examined how amputation may affect the stigma experience in different cultures and/or regions. Given the reported negative associations with digital amputation in Eastern cultures,[7-9, 26] it would be illuminating to gather similar data in Asian and Asian-American populations.

Because this study lacks a non-amputated control group, we are somewhat limited in our ability to assess how the stigma experience of amputees differs from that of non-amputees. Fortunately, this limitation is mitigated by the design of the Neuro-QOL stigma scale which is centered around a reference population mean of 50. Detection of depression preceding amputation by way of chart review is a method that has been used in similar studies[35], but it is possible that cases could have been missed. Additionally, because the overwhelming majority of patients in this study (90%) had amputated only 1 or 2 fingers, it is possible that we failed to detect a real impact of more severe injury patterns affecting greater than two fingers. Finally, it should be noted that the Neuro-QOL stigma scale was designed for neurological conditions and has not been specifically validated to measure stigma associated with physical differences. Despite this, the questionnaire contains no condition-specific language, and elements of this questionnaire have been used in prior studies focused on digital amputation.[7-9]

In evaluating a patient's risk for a severe stigma experience after digital amputation, our data suggest that *who the patient is* may be more important than exactly *what happened to their hand*. While we have previously targeted patients with more severe injuries for discussion of coping with physical stigma, our findings suggest that attention should perhaps instead be focused on digital amputees who are young, depressed, and/or involved in a WC case. Though the effectiveness of anticipatory psychological support cannot be presumed, a surgeon may be of service to the at-risk patient by offering and encouraging referral to a mental health provider who can offer both depression treatment and/or support the patient's process of coping and adjustment. Future studies should seek to clarify the stigma experience of digital amputees in different cultures, investigate what specific measures can be used to mitigate negative outcomes in at-risk patients, and investigate how digital replantation affects the stigma experience.

Declarations

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Code Availability: NA

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Consent to Participate: All study enrollees provide consent to participate.

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Tables

Table 1: Comparison of Entire Digital Amputee Cohort and Follow-up Study Cohort (Continuous Variables)

Explanatory Variable	Entire Digital Amputee Cohort (n=1109)		Follow-up Study Cohort (n=164)		p
	Mean	Standard Deviation	Mean	Standard Deviation	
Age at Amputation (y)	47.6	17.3	51.6	16.4	0.006
Area Deprivation Index	61.7	23.6	50.9	24.1	0.000
Time Since Surgery (y)	5.1	3.0	4.4	2.9	0.000
Number of Amputated Fingers	1.5	1.1	1.4	1.1	0.281

Table 2: Comparison of Entire Digital Amputee Cohort and Follow-up Study Cohort (Dichotomous and Interval Variables)

		Entire Digital Amputee Cohort (n=1109)	Follow-up Study Cohort (n=164)	p
Gender	Male	884 (80%)	85 (52%)	<0.05
	Female	225 (20%)	79 (48%)	
Ethnicity	White	747 (67%)	146 (89%)	<0.05
	African American	343 (31%)	15 (9%)	
	Hispanic	5 (<1%)	0 (0%)	
	Asian	9 (1%)	2 (1%)	
	Native American	5 (<1%)	1 (1%)	
Thumb Amputation	Yes	216 (19%)	30 (18%)	0.720
	No	893 (81%)	134 (82%)	
Most Proximal Level (Non-Thumb)	Distal Phalanx	317 (29%)	42 (26%)	0.111
	Distal Interphalangeal Joint	152 (14%)	18 (11%)	
	Middle Phalanx	240 (22%)	16 (10%)	
	Proximal Interphalangeal Joint	133 (12%)	12 (7%)	
	Proximal Phalanx	217 (20%)	17 (10%)	
	Metacarpophalangeal Joint	171 (15%)	11 (7%)	
	Metacarpal	198 (18%)	25 (15%)	
Most Proximal Level (Thumb)	Distal Phalanx	83 (38%)	11 (37%)	0.574
	Interphalangeal Joint	56 (26%)	8 (27%)	
	Proximal Phalanx	44 (20%)	9 (30%)	
	Metacarpophalangeal Joint	24 (11%)	2 (7%)	
	Metacarpal	9 (4%)	0 (0%)	
Dominant Side Injury	Yes	341 (48%)	80 (50%)	0.652
	No	369 (52%)	80 (50%)	
	Unknown	388	4	

Mechanism	Trauma	828 (75%)	128 (78%)	0.349
	Other	281 (25%)	36 (22%)	
Workers Compensation	Yes	290 (28%)	32 (20%)	<0.05
	No	754 (72%)	132 (80%)	
	Unknown	65	0	

Table 3: Bivariate Relationships Between Explanatory Variables and Neuro-QOL Stigma

Explanatory Variable	Unstandardized Beta	Standard Error	Standardized Beta	R-Squared	p
Time Since Amputation (y)	-0.04	0.21	-0.14	0.000	0.855
Age at Amputation (y)	-0.13	0.035	-0.281	0.079	<0.05
Male Gender	-1.384	1.181	-0.092	0.008	0.243
Area Deprivation Index	0.058	0.024	0.184	0.034	<0.05
Education Level (Associate's or Higher)	-2.706	1.19	-0.179	0.024	<0.05
Depression at Time of Injury	4.2	2.03	0.161	0.030	<0.05
Number of Amputated Digits	0.818	0.53	0.12	0.140	0.125
Thumb Involvement	1.598	1.528	0.082	0.007	0.297
Proximal Amputation Level	0.39	1.19	0.026	0.328	0.743
Dominant Side Injury	1.731	1.191	0.115	0.130	0.15
Traumatic Mechanism	0.805	1.431	0.044	0.002	0.574
Worker's Compensation	4.7	1.45	0.25	0.060	<0.05

Table 4: Final Model for Neuro-QOL Stigma in Digital Amputees after Stepwise Multivariable Regression (Entered variables with bivariate p <0.2)					
R-Squared	Explanatory Variable	Unstandardized Beta	Standard Error	Standardized Beta	p
0.15	Age at Amputation	0.12	0.03	-0.25	<0.05
	Workers Compensation	4.00	1.42	0.21	<0.05
	Depression at Time of Amputation	4.22	1.93	0.16	<0.05

Table 5: Correlation Between Neuro-QOL Stigma and Other Functional and Psychosocial Outcomes			
Secondary PRO Measures		Pearson's r	p
PROMIS Upper Extremity Function		-0.56	<0.05
PROMIS Depression		0.69	<0.05
PROMIS Anxiety		0.61	<0.05
PROMIS Anger		0.56	<0.05
PROMIS Ability to Participate in Social Roles and Activities		-0.64	<0.05
PROMIS Pain Interference		0.54	<0.05

Figures

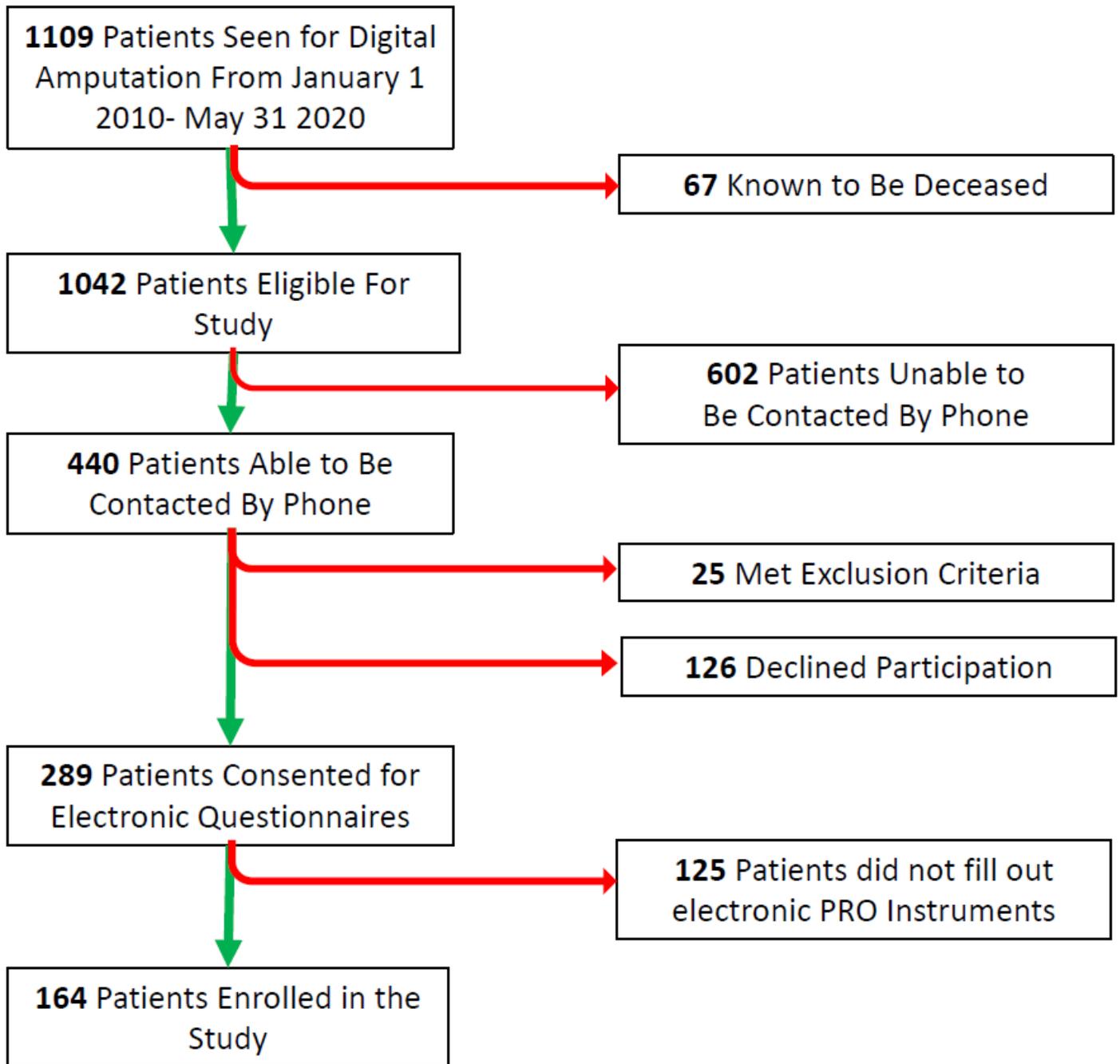


Figure 1

Flow diagram detailing eligible patient inclusion and exclusion from the follow-up group.

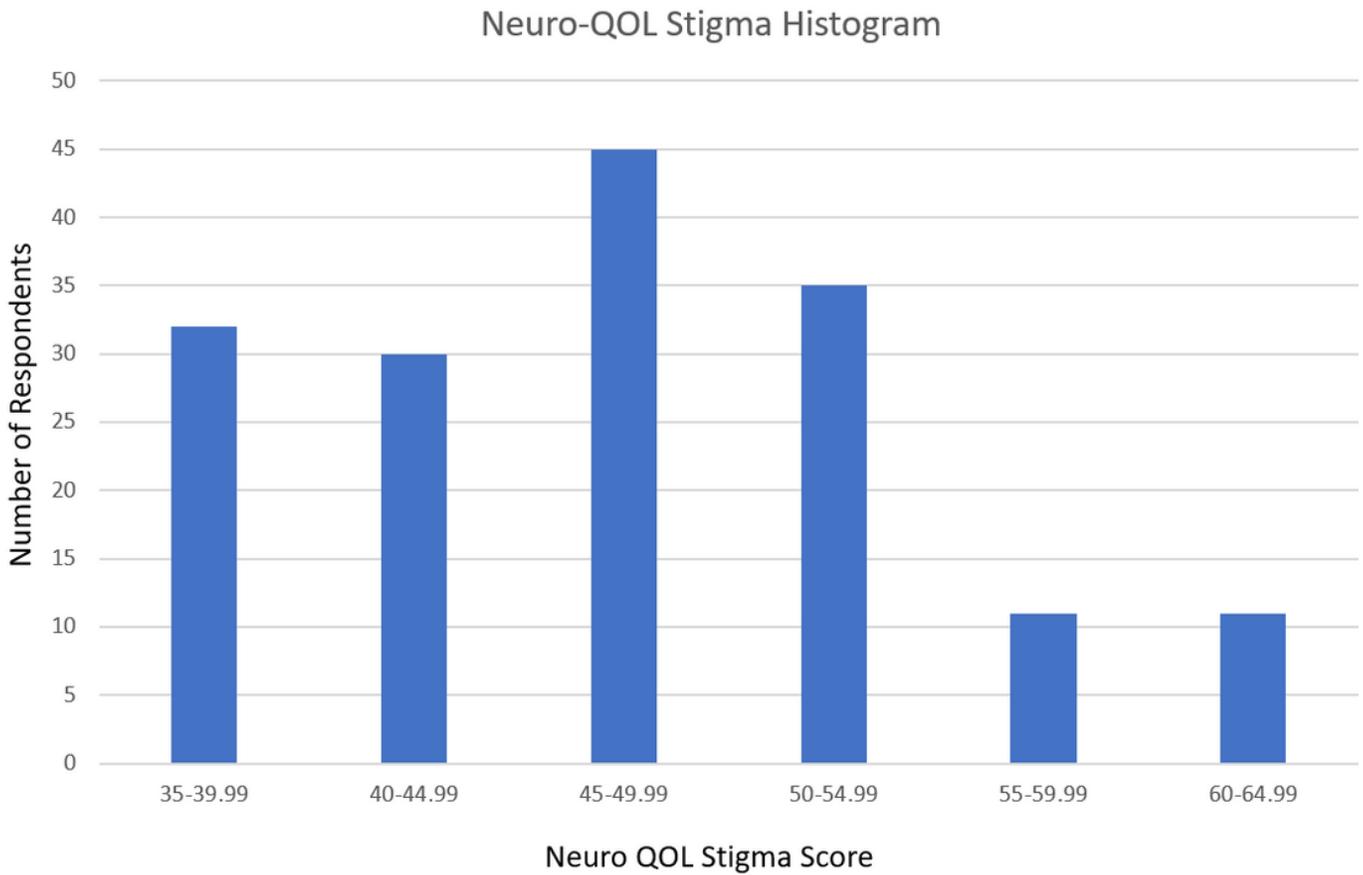


Figure 2

Histogram demonstrating the distribution of Neuro-QOL scores in the respondent digital amputee population.

Supplementary Files

This is a list of supplementary files associated with this preprint. Click to download.

- [Appendix1STIGMAItemBank.pdf](#)
- [SPSSDataAllRespondents.sav](#)