

## A NEW ERA OF SEEKING KNOWLEDGE FOR #LYMPHEDEMA ON SOCIAL MEDIA: A DETAILED INSTAGRAM HASHTAG ANALYSIS

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### ABSTRACT

*Instagram® is one of the most active social media platforms with over a billion users worldwide. Since the importance of education on lymphedema has been established due to the chronic nature of the disease, seeking knowledge attracts much attention not only clinically but also on social platforms such as Instagram®. Our aim was to examine content by analyzing posts tagged with hashtags on Instagram® related to lymphedema. Nine predefined hashtags related to lymphedema were used to search posts uploaded to Instagram® via the Apify tool. Retrieved public posts were classified and analyzed by four researchers for their content and post-type. We found that the vast majority of sharing on Instagram® in the context of lymphedema and its related aspects have relatively low scores for both relevancy and accuracy with a 77% irrelevancy rate. The best posts were those determined to be educational, which were found 57% relevant and correct. Medical professionals should consider that disseminating true guidance and therapy carries importance for patients with lymphedema and treatment success. The ability for patients to reach knowledge via social media might also be an important aspect in relieving suffering due to lymphedema. However, our results demonstrate that Instagram® might not*

*be a good platform for patients to discover reliable information about lymphedema.*

**Keywords:** lymphedema, social media, hashtag, Instagram

Since smartphones have emerged as crucial tools in parallel with the development of the Internet and social media, their impact has dramatically changed. Social media is not only used for leisure time activities but also in a quite broader range, such as for seeking knowledge about the illness suffered from or therapy from potential caregivers, especially in the last decade (1). Social media has also recently been of note engaged with medicine and its related topics (therapy, education, surgery, etc.) (2).

Instagram® is one of the most active social media platforms since its first establishment. 80 million new posts are uploaded each day among over a billion users (3-5). The posts on Instagram focusing on health can be viewed in a variety of ways (6). In the context of seeking health care, 42% of plastic surgeons reported that their patients look for aesthetic surgery on different social media platforms (7). In the US, 42% of people search for information associated with health care, while 45% of people stated that their decision is affected by their search results on social media (8).

However, online information obtained from social media is not always correct or reliable (3,9). In addition, Muralidhara et al (6) reported that most posts have no relevant or specific tags which can help identify them directly.

Lymphedema has been reported to affect up to 70% of patients with breast cancer surgery and treatment (10). Besides breast cancer, other types of cancer (ovarian, cervix, prostate, etc.) and their treatment can also cause lymphedema (11). Lymphedema needs long-term care; however, many patients might not be able to reach true guidance and therapy. Studies show that there is a gap between lymphedema education and related aspects such as risk management and reduction (12,13). Since the importance of education on lymphedema has been established due to the chronic nature of the disease, seeking knowledge and education attracts much attention not only in clinical settings but also in other platforms such as social media (14).

Inappropriate management and therapy can worsen clinical care of lymphedema (15). Unfortunately, there is a huge amount of wrong and potentially detrimental modalities regarding lymphedema management, which can affect patients not only clinically but also psychologically due to the failure of those misguided modalities (16). Our study aim was to analyze Instagram® posts using hashtags related to "lymphedema" and determine whether the posts are relevant to disease or treatment and their reliability.

## *METHODS*

The study was a retrospective review of social posts on the publicly accessible Instagram®. The posts were collected using an automated scripting tool for web crawling and data scraping (17). This software enables the download of publicly available data such as posts, user profiles, hashtags, and locations. Since the study contains only publicly accessible data, an ethical board approval was not needed nor obtained.

### *Data Selection*

Posts were filtered using nine hashtags including #lymphedema, #linfedema, #lymphoedema, #lymphedemawarrior, #lymphoedemawarrior, #lymphedema-awareness, #lymphoedemaawareness, #primarylymphedema, and #secondarylymphedema. A set of 4,044 posts were retrieved between April 27 and May 14, 2020, in two batches. A few dated back up to 5 years prior from a total of 132,406 posts labeled with the nine hashtags given above.

Apart from the post content, Instagram® user data of these posts were also retrieved for further analysis after a subsequent batch of post retrievals (May 28, 2020). Post-specific hashtag counts were evaluated via a software script. The first batch (3,283 posts) of all retrieved 4,044 posts are selected from the "top" (according to Instagram's sorting algorithm) posts from each hashtag according to their frequencies. For example, since the count of posts with hashtag #lymphedemaawareness were 10,536 and with #lymphoedemaawareness just 2,029, corresponding retrieved posts for these hashtags were 500 and 250, respectively. The maximum number of posts collected for any hashtag was limited to 500 for this iteration, due to data scraper software limitations and the number of coders available. For the remaining second batch of post-retrieval, a random subsample of 761 posts was collected using different query settings for the Instagram® API for scraping. Hashtag frequencies for the filtered posts are provided in *Table 1*.

The third column in *Table 1* provides total count of other selected hashtags (remaining eight) for each hashtag and its share among this count. Similarly, the last column indicates the count of all hashtags used regardless of their relationship with lymphedema.

Since all posts can be tagged with multiple hashtags, the sample codebase for analysis was reduced to a unique set of 3,169 posts (shared by 936 distinct users) after removing the repetitions. The posts were distributed randomly according to post owner users to maintain consistency and to reduce bias in the coding process.

**TABLE 1**  
**Frequency Statistics for Identified and Selected Hashtags**

Selected Hashtags ( <i>n</i> total = 3,911 posts)	Frequency <i>n</i> (% in selected)	Frequency with other selected <i>n</i> (% share)	Frequency all <i>n</i> (% in all)
#lymphedema	592 (15.1)	886 (66.8)	7,988 (7.4)
#linfedema	750 (19.2)	901 (83.2)	10,796 (6.9)
#lymphoedema	746 (19.1)	1,124 (66.4)	10,459 (7.1)
#lymphedemawarrior	508 (13.0)	945 (53.8)	7,074 (7.2)
#lymphedemaawareness	507 (13.0)	935 (54.2)	6,790 (7.5)
#lymphoedemaawareness	265 (6.8)	424 (62.5)	3,387 (7.8)
#primarylymphedema	260 (6.6)	626 (41.5)	4,005 (6.5)
#secondarylymphedema	250 (6.4)	441 (56.7)	4,129 (6.1)
#lymphoedemawarrior	33 (0.8)	39 (84.6)	299 (11.0)

The size of this unique post set was finally reduced to 3,065 (posted by 917 distinct users and approximately 2.3% of all posts with the hashtags searched for), due to removed users or posts during the study. These posts were analyzed for both qualitative content quality regarding the hashtags used and qualitative content quality regarding the hashtags used and interaction statistics that summarize post-specific quantities such as like or view counts, and user-specific ones such as follower counts.

All data file entries, coder assessments, and analyses were performed using Microsoft Excel software, except for Cohen's kappa coefficient evaluations in inter-coder reliability analysis (18,19), which was accomplished using MATLAB (20,21).

All posts with the selected hashtags were analyzed without exclusion. All languages were accepted for analysis and coded in five categories, namely English, German, Spanish, Portuguese, and Other. Some post links were

broken and not reachable because of deleted posts mainly due to removed users.

### *Coding*

Four coders who are specialized in lymphedema examined the unique posts independently within a 5-week period (May 20 – June 29): Coder 1, 845; Coder 2, 785; Coder 3, 844; and Coder 4, 591 posts. A random selection (20% of the overall sample in post counts) from the coded posts of each coder was used to assess the inter-coder reliability. 448 of the posts were analyzed by at least two coders (47 posts by all four, 73 by three, and 328 by two). Each coder analyzed and characterized the posts according to five features: 1. Post context type; 2. Post content; 3. Post visual type; 4. Post language; 5. Post sharing (source) type. Coders also recorded the time and up to date like counts of the posts during their analysis. The categories for each post characteristic are given below:

### 1. Post context type

The four qualitative categories for post context are: Educational (any information, course and online seminar about lymphedema and lymph system); Personal experience or narrative (memories, daily life, treatment sessions and outcomes of surgery about lymphedema); Advertisement/commercial (products and services, lymphedema clinics, physicians or physiotherapists promoting their businesses, etc.); and Others (posts that do not fall into any of the prior three categories).

### 2. Post content

Post content, whether the text comment of the user or the visuals (still images or video) used in the post was similarly coded into three categories at first. These were: Correct and relevant content (if the information shared in the post is about lymphedema and lymphatic system regarding the hashtags used, expert opinion, patient's experiences, and/or the proposed therapy is valid); Incorrect content (relevant to hashtags analyzed but involving incorrect information or suggestions); and no relevant information (no information about lymphedema despite the hashtags involved). Since posts coded as incorrect were very scarce (18 posts = 0.6%), they are also counted in the last category corresponding to a binary coding for this feature.

### 3. Post visual type

The visual used on the post, either an image or a video, was placed/coded in one of the seven categories: Personal shoots (still photos or videos taken as a selfie or by others); Photo/picture of a treatment / therapeutic practice; Video of a treatment; Brochure/banner/poster; Visual for product advertisement/promotion; Visual for a treatment ad/promotion; and lastly Irrelevant (for posts with all images/videos that have no obvious relation to lymphedema and lymphatic system disorders despite the hashtags involved).

### 4. Post language

All posts analyzed were categorized concerning the languages used in the text of the first comment and shared visuals regardless of the hashtags' language. Depending on the frequencies encountered, five distinct groups are English, German, Spanish, Portuguese, and Other.

### 5. Post sharing type

Post sharing type is selected as either individual or organization (hospital, clinic, company, and association, etc.) regardless of user accounts' being health-related or not.

### *Inter-Coder Reliability Analysis*

Following the methods in Kearney et al (22), observed agreement percentages between all pairs of coders were calculated using Cohen's kappa values, which has been utilized for interrater reliability assessments (20).

### *RESULTS*

Most of the visuals shared in the posts are still images (89% with photos, pictures, etc.), while the remaining 11% contain videos. The classification of the posts using the various coding characteristics is summarized in *Table 2*, with corresponding content coding information for each category. In terms of context categories, educational posts have the highest relevant and correct content rate with 67.8%. Similarly, posts with irrelevant visuals have mostly irrelevant content (93.6%).

Likewise, when focused only on posts with relevant and correct content (n=707) from context and sharing type perspectives (*Table 3*), the educational posts again have a higher share (57.4%). However, despite most posts with correct content are shared by individuals (57.7%), this group is also larger for irrelevant content as well (66.2%).

Post-content feature is also analyzed from a popularity aspect regarding the number of likes for posts and the followers of users that share them (*Table 4*). In this respect, popularity seems unrelated to the relevance

**TABLE 2**  
**Frequency Statistics for All Feature Categories Used in Post Content Coding Analysis**

<i>Feature Categories (n= 3,065 posts)</i>	<i>Coded n (%)</i>	<i>Post Content % Correct - Irrelevant</i>
<b><i>Post Context Type</i></b>		
Educational	599 (19.5)	67.8 - 32.2
Personal experience	659 (21.5)	28.5 - 71.5
Advertisement / Commercial	347 (11.3)	22.2 - 77.8
Other	1,460 (47.6)	2.5 - 97.5
<b><i>Post Content</i></b>		
Correct	707 (23.1)	-
Irrelevant	2,358 (76.9)	
<b><i>Post Visual Type</i></b>		
Personal shoots	390 (12.7)	37.2 - 62.8
Irrelevant	1,463 (47.7)	6.4 - 93.6
Photo of a treatment	289 (9.4)	33.2 - 66.8
Video of a treatment	65 (2.1)	46.2 - 53.8
Brochure/Banner/Poster	578 (18.9)	49.5 - 50.5
Advertisement visual for a product	161 (5.3)	17.4 - 82.6
Advertisement visual for a treatment	119 (3.9)	23.5 - 76.5
<b><i>Post Language</i></b>		
English	2,081 (67.9)	20.7 - 79.3
Spanish	337 (11.0)	27.9 - 72.1
Portuguese	91 (3.0)	27.5 - 72.5
German	60 (2.0)	5.0 - 95.0
Others	496 (16.2)	31.0 - 69.0
<b><i>Post Sharing Type</i></b>		
Individual	1,970 (64.3)	20.7 - 79.3
Organizational	1,095 (35.7)	27.3 - 72.7

**TABLE 3**  
**Post Content Analyzed for Post Context and Post Sharing Type**

<b>Posts (n= 3,065 )</b>	<b>Correct n (% in Correct)</b>	<b>Irrelevant Info n (% in Irrelevant Info)</b>
<b><i>Post Context Type</i></b>		
Educational	406 (57.4)	193 (8.2)
Personal experience	188 (26.6)	471 (20.0)
Advertisement / Commercial	77 (10.9)	270 (11.5)
Other	36 (5.1)	1,424 (60.4)
<b><i>Post Sharing Type</i></b>		
Individual	408 (57.7)	1,562 (66.2)
Organizational	299 (42.3)	796 (33.8)

**TABLE 4**  
**Popularity (by Likes and Followers) by Post Content Relevance**

	<b>Likes Count <i>n</i> (%)</b>	<b>Number of Users</b>	<b>Average Number of Followers</b>	<b>Change Rate % in Likes Count</b>
<b><i>Post Content</i></b>				
Correct and relevant	47,821 (22.2)	381	2,099	20.6
Irrelevant information	167,352 (77.8)	711	2,325	34.0

**TABLE 5**  
**Post Content for Determined to be Correct or Irrelevant for the Selected Hashtags**

<b>Hashtags (<i>n</i>= 3,065 posts)</b>	<b>Correct <i>n</i> (%)</b>	<b>Correct % within Hashtag</b>	<b>Irrelevant <i>n</i> (%)</b>	<b>Irrelevant % within Hashtag</b>
#lymphedema	104 (14.7)	17.6	488 (20.7)	82.4
#linfedema	231 (32.7)	30.8	519 (22.0)	69.2
#lymphoedema	155 (21.9)	20.8	591 (25.1)	79.2
#lymphedemawarrior	73 (10.3)	14.4	435 (18.4)	85.6
#lymphedemaawareness	114 (16.1)	22.5	393 (16.7)	77.5
#lymphoedemaawareness	91 (12.9)	34.3	174 (7.4)	65.7
#primarylymphedema	76 (10.7)	29.2	184 (7.8)	70.8
#secondarylymphedema	84 (11.9)	33.6	166 (7.0)	66.4
#lymphoedemawarrior	2 (0.3)	6.1	31 (1.3)	93.9

of post content regarding lymphedema. On the contrary, posts with irrelevant information have gained more popularity through the 5-week coding period (34%).

Lastly, the content of posts for selected hashtags is presented in *Table 5*. The posts tagged with lymphedemawarrior or lymphoedemawarrior were found to have the highest rate of irrelevance, 85.6%, and 93.9%, respectively.

Observed agreement rates in post content ranged from 78.7% to 91.2%, with a mean agreement of 85.6% and a standard deviation

of 4.6%. Cohen's kappa score analysis produced a mean kappa value of 0.59 with a 0.12 standard deviation. These reliability statistics showed moderate to substantial overall agreement among all coders (18).

#### **DISCUSSION**

This study showed that the vast majority of sharing in Instagram® social media for the posts identified as relating to lymphedema using our hashtags failed not only in relevancy (76% irrelevancy rate), but also in accuracy.

However, according to post context, over 67% of posts coded as educational were found as relevant and correct. This rate should not be thought of as sufficient in the field of health care.

Technologically savvy patients consult online resources and social media platforms to get information about their symptoms, diagnosis, or treatment (3,23). About 60% of adults in the US reported accessing the internet for health information (24). Despite the potential benefits of finding health information on the internet, the possibility of misinformation is a serious problem (25). The reliability and accuracy of the posts shared on Instagram® are controversial because it is a 'social' platform where everyone shares their opinion. Instagram® is not subject to rigorous peer review or content regulation (1). Numerous studies show that there is a substantial amount of misinformation regarding health issues on social media that can lead to potentially dangerous health practices (26).

Patients with lymphedema can suffer from heaviness and/or tightness related to their swollen extremities. The socio-cultural and economical characteristics along with patients' demographics should be considered as they might have undeniable impacts on treatment and sustainable management of lymphedema (27). In this regard, body satisfaction and image, psychological problems, decreased self-esteem along many other problems can go with the main clinical problems associated with lymphedema. The Royal Society for Public Health reported that Instagram® has a detrimental effect on one's anxiety levels and body dissatisfaction by promoting the feeling of self-inadequacy (28). In our study, #lymphedema itself showed over 82% irrelevancy according to the shared posts. Patients might be affected negatively by irrelevant posts and objectification of their status compared to other shared ones.

Images are reported as powerful health communication tools because of their potential impact on people's knowledge, attitudes, and perceptions of health-related issues (29,30). Patients and their caregivers might benefit from social media concerning possible risks of

treatments, prognoses, complications, medical practice, and indications. This might also affect the acceptance of and consent with the treatment options proposed by health professionals (31). Fung et al (23) reported that although social media is seen as an effective visual communication tool for access, concerns have arisen about the lack of information diversity and exposure to undesirable information. Moreover, it was reported that shared photos and videos never undergo any review or rating process, and users can choose whatever hashtags they want, leaving posts with little credibility (32,33). Our study has also similar results about the presence of a high number of incorrect or irrelevant posts for lymphedema. For example, not only did individuals' posts showed a lack of correct content, but also organizational posts as well (27.3% correctness rate). This emphasizes the necessity for reliable and approved information by health professionals or health organizations on social platforms.

Instagram® can provide education for free in the context of health care, but the value of that information most likely becomes debatable (3,5,34,35). Dorfman et al (3) reported that over 67% of data resulted in a self-promotional aspect compared to education which was found in only 33%. Our results showed only 20% of posts were considered educational, yet those were correct in the mild to moderate rate of 68%. This result can be attributed to the specific nature of lymphedema along with patient characteristics, yet its effect on patients can cause a psychological burden.

Instagram® posts might be beneficial to share experiences among sufferers, especially in healthcare. Using hashtags can simply provide reach to relevant content, and patients might share their personal experiences for true guidance. Seeing others' experiences might mitigate the psychological burden of the disease and contribute to motivation for therapy and management (36-38). This might be more appropriate for patients who suffer from a chronic illness such as lymphedema which needs lifelong care. However, our results showed that posts in personal experience resulted in only 29% relevancy. This result can

be interpreted as not only insufficient but also debatable whether having true or focused experience related to the disease, especially when considered for specific filters that can manipulate the true results or benefit. For instance, in a post lacking a scientific approval and/or clinical basis, one might still wonder how she/he can reach others without thinking about the different nature of lymphedema. This might detrimentally impact one's treatment or therapy process as well as her/his motivation. In our opinion, this carries much importance since patients with lymphedema suffer mostly swelling as well as aesthetic problems and such filters can misguide the ones who try to be motivated and successful.

Instagram® has been testing to remove "like" counts in many countries such as Canada, Japan, and Australia due to the negative connotations (39). In our results, like counts in posts with irrelevant information were 3.5 times more frequent than those with correct and relevant content. This can be interpreted as misleading, so removing like counts such as in aforementioned countries might provide a relatively good option for improving dissemination of true information. On the other hand, shared data by laypeople might distort the expectancy of using true hashtags and thereby reachable true data might be hindered. For instance, Dorfman et al (3) reported an overall 20 times more posts were analyzed in hashtags for unfocused and focused medical terminology (3). In our study, nearly half of posts were found irrelevant in terms of both post context type and post visual type. In addition, most of the educational posts have correct content, while mainly personal experience and advertisement/commercial posts according to the post context type have no relevant content about lymphedema. Moreover, most of the advertisement visuals for a product and treatment posts were irrelevant content to lymphedema. Many users might post incorrect content using hashtags about lymphedema for various reasons such as gaining followers or popularity.

To our knowledge, this is the first study analyzing lymphedema hashtags in social media. There are some strengths and limita-

tions concerning this study. Using a relatively large number of hashtags related to lymphedema and authors' having moderate to excellent experience in the field of lymphedema treatment are considered as the main strengths. Moreover, having used a time frame to track like counts of posts over time can be accepted as additional strengths, along with analyzing the posts within a quite strict frame and steps. As for limitations, the major one is the dependence mainly on Instagram's sorting mechanism for post selections, even when using third-party software applications for data gathering. Although a few posts examined were 5 years old, our findings may not generalize to other time frames than the year we are in but provide a cross-section of posts about lymphedema throughout the growing popularity of the application. Secondly, this study focuses only on the original post content disregarding other users' reactions (shared as comments), due to the obvious load of extra analysis involved. This constraint might be overcome in future studies by incorporating sophisticated software tools based on artificial intelligence and machine learning methods used for text mining, in analyses of content, especially from social media. A final limitation was due to the vast amounts of data, we limited posts to 500 in each category. While this is still a major undertaking, there is a chance that analysis of all posts may provide different results. Further studies could also examine other social media platforms in a similar analysis.

## *CONCLUSION*

Since Instagram® is still growing in terms of its number of users and posts uploaded each day, health professionals should consider that disseminating true guidance and therapy carries great importance not only in the view of patients but also in the aspect of treatment success. Creating awareness to reach knowledge via social media can be accepted as important, however establishing true knowledge especially in healthcare is also of high importance. Informing patients with lymphedema as well as their caregivers in



terms of utilizing social media should be included in patient education. Overall, our results show that it is not possible to say that Instagram® is the right platform for engaging with individuals and obtaining information about lymphedema due to the abundance of misinformation arising despite its easy accessibility.

### CONFLICT OF INTEREST

All authors declare no competing financial interests exist.

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