WHAT ARE OUR PATIENTS TELLING EACH OTHER THAT THEY AREN'T TELLING US?

A SOCIAL MEDIA CONTENT ANALYSIS EXAMINING PROMINENTLY USED OPEN SOURCE GROUPS ON SOCIAL MEDIA PLATFORMS FOR NOVEL SOLUTIONS TO COMMONLY EXPERIENCED PROSTHETIC PROBLEMS

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Anna-Clark Seibert, MSPO

University of Pittsburgh, 2018

Aim of the Study: The specific aims of this study were to investigate real-world social media interactions among the amputee community, targeting novel approaches to commonly experienced prosthetic problems. Potential areas of insight included information regarding challenges that were being faced, life hacks in use, advice being given across message boards, and negative impacts of their prostheses users experience that might be corrected with future research development if prosthetics practitioners were aware of the problems being discussed.

Background: Social media content analysis has been used in the Technology and Communications fields for years, but it has only recently been applied to healthcare. After a review of the literature it was determined that content analysis of social media has never previously been applied to the field of prosthetics and orthotics.

Methods: The approach was to examine specifically identified, open-access social media groups across multiple social media platforms, data-mining posts and coding the information accordingly in order to perform statistical analysis across groups, subject matters, and social media platforms. Topics of interest included common prosthetic problems, comfort, cosmesis, skin type, comorbidities, emerging technologies, phantom pain, and prosthetics life hacks.

Results: Statistical analysis was performed based on the numbers of postings pertaining to certain topics in order to compare data across social media groups, social media platforms, identifiable user demographics, and any other potentially pertinent relationships that could be analyzed. The outcomes for this project include the codes, the categories, and the resultant findings of the statistical analysis.

Conclusions: The most commonly identified problem within the data was comfort. Facebook data proved more likely to have posters sharing stories, posters on Reddit were more likely to be asking questions. Advertisements were more prominent on Facebook while research based posts were more common on Reddit. Life hacks were rarely discussed. Family members of amputees were more likely to discuss the injury location, cause, and comorbidities than amputees themselves were. Facebook posters were more likely to fall into the category of advocacy groups. Posters on Reddit were more likely to fall into the categories of health care providers, vendors, and those considering undergoing amputation surgery.

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PREFACE

For my husband Matthew Seibert: With immense gratitude and in special recognition of the support which you have lent me throughout this process, without which this endeavor would not have been possible.

1.0 INTRODUCTION

In the United States there are over two million people living with limb loss, and approximately 185,000 amputations occur every year. (Ziegler-Graham, MacKenzie, Ephraim, Travison, & Brookmeyer, 2008) The majority of amputations in the US are caused by complications due to vascular disease, although traumatic amputation and cancer both account for a percentage as well. (Amputee Coalition, 2017) The limb loss community is made up of around 30% upper extremity amputees and 70% lower extremity amputees (LeBlanc, 2008), with annual incidence rates of amputation occurring at around 1.2 - 4.4 per 10,000 people worldwide. (Ephraim, Dillingham, Sector, Pezzin, & Mackenzie, 2003)

1.1 AIM OF THE STUDY

As has often been shown in studies, the Reactivity Effect (as well as several other mechanisms which limit patient-practitioner communication) could very well be limiting what patients discuss with the health care providers, but the idea behind this study was that they might be more free and open in their discourse with each other.(Levitt & List, 2011)Traditional models -using surveys to directly ask patients about their experiences and their desires for future technologies- are abundant in the literature. When the archives of the Journal of Orthotics and Prosthetics was

searched for the keyword "survey," 28 results were populated just from publications within the last five years (search was conducted on March 15th, 2018). Similar studies span decades, and offer a plethora of information, however they may not be as insightful as practitioners often hope that they are. What if we could be the proverbial fly on the wall? What might we learn that we were previously unaware of? The intention of this study was to determine the answers to these questions. When viewed through the eyes of the optimistic, the results of such a study could potentially to open doors to future research, unlock new insights into the daily struggles of prosthetics patients, and the results could be beneficial to the advancement of the field.

Perhaps the biggest obstacle standing in the way of most prosthetics research is low subject/participant numbers. A social media content analysis eliminates this hurdle as the subjects are already conveniently grouped, en masse, from all corners of the internet in publicly accessible forums. The purpose of this research was to delve into the attitudes, ideas, and hopes of the social media minded prosthetics patient, to see what challenges are being experienced on a daily basis among the target population, what life-hacks are in use by the patients, what advice is being given across message boards to the patients, and what negative impacts from their prostheses they experience that might be corrected with future research and future development if only prosthetics practitioners were aware of the problems being discussed.

1.2 BACKGROUND RESEARCH

1.2.1 State of the Science

Social media content analysis has been used in the Technology and Communications fields for years, and it is widely used in politics, but it has only recently been applied to healthcare. As such, finding studies on which to base this study's methodology was difficult. Although the

application is new, it is likely to gain popularity within medical communities in the coming years. The hope is that the model defined by this research could be used for future studies, both within the field of prosthetics and orthotics as well as across the board in other healthcare communities, and help to make the idea of social media content analysis more accessible to various researchers who would not have previously considered such an undertaking.

1.2.2 Information Source

Two databases were used in order to search for relevant articles: PubMed and DovePress. PubMed is a searchable database comprising more than 26 million citations that is hosted by the National Center for Biotechnology Information, which is a division of the National Library of Medicine and the National Institute of Health. DovePress is a searchable database hosted by a United Kingdom based company that specializes in the consolidation and publication of peer-reviewed journals in the Science, Technology, Engineering, and Mathematics subjects, especially within the medical community. The databases were searched for relevant content from January 23 - February 22, 2017.

1.2.3 Search Strategy

When searching databases, a combination of Boolean operators and synonyms were utilized in order to maximize search results. The first step was to define the text words. The primary search vocabulary included "social media," "content analysis," "prosthetics," and "orthotics." From this point synonyms were defined in order to further expand retrievable results. "Twitter," "YouTube," "Facebook," "Instagram," "LinkedIn," "Reddit," and "Google plus" were all used to expand the search term "social media." The search term "content analysis" was expanded by also including searches for "qualitative review" and "literature review." These expanded synonyms were then strung together in over fifty combinations using "AND" as the operator in order to maximize the likelihood of applicability and the relevance of the returned results. Examples for searches in PubMed and Dove Press can be found in Tables 1 and 2.

Table 1: PubMed Search Results

Query	Items found
Search ((((((social media AND qualitative review)))) AND (prosthetics OR orthotics))))	0
Search ((((((social media AND literature review)))) AND (prosthetics OR orthotics))))	0
Search ((((social media AND content analysis)))) AND (prosthetics OR orthotics)))	0
Search (((qualitative review) AND (prosthetics OR orthotics)))	8
Search ((qualitative review) AND prosthetics) AND orthotics	3
Search (((literature review) AND (prosthetics OR orthotics)))	734
Search ((literature review) AND prosthetics) AND orthotics	91
Search (((content analysis) AND (prosthetics OR orthotics)))	20
Search ((content analysis) AND prosthetics) AND orthotics	8
Search (twitter) AND qualitative review	12
Search (youtube) AND qualitative review	7
Search (linkedin) AND qualitative review	1
Search (facebook) AND qualitative review	12
Search (google plus) AND qualitative review	9
Search (instagram) AND qualitative review	0
Search (reddit) AND qualitative review	0
Search (twitter) AND literature review	99
Search (youtube) AND literature review	51
Search (linkedin) AND literature review	7
Search (facebook) AND literature review	99
Search (google plus) AND literature review	122
Search (instagram) AND literature review	3
Search (reddit) AND literature review	0
Search (twitter) AND content analysis	189
Search (youtube) AND content analysis	90
Search (facebook) AND content analysis	132
Search (google plus) AND content analysis	5
Search (linkedin) AND content analysis	2
Search (instagram) AND content analysis	14
Search (reddit) AND content analysis	2
Search (((social media AND content analysis))) AND (prosthetics OR orthotics)	0
Search (reddit) AND orthotics	0
Search (reddit) AND prosthetics	0
Search (instagram) AND orthotics	0
Search (instagram) AND prosthetics	0
Search (linkedin) AND orthotics	0
Search (linkedin) AND prosthetics	1
Search (google plus) AND orthotics	0
Search (google plus) AND prosthetics	0
Search (facebook) AND orthotics	0
Search (facebook) AND prosthetics	0
Search (youtube) AND orthotics	0
Search (youtube) AND prosthetics	0
Search (twitter) AND orthotics	1
Search (Twitter) AND prosthetics	0
Search ((social media) AND prosthetics) AND orthotics	0
Search (social media) AND prosthetics	2
Search (social media) AND orthotics	1
Search (social media) AND qualitative review	123
Search (social media) AND literature review	1560
Search (social media) AND content analysis	911

Table 2: DovePress Search Results

Search	Add to builder	Query	Items
1	Add	((((((twitter) OR instagram) OR youtube) OR facebook) OR google plus) OR reddit) OR linkedin	13
2	Add	((reddit) AND (content analysis OR literature review OR qualitative review))	0
3	Add	((instagram) AND (content analysis OR literature review OR qualitative review))	0
4	Add	((linkedin) AND (content analysis OR literature review OR qualitative review))	0
5	Add	(linkedin) AND (content analysis OR literature review OR qualitative review)	0
6	Add	(google plus) AND (content analysis OR literature review OR qualitative review)	0
7	Add	(youtube) AND (content analysis OR literature review OR qualitative review)	0
8	Add	(facebook) AND (content analysis OR literature review OR qualitative review)	0
9	Add	(twitter) AND (content analysis OR literature review OR qualitative review)	0
10	Add	(twitter OR reddit OR instagram OR google plus OR facebook OR linkedin OR youtube) AND (content analysis OR literature review OR qualitative review)	0
11	Add	(prosthetics OR orthotics) AND (content analysis OR literature review OR qualitative review)	0
12	Add	(social media) AND (content analysis OR literature review OR qualitative review)	0
13	Add	(prosthetics OR orthotics)	19
14	Add	(reddit) AND (prosthetics OR orthotics)	0
15	Add	(instagram) AND (prosthetics OR orthotics)	0
16	Add	(linkedin) AND (prosthetics OR orthotics)	0
17	Add	(google plus) AND (prosthetics OR orthotics)	0
18	Add	(facebook) AND (prosthetics OR orthotics)	0
19	Add	(youtube) AND (prosthetics OR orthotics)	0
20	Add	(twitter) AND orthotics	0
21	Add	(twitter) AND prosthetics	0
22	Add	social media	16
23	Add	(social media) AND orthotics	0
24	Add	(social media) AND prosthetics	0
25	Add	(social media) AND qualitative review	0
26	Add	(social media) AND literature review	0
27	Add	(social media) AND content analysis	0

1.2.4 Search Results

After a review of PubMed and DovePress using the defined key words and their various combinations, it was determined that content analysis of social media has never previously been specifically applied to the field of prosthetics and orthotics. It was also determined that, while there have been studies in other healthcare fields related to social media use, there was no specific methodology that has been used that lends itself well to mimicry for this study.

Of the studies related to social media conducted thus far in the healthcare fields, few were looking at variables such as could be considered similar to this study's design. Those studies that were most useful towards the design of this methodology and the refining of this study are summarized below.

Tasnima Abedin et al. looked at comment threads in Facebook groups, analyzing for usefulness of commentary as a rubric for the potential use of Facebook as a tool for dissemination of information regarding diabetic foot care. They found that social media could be a useful platform for patient education, though it is currently underutilized and the amount of misinformation is, unfortunately, currently high. They encouraged healthcare teams to get involved in the dissemination of diabetic foot care information on social media, and to provide help to those patients using social media as a means to answer their diabetic foot care questions. (Abedin et al., 2017)

Sinnenberg et al. performed the first systematic review of Twitter-based studies, developing a new taxonomy to describe its use in health research. In their research, they found that most studies performed have so far either analyzed the content of tweets or monitored the volume of tweets regarding specific topics. Of over 1,000studies mentioning Twitter, 137 were analyzed in their review, most of which had been published in the previous two years. The fields in which healthcare related Twitter-based studies have so far been conducted include public health, infectious disease, behavioral medicine, and psychiatry. Twitter-based health research is still fairly new, but clearly a growing concept, and Sinneberg et al. suggested that many "distillable features" including user demographics are currently underutilized in Twitter-based health research and provide avenues for future research. (Sinnenberg et al., 2017)

Marcon et al. used Twitter's Search Application Programming Interface to examine the public opinions surrounding spinal manipulation therapy (SMT) and the presence or absence of critical information regarding the technique in Twitter debates on the subject. While they found an abundance of tweets singing the praises of the technique, they found very little discussion concerning the efficacy or risks of the practice. They drew the conclusion that, while discussion was taking place regarding SMT and chiropractic care, the information available on the platform was "far from balanced or informed." (Marcon, Klostermann, & Caulfield, 2016)

Rozenkrantz et al. scanned the content of available YouTube videos that came up following certain search terms in order to analyze their usefulness in patient education regarding imaging examinations. They found the availability of educational YouTube videos regarding common imaging examinations to be high, as well as the interest in those videos, and determined that YouTube could be utilized as a valuable patient resource, however the videos mostly focused on patient experience. While this is not necessarily a negative focus, they pointed out that very few videos reviewed mentioned health or safety risks or talked about the role of the radiologist during the procedure. With the deficiencies that they noted in the available videos' composition, they offered many suggestions for future improvement to imaging related YouTube content and lauded the platform as a useful source for patient information.(Rosenkrantz, Won, & Doshi, 2016)

Chou et al. examined the impact of social media on health communication in the United States by identifying the sociodemographic factors and health-related factors that are associated with social media use. Their data stemmed from a 2007 Health Information National Trends Study, which is survey based. Participants who acknowledged having access to the internet were subsequently asked whether they had participated in an online support group, written a blog, or visited a social networking site in the past year. The data collected showed that 69% of American adults report having internet access, of which 5% participate in online support groups, 7% blog, and 23% utilize social media sites (numbers which have likely increased since the publication of this research). Younger adults reported more frequent use, and age seemed to be the only significant influencing predictor of use of social media and blogging. Support group predictors, by contrast, included age, a personal history with cancer, and poor overall health. They found overall that social media use was not influenced by education, race, ethnicity, or health care

access, and therefore its reach as a health communications tool is only limited by the age group towards which the information is targeted. (Chou, Hunt, Beckjord, Moser, & Hesse, 2009)

The study with the most similar research design to this project was a study performed by Dr. Michelle Litchman and colleagues involving the use of Instagram hash tags to track insulin pump placement locations(Woodruff, Arrington, & Litchman, 2017), which has been presented at a conference but has not yet been published. (Litchman, 2017) She has graciously agreed to join the thesis committee for this project and assist in the development of an appropriate methodology.

As such, a new model was devised by the team and explained for the purposes of the completion of this study, as well as for potential future use in similar studies across the healthcare fields.

2.0 SPECIFIC AIMS

The specific aims of this research study were to investigate real-world social media interactions among the amputee population, to uncover and disseminate novel approaches to commonly experienced prosthetic problems. Discovering challenges that patients were discussing, or information about what doesn't work for our patients was also investigated as this information could provide valuable insights and lead to useful data. Statistical analysis performed across groups, subject matters, social media platforms, and across certain specific patient populations aimed to answer the main research question by discovering what our patients were discussing within these forums, how those discussions differed across platforms and pages, and gaining insights into those areas which might benefit from future social media content analysis or altered research methodology.

3.0 METHODS

The approach was to examine specifically identified, open-access (non-private) social media groups across multiple social media platforms, data-mining discussions that are taking place and coding the information accordingly in order to perform statistical analysis across groups, subject matters, social media platforms, and across certain specific patient populations.

The proposal for this research project went before an Internal Review Board (IRB) in August of 2017, and was approved in November of 2017. The first step after IRB approval was obtained was to determine the specific populations to examine, which involved determining which social media platforms to investigate, and the groups to analyze within those platforms. This was determined by comparing the number of members within the social media groups first and foremost, as a higher number of group members improved the likelihood of higher amounts of data (number of postings) available for collection. The frequency of postings, and the average number and frequency of responses, were also considered when determining which social media groups to utilize for the study. Those groups with the highest usage were analyzed in order to access the largest amount of potential data.

It is notoriously difficult to identify population characteristics on social media. It can be impossible to identify the age of the participant, their race, or their gender, but most importantly for our purposes: it can be impossible to determine whether the person commenting is an amputee, a caregiver, a medical provider, or even a casual observer, so for this style of research it was most beneficial to group the users together and analyze their data collectively. A recent study on this very subject attempted to differentiate between social media users with disabilities and non-representative users without disabilities on Reddit. Yu and Brady compared amputees with non-amputees in terms of linguistic behavior, online interactions, and community

characteristics in order to develop a feature extraction method to classify users and detect amputees with 88% accuracy in amputee related subReddits. (Yu & Brady, 2017) Though their extraction feature was not utilized for this research, it could potentially be utilized in future studies to better identify the prosthetics user community within social media pages related to amputee support. When possible, if the information was specifically stated, the poster type was coded in order to draw comparisons when feasible by looking only at those specific postings in which the poster identified themselves as living with an amputation, being the family member of an amputee, etcetera (etc.).

No individual user profiles were analyzed, and no user profiling was specifically conducted beyond those user characteristics which were explicitly identified within the parent post. As such, it is impossible to know how many unique posters were analyzed in the study, as post origins were not identified. It is only possible to know the numbers of posts which were coded and the population characteristics defined within those posts. This was done in order to remain true to the IRB specifications and to preserve user anonymity.

By utilizing a veteran specific social media group, it was possible to analyze military veterans against the population at large. A veteran specific group was chosen intentionally in order to look more in depth at this population and compare it to the population at large.

3.1 DATA SOURCES

Social media sites chosen for inclusion in the study were Facebook and Reddit, as they have a similar posting layout/style with a tabulated number of likes and comments which makes coding them using the same techniques possible and their data comparable. Two groups were chosen from each site for data collection. The four groups chosen for final inclusion in the study were the main Amputee Coalition Facebook community page (https://www.facebook.com/pg/AmputeeCoalition/community/?ref=page_internal), as it has the highest total number of members and is one of the most active Facebook pages among amputees

with 116,000+ total followers, the Blesma: The Limbless Veteran Facebook community page (https://www.facebook.com/pg/blesma/community/?ref=page_internal), as it is the most highly populated Facebook page among veterans specific to the amputee population with 27,000+ total followers, the amputee specific SubReddit (https://www.reddit.com/r/amputee/), as Reddit has a high volume of postings made daily and is aimed at specific/niche populations of readers, and lastly the prosthetics specific SubReddit (https://www.reddit.com/r/Prosthetics/), as adding a secondary SubReddit specific to the amputee/prosthetics user populations increased the total amount of collectible data in order to better compare the Reddit posting population(s) to the Facebook posting population(s) and their subsequent user communities.

3.2 DATES OF DATA INCLUSION

Only postings made within a specified timeframe were analyzed. Upon submission to the IRB, one calendar year previous to the submission date was chosen for inclusion in the study in order to maximize the potential for relevant data. Posts older than one year from the submission date were not included as they were more likely to contain outdated information, and posts that were made more recently than the date of IRB submission were excluded as they did not fall within the IRB parameters of only including data within the study that existed upon application for IRB approval. This was done primarily to preserve the relevancy of the posts being identified, to ensure a successful IRB approval process, and also to maintain the proposed timeline for completion of the project. The dates from which posts were collected as data spanned from August 15, 2016 - August 15, 2017.

3.3DATA COLLECTION

Once target groups were identified and inclusion dates were specified, data collection began. The content of all parent posts made across the selected social media groups within the specified timeframe was collected -along with information such as the date and timestamp of the posting, the total numbers of likes, shares, and comments, and the source URL of any images or videos that were attached to the initial posting- into a centralized excel document, with each post being numbered in the order in which it was collected (oldest post to most recent post) from each individual social media site. Only parent posts (also known as "seed posts") were collected, as replies and subsequent comment threads would have added more data than could feasibly be coded and analyzed within the proposed timeframe of the study's completion. Each post was then assigned a unique ten digit post ID number.

This ID number was generated by combining the date of the post (first five digits), the ones value of the time at which the post was generated to the minute with seconds entered as 00 (6th digit), and the last four digits represent the ones value of the posts total number of likes, shares, and comments, in that order, followed by the ones value of the number posting which that post represented out of the total number of posts from that specific social media source (for example, the first post collected from a specific site would be "1" whereas the fifty first post collected from that site would be "51," the ones value for both posts being the same).The final function used to calculate this ID number using these parameters was:

```
=TRIM(“Date”)&RIGHT(“Time”,1)&
RIGHT(“Likes”,1)&RIGHT(“Shares”,1)&
RIGHT(“Comments”,1)&
RIGHT(“Post #”,1).
```

The generated ID numbers were checked for duplicates at multiple stages of the function inclusion by performing a data copy of all of the ID numbers into a new excel document, and then selecting "Data: Remove Duplicates" and looking at the total number of duplicates which were removed. It was found that simply including the dates and timestamps was not complex

enough to ensure that there were no duplicates. As such, additional parameters were added and subsequent duplication checks were performed until there were no longer any repeated numbers and the final function for the ID generation (enumerated previously) was created. When the total number of duplicates removed equaled zero, enough parameters and digits had been incorporated into the ID number to ensure its uniqueness. Once all of the data had been collected and assigned a unique ID number, it was ready to be coded.

3.4 DATA CODING

Content analysis research "is like a box of chocolates, you never know what you're going to get." (Zemeckis et al., 1994)The anticipation was that discussions were taking place among the amputee population within the confines of these social media groups regarding key issues in prosthetics. After all, these communities exist for prosthetics patients to share their stories, their struggles, their successes, to ask questions, to get answers, and to enjoy a sense of camaraderie in circumstance. Areas that were considered likely topics of discussion included fit, cosmesis, wound care, functionality, emerging technologies, weight of the device, what works, what doesn't work, comfort, and the social stigma associated with wearing a prosthesis, but there was no real way to predict what specific issues were being discussed beyond what has been noted in previous prosthetics research. Legro et al.'s study in 1999 suggested that major issues of importance among the amputee population included fit, function of the device, non-mechanical qualities of the device such as cosmesis, and advice about recovery and preparing for life as a new amputee. (Legro et al., 1999) Klute et al. in 2009 found similarly that study participants identified needs for improvement in socket systems, foot and ankle componentry, alignment with the residual limb, a better understanding of the recovery process after amputation and improved amputee support systems, and improvements in quality of care via remote monitoring systems. Interestingly, their research did not find a significant difference in the identified needs of the dysvascular amputee community and the traumatic limb loss community. (Klute et al., 2009)These factors were included within the codebook as potential areas of insight to be gained from this research, though there was no real way to predict what the discussions taking place across social media pages might contain.

3.4.1 Creating the Codebook

A codebook was created by Seibert and Litchman in which potential topics of discussion were included as coding parameters. These potential topics were selected based on the previous

knowledge and expertise of the researchers, who have experience with both social media content analysis as well as the amputee population and the prosthetics community in general. Those topics that were likely to be discussed within individual posts became the "codes." For example: possible codes included 3D printing, MP knees, and hydraulic ankles. After all of the potential codes had been laid out those codes were collapsed into broader “categories.” For example: the previous codes would all fall under the umbrella of emerging technologies.

An excel document was created with each of the chosen categories delineated as column headers and the subsequent codes were numerically listed below them. Some categories were coded simply as "discussed" vs. "not discussed" whereas other categories has a long list of possible codes such as "amputation types." This document became the skeleton of the initial codebook.

Once an initial codebook had been defined, a random sample of twenty posts was selected for use in codebook refinement and to examine the study's internal validity based on the revised version of the codebook. Those 20 posts were coded using the initial codebook and alterations were made to the codebook in areas that were found to be deficient. Once revision was completed, those 20 posts were then re-coded using the revised codebook by two separate investigators in order to compare the results and perform an internal validity check. A high degree of similarity in coding between researchers was desired as this would lead to minimal discrepancies based on data interpretation between individuals. For each of the 20 posts there were 38 categories of code, leading to 760 possible coding choices made by each examiner. Out of those 760 coding choices, the final two sets of coded data only differed in 15 fields, achieving a 98% similarity in coding between researchers. Once satisfied that the codebook functioned as intended, and within a high percentage of accuracy between coders (with only a 2% deviation between coders), the data coding began.

Room was left within the constraints of the codebook to add categories of code as needed throughout the coding process, or for more specific codes to be added to already included categories, but the base codebook was deemed sufficient to begin transcribing data and it was hoped that few if any categories of coding had been overlooked throughout this initial process.

3.4.2 Coding the Data

The content of parent posts made within the approved timeframe within the specified groups were examined and coded using the devised and refined codebook. Associated comment threads were not further analyzed due to time constraints, though this would be an excellent avenue of future research to consider. Data coding required physically combing through the posts within the selected communities and analyzing their content based on the codebook until each post was defined by a string of numeric values representing its function, its poster type, its origin, its number of likes/comments/shares, and its subject matter. The final codebook can be found in Appendix A.

Once data collection and its subsequent coding had been completed, statistical analysis was performed based on the numbers of postings pertaining to certain topics in order to compare data across groups, user demographics, social media platforms, and any other potentially pertinent relationships that could be analyzed. This analysis became the main body of results for the study.

The outcome measures for this project include the codes, the categories, and the resultant findings of the statistical analysis.

4.0 RESULTS

4.1 TOTAL DATA SET

4.1.1 Represented Social Media Groups, Posters, and Types of Posts

The total data set consisted of 1,305 individual posts, of which 603 (46%) were extracted from the Amputee Coalition Facebook page, 330 (25%) were extracted from the Blesma Facebook page, 112 (9%) were extracted from the Prosthetics SubReddit, and 260 (20%) were extracted from the Amputee SubReddit. See Figure 1 for a visual representation of the data sources.

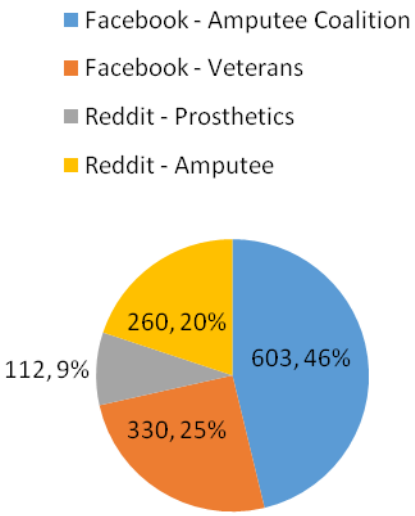

Figure 1: Percentage of Posts by Social Media Group

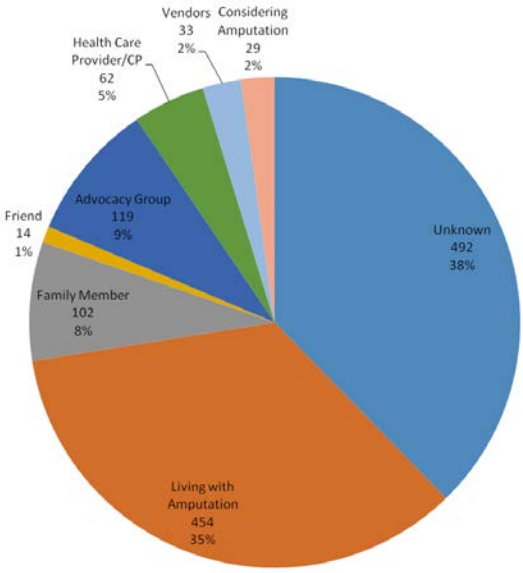

Figure 2: Percentage of Posts by Type of Poster

There were several different types of posters utilizing these sites. Those posters who could be identified by type were categorized as self-identified amputees (N=454, 35%), family members of amputees (N=102, 8%), friends of an amputee (N=14, 1%), advocacy groups (N=119, 9%), health care professionals including prosthetists (N=62, 5%), prosthetic vendors (N=33, 2%), and individuals who are considering undergoing an amputation for various reasons (N=29, 2%). Over one-third of posts could not identify the type of poster (N=492, 38%). Among those who self-identified as having an amputation, 24 were from the veteran group and 430 were from the general groups. There were more posts from Facebook (N=933, 71%) compared to Reddit (N=372, 29%). See Figure 2 for a visual representation of the types of posters.

Six specific types of posts were categorized and coded, defining whether the posts consisted of inquiries (N=327, 25%), anecdotes (N=514, 39%), or advertisements (N=227, 17%), or were seeking (N=72, 6%) or providing (N=82, 6%) emotional support, or were somehow pertaining to a research project or study (N=72, 6%). Of the total data analyzed (N=1,305), some data fell into multiple categories, while other data met none of the defined categories of coding criterion. See Figure 3 for a visual representation of the types of posts.

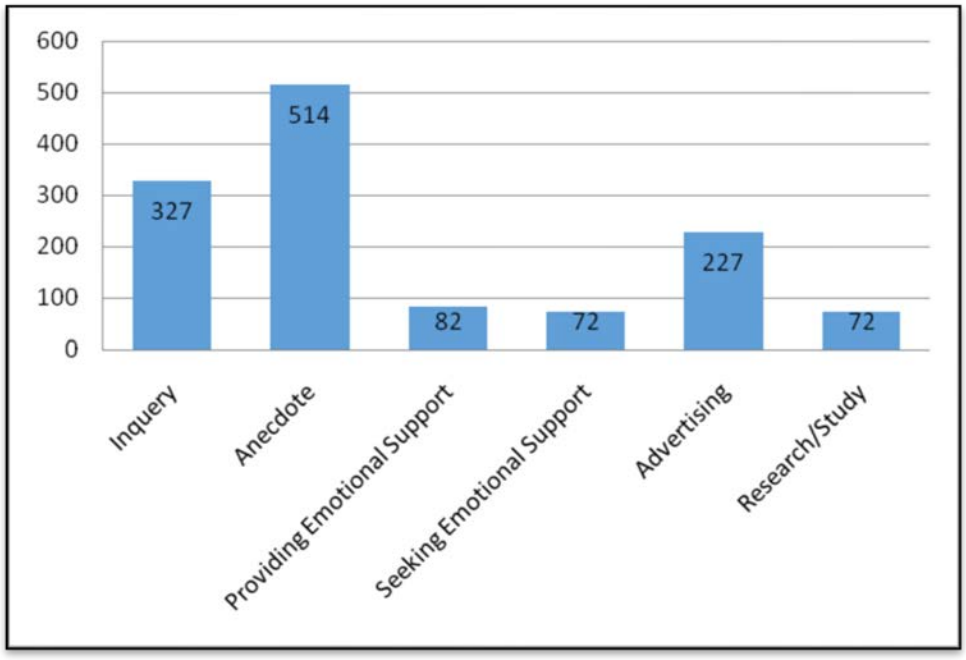

Figure 3: Post Type Breakdown

4.1.2 Amputations Discussed - Types and Causes

While 664 total posts contained no mention of an amputation (51% of the data), there were many times in the data where posters discussed the types of amputations that they or their loved one had experienced or the causes of their or their loved one's amputations, and these amputation types and amputation causes were coded for. Some posts mentioned as many as four separate and specific amputations or amputation levels. One hundred and thirty posts mention an amputation but do not specify the amputation type/level. Of those amputation levels discussed, 77 upper extremity amputations were specifically mentioned. Twenty nine posts mention a below elbow amputation, 28 posts mention an above elbow amputation, 13 posts mention a partial hand amputation, and seven mention a shoulder disarticulation. There were no posts that discussed a through elbow amputation/disarticulation. Five hundred and forty seven lower extremity

amputations were specifically mentioned. Of these, 302 were below knee amputations, 209 were above knee amputations, 18 were partial foot amputations, three were through knee amputations/knee disarticulations, and 15 were hip disarticulations. Five hundred and two posts mention an amputation/s but not the cause of said amputation/s, accounting for 39% of the total data. Fifty nine posts specifically mentioned trauma as the cause of the amputation/s (5%), six mentioned vascular issues as the cause (<1%), 42 were congenital amputations (3%), 16 were due to cancer (1%), and 16 were due to infection or septic shock (1%). See Table 3 for a list of the types of amputations mentioned within the analyzed posts. See Figure 4 for a visual representation of the reasons for amputations which were discussed.

Table 3: Types of Amputations Discussed, first amputation mentioned through fourth amputation mentioned

Amputations Discussed	1st	2nd	3rd	4th	Total #
Not Discussed					664
Unknown	114	11	3	2	130
Below Elbow	27	2	0	0	29
Above Elbow	18	7	2	1	28
Below Knee	258	41	1	2	302
Above Knee	167	32	7	3	209
Partial Hand	9	3	1	0	13
Partial Foot	14	4	0	0	18
Through Elbow	0	0	0	0	0
Through Knee	3	0	0	0	3
Shoulder Disarticulation	7	0	0	0	7
Hip Disarticulation	15	0	0	0	15

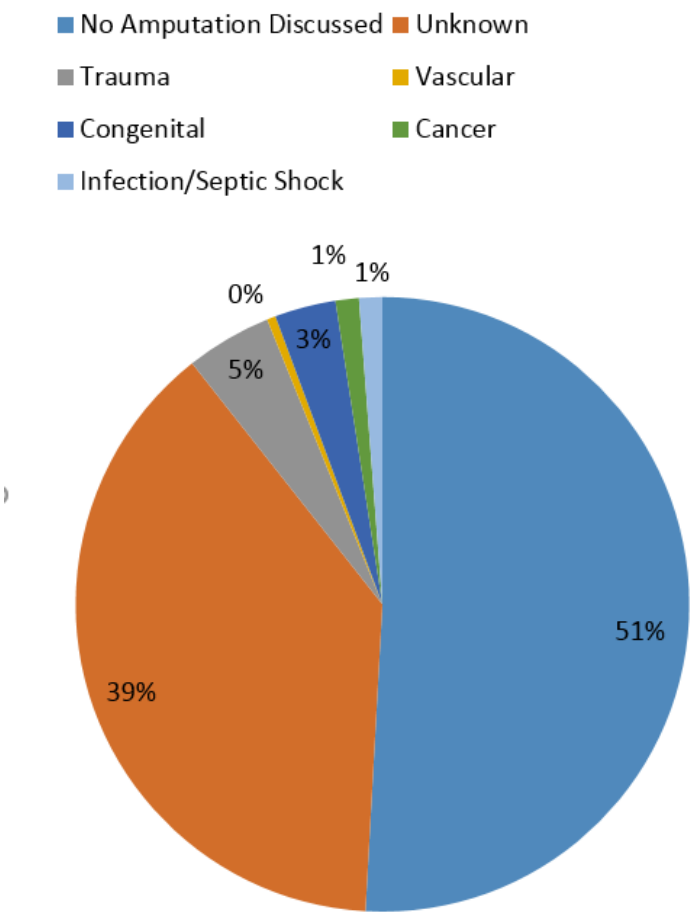

Figure 4: Reason for Amputation

4.1.3 Insurance and Cost as a Barrier for Care

Thirteen posters specifically mentioned having insurance (1%) while three specifically mentioned lacking coverage. Twenty two posters discussed insurance coverage as a barrier for obtaining devices/care (2%) while one poster said it was not a barrier. Ten posters mentioned out of pocket costs as being a barrier to them getting the devices/supplies and care that they need (1%). See Table 4 for a list of the insurance metrics collected.

Table 4: Insurance Metrics

Did the Poster Have Insurance?	
Unknown	1289
Yes	13
No	3
Was Insurance Coverage a Barrier to Obtaining Needed Devices/Supplies?	
Unknown	1282
Barrier	22
Not a Barrier	1
Was OOP Cost a Barrier to Obtaining Needed Devices/Supplies?	
Unknown	1295
Barrier	10
Not a Barrier	0

4.1.4 Common Amputee Problems and Concerns

Potential common concerns that were categorized and subsequently coded for included common amputee complaints such as sweat, energy expenditure, phantom sensation, phantom pain, and skin breakdown, common device problems such as liners, socks, cosmesis, comfort, and alignment, available advancements such as alternative device options (comparing device types),

emerging technologies (i.e.: microprocessor knees, myo-controlled hands, osseointegration, etc.), and adaptive technologies (i.e.: hand steering controls for driving, powered wheelchairs, etc.), and lastly common amputee comorbidities such as depression, anxiety, diabetes, and traumatic brain injury ("TBI") (included in anticipation of veteran comorbidities and trauma related amputations).

Ten posters found sweat to be problematic (1% of the total data set), two mentioned energy expenditure being problematic (<1%), six discussed phantom sensation as being problematic (<1%), 24 mentioned phantom pain problems (2% of the total data set) while four mentioned specifically not having phantom pain problems (<1%), and three posters discussed problems with skin breakdown (<1%).

Thirteen posters discussed problems with liners (1%) while nine discussed specifically not having problems with liners (1%), one mentioned problems with socks while three mentioned specifically not having problems with socks (<1% each), and only one poster ever mentioned alignment, saying it was not a problem for them (<1%). Comfort was discussed frequently, with 49 posters having comfort related prosthetic problems (4% of all posters). Only five posters mentioned comfort in a positive light saying that they didn't have problems with device discomfort (<1%). Cosmesis was also mentioned recurrently, but in a more positive manner. Forty posters specifically mentioned not having issues with cosmesis(3% of all posters) while only five posters (<1%) specifically mentioned finding cosmesis to be a problematic concern.

As for technologies and alternative devices, five posters were seeking information about developing technologies (<1%), 19 posters were suggesting developing technologies to the other members of the message boards (2%), and 13 posters were selling developing technologies (1%, these posters including prosthetic vendor companies). Eight posters mentioned that they were seeking adaptive technologies (1%), 11 posters were suggesting adaptive technologies (1%), and five posters were selling adaptive tech (<1%). Seeking suggestions for alternative devices to what the user was currently using was common, with 41 posters seeking advice or information regarding alternative options (3%). Ten posters were suggesting alternative options to the message board (1%) and one poster was selling an alternative device option (<1%).

Common amputee comorbidities were not discussed frequently. Seventeen posters mentioned having depression (1%) while one specifically stated that they didn't suffer from

depression (<1%), nine mentioned having problems with anxiety (1%), six mentioned having diabetes (<1%), and TBI was never brought up. See Figure 5 for a visual representation of the amputee concerns which were discussed, and Figure 6 for the technology and alternative device discussion metrics.

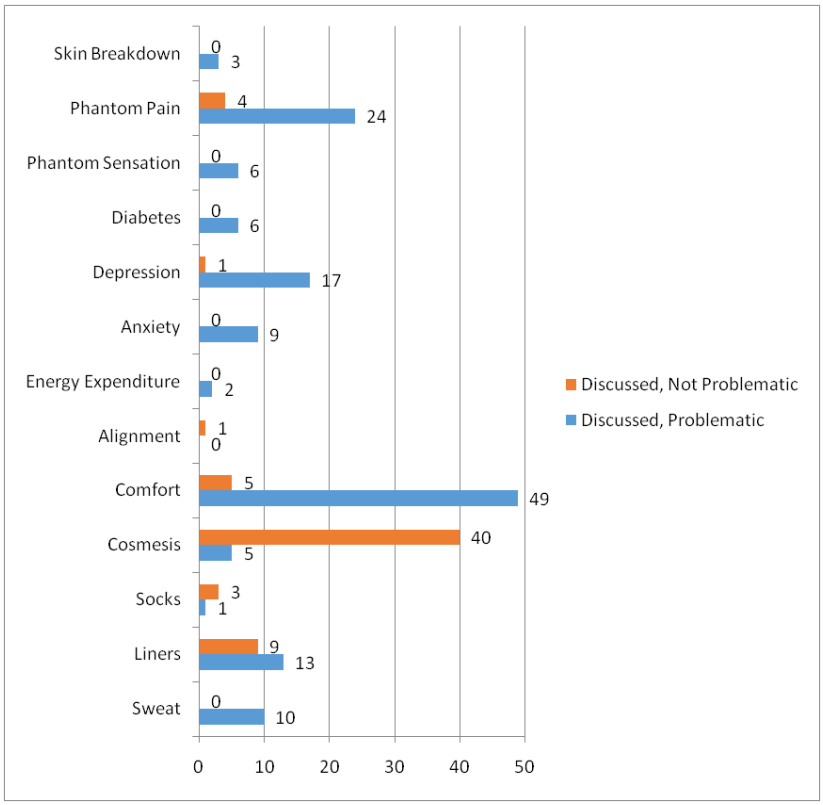

Figure 5: Common Amputee Concerns

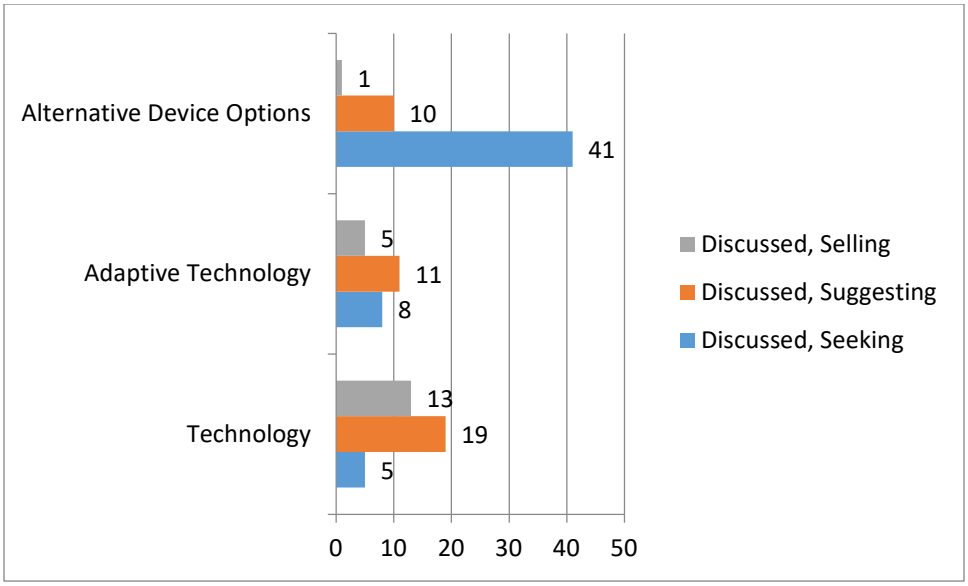

Figure 6: Technology and Alternative Device Options

4.1.5 Common Amputee Skin Disorders

Of the skin types and common skin problems that are often associated with the amputee community, some were discussed on the social media pages with more frequency than others. Specific skin problems were discussed 45 times in total (accounting for 3% of the complete data set). Rash and folliculitis were discussed three times each (accounting for 7% of skin issue discussions, each), ulcerations were mentioned once (2% of skin issue discussions), open wounds were discussed six times (13% of skin issue discussions), scar breakdown and adhesions were mentioned once (2% of skin issue discussions), bony prominence pain was discussed three times (7% of skin issue discussions), heterotopic ossification/bone spurs were discussed once (2% of skin issue discussions), swelling was mentioned 12 times (27% of skin issue discussions) and shrinkage was mentioned ten times (22% of skin issue discussions) for a total volume fluctuation discussion total of 22 times (49% of all skin issue discussions), discoloration was discussed three times (7% of skin issue discussions), and skin folds/creasing was brought up

twice (4% of skin issue discussions). See Figure 7 for a visual representation of the skin issues which were discussed as a percentage of all skin issues discussions.

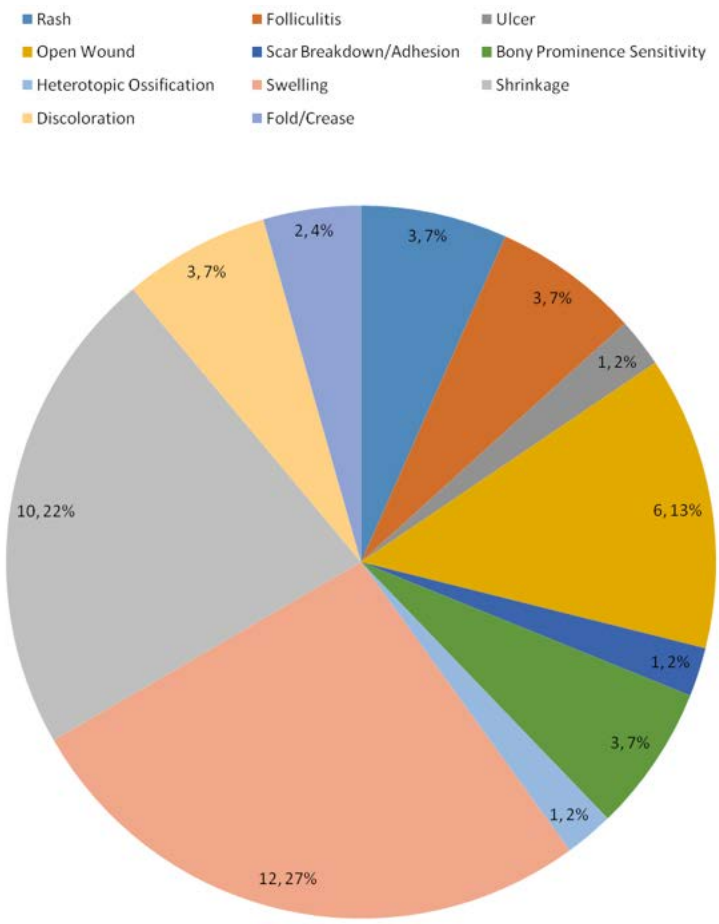

Figure 7: Specific Skin Issues Discussed as a Percentage of All Skin Issues Discussions

4.1.6 Participation in the Community

From there, the codebook looked into a few specific social interactions among the amputee community, coding for the categories of sports (performing in athletics as an amputee), attended events (conferences, special events hosted for amputees, or attending events as a "handicapped" person), and travel (traveling with a disability/vacations). Sports discussions accounted for 5% of the total postings (61 distinct posts), discussions regarding attended events accounted for 6% of the total postings (72 distinct posts), and travel discussions accounted for 1% of the total postings (11 distinct posts).

4.1.7 Life Hacks

The last categories coded for involved amputee life hacks. General life hacks and life hacks for pain were coded separately, though neither was mentioned with frequency. General life hacks were brought up four times total, with one poster mentioning using coconut and tea tree oils, two posters discussing the use of aloe vera gel, and one poster mentioning the use of magnesium and potassium for muscle spasms. Only one life hack for pain was ever mentioned, and the post was discussing specifically the use of medical marijuana.

Table of total values distributed across categories for the complete data set can be found in Appendix E: Comparative Data & Charts - All.

4.1.8 User Interactions by Social Media Platform

As seen in Table 5, Facebook posts received more feedback in the form of likes and comments, both overall and as an average response per post. Shares was not a trackable function via the Reddit platform.

Table 5: User Interactions by Platform and Page

	Total			Average		
	Likes	Shares	Comments	Likes	Shares	Comments
Total Data Set	109810	13493	12085	83.6	10.3	9.3
Facebook - AC	102410	13036	9785	170.1	21.7	16.3
Facebook - Blesma	5297	457	2300	16.1	1.4	7.0
Reddit - Prosthetics	810	N/A	445	7.3	N/A	4.0
Reddit - Amputee	1293	N/A	1466	5.0	N/A	5.7
All Facebook	107707	13493	10174	109.9	14.0	10.5
All Reddit	2103	N/A	1911	5.7	N/A	5.2

5.0 DISCUSSION AND CONCLUSIONS

This is the first social media content analysis performed within the field of prosthetics. As such, as many findings as possible were included in the discussion in order to draw pertinent conclusions wherever feasible. Answers to main research questions as well as population composition and additional interesting findings are summarized below.

5.1 TYPES OF POST BY SOCIAL MEDIA PLATFORM

While Facebook data proved more likely to have posters sharing their stories, Reddit seems to be the place where patients go to ask their questions. Advertisements were more likely to be posted on the Facebook pages than the Reddit pages, while research and study based posts were more prevalent in the Reddit community. See Figure 8 for a visual representation of the types of posts as a percentage of the data.

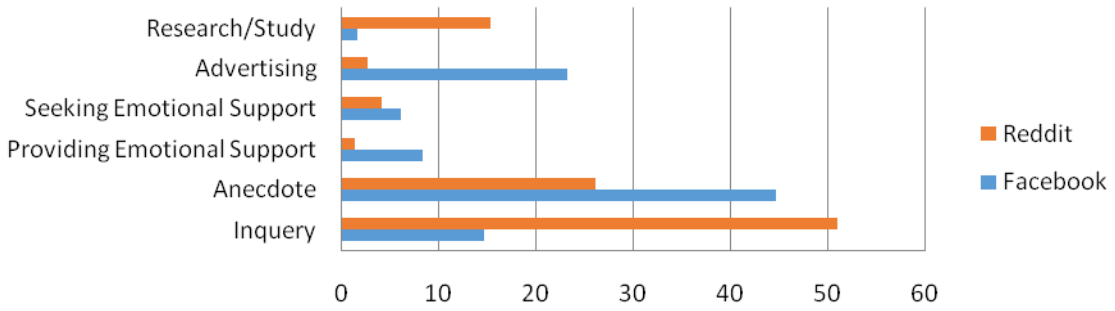

Figure 8: Type of Post as a Percentage of the Data by Platform

5.2 MOST COMMON ISSUES DISCUSSED BY SOCIAL MEDIA PLATFORM

Though the amount of posts regarding specific common issues among amputees was fairly comparable between Facebook and Reddit, there were instances where the conversations were more likely to turn up on one of the social media platforms as compared to the other. Technology and alternative device options were more frequently discussed on Reddit, while adaptive technologies were more frequently discussed on Facebook. Cosmesis was much more frequently discussed on Facebook, and was rarely mentioned as a problematic issue. Across all of the social media pages analyzed in this study, cosmesis was only discussed in a negative context (I wish my device was a closer match to my skin tone, etc.) five times, whereas it was discussed in a positive context (I love how my device looks, etc.) 40 times. Positive posts regarding cosmesis accounted for the third highest number of coded posts out of all coded common amputee concerns in the data set. This is interesting, as previous research has shown cosmesis to be a fairly low priority concern for amputees, with only 7% of amputees citing it as their main device concern. (Nielsen, 1991)In previous survey analysis, 52% percent of amputees cited comfort as their main concern, while 38% cited functionality as their main concern. (Nielsen, 1991)In the same study, it was shown that 57% of amputees surveyed experienced moderate to severe pain throughout the day, continuing to wear their prosthesis anyway. (Nielsen, 1991)As such, it is perhaps unsurprising that comfort problems were discussed more frequently than any other

commonly cited amputee concern in the data, with 49 posters citing problems with device comfort. The other single most discussed category coded for was alternative device options, which with 41 posts seeking suggestions for an alternative device. As these posters were looking for a device alternative, these posts could also reflect comfort issues with their posters' current device design. See Figure 9 for a visual representation of the common amputee concerns discussed broken down by platform.

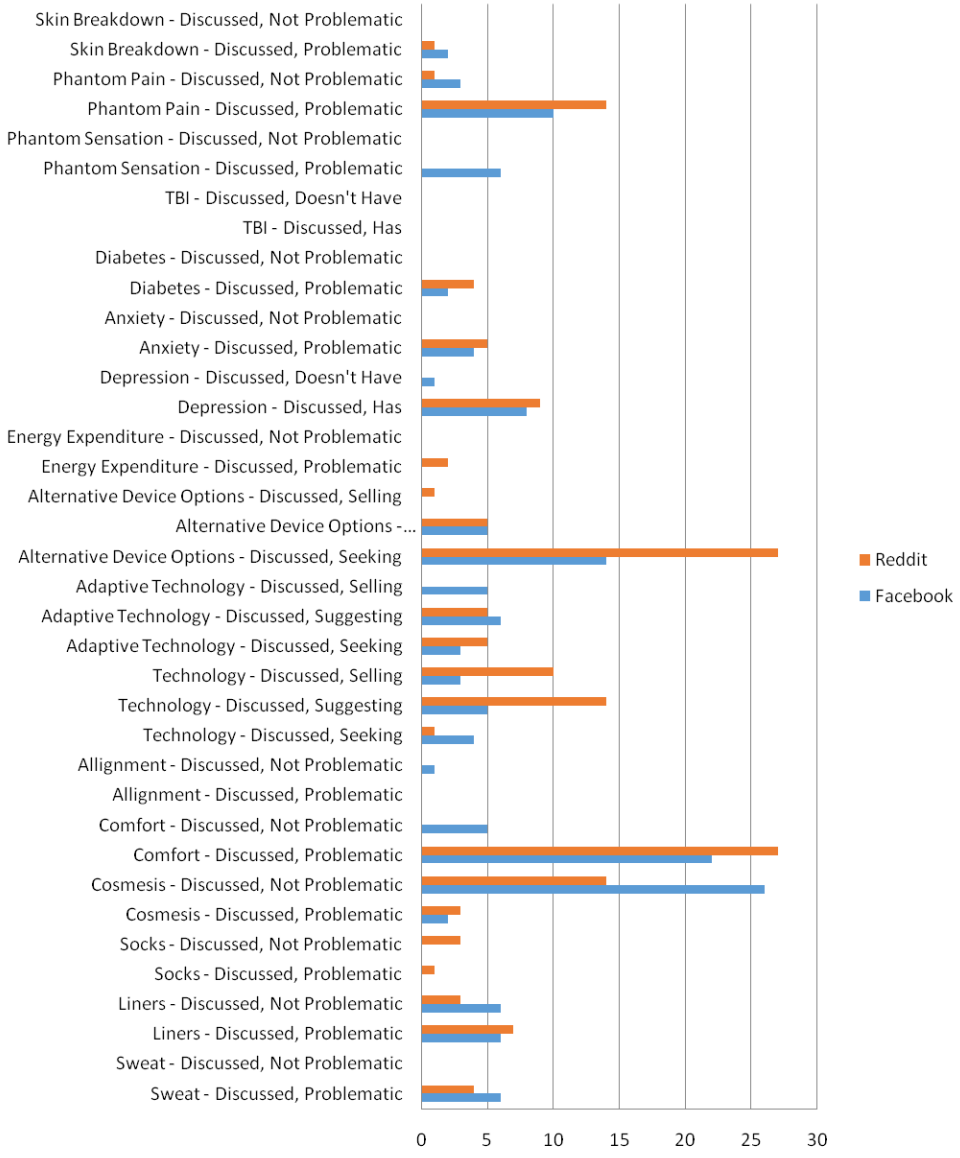

Figure 9: Common Concerns - Number of Posts by Platform

5.3 TYPES OF AMPUTATIONS DISCUSSED

As the limb loss community is made up of around 70% lower extremity amputees and 30% upper extremity amputees (LeBlanc, 2008), it is unsurprising that the majority of discussed amputations within the data were lower extremity amputations. Lower extremity amputations accounted for 87.66% of those amputations which were identified in the data while upper extremity amputations accounted for 12.34% of those amputations specifically discussed. The complete breakdown of limb loss discussions by amputation level can be found in Table 6 below. Previous studies have shown shoulder disarticulation to account for 1.1% of all amputations, above elbow to account for 3.7%, through elbow represents at 0.3%, below elbow at 8.6%, partial hand or wrist at 0.8%, hip disarticulation at 1.8%, above knee amputation at 44.1%, through knee at 1%, below knee at 36.8%, and ankle or partial foot at 1.7%. (Glatlly, 1963) The data collected in this study differs from these known percentages, which begs the question: why? It is possible that the age of social media user again plays a role in the level of amputation which we are seeing discussed. Most upper extremity amputations are resultant of trauma(Dillingham, Pezzin, & MacKenzie, 2002), and younger amputees are more likely to have experienced limb loss due to trauma (Glatlly, 1963), and social media platforms are more commonly utilized by people under the age of 65(Center, 2018). All of these factors could be working together to explain the disproportionate representation of upper extremity amputation levels among the data. It is also possible that different levels of amputation create/generate more associated problems than other amputation levels, leading to higher rates of discussion among those amputee types. This is a possible consideration for why the amount of posts pertaining to below knee amputations and hip disarticulations varies so widely from the known amputation level demographics.

Table 6: Amputation Level

Amputation Level	Post #	Post %
Below Elbow	29	4.647436
Above Elbow	28	4.487179
Below Knee	302	48.39744
Above Knee	209	33.49359
Partial Hand	13	2.083333
Partial Foot	18	2.884615
Through Elbow	0	0
Through Knee	3	0.480769
Shoulder Disarticulation	7	1.121795
Hip Disarticulation	15	2.403846

5.4 TYPES OF POSTERS BY SOCIAL MEDIA PLATFORM

As seen in Figure 2 in the Results, the types of posters utilizing social media that could be identified are overall made up mostly of amputees, family members of amputees, and advocacy groups. As 71% of the data was collected from Facebook posts, however, this breakdown is heavily influenced by the types of posters utilizing Facebook. When Facebook and Reddit users are analyzed individually, whether by platform or by page, it becomes apparent that while Facebook posters are more likely to fall into the categories of advocacy groups, Reddit users are more likely to fall into the categories of health care providers, vendors, and those considering amputation. This is interesting for a few reasons. First, it illustrates that advocacy groups are underutilizing Reddit as an advocacy outreach tool compared to Facebook, at a ratio of 118 posts to one between the two platforms. The most utilized Facebook page used in this study received an average of 1.65 posts per day, while the most utilized Reddit page used in this study received an average of 0.71 posts per day. At just under half the amount of interactions, Reddit could still prove to be a useful outreach tool for advocacy groups that are currently largely ignoring it as a platform. Second, it shows that healthcare providers are underutilizing Facebook as a patient outreach tool compared to Reddit, with twice the number of posts taking place on Reddit. As 51.6% of all healthcare provider posts analyzed were also coded as involving research,

increasing the use of amputee related Facebook pages such as the Amputee Coalition page could improve study participation and the effectiveness of future research in the field of O&P. Third, it shows that posters who are considering amputations for various reasons are reaching out to the Reddit user community for advice at 6.25 times the rate of the Facebook community, with 25 total posts on Reddit from this user group compared to only four on Facebook. This data could be utilized by the (as already discussed) higher numbers of healthcare providers utilizing Reddit as a platform as a means of improving outreach and communication with a user population that may soon be joining the ranks of our patient community. Previous research shows that new amputees gained most of their information at the time of their amputation from providers and resources outside of the field of prosthetics, with 25% receiving the most information from their physical therapist, 23% receiving it from their surgeon, and 22% receiving it from other amputees while only 19% received the majority of their needed information from a prosthetics practitioner, and 44% of amputees surveyed reported not having access to enough information to make informed decisions regarding their care at the time of their amputation.(Nielsen, 1991)This is concerning, as the same study showed that, when asked, 65% of participants cited their prosthetist as their most useful source of information regarding their amputation, and 76% cited using information gained from their prosthetist more often than any other source. This data, with 29 posters reaching out to other members of the amputee community for advice about upcoming or considered amputations, is another indication that communication with patients preparing to undergo amputation surgeries could be improved. As the majority of advice regarding potential amputations was being sought on Reddit, perhaps this platform could be a useful outreach tool for prosthetics practitioners to continue to improve the lives of our patients - even before they become our patients. See Figure 10 for a visual representation of the posts per day by social media page. See Figure 11 for a visual representation of the types of posters broken down by social media platform and Figure 12 for a the types of posters broken down by social media page.

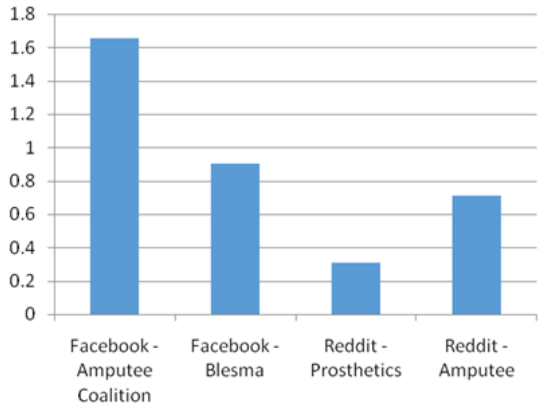

Figure 10: Posts per Day by Social Media Page

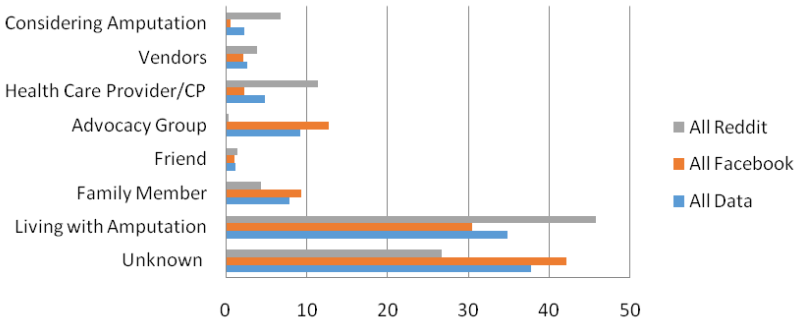

Figure 11: Type of Poster as a Percentage of the Data - By Platform

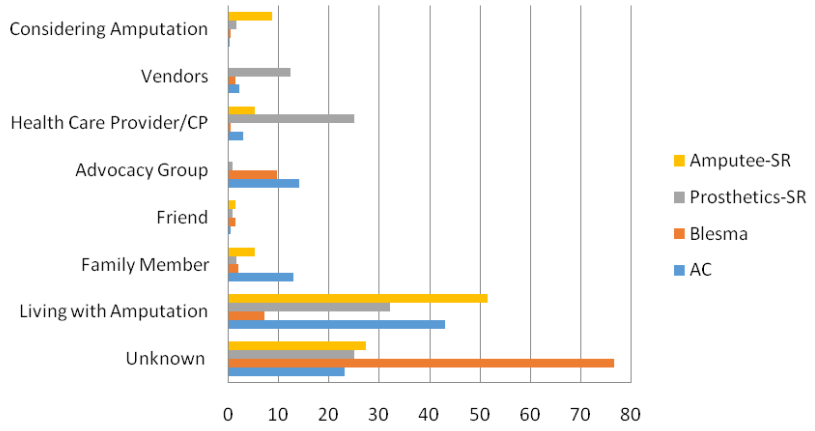

Figure 12: Type of Poster as a Percentage of the Data - By Page

5.5 UNEXPECTED RESULTS – CODES AND CATEGORIES ADDED

The amount of data that was coded as being posted by people considering undergoing amputation is itself unexpected and interesting. This particular code was not originally included in the codebook and was added later as review of the data showed it to be a necessary classification. Posters who were considering amputation ended up accounting for 2% of the total data set, which is a large amount for a user population whose inclusion was not predicted by the researchers. Other codes and categories that were unanticipated originally that were added to the codebook during data review included infection/septic shock for the category of "reason for amputation" (accounting for 16 total posts and 1% of the overall data), socks as a category and its subsequent codes (mentioned by four total posts and included as a category because it was seen more than once), swelling, discoloration, shrinkage, and skin folds/creases were all codes added under the category of "skin type" (accounting cumulatively for 27 total posts and comprising 60% of all skin type/issue discussions), coconut and tea tree oil, aloe vera gel, and magnesium and potassium for muscle spasms were all codes added under the category of "general life hacks" and medical marijuana was added under the category of "life hacks for pain"

(life hacks were seen rarely in the data and all mentions were coded for inclusion per the initial intent of the study). While these codes and categories were not originally anticipated, their addition adds depth to the data interpretation and the necessity of their addition demonstrates first-hand that practitioners don't always anticipate every need of our patients.

5.6 UNEXPECTED RESULTS – CODES AND CATEGORES UNDER-REPRESENTED

Just as several codes were unanticipated by the researchers for initial inclusion, several codes were included by the researchers that turned out to represent a surprisingly small percentage of the data or which weren't represented in the data at all. Friends of amputees only accounted for 14 total posts and 1% of the data. Vascular issues as a cause for amputation were only discussed six times within the 641 total posts discussing amputations and of the 149 posts which specifically discussed the cause of said amputation/s. This value is not remotely representative of the known causes of most amputations. Dysvascular disease is the number one cause of amputation in the United States, accounting for 82% of new amputations, whereas in this data it only accounts for 1% of the total number of amputations discussed.(Dillingham et al., 2002) This shows that amputees whose limb loss was resultant of vascular issues are less likely to mention the cause of their amputation than amputees whose limb losses were results of other causes. Though purely conjecture, it is possible that amputees whose limb loss was a result of dysvascular disease feel more responsible for their own circumstance than perhaps those whose limb loss was caused by congenital amputation, trauma, and cancer -things which might feel more beyond your control as a patient- and are therefore less likely to discuss the cause in an open forum. It has been shown previously that 28.7% of amputees experience significant depressive symptoms, and that this number increases with comorbid conditions and poverty level income (among other risk factors), and that less than half of those amputees with significant depressive symptoms received mental health services with 32.9% reporting that they needed mental health services but were unable to receive them. (Darnall et al., 2005) As two thirds of amputations due to dysvascular disease occur in patients with comorbid diabetes, (Ziegler-Graham et al., 2008) and the incidence rates of diabetes also increases in low income

populations(Rabi et al., 2006)it would stand to reason that those patients who experience limb loss due to dysvascular diseases likely experience higher rates of depression with this increase in depressive risk factors. If this is the case, it could show that more counseling would be beneficial for patients experiencing limb loss, as well as more intervention based counseling for the dysvascular disease community regarding the prevention of future limb loss and lifestyle changes which could help prevent future amputations. This interpretation is further supported by the fact that diabetes was only mentioned six times in the data. As 54% of all amputees experienced limb loss secondary to dysvascular disease, and -as previously stated- two thirds of those amputees have a comorbid diagnosis of diabetes, this is an under-representative value from what might be expected.(Ziegler-Graham et al., 2008)It is also possible, and perhaps more likely, that people who suffer limb loss at the hands of birth defects, trauma, and cancer are representative of a younger population of amputees than those whose limb loss was resultant of vascular diseases, making them more prone to utilize social media than their older counterparts. According to Pew research, in 2018 only 35% of Americans aged 65 and older use social media sites, compared to 64% of 50-64 year olds, 78% of 30-49 year olds, and 88% of 18-29 year olds.(Center, 2018)As trauma is a more likely cause of amputation in younger populations and dysvascular diseases is a more common cause of amputations in populations over 65 years of age, this could explain why trauma was discussed in the data disproportionately more often than vascular issues when compared to the known ratios of limb loss etiologies. (Ziegler-Graham et al., 2008) See Figure 13 for a visual representation of the reasons for discussed amputations as a percentage of all amputation discussions.

Alignment was anticipated as a category in the codebook, but was only mentioned once in the data, and skin breakdown was only mentioned three times. Energy expenditure, a known problem among the amputee population as it has been shown that walking speed decreases and oxygen consumption increases as lower extremity amputation level moves proximally in amputee specific pathologic gait functionality when compared to normal gait, was also barely discussed in the data with only two coded occurrences.(Waters & Mulroy, 1999)TBI was included as a comorbidity as it was anticipated that those whose limb loss was a result of military service and related trauma would be likely to have other side effects of that trauma. It was never mentioned in the data. Anticipated codes originally included in the codebook for general lifehacks (hacks for high heeled shoes and volume fluctuations) and lifehacks for pain (mirror

box therapy and electrical stimulation) were never brought up. While additional codes were added in these categories, total posts discussing all life hacks only accounted for five points of data. One of the original intents of this study was to analyze lifehacks in use by amputees, only to discover that if our patients are -in fact- using hacks, they are not discussing them with each other on these particular platforms/pages, or they at least do not appear in the parent posts.

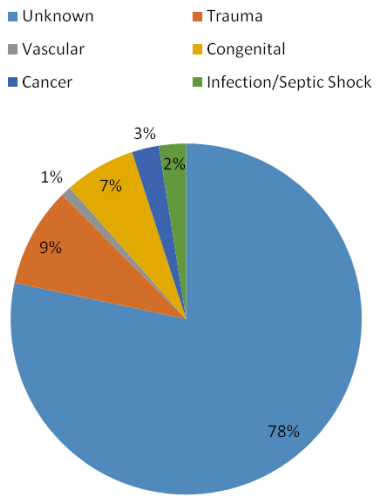

Figure 13: Reasons for Discussed Amputations as a Percentage of All Amputations Discussed

5.7 FAMILY MEMBERS AS PATIENT ADVOCATES

While reading through the data during the coding process, it began to stand out that posts which discussed the cause of the amputations were more often than not also posts where the poster was identified as a family member of someone with an amputation. This posed an intriguing series of questions that would not have been considered within the context of the data otherwise: what are our patients' family members most concerned with? What are they most likely to talk about? How does their approach to social media support pages differ from the amputee population?

Twenty percent of those posters who identified as having an amputation discussed the cause of their amputation, whereas 34.5% of family members discussed the amputation cause. Eighty percent of amputees identified the specific level of limb loss, whereas 91.4% of family members identified the amputation level. Two percent of amputees discussed adaptive technologies such as powered wheelchairs or adaptive driving systems, whereas 3.4% of family members discussed adaptive technologies. Two percent of amputees discussed depression while 6% of family members did, and only 0.2% of amputees discussed diabetes compared to 2.6% of family members. All told, family members of amputees discussed the cause of the injury with 72% more frequency, the body part affect with 14% higher frequency, adaptive technologies at a rate of 72% more frequently, depression with 202% more frequency, and diabetes with 1193% more frequency. This analysis indicates that it may be easier for posters who are one degree removed from the limb loss to talk about certain topics in an open forum (such as diabetes or depression or the cause of the amputation) than it may be for the amputee themselves. As practitioners, it is useful to remember that family members are a valued part of the care team and that their concerns should be as valid to us as the concerns of the patients that they represent. While certainly not comprehensive, this insight into the concerns of our patient's family members is an enlightening and unforeseen use of the data collected.

6.0 STUDY LIMITATIONS AND AREAS OF FUTURE RESEARCH

Though this research had the potential to return valuable information, the results may not be generalizable to the prosthetics patient population at large due to only including and investigating those patients who utilize social media. Attempts were made to include a varied array of subjects, including specifically searching out veterans forums in order to draw comparisons between veterans and the wider amputee population. As most veterans within the limb loss community are younger and lost their limb(s) due to traumatic amputation, compared with the majority of the limb loss community which lost their limb(s) at an older age due to complications from vascular diseases, it was hoped that comparing these two populations could show a disparity in discourse and provide insight into the specific needs of the traumatic limb loss community or the veteran amputee population. Although a veteran specific group was chosen intentionally in order to look more in depth at this population, the limited number of postings within that group as well as the decreased number of overall members of that group by comparison to the other groups decreased the potential for discovering statistically relevant findings.

It is also possible that by researching only open source groups, data may be limited to only those subjects which patients were comfortable discussing publicly. It's possible that prosthetics patients may be discussing more personal details or asking more in-depth questions in the private social media groups which require administrator permissions to join, and which aren't visible to the general public. Including private groups would have resulted in IRB consent barriers, however, so these potential subject populations were eliminated from consideration for this study.

The types of posters were coded for - when explicitly identified within the data - in order to draw comparisons by looking only at those specific postings in which the poster identified themselves as living with an amputation, being the family member of an amputee, etc., but the limited number of these posts decreased the likelihood of their value being statistically significant.

Parent posts were collected as data and coded accordingly, but associated comment threads were not further analyzed due to time constraints. This would be an excellent avenue of future research to consider. It is possible that by eliminating comment threads from the coded data that valuable information was excluded from the study, especially when one considers that the replies to the original threads are where most of the advice and unique solutions and possible life hacks are likely to reside. It is also possible that certain members of the social media community may respond to posts made by other individuals where they wouldn't initiate a post themselves. This is the main limitation in the methodology of this study which the researchers would recommend rectifying in future research.

One of the original intents of this study was to analyze life hacks in use by amputees, only to discover that if our patients are -in fact- using life hacks, they are not discussing them with each other on these particular platforms/pages (at least not as parent posts). Another potential avenue of future research would be to specifically search for and collect as data posts which incorporated specific hash tags. By only coding data which incorporated hash tags such as #AmputeeLifeHack or #ProstheticsLifeHack, it would create an initial data inclusion criteria which would ensure that life hacks were discussed within the data. This would also allow more varied platforms to be analyzed, such as Twitter and Instagram.

In the data from this study, it was shown that certain amputation levels were discussed more so than others, and the rates of discussion of those amputation levels did not correspond to the known ratios of amputation levels in the amputee populations. As discussed in the study, is possible that this was due to different levels of amputation creating/generating more associated problems than other amputation levels. Another potential area of future research would be to investigate which issues were discussed most frequently among posts pertaining to specific amputation levels. By pairing this data together, it is possible that better patient resources could be designed and better patient outreach could be offered in the future.

APPENDIX A

The Codebook

Part 1

Table 7: Code Book Categories - Part 1

Post #	Post ID	Social Media Group	Type of Poster	Post - Inquiry	Post - Anecdote	Post - Provide Emotional Support	Post - Seek Emotional Support	Post - Advertising	Post - Research / Study
#	#	N/A	0 - Unknown	0 - No	0 - No	0 - No	0 - No	0 - No	0 - No
		1 - Facebook Amputee Coalition	1 - Living with Amputation	1 - Yes	1 - Yes	1 - Yes	1 - Yes	1 - Yes	1 - Yes
		2 - Facebook Blesma	2 - Family Member of Amputee	N/A	N/A	N/A	N/A	N/A	N/A
		3 - Reddit Prosthetic	3 - Friend of Amputee	N/A	N/A	N/A	N/A	N/A	N/A
		4 - Reddit Amputee	4 - Advocacy Group	N/A	N/A	N/A	N/A	N/A	N/A
		N/A	5 - Health Care Provider	N/A	N/A	N/A	N/A	N/A	N/A
		N/A	6 - Vendors	N/A	N/A	N/A	N/A	N/A	N/A
		N/A	7 - Considering Amputation	N/A	N/A	N/A	N/A	N/A	N/A
		N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A
		N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A
		N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A
		N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A

Part 2

Table 8: Code Book Categories - Part 2

# Likes	# Shares	# Comments	Reason for Amputation	Body Part 1	Body Part 2	Body Part 3	Body Part 4
#	#	#	0 - No Amputation Discussed	0 - Not Discussed	0 - Not Discussed	0 - Not Discussed	0 - Not Discussed
			1 - Unknown	1 - Unknown	1 - Unknown	1 - Unknown	1 - Unknown
			2 - Trauma	2 - Below Elbow	2 - Below Elbow	2 - Below Elbow	2 - Below Elbow
			3 - Vascular	3 - Above Elbow	3 - Above Elbow	3 - Above Elbow	3 - Above Elbow
			4 - Congenital	4 - Below Knee	4 - Below Knee	4 - Below Knee	4 - Below Knee
			5 - Cancer	5 - Above Knee	5 - Above Knee	5 - Above Knee	5 - Above Knee
			6 - Infection / Septic Shock	6 - Partial Hand	6 - Partial Hand	6 - Partial Hand	6 - Partial Hand
			N/A	7 - Partial Foot	7 - Partial Foot	7 - Partial Foot	7 - Partial Foot
			N/A	8 - Through Elbow	8 - Through Elbow	8 - Through Elbow	8 - Through Elbow
			N/A	9 - Through Knee	9 - Through Knee	9 - Through Knee	9 - Through Knee
			N/A	10 - Shoulder Disarticulation	10 - Shoulder Disarticulation	10 - Shoulder Disarticulation	10 - Shoulder Disarticulation
			N/A	11 - Hip Disarticulation	11 - Hip Disarticulation	11 - Hip Disarticulation	11 - Hip Disarticulation

Part 3

Table 9: Code Book Categories - Part 3

Have Insurance	Insurance Coverage of Device / Supplies	Out of Pocket Cost	Sweat	Liner	Socks	Cosmesis	Comfort	Alignment
0 - Unknown	0 - Unknown	0 - Unknown	0 - Not Discussed	0 - Not Discussed	0 - Not Discussed	0 - Not Discussed	0 - Not Discussed	0 - Not Discussed
1 - Yes	1 - Barrier	1 - Barrier	1 - Discussed, Problematic	1 - Discussed, Problematic	1 - Discussed, Problematic	1 - Discussed, Problematic	1 - Discussed, Problematic	1 - Discussed, Problematic
2 - No	2 - Not a Barrier	2 - Not a Barrier	2 - Discussed, Not Problematic	2 - Discussed, Not Problematic	2 - Discussed, Not Problematic	2 - Discussed, Not Problematic	2 - Discussed, Not Problematic	2 - Discussed, Not Problematic
N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A
N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A
N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A
N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A
N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A
N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A
N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A
N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A
N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A

Part 4

Table 10: Code Book Categories – Part 4

Emerging Technology	Adaptive Technology	Alternative Device Options	Energy Expenditure	Depression	Anxiety	Diabetes	TBI
0 - Not Discussed	0 - Not Discussed	0 - Not Discussed	0 - Not Discussed	0 - Not Discussed	0 - Not Discussed	0 - Not Discussed	0 - Not Discussed
1 - Discussed, Seeking	1 - Discussed, Seeking	1 - Discussed, Seeking	1 - Discussed, Problematic	1 - Discussed, Has	1 - Discussed, Problematic	1 - Discussed, Problematic	1 - Discussed, Has
2 - Discussed, Suggesting	2 - Discussed, Suggesting	2 - Discussed, Suggesting	2 - Discussed, Not Problematic	2 - Discussed, Doesn't Have	2 - Discussed, Not Problematic	2 - Discussed, Not Problematic	2 - Discussed, Doesn't Have
3 - Discussed, Selling	3 - Discussed, Selling	3 - Discussed, Selling	N/A	N/A	N/A	N/A	N/A
N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A
N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A
N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A
N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A
N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A
N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A
N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A
N/A	N/A	N/A	N/A	N/A	N/A	N/A	N/A

Part 5

Table 11: Code Book Categories - Part 5

Phantom Sensation	Phantom Pain	Skin Breakdown	Skin Type	Sports	Attended Events	Travel	General Life Hacks	Life Hacks for Pain
0 - Not Discussed	0 - Not Discussed	0 - Not Discussed	0 - Not Applicable	0 - Not Discussed	0 - Not Discussed	0 - Not Discussed	0 - Not Applicable	0 - Not Applicable
1 - Discussed, Problematic	1 - Discussed, Problematic	1 - Discussed, Problematic	1 - Rash	1 - Discussed	1 - Discussed	1 - Discussed	1 - High Heeled Shoes	1 - Mirror Box Therapy
2 - Discussed, Not Problematic	2 - Discussed, Not Problematic	2 - Discussed, Not Problematic	2 - Folliculitis	N/A	N/A	N/A	2 - Go Bag for Volume Fluctuations	2 - Electrical Stimulation
N/A	N/A	N/A	3 - Ulcer	N/A	N/A	N/A	3 - Coconut and Tea Tree Oil	3 - Medical Marijuana
N/A	N/A	N/A	4 - Open Wound	N/A	N/A	N/A	4 - Aloe Vera Gel	N/A
N/A	N/A	N/A	5 - Scar Breakdown / Adhesion	N/A	N/A	N/A	5 - Mg and K for Muscle Spasms	N/A
N/A	N/A	N/A	6 - Bony Prominence Sensitivity	N/A	N/A	N/A	N/A	N/A
N/A	N/A	N/A	7 - Heterotopic Ossification	N/A	N/A	N/A	N/A	N/A
N/A	N/A	N/A	8 - Swelling	N/A	N/A	N/A	N/A	N/A
N/A	N/A	N/A	9 - Discoloration	N/A	N/A	N/A	N/A	N/A
N/A	N/A	N/A	10 - Shrinkage	N/A	N/A	N/A	N/A	N/A
N/A	N/A	N/A	11 - Skin Folds / Creases	N/A	N/A	N/A	N/A	N/A

APPENDIX B

Additional Data Analysis

Facebook vs. Reddit

Represented Social Media Groups, Posters, and Types of Posts

Facebook posts accounted for 71% of the total data with 933 posts, while Reddit accounted for 29% of the data with 372 posts.

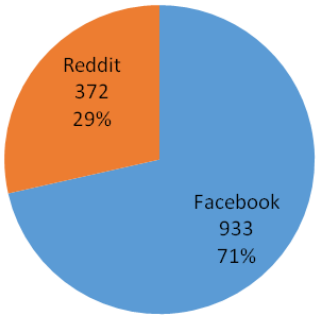

Figure 14: Facebook vs. Reddit

The types of posters who are utilizing Facebook consisted of 284 posts made by people who were self-identified as amputees (31% of Facebook posts), 86 posts in which the posters identified as being family members of amputees (9% of Facebook posts), and nine posters who identified as being friends of an amputee (1% of Facebook posts). One hundred eighteen posts were made by advocacy groups (13% of Facebook posts), 20 posts were made by health care professionals including prosthetists (2% of Facebook posts), 19 posts were made by prosthetic vendors (2% of Facebook posts), and four posts were made by individuals who are considering undergoing an amputation for various reasons (<1% of posts). Three hundred and ninety three Facebook posts were unable to be identified and coded by a specific type of poster (42% of all Facebook posts). The types of posters who are utilizing Reddit consisted of 170 self-identified amputees (46% of Reddit posters), 16 posters who identified as being family members of amputees (4% of Reddit posters), and five posters who identified as being friends of an amputee (1% of Reddit posters). Just one post was made by an advocacy group (<1% of Reddit posts), 42 posts were made by health care professionals including prosthetists (11% of Reddit posts), 14 posts were made by prosthetic vendors (4% of Reddit posts), and 25 posts were made by individuals who are considering undergoing an amputation for various reasons (7% of posts). Ninety nine Reddit posts were unable to be identified and coded by a specific type of poster (27% of all Reddit posts).

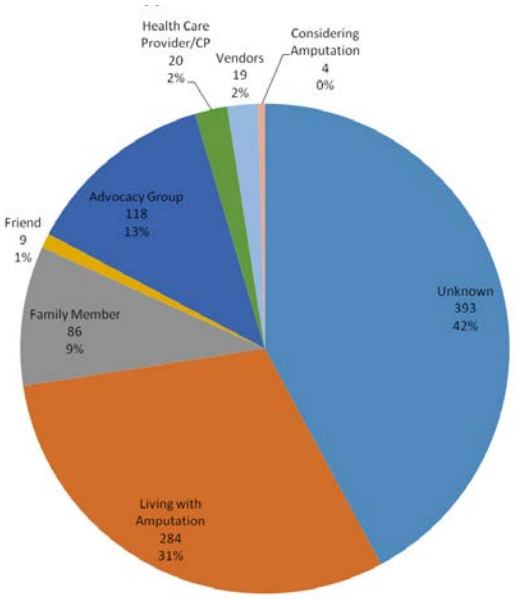

Figure 15: Type of Poster – Facebook

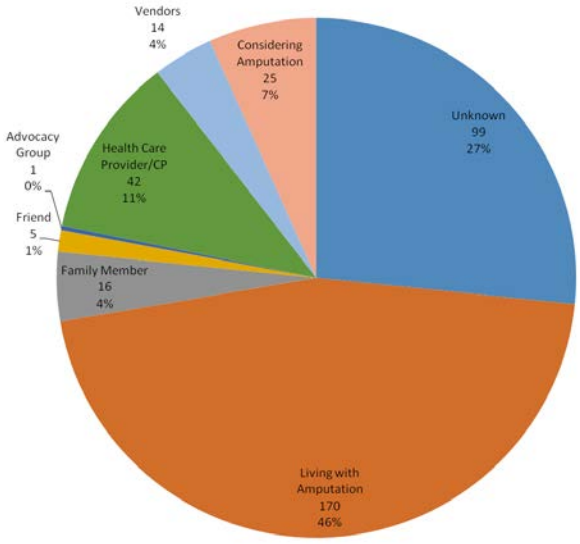

Figure 16: Type of Poster - Reddit

Of the 933 total Facebook posts analyzed, 137 were identified as inquires (25%) and 417 were identified as anecdotes or stories (39%). Seventy seven posts were identified as providing emotional support (6%) and 57 were identified as seeking emotional support (6%). Two hundred and seventeen posts were identified as advertisements of some kind (17%) and 15 posts were identified as pertaining to a research study or project (6%). Of the 372 total Reddit posts analyzed, 190 were identified as inquires (51%) and 97 were identified as anecdotes or stories (26%). Five posts were identified as providing emotional support (1%) and 15 were identified as seeking emotional support (4%). Ten posts were identified as advertisements of some kind (3%) and 57 posts were identified as pertaining to a research study or project (15%).

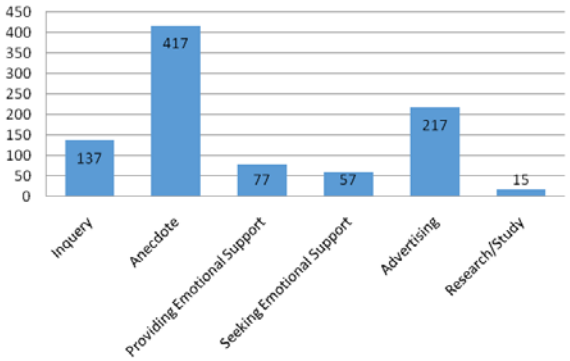

Figure 17: Type of Post – Facebook

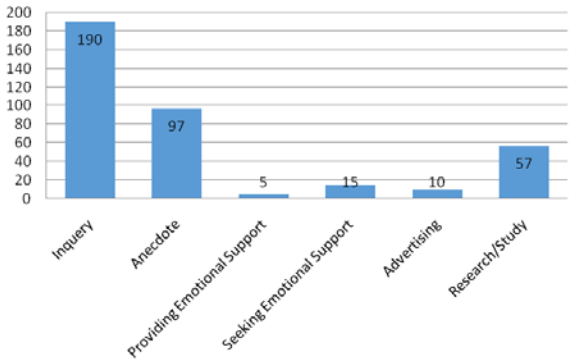

Figure 18: Type of Post - Reddit

Amputations Discussed - Types and Causes

Five hundred and eighteen Facebook posts contained no mention of an amputation (56% of the data). Eighty seven posts mention an amputation but do not specify the amputation type/level (18% of discussed amputations). Of those amputation levels discussed, 29 upper extremity amputations were specifically mentioned. Ten posts mention a below elbow amputation (2% of discussed amputations), 18 posts mention an above elbow amputation (4% of discussed amputations), and one post mentions a partial hand amputation (<1% of discussed amputations). There were no posts that discussed a through elbow amputation/disarticulation or a shoulder disarticulation. Three hundred and sixty two lower extremity amputations were specifically mentioned. Of these, 197 were below knee amputations (41% of discussed amputations), 153 were above knee amputations (32% of discussed amputations), ten were partial foot amputations (2% of discussed amputations), and two were hip disarticulations (1% of discussed amputations). There were no posts which mentioned through knee amputations/knee disarticulations. Three hundred and forty nine posts mention an amputation/s but not the cause/s of said amputation/s, accounting for 37% of the Facebook data. Thirty seven posts specifically mentioned trauma as the cause of the amputation/s (4% of all Facebook data), one mentioned vascular issues as the

cause (<1%), 12 were congenital amputations (1%), ten were due to cancer (1%), and six were due to infection or septic shock (1%).

One hundred and forty six Reddit posts contained no mention of an amputation (39% of the data). Forty three posts mention an amputation but do not specify the amputation type/level (16% of discussed amputations). Of those amputation levels discussed, 48 upper extremity amputations were specifically mentioned. Nineteen posts mention a below elbow amputation (7% of discussed amputations), ten posts mention an above elbow amputation (4% of discussed amputations), 12 posts mention a partial hand amputation (4% of discussed amputations), and seven posts mention shoulder disarticulations (2% of discussed amputations). There were no posts that discussed a through elbow amputation/disarticulation. One hundred eighty five lower extremity amputations were specifically mentioned. Of these, 105 were below knee amputations (38% of discussed amputations), 56 were above knee amputations (20% of discussed amputations), eight were partial foot amputations (3% of discussed amputations), three were through knee amputations/knee disarticulations (1% of discussed amputations), and 13 were hip disarticulations (5% of discussed amputations). One hundred and fifty three posts mention an amputation/s but not the cause/s of said amputation/s, accounting for 41% of the Reddit data. Twenty two posts specifically mentioned trauma as the cause of the amputation/s (6% of all Reddit data), five mentioned vascular issues as the cause (1%), 30 were congenital amputations (8%), six were due to cancer (2%), and ten were due to infection or septic shock (3%).

Table 12: Amputations Discussed - Facebook

Amputations Discussed (Facebook)	1st	2nd	3rd	4th	Total #
Not Discussed					518
Unknown	75	7	3	2	87
Below Elbow	9	1	0	0	10
Above Elbow	12	4	1	1	18
Below Knee	178	16	1	2	197
Above Knee	117	26	7	3	153
Partial Hand	1	0	0	0	1
Partial Foot	8	2	0	0	10
Through Elbow	0	0	0	0	0
Through Knee	0	0	0	0	0
Shoulder Disartic	0	0	0	0	0
Hip Disartic	2	0	0	0	2

Table 13: Amputations Discussed - Reddit

Amputations Discussed (Reddit)	1st	2nd	3rd	4th	Total #
Not Discussed					146
Unknown	39	4	0	0	43
Below Elbow	18	1	0	0	19
Above Elbow	6	3	1	0	10
Below Knee	80	25	0	0	105
Above Knee	50	6	0	0	56
Partial Hand	8	3	1	0	12
Partial Foot	6	2	0	0	8
Through Elbow	0	0	0	0	0
Through Knee	3	0	0	0	3
Shoulder Disartic	7	0	0	0	7
Hip Disartic	13	0	0	0	13

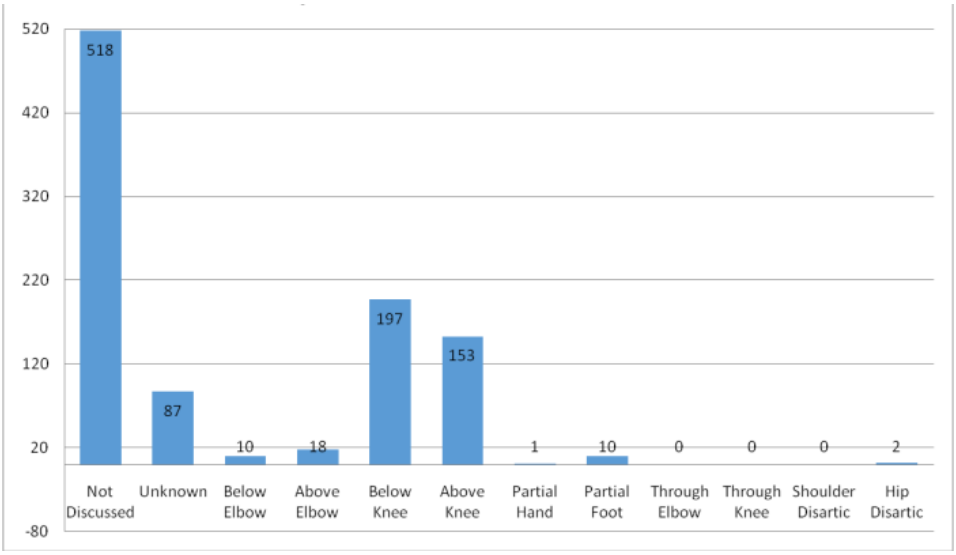

Figure 19: Amputations Discussed – Facebook Bar Chart

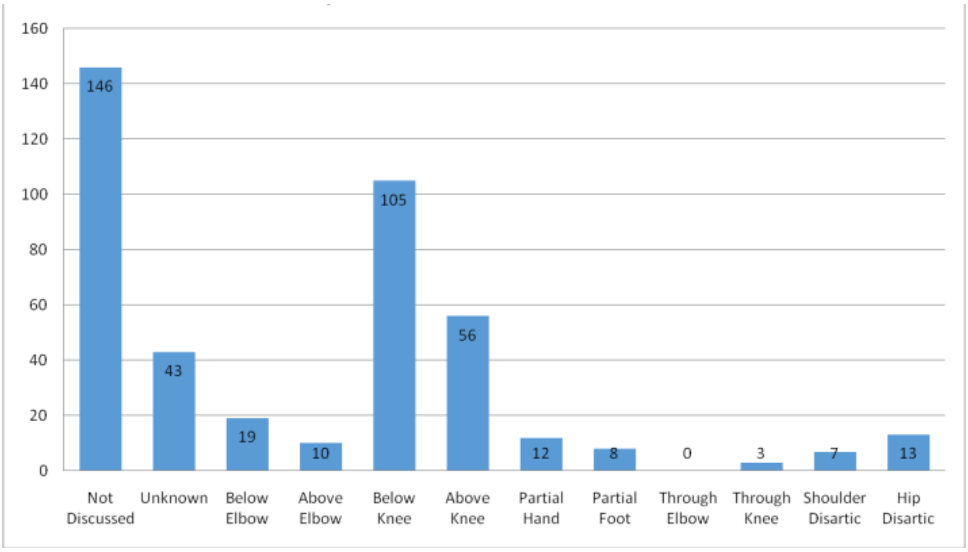

Figure 20: Amputations Discussed –Reddit Bar Chart

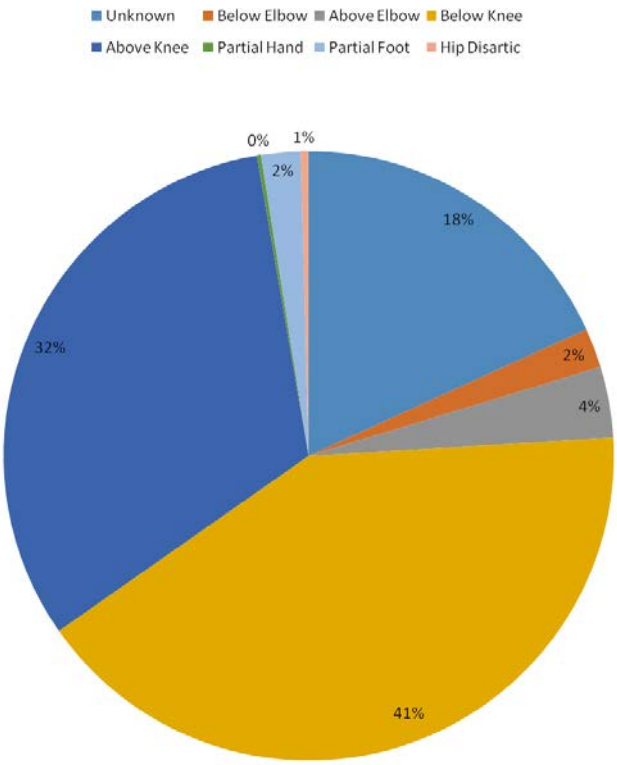

Figure 21: Amputations Discussed - Facebook Pie Chart

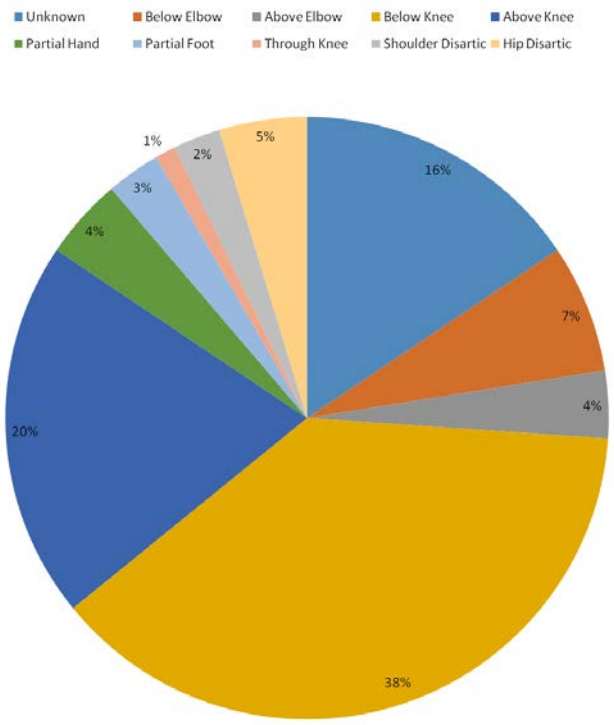

Figure 22: Amputations Discussed - Reddit Pie Chart

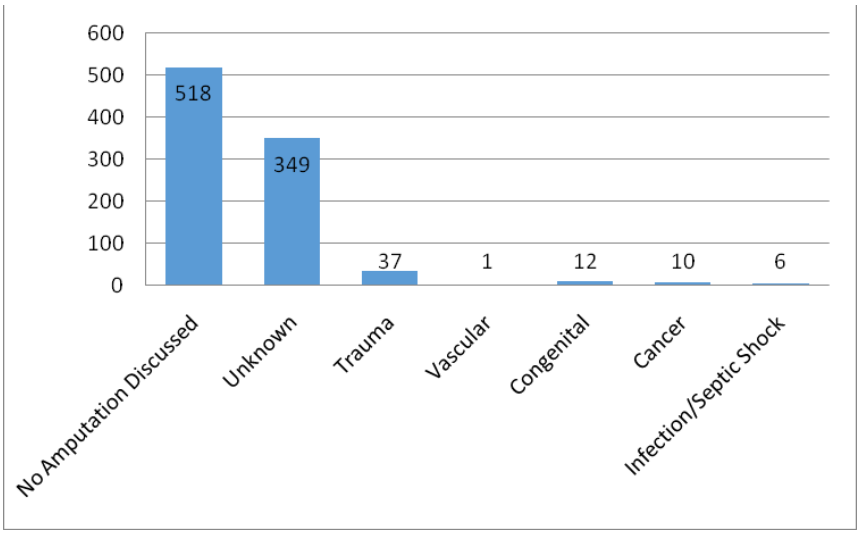

Figure 23: Reason for Amputation - Facebook Bar Graph

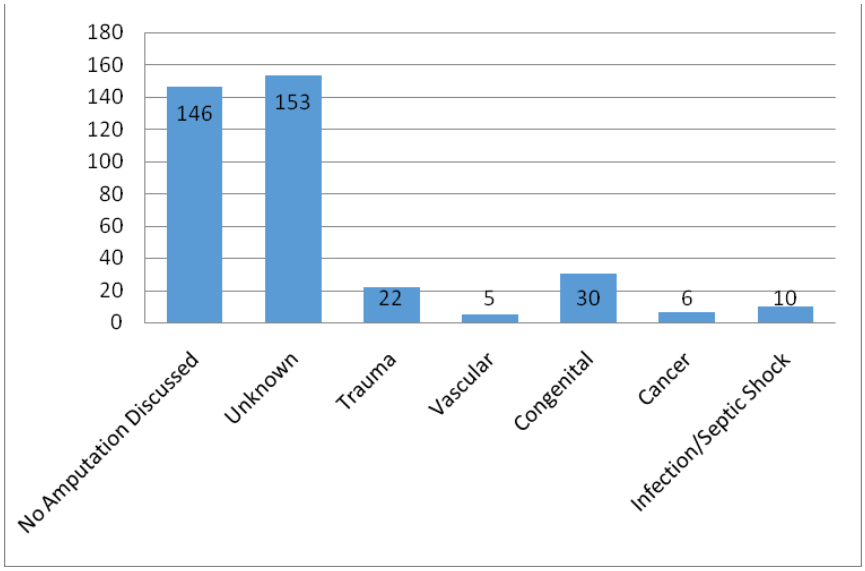

Figure 24: Reason for Amputation - Reddit Bar Graph

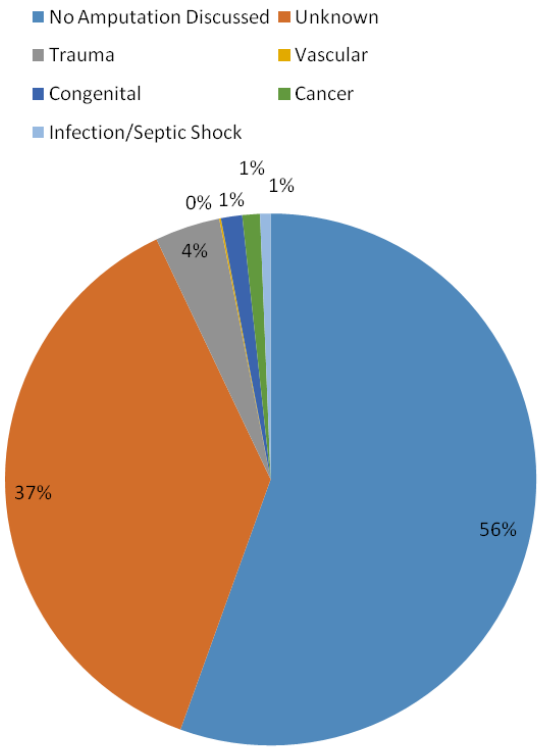

Figure 25: Reason for Amputation - Facebook Pie Chart

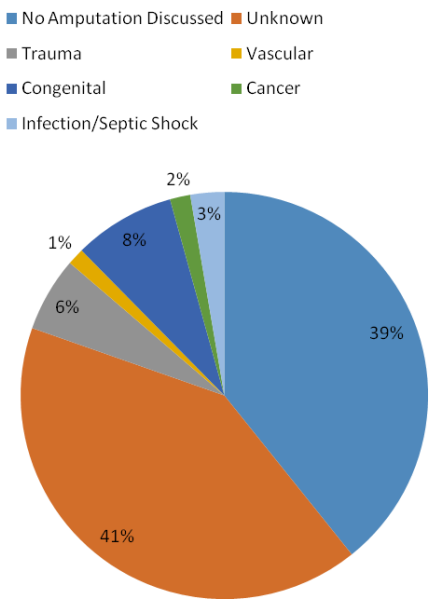

Figure 26: Reason for Amputation - Reddit Pie Chart

Insurance as a Barrier for Care

Ten posters on Facebook specifically mentioned having insurance (1%) while one specifically mentioned lacking coverage. Seventeen posters discussed insurance coverage as a barrier for obtaining devices/care (2%) while one poster said it was not a barrier. Four posters mentioned out of pocket costs as being a barrier to them getting the devices/supplies and care that they need (<1%). Three posters on Reddit specifically mentioned having insurance (1%) while two specifically mentioned lacking coverage. Five posters discussed insurance coverage as a barrier for obtaining devices/care (1%). Six posters mentioned out of pocket costs as being a barrier to them getting the devices/supplies and care that they need (2%).

Table 14: Barriers to Care - Facebook vs. Reddit

Barriers to Care - Facebook		Barriers to Care - Reddit	
Did the Poster Have Insurance?		Did the Poster Have Insurance?	
Unknown	922	Unknown	367
Yes	10	Yes	3
No	1	No	2
Was Insurance Coverage a Barrier to Obtaining Needed Devices/Supplies?		Was Insurance Coverage a Barrier to Obtaining Needed Devices/Supplies?	
Unknown	915	Unknown	367
Barrier	17	Barrier	5
Not a Barrier	1	Not a Barrier	0
Was OOP Cost a Barrier to Obtaining Needed Devices/Supplies?		Was OOP Cost a Barrier to Obtaining Needed Devices/Supplies?	
Unknown	929	Unknown	366
Barrier	4	Barrier	6
Not a Barrier	0	Not a Barrier	0

Common Amputee Problems and Concerns

Six posters on Facebook found sweat to be problematic (1% of the Facebook data set), six discussed phantom sensation as being problematic (<1%), ten mentioned phantom pain problems (2% of the Facebook data set) while three mentioned specifically not having phantom pain problems (<1%), and two posters discussed problems with skin breakdown (<1%). Energy Expenditure was never mentioned in the Facebook data. Four posters on Reddit found sweat to be problematic (1% of the Reddit data set), two discussed energy expenditure as a problem (<1%), 14 mentioned phantom pain problems (2% of the Reddit data set) while one mentioned specifically not having phantom pain problems (<1%), and one poster discussed problems with skin breakdown (<1%). Phantom Sensation was never mentioned in the Reddit data.

Six Facebook posters discussed problems with liners (1%) while six discussed specifically not having problems with liners (1%), and only one poster ever mentioned alignment, saying it was not a problem for them (<1%). Comfort was discussed frequently, with

22 posters having comfort related prosthetic problems (4% of Facebook posters). Only five posters mentioned comfort in a positive light saying that they didn't have problems with device discomfort (1%). Cosmesis was also mentioned recurrently, but in a more positive manner. Twenty six posters specifically mentioned not having issues with cosmesis (3% of Facebook posters) while only two posters (<1%) specifically mentioned finding cosmesis to be a problematic concern. Socks were never discussed in the Facebook data. Seven Reddit posters discussed problems with liners (1%) while three discussed specifically not having problems with liners (1%), one poster mentioned socks being problematic (<1%), while three posters specifically mentioned socks not being problematic (1%). Comfort was discussed frequently, with 27 posters having comfort related prosthetic problems (7% of Reddit posters). No Reddit users mentioned comfort in a positive light. Cosmesis was also mentioned recurrently, but in a more positive manner. Fourteen posters specifically mentioned not having issues with cosmesis (4% of Reddit posters) while only three posters (<1%) specifically mentioned finding cosmesis to be a problematic concern. Alignment was never discussed in the Reddit data.

As for technologies and alternative devices, four Facebook posters were seeking information about developing technologies (<1%), five posters were suggesting developing technologies to the other members of the message boards (<1%), and three posters were selling developing technologies (<1%, these posters including prosthetic vendor companies). Three Facebook posters mentioned that they were seeking adaptive technologies (<1%), while six posters were suggesting adaptive technologies (<1%) and five posters were selling adaptive tech (<1%). Fourteen Facebook posters were seeking advice or information regarding alternative device options (1%). Five Facebook posters were suggesting alternative options to the message board (<1%). No one on Facebook was selling alternative device options. One Reddit poster was seeking information about developing technologies (<1%), 14 posters were suggesting developing technologies to the other members of the message boards (4%), and ten posters were selling developing technologies (3%, these posters including prosthetic vendor companies). Five Reddit posters mentioned that they were seeking adaptive technologies (1%), while five posters were suggesting adaptive technologies (1%). No one on Reddit was selling adaptive technology. Seeking suggestions for alternative devices to what the user was currently using was common, with 27 Reddit posters seeking advice or information regarding alternative options (7%). Five

Reddit posters were suggesting alternative options to the message board (1%) and one poster was selling an alternative device option (<1%).

Common amputee comorbidities were not discussed frequently on either site. Eight Facebook posters mentioned having depression (1%) while one specifically stated that they didn't suffer from depression (<1%), four mentioned having problems with anxiety (<1%), and two mentioned having diabetes (<1%). Nine Reddit posters mentioned having depression (2%), five mentioned having problems with anxiety (1%), four mentioned having diabetes (1%), and TBI was never brought up on either site.

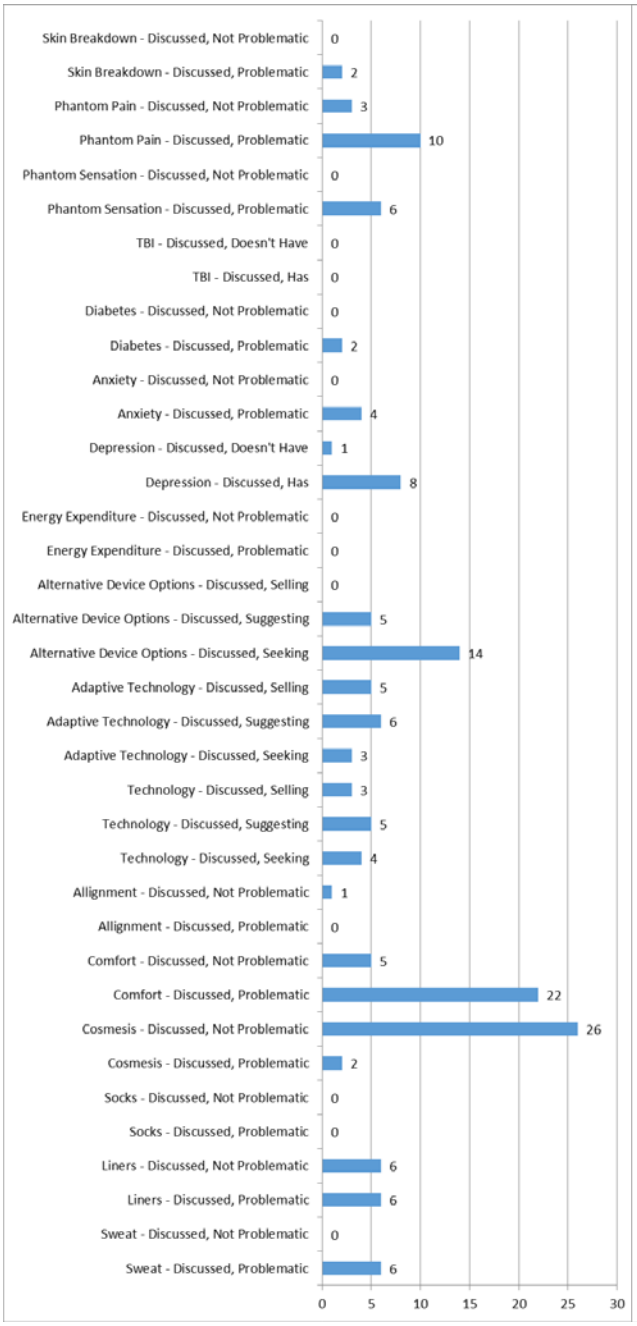

Figure 28: Potential Common Concerns - Facebook

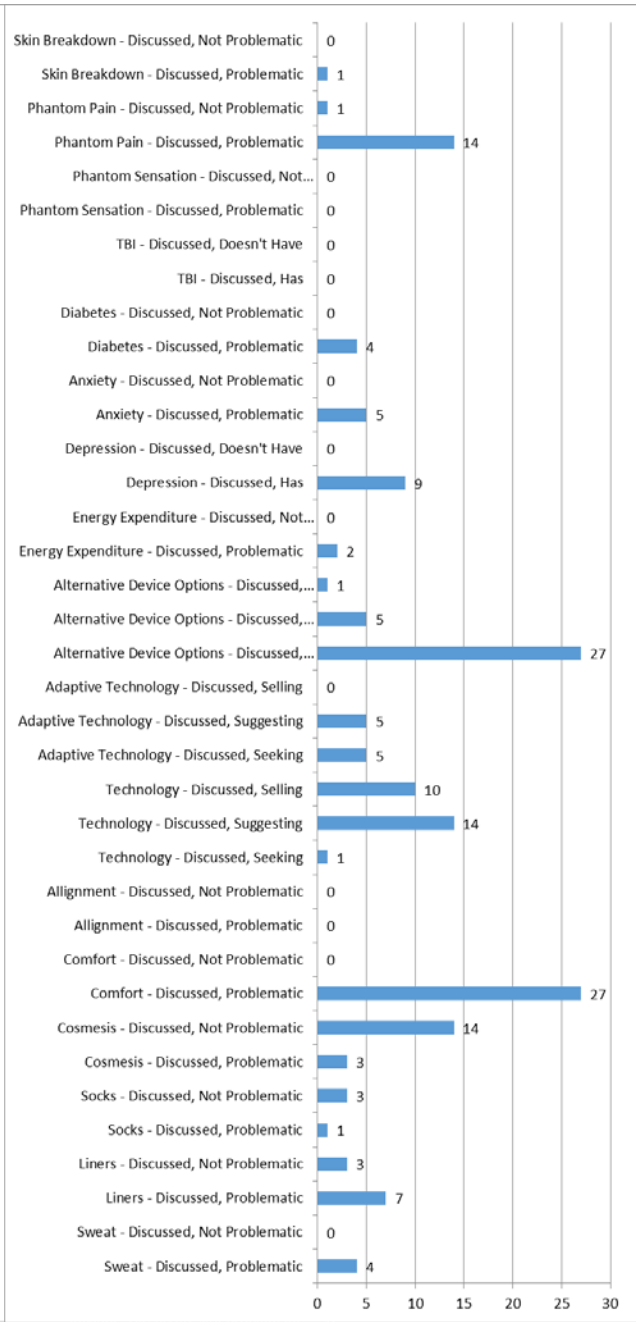

Figure 27: Potential Common Concerns - Reddit

Common Amputee Skin Disorders

Specific skin problems were discussed on Facebook 23 times in total (accounting for 2% of the Facebook data set). Rash was discussed three times (accounting for 13% of skin issue discussions) and folliculitis was discussed once (accounting for 4% of skin issue discussions), open wounds were discussed three times (13% of skin issue discussions), bony prominence pain was discussed once (4% of skin issue discussions), heterotopic ossification/bone spurs were discussed once (4% of skin issue discussions), swelling was mentioned six times (26% of skin issue discussions) and shrinkage was mentioned three times (13% of skin issue discussions) for a total volume fluctuation discussion total of nine times (39% of all skin issue discussions), discoloration was discussed three times (13% of skin issue discussions), and skin folds/creasing was brought up twice (9% of skin issue discussions). Ulcerations and scar breakdown/adhesions were never mentioned on Facebook. Specific skin problems were discussed on Reddit 22 times in total (accounting for 6% of the Reddit data set). Folliculitis was discussed twice (accounting for 9% of skin issue discussions), ulcers were mentioned once (4% of skin issue discussions), open wounds were discussed three times (14% of skin issue discussions), scar breakdown/adhesions were discussed once (4% of skin issue discussions), bony prominence pain was discussed twice (9% of skin issue discussions), swelling was mentioned six times (27% of skin issue discussions) and shrinkage was mentioned seven times (32% of skin issue discussions) for a total volume fluctuation discussion total of 13 times (59% of all skin issue discussions). Rash, discoloration, skin folds/creases, and heterotopic ossification were never mentioned on Reddit.

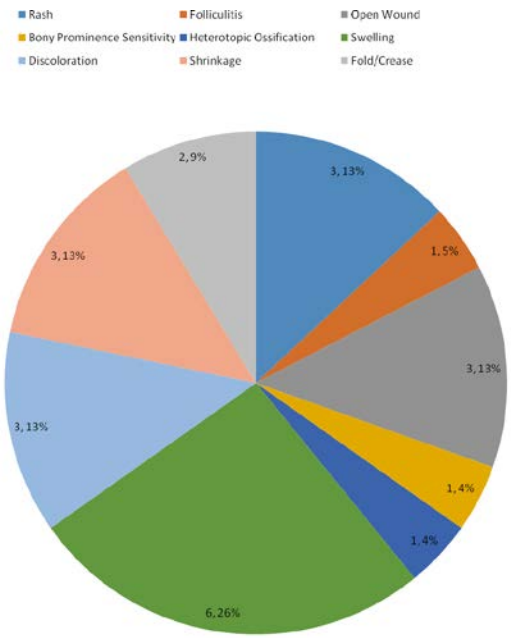

Figure 29: Specific Skin Issues Discussed as a Percentage of Skin Issues Discussions – Facebook

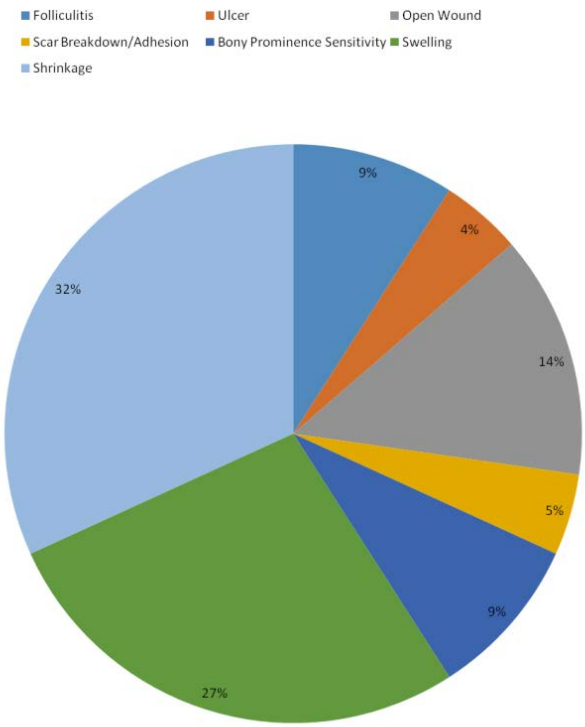

Figure 30: Specific Skin Issues Discussed as a Percentage of Skin Issues Discussions - Reddit

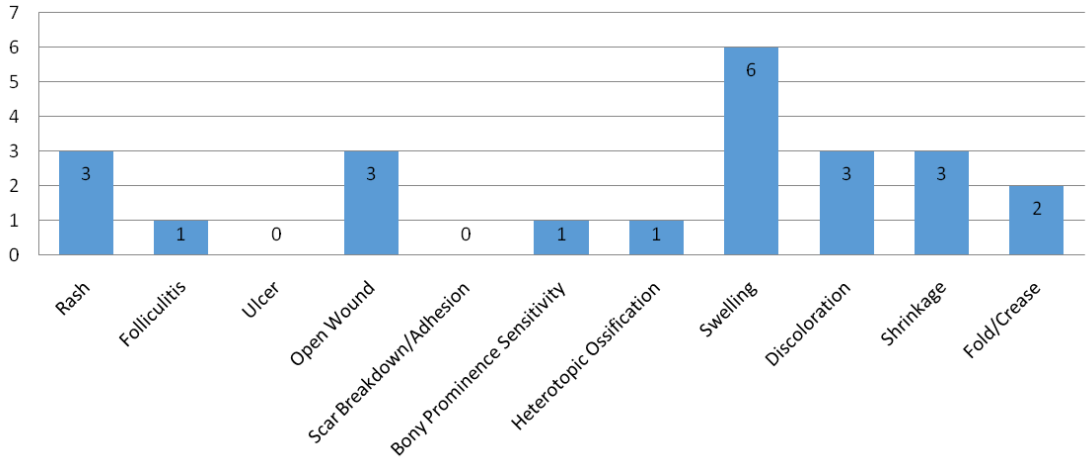

Figure 31: Skin Issues Discussed – Facebook

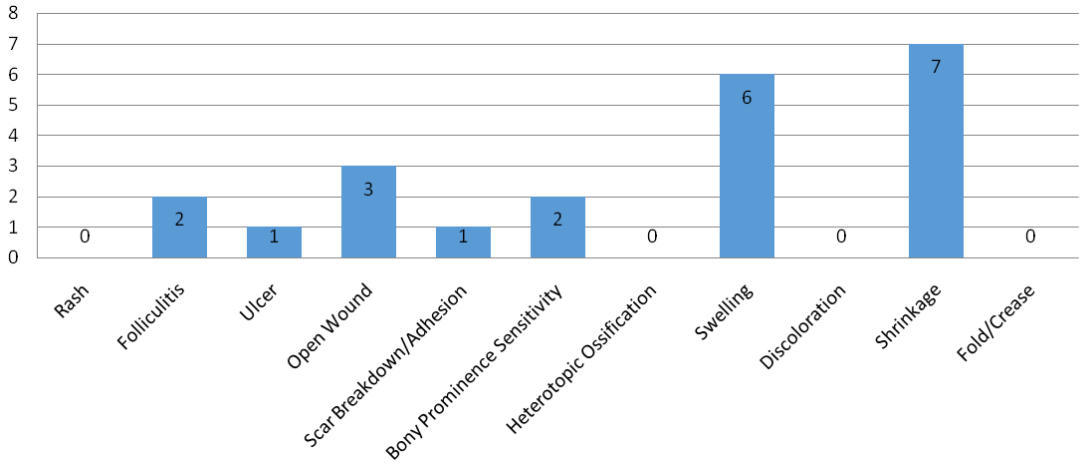

Figure 32: Skin Issues Discussed - Reddit

Participation in the Communiy

Sports discussions accounted for 5% of the total Facebook postings (51 distinct posts), discussions regarding attended events accounted for 7% of the total Facebook postings (69 distinct posts), and travel discussions accounted for <1% of the total Facebook postings (3 distinct posts). Sports discussions accounted for 3% of the total Reddit postings (10 distinct posts), discussions regarding attended events accounted for 1% of the total Reddit postings (3 distinct posts), and travel discussions accounted for 2% of the total Reddit postings (8 distinct posts).

Life Hacks

General life hacks were brought up once on Facebook, with one poster mentioning using coconut and tea tree oils. One life hack for pain was mentioned on Facebook, and the post was discussing specifically the use of medical marijuana. General life hacks were brought up three times on Reddit, with two posters discussing the use of aloe vera gel and one poster mentioning the use of magnesium and potassium for muscle spasms. No life hacks for pain were mentioned on Reddit.

Table of total values distributed across categories for the Facebook data set can be found in Appendix E: Comparative Data & Charts - FB.

Table of total values distributed across categories for the Reddit data set can be found in Appendix E: Comparative Data & Charts - Red.

Amputee Coalition vs. Blesma

Represented Social Media Groups, Posters, and Types of Posts

Amputee Coalition [referred to from here as "AC"] posts accounted for 65% of the Facebook data with 603 posts, while Blesma: The Limbless Veteran [referred to from here as "Blesma"] accounted for 35% of the Facebook data with 330 posts.

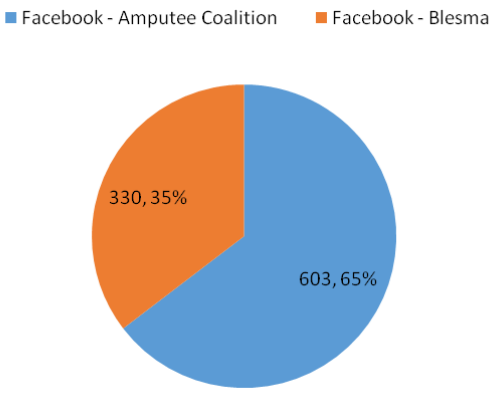

Figure 33: Amputation Coalition vs. Blesma

The types of posters who are utilizing AC consisted of 260 self-identified amputees (43% of AC posters), 79 people who identified as being family members of amputees (13% of AC posters), and four posters who identified as being friends of an amputee (1% of AC posters). Eighty six posts were made by advocacy groups (14% of AC posts), 18 posts were made by health care professionals including prosthetists (3% of AC posts), 14 posts were made by prosthetic vendors (2% of AC posts), and two posts were made by individuals who are considering undergoing an amputation for various reasons (1% of posts). One hundred and forty AC posts were unable to be identified and coded by a specific type of poster (23% of all AC posts). The types of posters who are utilizing Blesma consisted of 24 self-identified amputees (7% of Blesma posters), seven posters who identified as being family members of amputees (2% of Blesma posters), and five posters who identified as being friends of an amputee (1% of Blesma posters). Thirty two posts were made by an advocacy group (10% of Blesma posts), two posts were made by health care professionals including prosthetists (1% of Blesma posts), five posts were made by prosthetic vendors (1% of Blesma posts), and two posts were made by individuals who are considering undergoing an amputation for various reasons (1% of posts). Two hundred and fifty three Blesma posts were unable to be identified and coded by a specific type of poster (77% of all Blesma posts).

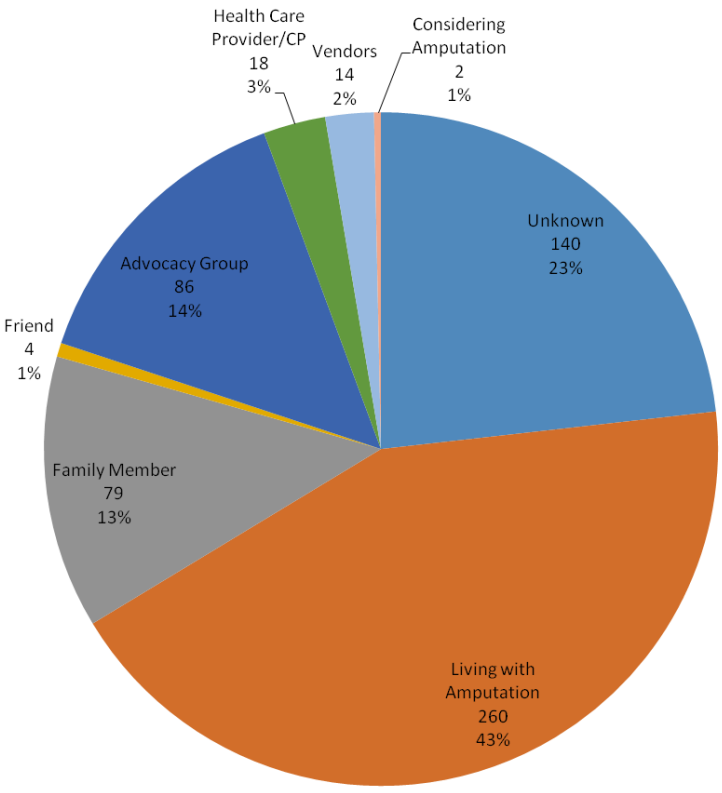

Figure 34: Type of Poster – AC Pie Chart

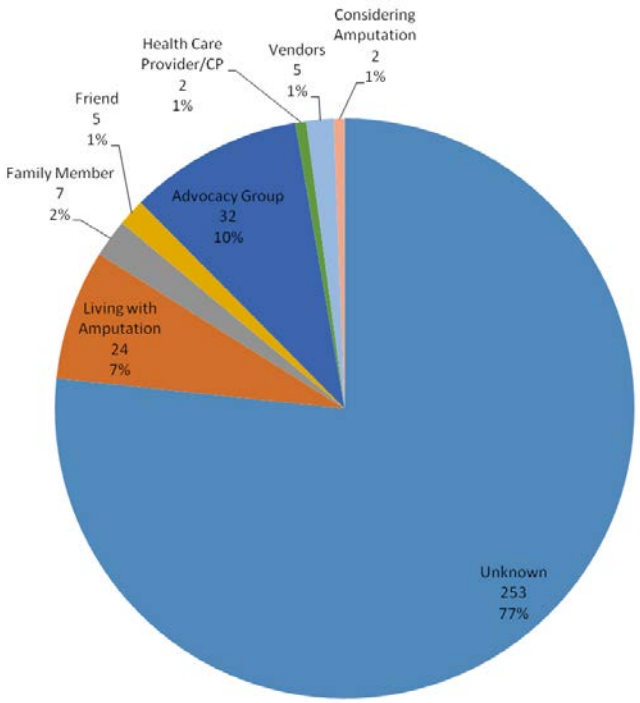

Figure 35: Type of Poster – Blesma Pie Chart

Of the 603 total AC posts analyzed, 125 were identified as inquires (21%) and 260 were identified as anecdotes or stories (43%). Fifty three posts were identified as providing emotional support (9%) and 12 were identified as seeking emotional support (2%). One hundred and eleven posts were identified as advertisements of some kind (18%) and 14 posts were identified as pertaining to a research study or project (2%). Of the 330 total Blesma posts analyzed, 12 were identified as inquires (4%) and 157 were identified as anecdotes or stories (48%). Twenty four posts were identified as providing emotional support (7%) and 45 were identified as seeking emotional support (14%). One hundred and six posts were identified as advertisements of some kind (32%) and one post was identified as pertaining to a research study or project (<1%).

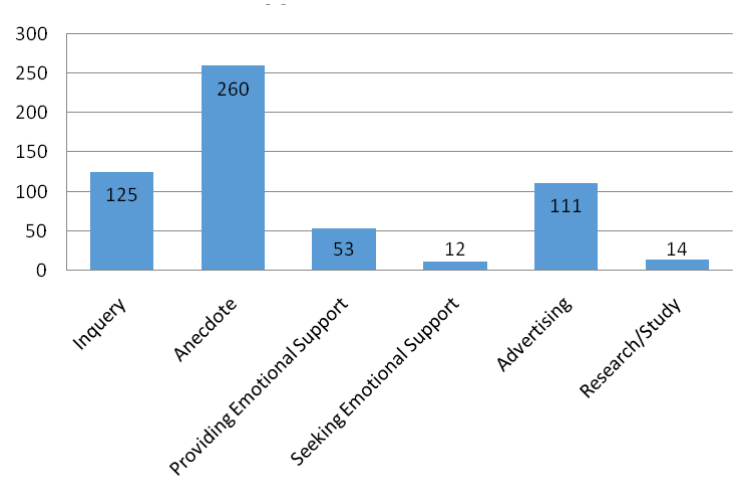

Figure 36: Type of Poster – AC Bar Graph

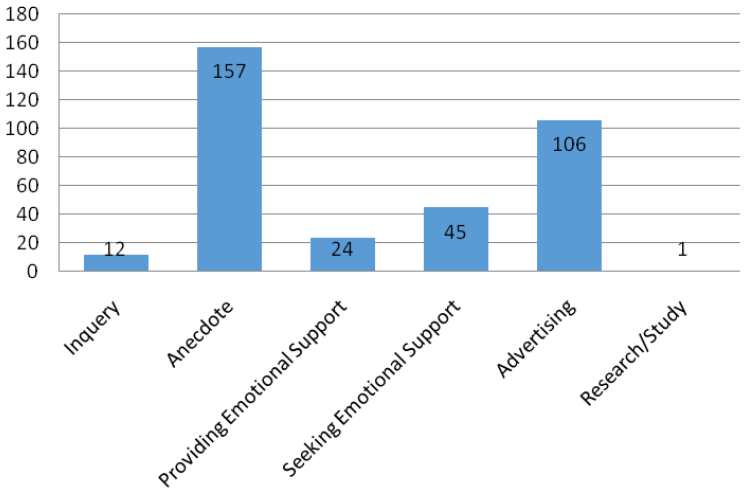

Figure 37: Type of Poster – Blesma Bar Graph

Amputations Discussed - Types and Causes

Two hundred and thirty seven AC posts contained no mention of an amputation (39% of the data). Seventy three posts mention an amputation but do not specify the amputation type/level (18% of discussed amputations). Of those amputation levels discussed, 25 upper extremity amputations were specifically mentioned. Eight posts mention a below elbow amputation (2% of discussed amputations), 16 posts mention an above elbow amputation (4% of discussed amputations), and one post mentions a partial hand amputation (<1% of discussed amputations). There were no posts that discussed a through elbow amputation/disarticulation or a shoulder disarticulation. Three hundred and fifteen lower extremity amputations were specifically mentioned. Of these, 174 were below knee amputations (42% of discussed amputations), 129 were above knee amputations (31% of discussed amputations), ten were partial foot amputations (2% of discussed amputations), and two were hip disarticulations (1% of discussed amputations). There were no posts which mentioned through knee amputations/knee disarticulations. Three hundred and thirteen posts mention an amputation/s but not the cause/s of said amputation/s, accounting for 52% of the AC data. Twenty five posts specifically mentioned trauma as the cause of the amputation/s (4% of all AC data), one mentioned vascular issues as the cause (<1%), 12 were congenital amputations (2%), ten were due to cancer (2%), and five were due to infection or septic shock (1%).

Two hundred and eighty one Blesma posts contained no mention of an amputation (85% of the data). Fourteen posts mention an amputation but do not specify the amputation type/level (22% of discussed amputations). Of those amputation levels discussed, four upper extremity amputations were specifically mentioned. Two posts mention a below elbow amputation (3% of discussed amputations), and two posts mention an above elbow amputation (3% of discussed amputations). There were no posts that discussed a through elbow amputation/disarticulation, a partial hand amputation, or a shoulder disarticulation. Forty seven lower extremity amputations were specifically mentioned. Of these, 23 were below knee amputations (35% of discussed amputations), and 24 were above knee amputations (37% of discussed amputations). No partial foot amputations, through knee amputations/knee disarticulations, or hip disarticulations were mentioned. Thirty six posts mention an amputation/s but not the cause/s of said amputation/s,

accounting for 11% of the Blesma data. Twelve posts specifically mentioned trauma as the cause of the amputation/s (4% of all Blesma data), and one was due to infection or septic shock (<1%). There was no mention of vascular issues, cancer, or congenital amputation as causes.

Table 15: Amputations Discussed, First Amputation Mentioned Through Fourth Amputation Mentioned - AC

Amputations Discussed - AC	1st	2nd	3rd	4th	Total #
Not Discussed					237
Unknown	64	5	2	2	73
Below Elbow	7	1	0	0	8
Above Elbow	10	4	1	1	16
Below Knee	163	8	1	2	174
Above Knee	100	20	6	3	129
Partial Hand	1	0	0	0	1
Partial Foot	8	2	0	0	10
Through Elbow	0	0	0	0	0
Through Knee	0	0	0	0	0
Shoulder Disartic	0	0	0	0	0
Hip Disartic	2	0	0	0	2

Table 16: Amputations Discussed, First Amputation Mentioned Through Fourth Amputation Mentioned - Blesma

Amputations Discussed - Blesma	1st	2nd	3rd	4th	Total #
Not Discussed					281
Unknown	11	2	1	0	14
Below Elbow	2	0	0	0	2
Above Elbow	2	0	0	0	2
Below Knee	15	8	0	0	23
Above Knee	17	6	1	0	24
Partial Hand	0	0	0	0	0
Partial Foot	0	0	0	0	0
Through Elbow	0	0	0	0	0
Through Knee	0	0	0	0	0
Shoulder Disartic	0	0	0	0	0
Hip Disartic	0	0	0	0	0

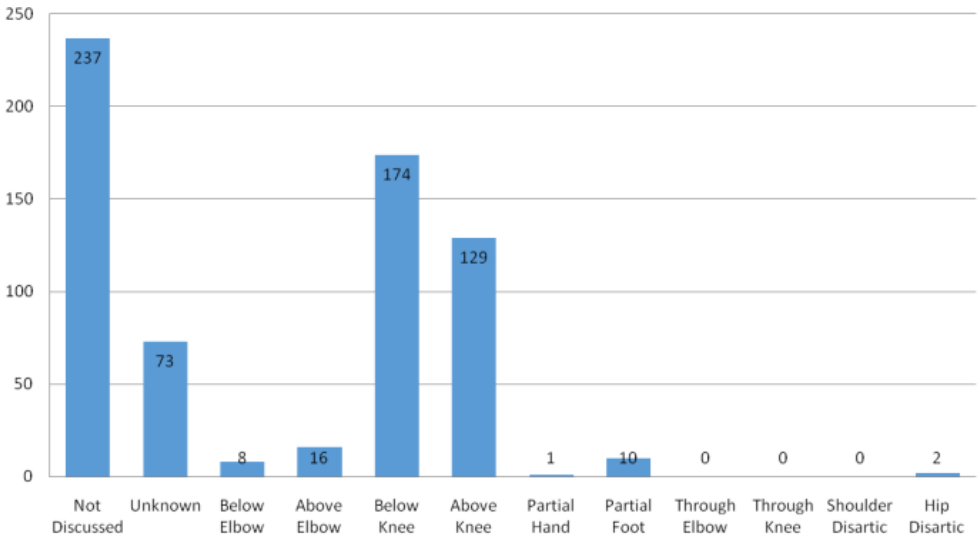

Figure 38: Amputations Discussed - AC Bar Graph

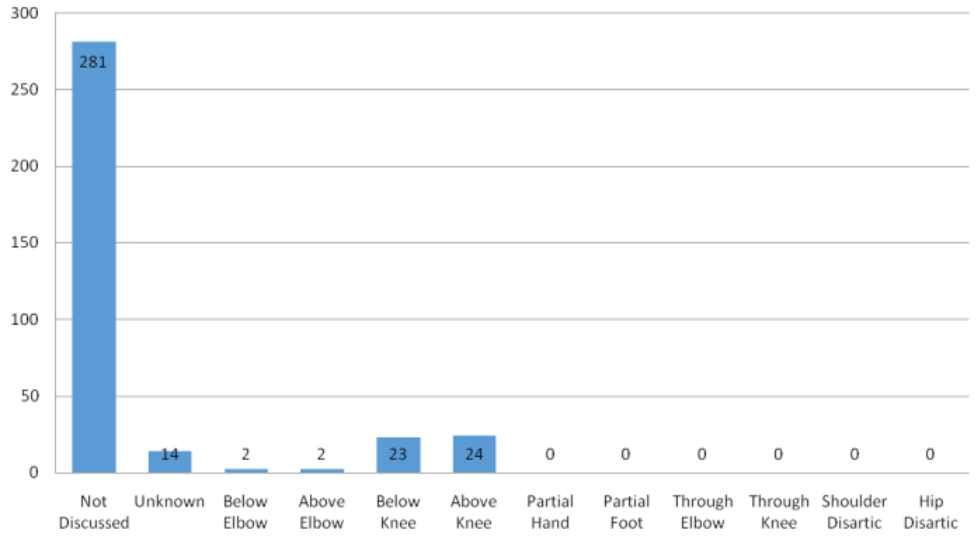

Figure 39: Amputations Discussed - Blesma Bar Graph

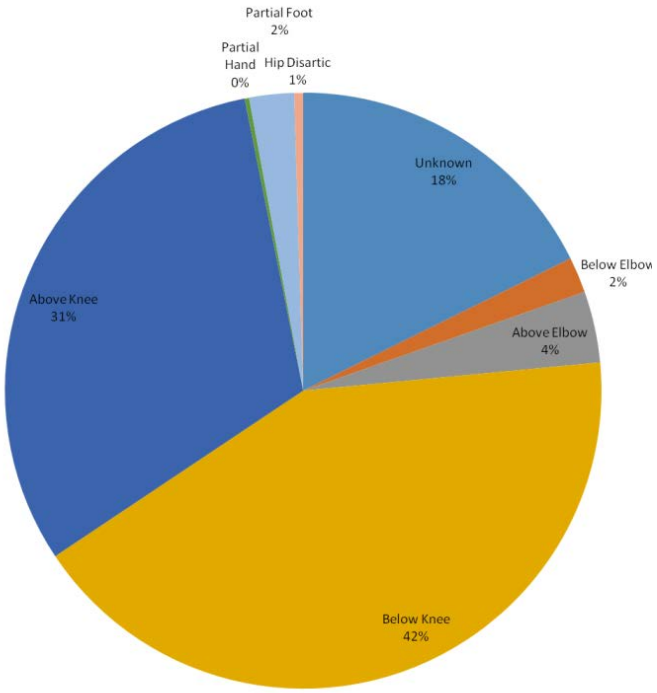

Figure 40: Amputations Discussed as a Percentage of Amputation Discussions - AC Pie Chart

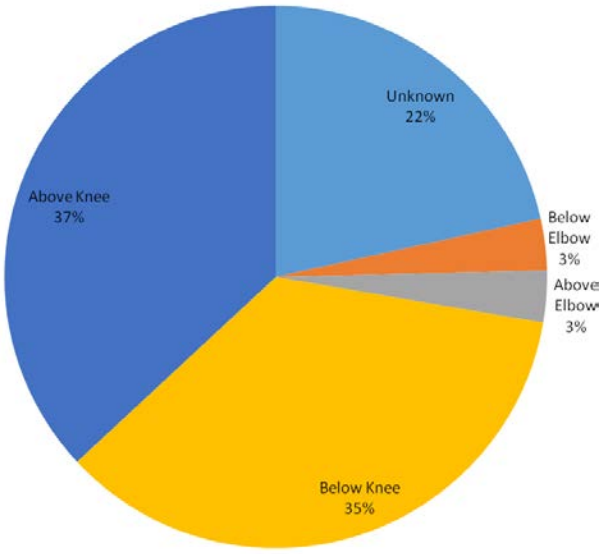

Figure 41: Amputations Discussed as a Percentage of Amputation Discussions- Blesma Pie Chart

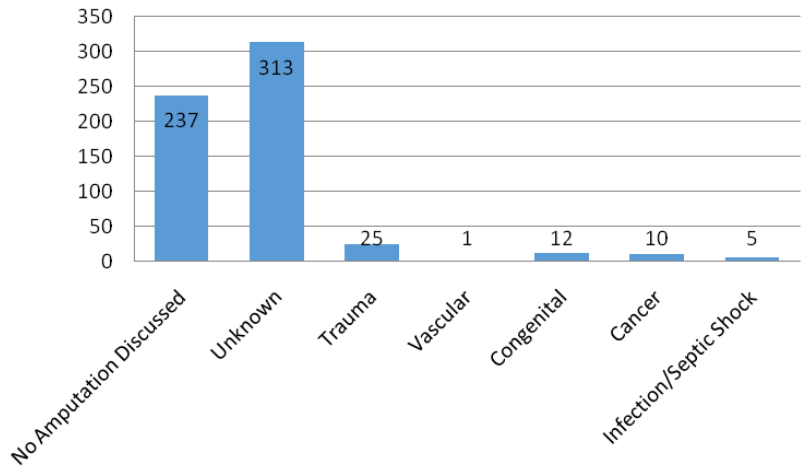

Figure 42: Reason for Amputation – AC

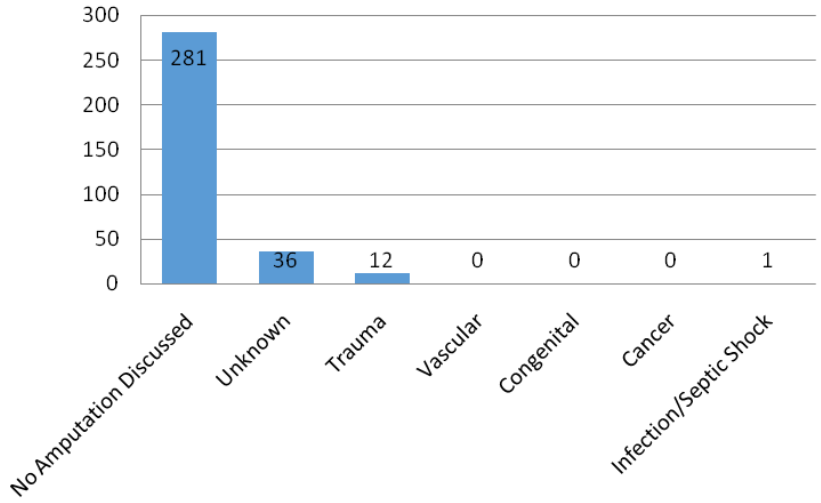

Figure 43: Reason for Amputation - Blesma

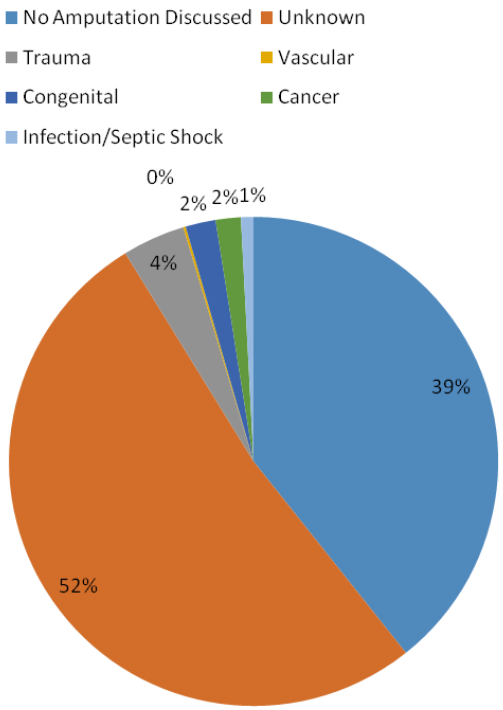

Figure 44: Reason for Amputation - AC Pie Chart

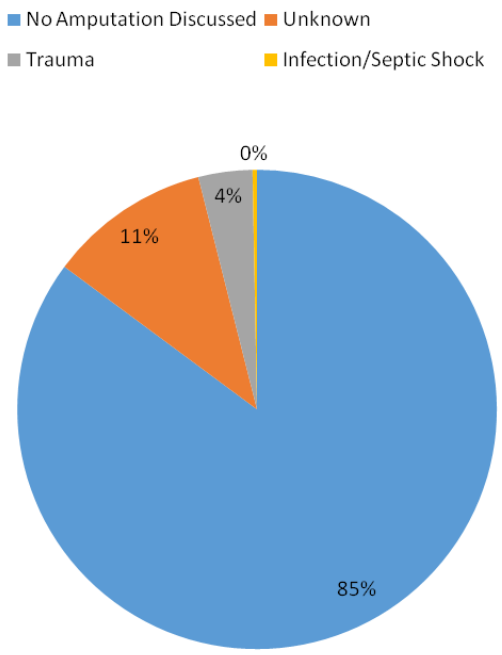

Figure 45: Reason for Amputation - Blesma Pie Chart

Insurance as a Barrier for Care

Ten posters on AC specifically mentioned having insurance (2%) while one specifically mentioned lacking coverage. Seventeen posters discussed insurance coverage as a barrier for obtaining devices/care (3%) while one poster said it was not a barrier. Four posters mentioned out of pocket costs as being a barrier to them getting the devices/supplies and care that they need (1%). Insurance and out of pocket costs were never mentioned on Blesma.

Table 17: Barriers to Care - Amputee Coalition vs. Blesma

Barriers to Care - AC		Barriers to Care - Blesma	
Did the Poster Have Insurance?		Did the Poster Have Insurance?	
Unknown	592	Unknown	330
Yes	10	Yes	0
No	1	No	0
Was Insurance Coverage a Barrier to Obtaining Needed Devices/Supplies?		Was Insurance Coverage a Barrier to Obtaining Needed Devices/Supplies?	
Unknown	585	Unknown	330
Barrier	17	Barrier	0
Not a Barrier	1	Not a Barrier	0
Was OOP Cost a Barrier to Obtaining Needed Devices/Supplies?		Was OOP Cost a Barrier to Obtaining Needed Devices/Supplies?	
Unknown	599	Unknown	330
Barrier	4	Barrier	0
Not a Barrier	0	Not a Barrier	0

Common Amputee Problems and Concerns

Six posters on AC found sweat to be problematic (1% of the AC data set), six discussed phantom sensation as being problematic (1%), ten mentioned phantom pain problems (2% of the AC data set) while three mentioned specifically not having phantom pain problems (<1%), and two posters discussed problems with skin breakdown (<1%). Energy Expenditure was never mentioned in the AC data. Sweat, energy expenditure, phantom sensation, phantom pain, and skin breakdown were never mentioned in the Blesma data.

Six AC posters discussed problems with liners (1%) while six discussed specifically not having problems with liners (1%), and only one poster ever mentioned alignment, saying it was not a problem for them (<1%). Comfort was discussed frequently, with 20 posters having comfort related prosthetic problems (3% of AC posters). Only five posters mentioned comfort in a positive light saying that they didn't have problems with device discomfort (1%). Cosmesis was also mentioned recurrently, but in a more positive manner. Twenty six posters specifically mentioned not having issues with cosmesis (4% of AC posters) while only two posters (<1%)

specifically mentioned finding cosmesis to be a problematic concern. Socks were never discussed in the AC data. Comfort was discussed in the Blesma data, with two posters having comfort related prosthetic problems (1% of Blesma posters). Liners, socks, cosmesis, and alignment were never discussed in the Blesma data.

As for technologies and alternative devices, four AC posters were seeking information about developing technologies (<1%), four posters were suggesting developing technologies to the other members of the message boards (<1%), and two posters were selling developing technologies (<1%, these posters including prosthetic vendor companies). Three AC posters mentioned that they were seeking adaptive technologies (<1%), while one posters were suggesting adaptive technologies (<1%). No posters on AC were selling adaptive technologies. Thirteen AC posters were seeking advice or information regarding alternative device options (2%). Four AC posters were suggesting alternative options to the message board (<1%). No one on AC was selling alternative device options. No Blesma posters were seeking information about developing technologies, but one poster was suggesting developing technologies to the other members of the message board (<1%), and one poster was selling developing technologies (<1%). Five Blesma posters mentioned that they were suggesting adaptive technologies (2%), and five posters were selling adaptive technologies (2%). No one on Blesma was seeking adaptive technology. One Blesma poster was seeking advice or information regarding alternative device options (<1%). One Blesma poster was suggesting alternative device options to the message board (<1%). No Blesma posters were selling alternative device options.

Common amputee comorbidities were not discussed frequently on either site. Seven AC posters mentioned having depression (1%) while one specifically stated that they didn't suffer from depression (<1%), two mentioned having problems with anxiety (<1%), and two mentioned having diabetes (<1%). One Blesma poster mentioned having depression (<1%), two mentioned having problems with anxiety (1%), and diabetes was never mentioned by Blesma posters. TBI was never brought up on either Facebook page.

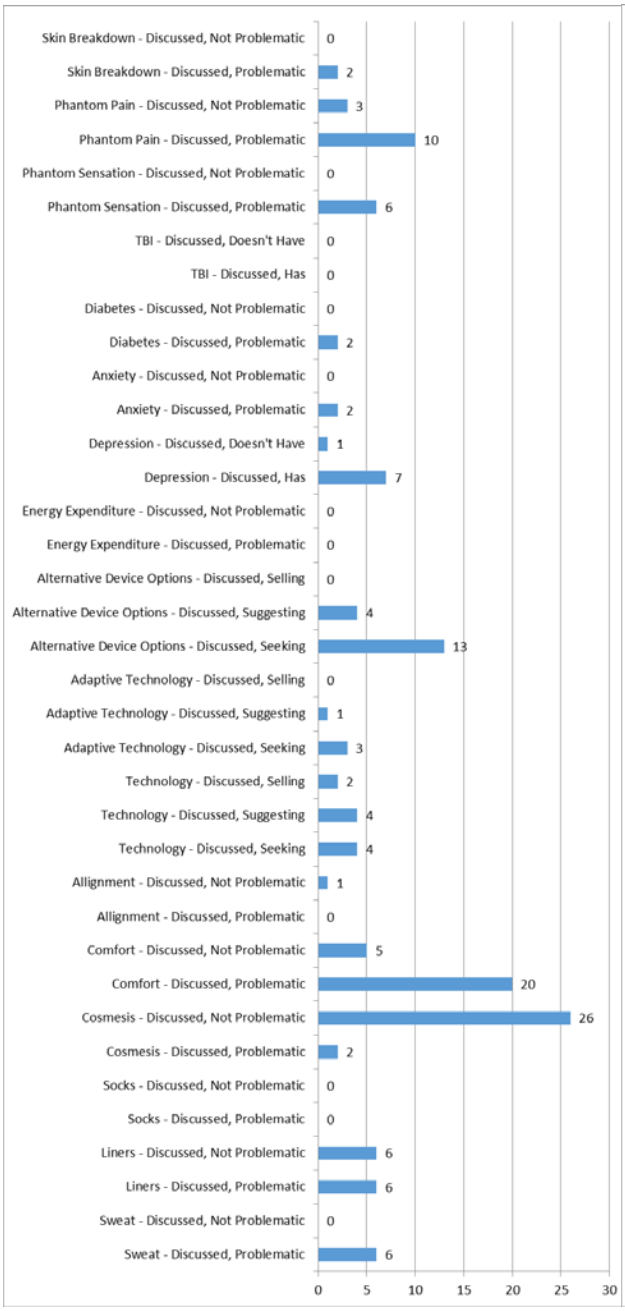

Figure 47: Potential Common Concerns - AC

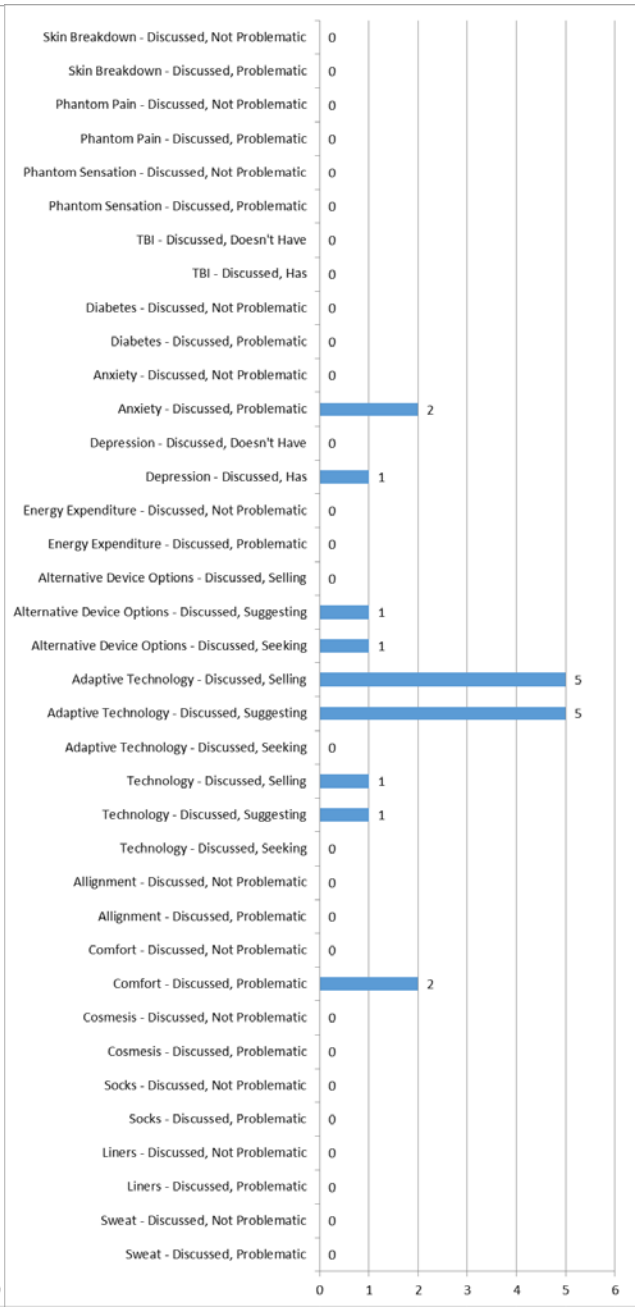

Figure 46: Potential Common Concerns - Blesma

Common Amputee Skin Disorders

Specific skin problems were discussed on AC 23 times in total (accounting for 4% of the AC data set). Rash was discussed three times (accounting for 13% of skin issue discussions) and folliculitis was discussed once (accounting for 4% of skin issue discussions), open wounds were discussed three times (13% of skin issue discussions), bony prominence pain was discussed once (4% of skin issue discussions), heterotopic ossification/bone spurs were discussed once (4% of skin issue discussions), swelling was mentioned six times (26% of skin issue discussions) and shrinkage was mentioned three times (13% of skin issue discussions) for a total volume fluctuation discussion total of nine times (39% of all skin issue discussions), discoloration was discussed three times (13% of skin issue discussions), and skin folds/creasing was brought up twice (9% of skin issue discussions). Ulcerations and scar breakdown/adhesions were never mentioned on AC. Not a single skin type/issue/disorder was ever mentioned on Blesma.

Participation in the Community

Sports discussions accounted for 5% of the total AC postings (33 distinct posts), discussions regarding attended events accounted for 5% of the total AC postings (32 distinct posts), and travel discussions accounted for <1% of the total AC postings (3 distinct posts). Sports discussions accounted for 5% of the total Blesma postings (18 distinct posts), discussions regarding attended events accounted for 11% of the total Blesma postings (37 distinct posts), and travel was never discussed.

Life Hacks

General life hacks were brought up one time on AC, with a poster discussing the use of coconut and tea tree oil. One life hack for pain was mentioned on AC, with a user discussing the use of medical marijuana. No life hacks were discussed on Blesma.

Table of total values distributed across categories for the AC data set and the Blesma data set can be found in Appendix E: Comparative Data & Charts - FB.

Prosthetics SubReddit vs. Amputee SubReddit

Represented Social Media Groups, Posters, and Types of Posts

The Prosthetics SubReddit [referred to from here as "Prosthetics-SR"] posts accounted for 30% of the Reddit data with 112 posts, while the Amputee SubReddit [referred to from here as "Amputee-SR"] accounted for 70% of the Reddit data with 260 posts.

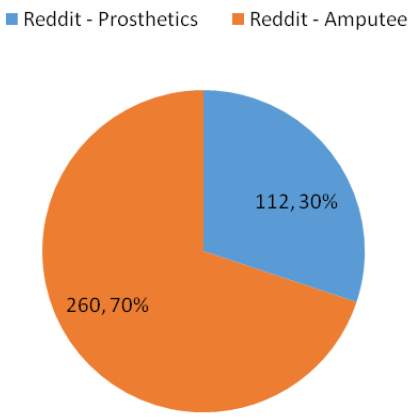

Figure 48: Amputee SubReddit vs. Prosthetics SubReddit

The types of posters who are utilizing Prosthetics-SR consisted of 36 self-identified amputees (32% of Prosthetics-SR posters), two posters who identified as being family members of amputees (2% of Prosthetics-SR posters), and one poster who identified as being a friend of an amputee (1% of Prosthetics-SR posters). One post was made by an advocacy group (1% of Prosthetics-SR posts), 28 posts were made by health care professionals including prosthetists

(25% of Prosthetics-SR posts), 14 posts were made by prosthetic vendors (12% of Prosthetics-SR posts), and two posts were made by individuals who are considering undergoing an amputation for various reasons (2% of posts). Twenty eight Prosthetics-SR posts were unable to be identified and coded by a specific type of poster (25% of all Prosthetics-SR posts). The types of posters who are utilizing Amputee-SR consisted of 134 self-identified amputees (52% of Amputee-SR posters), 14 posters who identified as being family members of amputees (5% of Amputee-SR posters), and four posters who identified as being friends of an amputee (2% of Amputee-SR posters). Zero posts were made by an advocacy group or vendors, 14 posts were made by health care professionals including prosthetists (5% of Amputee-SR posts), and 23 posts were made by individuals who are considering undergoing an amputation for various reasons (9% of posts). Seventy one Amputee-SR posts were unable to be identified and coded by a specific type of poster (27% of all Amputee-SR posts).

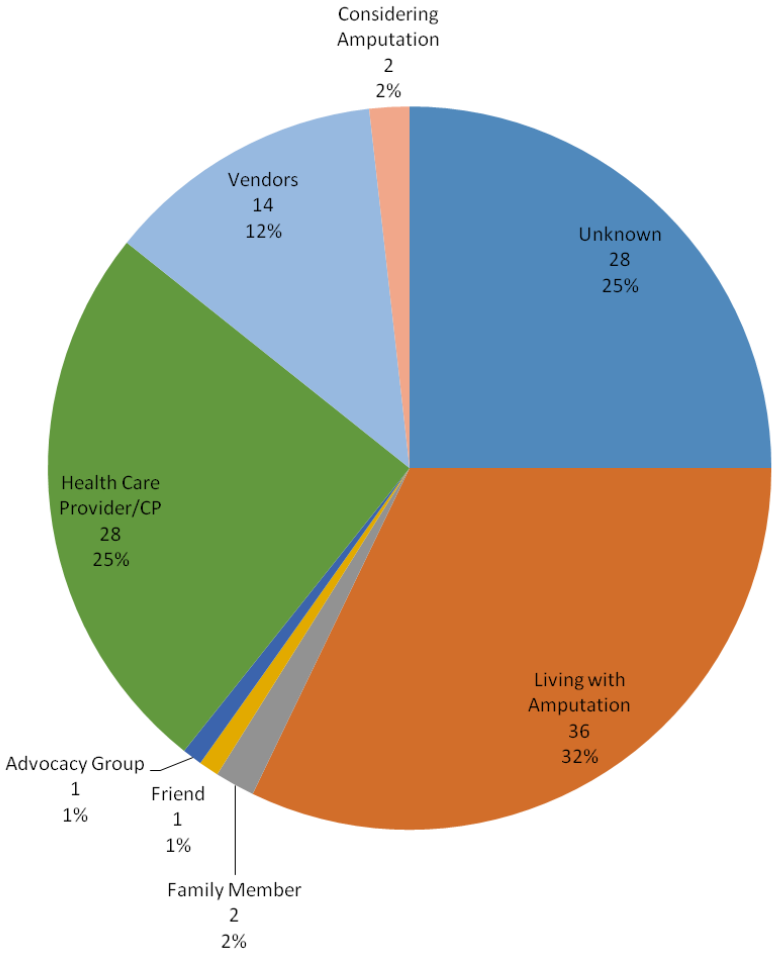

Figure 49: Type of Poster - Prosthetics SR

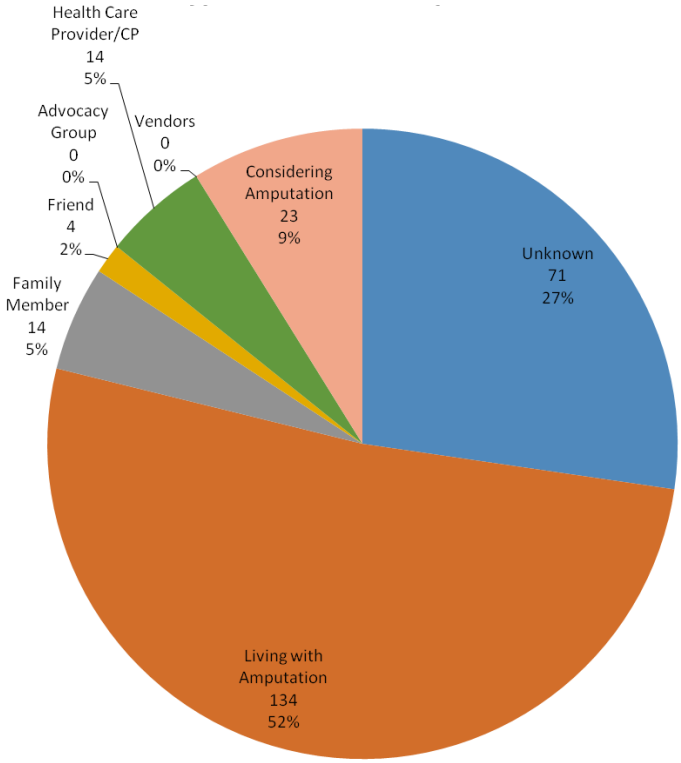

Figure 50: Type of Poster - Amputee SR

Of the 112 total Prosthetics-SR posts analyzed, 50 were identified as inquires (45%) and 34 were identified as anecdotes or stories (30%). One post was identified as providing emotional support (1%) and one was identified as seeking emotional support (1%). Nine posts were identified as advertisements of some kind (8%) and 12 posts were identified as pertaining to a research study or project (11%). Of the 260 total Amputee-SR posts analyzed, 140 were identified as inquires (54%) and 63 were identified as anecdotes or stories (24%). Four posts were identified as providing emotional support (2%) and 14 were identified as seeking emotional support (5%). One post was identified as an advertisement of some kind (<1%) and 45 posts were identified as pertaining to a research study or project (17%).

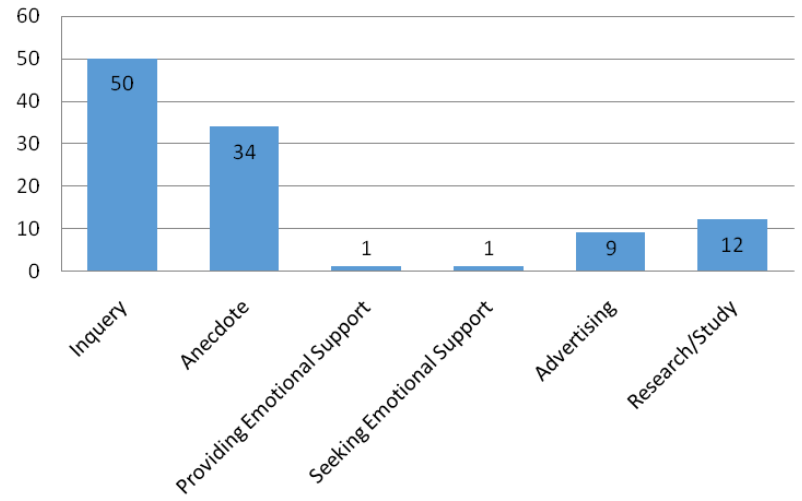

Figure 51: Type of Post - Prosthetics SR

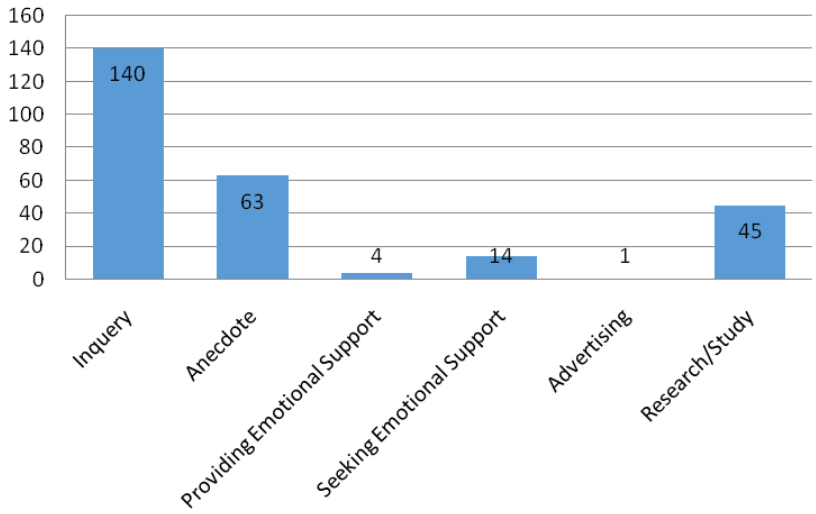

Figure 52: Type of Post - Amputee SR

Amputations Discussed - Types and Causes

Sixty Prosthetics-SR posts contained no mention of an amputation (53% of the data). Eleven posts mention an amputation but do not specify the amputation type/level (16% of discussed amputations). Of those amputation levels discussed, 20 upper extremity amputations were specifically mentioned. Ten posts mention a below elbow amputation (15% of discussed amputations), two posts mention an above elbow amputation (3% of discussed amputations), seven post mentions a partial hand amputation (10%), and one post mentioned a shoulder disarticulation (1%). There were no posts that discussed a through elbow amputation/disarticulation. Thirty seven lower extremity amputations were specifically mentioned. Of these, 21 were below knee amputations (31% of discussed amputations), 13 were above knee amputations (19% of discussed amputations), two were partial foot amputations (3% of discussed amputations), and one was a hip disarticulations (1% of discussed amputations). There were no posts which mentioned through knee amputations/knee disarticulations. Thirty two posts mention an amputation/s but not the cause/s of said amputation/s, accounting for 29% of the Prosthetics-SR data. Five posts specifically mentioned trauma as the cause of the amputation/s (4% of all Prosthetics-SR data), zero mentioned vascular issues as the cause, 13 were congenital amputations (12%), two were due to cancer (2%), and none were due to infection or septic shock.

Eighty six Amputee-SR posts contained no mention of an amputation (33% of the data). Thirty two posts mention an amputation but do not specify the amputation type/level (15% of discussed amputations). Of those amputation levels discussed, 28 upper extremity amputations were specifically mentioned. Nine posts mention a below elbow amputation (4% of discussed amputations), eight posts mention an above elbow amputation (4% of discussed amputations), five posts mentioned partial hand amputations (2% of discussed amputations), and six mentioned shoulder disarticulations (3% of discussed amputations). There were no posts that discussed a through elbow amputation/disarticulation. One hundred and forty eight lower extremity amputations were specifically mentioned. Of these, 84 were below knee amputations (40% of discussed amputations), 43 were above knee amputations (21% of discussed amputations), six were partial foot amputations (3% of discussed amputations), three were through knee

amputations/knee disarticulations (2% of discussed amputations), and 12 were hip disarticulations (6% of discussed amputations). One hundred and twenty one posts mention an amputation/s but not the cause/s of said amputation/s, accounting for 47% of the Amputee-SR data. 17 posts specifically mentioned trauma as the cause of the amputation/s (6% of all Amputee-SR data), five mention vascular issues as the cause (2% of all Amputee-SR data), 17 were congenital amputations (6% of all Amputee-SR data), four were due to cancer (2% of all Amputee-SR data), and ten were due to infection or septic shock (4% of all Amputee-SR data).

Table 18: Amputations Discussed - Prosthetics SR

Amputations Discussed - Prosthetics SR	1st	2nd	3rd	4th	Total #
Not Discussed					60
Unknown	11	0	0	0	11
Below Elbow	10	0	0	0	10
Above Elbow	2	0	0	0	2
Below Knee	13	8	0	0	21
Above Knee	11	2	0	0	13
Partial Hand	4	3	0	0	7
Partial Foot	2	0	0	0	2
Through Elbow	0	0	0	0	0
Through Knee	0	0	0	0	0
Shoulder Disartic	1	0	0	0	1
Hip Disartic	1	0	0	0	1

Table 19: Amputations Discussed - Amputee SR

Amputations Discussed - Amputee SR	1st	2nd	3rd	4th	Total #
Not Discussed					86
Unknown	28	4	0	0	32
Below Elbow	8	1	0	0	9
Above Elbow	4	3	1	0	8
Below Knee	67	17	0	0	84
Above Knee	39	4	0	0	43
Partial Hand	4	0	1	0	5
Partial Foot	4	2	0	0	6
Through Elbow	0	0	0	0	0
Through Knee	3	0	0	0	3
Shoulder Disartic	6	0	0	0	6
Hip Disartic	12	0	0	0	12

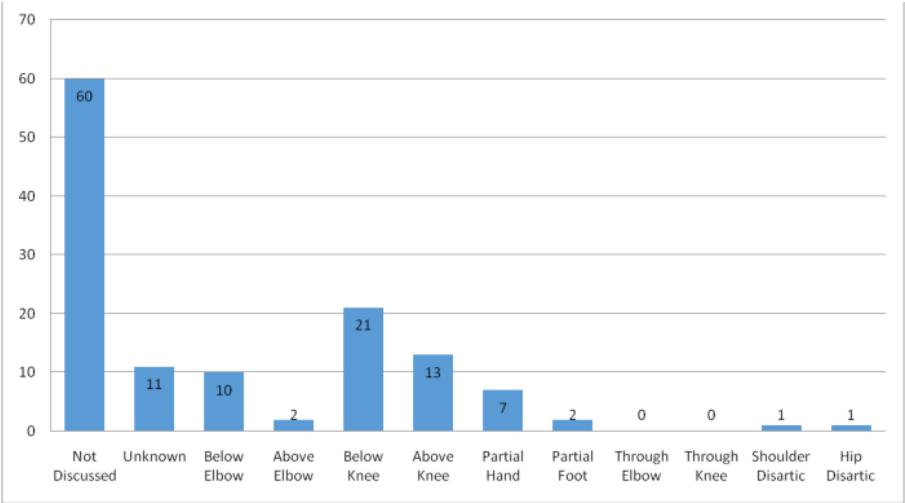

Figure 53: Amputations Discussed - Prosthetics SR

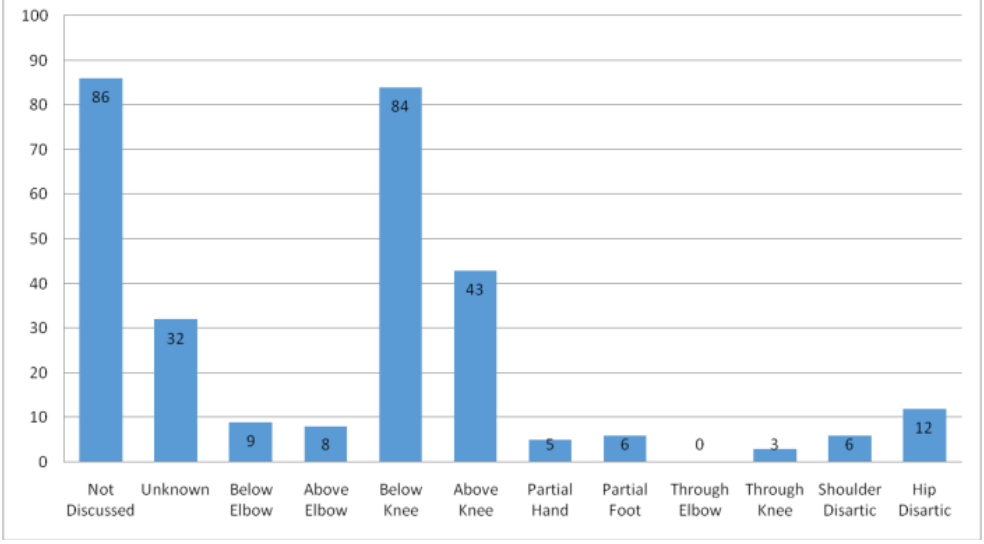

Figure 54: Amputations Discussed - Amputee SR

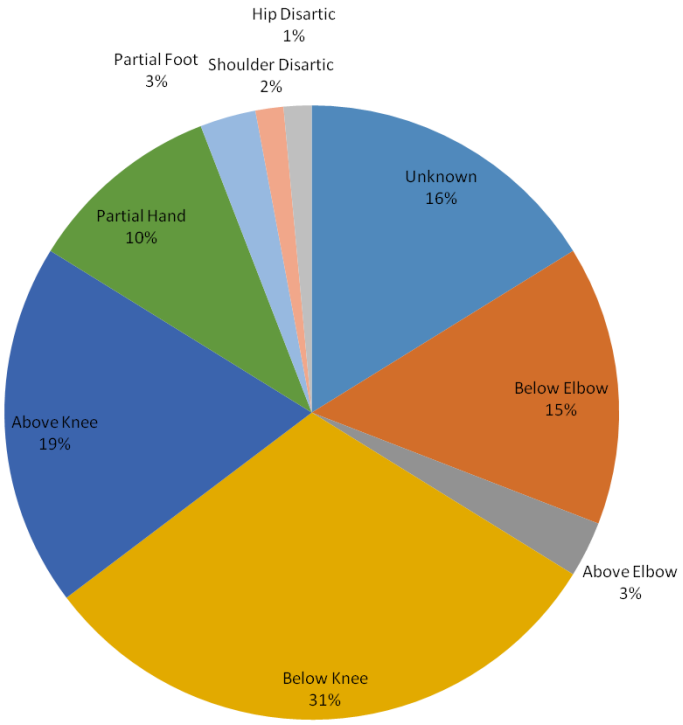

Figure 55: Amputations Discussed as a Percentage of Amputation Discussions - Prosthetics SR

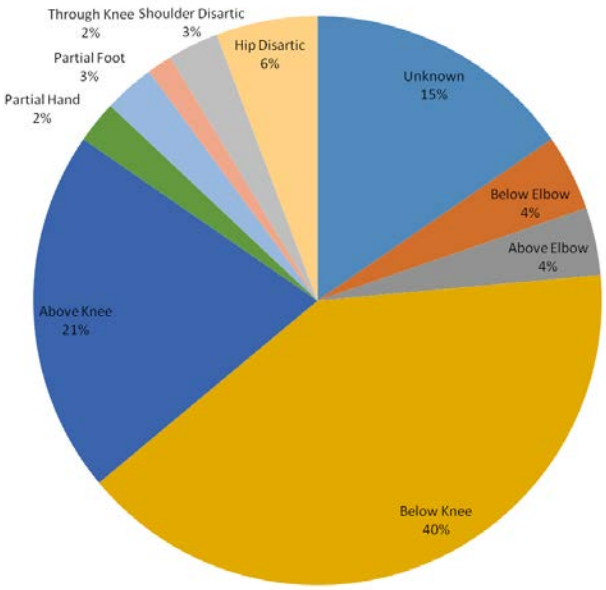

Figure 56: Amputations Discussed as a Percentage of Amputation Discussions - Amputee SR

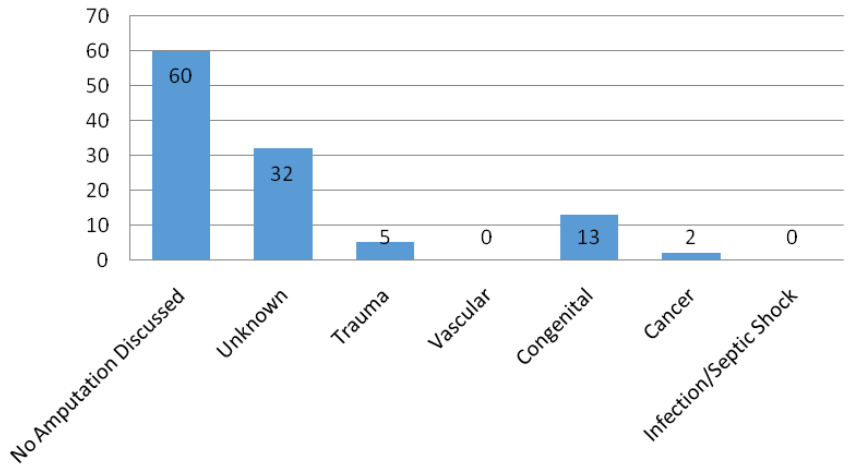

Figure 57: Reason for Amputation - Prosthetics SR

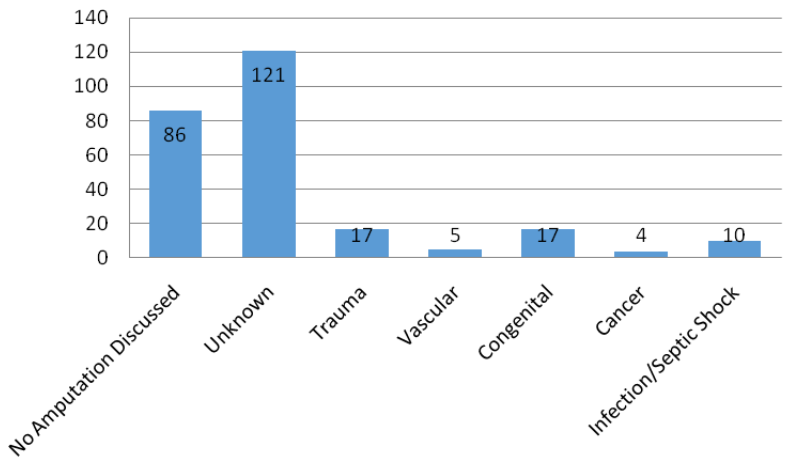

Figure 58: Reason for Amputation - Amputee SR

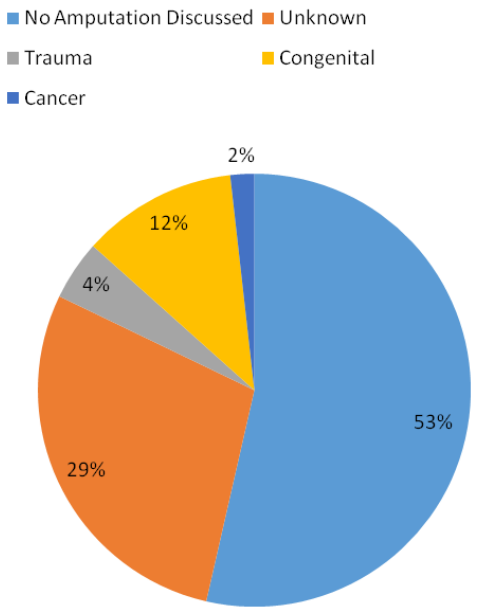

Figure 59: Reason for Amputation - Prosthetics SR Pie Chart

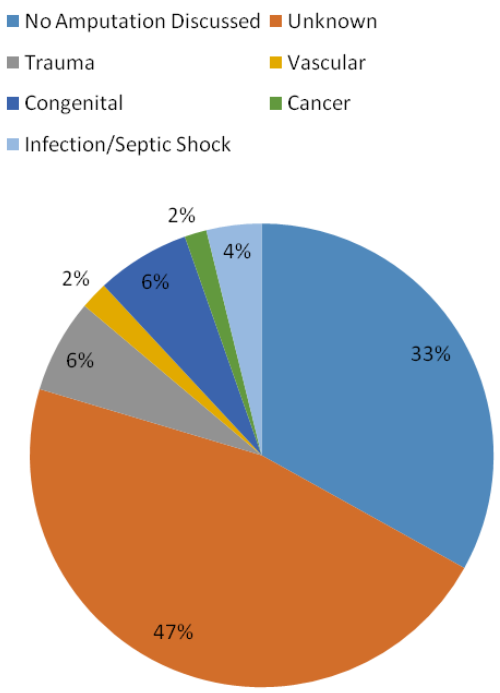

Figure 60: Reason for Amputation - Amputee SR Pie Chart

Insurance as a Barrier for Care

Three posters on Prosthetics-SR specifically mentioned out of pocket cost as a barrier for care (3%). Insurance was never mentioned on Prosthetics-SR. Three posters on Amputee-SR mentioned having insurance (1%) while two mentioned not having insurance (1%). Five posters mentioned insurance coverage as a barrier to care on Amputee-SR (2%), and three mentioned out of pocket expenses as a barrier to care (1%).

Table 20: Data Regarding Insurance Coverage - Prosthetics SR vs. Amputee SR

Barriers to Care - Prosthetics SR		Barriers to Care - Amputee SR	
Did the Poster Have Insurance?		Did the Poster Have Insurance?	
Unknown	112	Unknown	255
Yes	0	Yes	3
No	0	No	2
Was Insurance Coverage a Barrier to Obtaining Needed Devices/Supplies?		Was Insurance Coverage a Barrier to Obtaining Needed Devices/Supplies?	
Unknown	112	Unknown	255
Barrier	0	Barrier	5
Not a Barrier	0	Not a Barrier	0
Was OOP Cost a Barrier to Obtaining Needed Devices/Supplies?		Was OOP Cost a Barrier to Obtaining Needed Devices/Supplies?	
Unknown	109	Unknown	257
Barrier	3	Barrier	3
Not a Barrier	0	Not a Barrier	0

Common Amputee Problems and Concerns

Two posters on Prosthetics-SR discussed phantom pain problems (2% of the Prosthetics-SR data set). Sweat, Energy Expenditure, phantom sensation, and skin breakdown were never mentioned in the Prosthetics-SR data. Four posters on Amputee-SR discussed problems with sweat (2% of the Amputee-SR data set), two mentioned problems with energy expenditure (1% of the Amputee-SR data set), 12 discussed phantom pain problems (5% of the Prosthetics-SR data set) while one user specifically mentioned not having a problem with phantom pain (<1% of the Amputee-SR data set), one mentioned issues with skin breakdown (<1% of the Amputee-SR data set), and phantom sensation was never mentioned in the Amputee-SR data.

One Prosthetics-SR posters discussed problems with liners (1%) while one discussed specifically not having problems with liners (1%). Comfort was discussed by three posters having comfort related prosthetic problems (4% of Prosthetics-SR posters). Cosmesis was mentioned recurrently, with eight posters specifically mentioning not having issues with cosmesis (7% of Prosthetics-SR posters) while only one poster (<1%) specifically mentioned

finding cosmesis to be a problematic concern. Socks and alignment were never discussed in the Prosthetics-SR data. Six Amputee-SR posters discussed problems with liners (2%) while two discussed specifically not having problems with liners (1%). Comfort was discussed by 24 posters having comfort related prosthetic problems (9% of Amputee-SR posters). Cosmesis was mentioned by six posters specifically mentioning not having issues with cosmesis (2% of Amputee-SR posters) while only two posters (1%) specifically mentioned finding cosmesis to be a problematic concern. Socks were mentioned by one user as being problematic (<1% of Amputee-SR posters) and by three users as not being problematic (1% of Amputee-SR posters), and alignment was never discussed in the Amputee-SR data.

As for technologies and alternative devices, one Prosthetics-SR poster was seeking information about developing technologies (1%), nine posters were suggesting developing technologies to the other members of the message boards (8%), and seven posters were selling developing technologies (6%, these posters including prosthetic vendor companies). Two Prosthetics-SR posters mentioned that they were seeking adaptive technologies (2%), while two posters were suggesting adaptive technologies (2%). No posters on Prosthetics-SR were selling adaptive technologies. Eleven Prosthetics-SR posters were seeking advice or information regarding alternative device options (10%). Two Prosthetics-SR posters were suggesting alternative options to the message board (2%), and one person was selling an alternative device option (1%). No Amputee-SR posters were seeking information about developing technologies, but five posters were suggesting developing technologies to the other members of the message board (2%), and three posters were selling developing technologies (1%). Three Amputee-SR posters mentioned that they were seeking adaptive technologies (1%), and three posters were suggesting adaptive technologies (1%). No one on Amputee-SR was selling adaptive technology. Sixteen Amputee-SR posters were seeking advice or information regarding alternative device options (6%). Three Amputee-SR posters were suggesting alternative device options to the message board (1%). No Amputee-SR posters were selling alternative device options.

Common amputee comorbidities were not discussed frequently on the Prosthetics-SR site. One Prosthetics-SR poster mentioned having depression (1%), and two mentioned having problems with anxiety (2%). Diabetes was never mentioned on the Prosthetics-SR site. Eight Amputee-SR posters mentioned having depression (3%), three mentioned having problems with anxiety (1%), and four mentioned having problems with diabetes (2%). TBI was never brought up on either Reddit page.

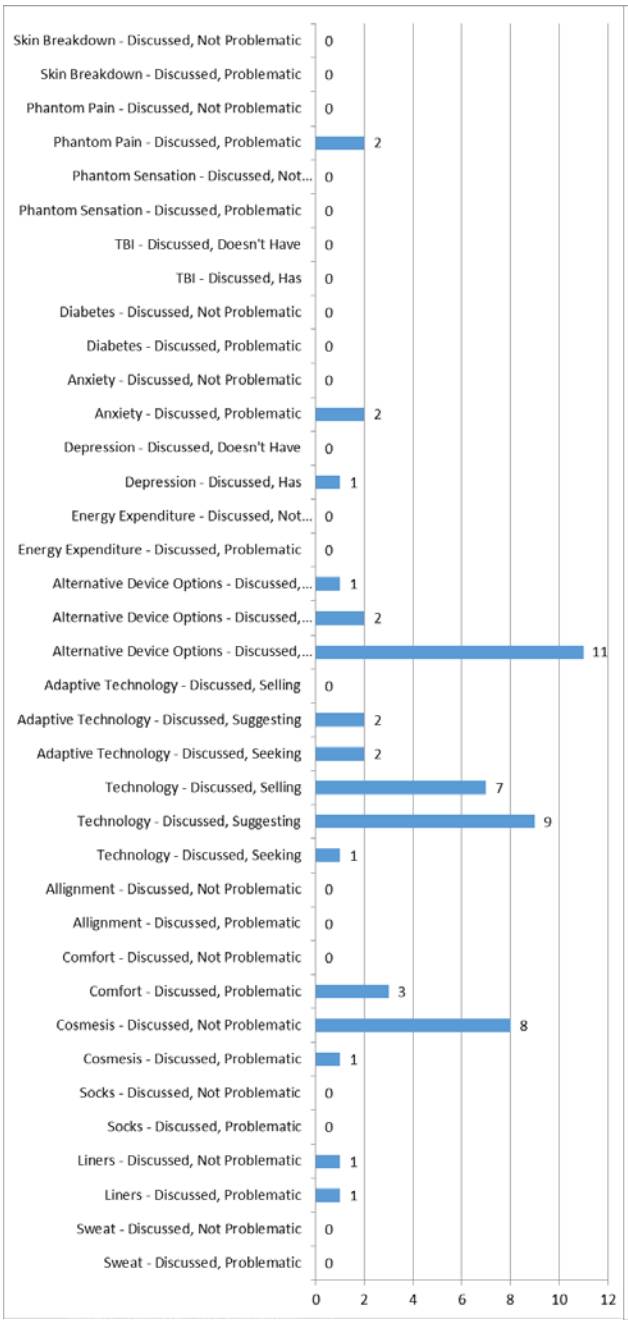

Figure 62: Potential Common Concerns - Prosthetics SR

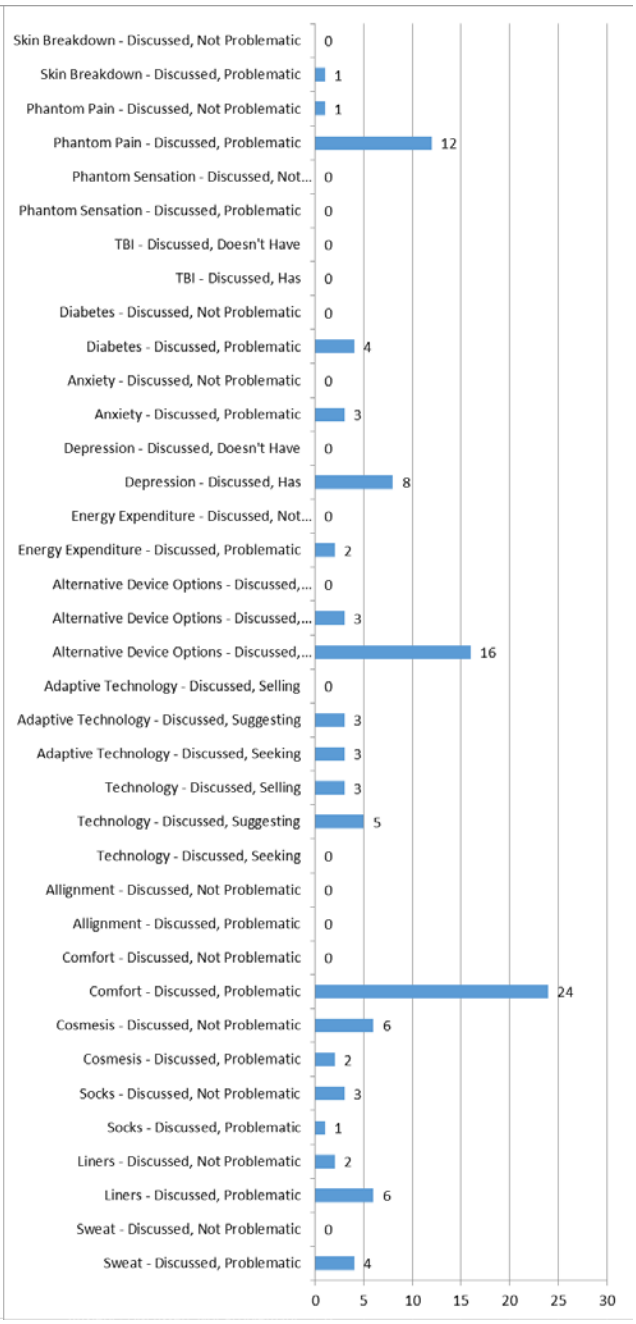

Figure 61: Potential Common Concerns - Amputee SR

Common Amputee Skin Disorders

Specific skin problems were discussed on Prosthetics-SR five times in total (accounting for 4% of the Prosthetics-SR data set). Folliculitis was discussed once (accounting for 20% of skin issue discussions), open wounds were discussed once (20% of skin issue discussions), swelling was mentioned once (20% of skin issue discussions) and shrinkage was mentioned twice (40% of skin issue discussions) for a total volume fluctuation discussion total of three times (60% of all skin issue discussions). Rash, bony prominence sensitivity, heterotopic ossification, ulcerations, discoloration, folds/creases in the skin, and scar breakdown/adhesions were never mentioned on Prosthetics-SR. Specific skin problems were discussed on Amputee-SR 17 times in total (accounting for 7% of the Amputee-SR data set). Folliculitis was discussed once (accounting for 6% of skin issue discussions), ulcerations were discussed once (6% of skin issue discussions), open wounds were discussed two times (12% of skin issue discussions), scar breakdown/adhesions were discussed once (6% of skin issue discussions), bony prominence pain was discussed twice (12% of skin issue discussions), swelling was mentioned five times (29% of skin issue discussions) and shrinkage was mentioned five times (29% of skin issue discussions) for a total volume fluctuation discussion total of ten times (58% of all skin issue discussions). Rash, ulcerations, discoloration, skin folds/creases, and heterotopic ossification were never mentioned on Amputee-SR.

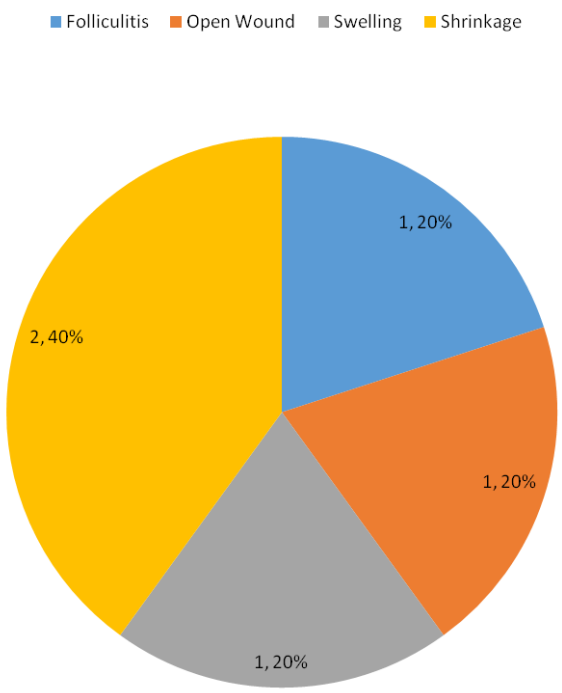

Figure 63: Specific Skin Issues Discussed as a Percentage of Skin Issue Discussions - Prosthetics SR

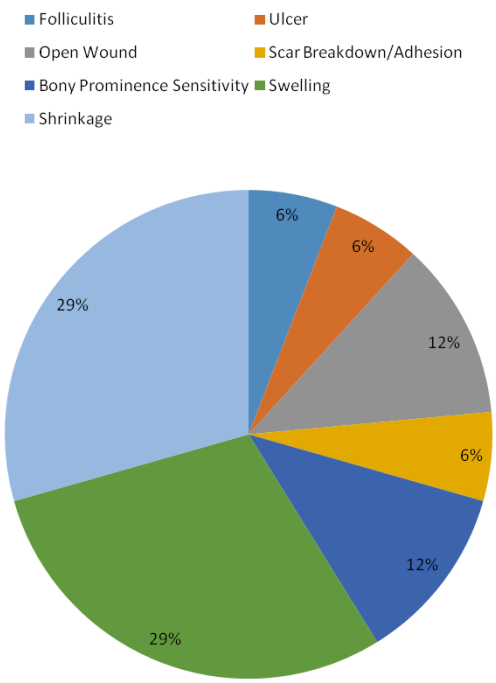

Figure 64: Specific Skin Issues Discussed as a Percentage of Skin Issue Discussions - Amputee SR

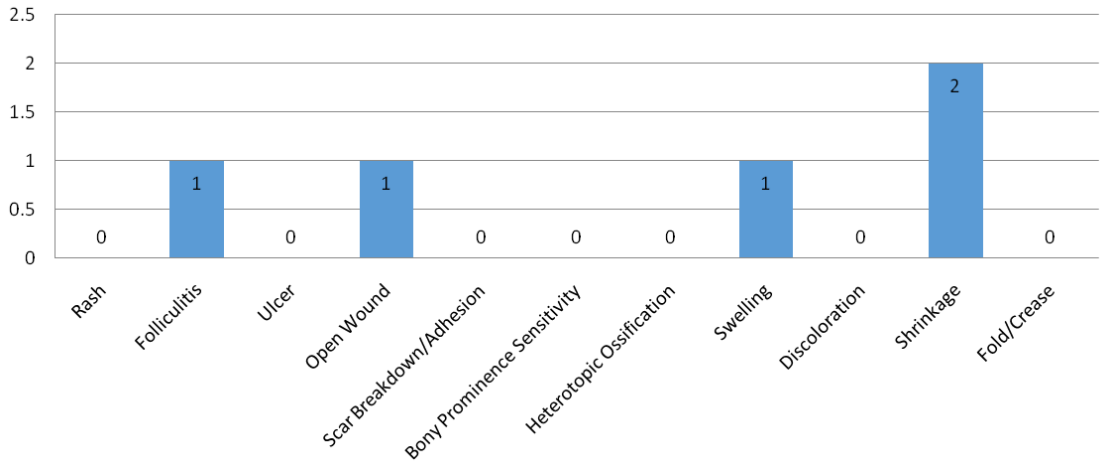

Figure 65: Skin Issues Discussed - Prosthetics SR

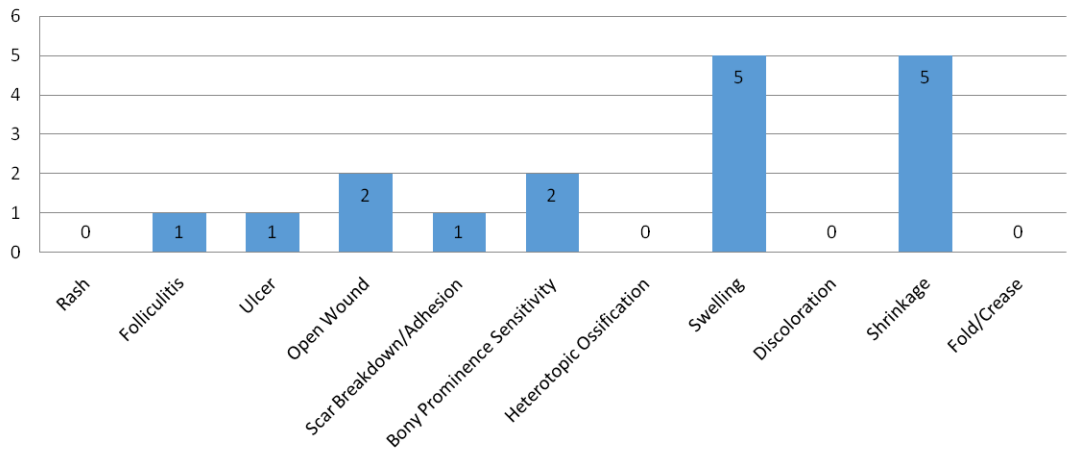

Figure 66: Skin Issues Discussed - Amputee SR

Participation in the Community

Sports discussions accounted for 1% of the total Prosthetics-SR postings (1 post), attended events were not discussed, and travel discussions accounted for 3% of the total Prosthetics-SR postings (3 distinct posts). Sports discussions accounted for 3% of the total Amputee-SR postings (9 distinct posts), discussions regarding attended events accounted for 1% of the total Amputee-SR postings (3 distinct posts), and travel accounted for 2% of the Amputee-SR data (5 distinct posts).

Life Hacks

General life hacks were brought up one time on Prosthetics-SR, with a poster discussing the use of aloe vera gel. No life hacks for pain was mentioned on Prosthetics-SR. General life hacks were discussed twice on Amputee-SR, with one poster discussing the use of aloe vera gel and one poster discussing the use of magnesium and potassium for muscle spasms. No life hacks for pain were discussed on Amputee-SR .

Table of total values distributed across categories for the Prosthetics-SR data set and the Amputee-SR data set can be found in Appendix E: Comparative Data & Charts - Red.

APPENDIX C

Raw Data Set

A complete set of all gathered data for this study

Linked Excel Document

APPENDIX D

Coded Data Set

A complete set of all coded data for this study

Linked Excel Document

APPENDIX E

Table and Chart Source Document

A complete set of all tables and charts created for this study

Linked Excel Document

APPENDIX F

Validity Check Source Document

A coding comparison between two individual researchers to validate the codebook.

Linked Excel Document

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