#Chronicillness, Posts with Medical Content Receive More Attention on Instagram: Content Analysis

Lindsey D. Daon, Fu-Shiuan Whitney Lee, Olga Saynina, C. Jason Wang

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Abstract

Background: Social media is an integral part of modern life in which people connect, learn, and share. The content shared on social media can drive behavior change as people, especially adolescents, seek to gain or maintain popularity. #Chronicillness is a rising trend on social media, yet the content and attention it garners remain poorly understood.

Objective: This study aimed to analyze Instagram posts related to chronic illness by examining their content and assessing if posts with medical-related content received greater attention.

Methods: To study individuals with chronic illness, publicly available Instagram posts were searched for hashtags related to chronic illness. We used a mixed-methods approach which included qualitative analysis of captions, hashtags, and photos for medical conditions, locations, and presence of medical equipment, alongside quantitative analysis to examine the relationship between medical content and attention. Multivariate analyses were performed to determine the odds of medical content Overperforming, a proxy measure for attention.

Results: Content analysis of 279 posts revealed caption themes including Medical Experiences, Illness Journey, Connection, and Non-illness Experiences. Among the posts, 97 (35%) included medical content, 52 (19%) featured advertisements, and 10 (4%) depicted invasive medical equipment. Hashtags covered a wide range of 107 different conditions. Posts with medical content exhibited significantly higher odds of overperforming (OR 1.85; 95% CI: 1.01, 3.42), as did posts with photos containing invasive medical equipment (OR 6.19; 95% CI: 1.16, 32.99).

Conclusions: Our findings underscore the potential reinforcing effect of sharing medical information on Instagram, the inadvertent promotion of invasive medical procedures as visible signs of illness, and the possibility of adolescents mimicking this attention-generating content. It is crucial to implement strategies for fostering positive and informed interactions within online communities, and to address the potential risks associated with overmedicalization, misinformation, and the commodification of health experiences.

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misinformation, and the commodification of health experiences.

Introduction

#Chronicillness, a growing trend on social media with over 4 million posts on Instagram and 3 billion views on TikTok.[1,2] Social media platforms, such as Instagram, TikTok, and Facebook, have become an integral part of modern life, and offer a new environment for people to connect, learn, and share. However, exposure to these platforms can drive behavior change as people mimic popular content, seeking to gain or maintain popularity and validation both online and offline.[3,4] The increasing popularity of chronic illness-related content raises concerns about the potential influence of such content, especially on adolescents.

Adolescents and young adults, who are increasingly engaging with online platforms and are highly influenced by their peers and social media influencers, represent a vulnerable population in the context of chronic illness-related content. Survey data from 2021 revealed that teenagers' screen time has reached nearly nine hours per day, with social media use excluding YouTube rising to 87 minutes daily.[5] Moreover, a higher percentage of adolescents (77%) follow social media influencers[6] compared to adults aged 32 to 38 years (57%).[7] The developmental stage of adolescence, marked by increased sensitivity to peer influence, a strong desire for social acceptance, and an evolving sense of self, further amplifies their susceptibility to online content.

Online communities play a crucial role for individuals with chronic illness, providing a space that is less restricted by physical limitations and allowing for connections with others facing similar challenges. This community was further solidified in 2013 when a popular blog post coined the term "Spoonie," which is a label used to self-identify as a person with chronic illness that people still use today.[8] Despite the positive aspects of social media use, journalists and other media have documented numerous examples of individuals exaggerating symptoms and undergoing unnecessary procedures to gain validation online.[9–12] This growing trend of chronic illness-related posts on platforms like Instagram and TikTok have yet to be well documented in the scientific literature.

Although prior research has provided insights on how individuals with chronic illnesses use social media for support and sharing experiences[13–15] and one study has shown how social media can trigger the psychogenic spread of illness,[16] little is known about the content that is shared or what content garners the most attention and holds the greatest potential to influence behavior. This study aimed to fill this gap by examining the content of Instagram posts related to chronic illness and assessing whether medical-related posts receive more attention.

Methods

Study Design

This was a mixed-methods study, combining qualitative and quantitative methods, to conduct a multimodal content analysis of Instagram posts. The analysis involved the qualitative examination of photos, hashtags, captions, and quantitative metrics, such as Overperforming scores, likes, comments, and followers. See Figure 1 for visual representation of the components of an Instagram post. Per Stanford University's institutional review board, this study examining publicly available Instagram posts is exempt from institutional review board approval and informed consent since it does not meet the criteria for human-subjects research.

Figure 1. Example Instagram post with the analyzed components of the post identified.

Adapted Instagram post created using Shutterstock photo.

Sampling and Data Collection

The units of analysis for this study are Instagram posts, which were selected using convenience sampling. Convenience sampling was necessary due to the large volume of Instagram posts and the desire to focus on more recent posts because content on social media changes over time. Three search terms (i.e., hashtags) were selected for their applicability to adolescents and young adults with chronic illness, representation of chronic illness in general rather than specific diseases, and the substantial number of posts associated with the hashtag: #chronicillness, #chronicallyill, and #spoonie.

To minimize the influence of algorithms on post selection, two independent reviewers (L.D. and F.W.L.) conducted separate searches on an arbitrarily chosen date (October 26, 2021) and chose qualifying posts from the "Most Recent" section of the search results. Posts were included if they were publicly available and appeared to be original content, such as photos, artwork, or products that person was promoting. Posts were excluded if they contained videos or the photos were non-original content, such as memes or reposted content from another person's account. Each reviewer selected posts in reverse chronological order until 100 posts for each hashtag were included, resulting in a total of 300 posts per reviewer. The reviewers cross-compared the selected posts to ensure that only common posts were included, removed duplicates, and resolved inclusion/exclusion inconsistencies resulting in a final sample of 279 posts.

The data for analysis, including caption text, hashtags, number of likes, overperforming score, etc., was downloaded from CrowdTangle and cleaned using Excel, ten days after identifying the posts. This 10-day delay allowed the posts to receive views, the bulk of which occur within the first few days after being posted. During data cleaning, the number of followers and country location for each account were verified by reviewing the associated account profiles and posts. This data was used for the descriptive statistics (e.g., likes, comments, total interactions, followers, number of photos, etc.) for all 279 posts. Photos were not included in the CSV file and were analyzed directly on the CrowdTangle website in March 2022. By the time photo analysis occurred, 19 posts had been removed or made private, thus only 260 posts underwent photo analysis and inclusion in the multivariate analysis. For a complete breakdown of post selection and data collection, see Figure 2.

Figure 2. Flowchart explaining the post selection process and inclusion/exclusion criteria.

Publicly available posts identified on initial search
#chronicillness (n = 4,205,359)
#chronicallyill (n = 412,172)
#spoonie (n = 2,775,018)

Posts are excluded according to exclusion criteria:
- Caption not written in English
- Photo(s) appear to be memes, reposted content, or videos
- Photo(s) appear not to be of or taken by a person with chronic illness

Posts identified on initial screen and added to *CrowdTangle*[a] (n = 300)
#chronicillness (n = 100, screened 241 posts)
#chronicallyill (n = 100, screened 245 posts)
#spoonie (n = 100, screened 247 posts)

Posts excluded due to duplicates or non-original content (n = 21)

Data downloaded from *CrowdTangle*
Posts with captions and hashtags analyzed (n = 279)
#chronicillness (n = 96)
#chronicallyill (n = 91)
#spoonie (n = 92)

Posts deleted or made private prior to photo analysis (n = 19)

Posts with photos analyzed (n = 260)
#chronicillness (n = 87)
#chronicallyill (n = 86)
#spoonie (n = 87)
Total photos analyzed (n = 406)

a: *CrowdTangle:* a tool created by *Meta* to track and analyze publicly available social media data
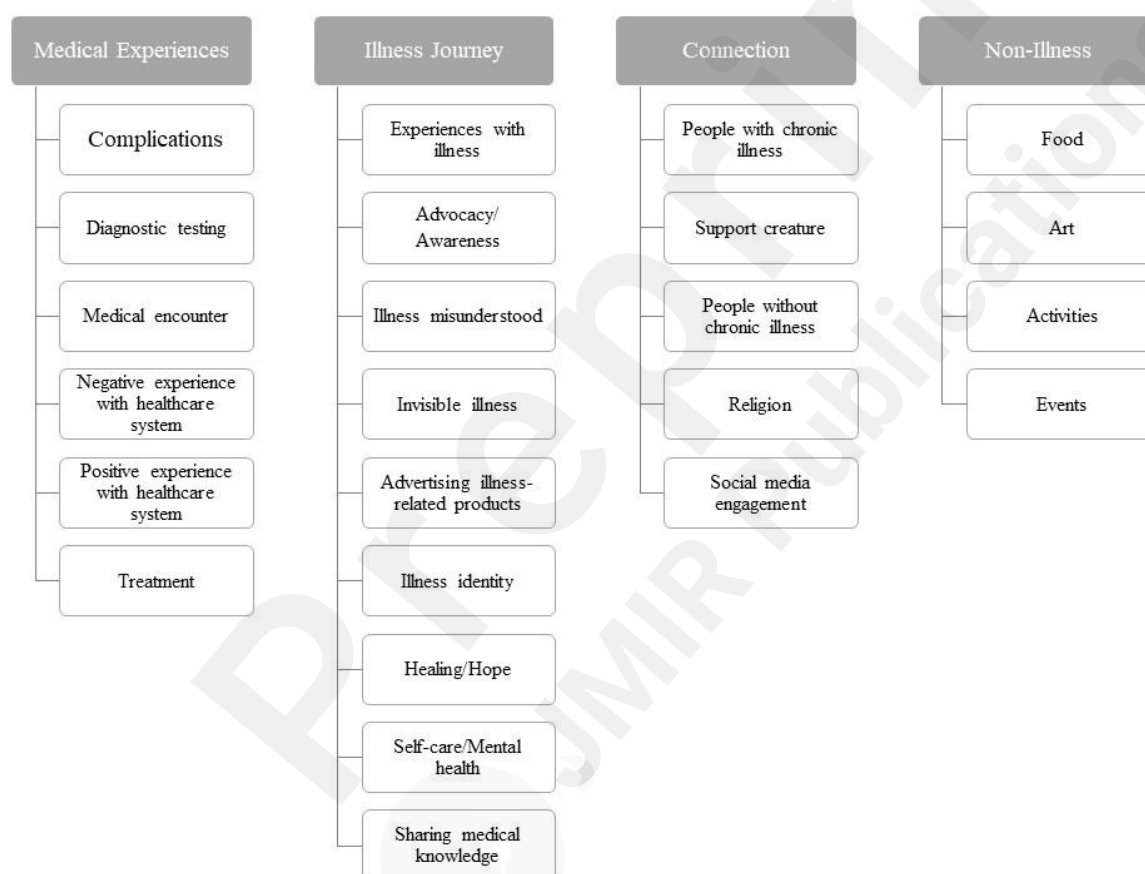
Qualitative Analysis

The qualitative analysis involved multimodal content analysis of Instagram posts, including the photos, hashtags, and captions. Multiple elements of the posts were utilized to determine gender and identify the presence of advertising content. Gender identification involved visually inspecting the photos and assessing the captions or hashtags for gender-specific language. Advertising content was defined as any promotional material related to businesses or products that have the potential to generate income, such as product shops, coaching services, or podcasts/blogs. Two coders (L.D. and F.W.L) collaborated to analyze the content of the posts.

Photo(s) for each post underwent visual content analysis simultaneously by the two coders. Each photo was coded for location, presence of medical equipment, presence of a support animal, and number of people. Location was coded by medical (e.g., hospital, clinic) or non-medical (e.g., yard, neighborhood, house). Medical equipment was coded by invasive (e.g., IVs, PICCs, feeding tubes) or non-invasive (e.g., medications, nasal cannula, mobility aids). If any photo within a post contained the theme of interest, the entire post was considered to have that theme for analysis purposes.

Hashtags underwent quantitative content analysis. They were coded for mentions of specific conditions and medical interventions. A hashtag was considered a condition if it included a specific diagnosis (e.g., chronic fatigue syndrome) but not a general symptom (e.g., fatigue). If a hashtag could be considered either a diagnosis or a symptom (e.g., anemia, headaches, gastroparesis, anxiety), it was coded as a diagnosis. Medical interventions included procedures, testing, and treatments.

Captions underwent content analysis using an iterative and inductive process. The initial categories and codes were based on a first pass review of the included post captions, existing frameworks, and the research question, and included healthcare-related, disease-related, personal feelings, interactions with others, life events/beliefs, and illness identity. The two coders then simultaneously reviewed the first twenty posts to ensure mutual agreement and understanding of the categories and emerging codes. The remaining posts were divided between the two team members for independent coding. As new codes emerged or at least every twenty to fifty posts, the coders met to review each other's work, refine categories and codes, and resolve inconsistencies. If a consensus was unable to be reached, a third team member (C.J.W.) was used as a tiebreaker. The final list of categories and codes can be seen in Figure 3.

Figure 3. Caption categories and codes

Quantitative Analysis

The Overperforming score[17], calculated by CrowdTangle, serves as a numeric indicator that compares a post's performance to similar posts created by the same account. A score greater than 1 indicates overperformance, a score less than 0 suggests underperformance, and scores between 0 and 1 are considered indeterminate. Overperforming was used as a proxy measure for attention as it indicates that a post receives more interactions (likes and comments) compared to similar posts from the same account.

The overperforming score was utilized as the primary dependent variable to investigate the association between medical content and post engagement. Bivariate and multivariate models were conducted by the data analyst (O.S.) to examine the dependent variable (overperforming score) in relation to several independent variables, outlined in Table 4. For the multivariate analysis, the overperforming score was transformed into a binary variable, categorizing a score of 1 or greater as "overperforming" and scores less than 1 as "not overperforming."

Results

Post Characteristics

279 posts were included in the descriptive statistics analysis (Table 1) and the caption and hashtag content analysis. Among these, only 260 posts containing 406 photos were used for the visual analysis and multivariate analysis (Figure 2). The median number of followers at the time of data collection was 661. Posts received a median of 25 likes and 3 comments. The median number of hashtags per post was 20. Of the analyzed posts, 110 (40%) were considered overperforming, and 52 (20%) contained marketing content. Most posts were authored by females (80%) and featured a single photo (85%). Age information was unavailable, but most posts appeared to be from adolescents or young adults based on visual inspection.

Table 1. Post Characteristics

Characteristic of Post	Median (Min; Max) n=279
Hashtags, Total	20 (1; 31)
Caption Length (in characters)	596 (29; 2200)
Conditions, Total in hashtags	2 (0; 18)
Followers, Total	656 (11; 266,248)
Likes, Total	25 (0; 14,936)
Comments, Total	3 (0; 525)
Interactions, Total	29 (0; 15,461)
Gender	**No. of Posts (%)**
Women	222 (79.6%)
Men	12 (4.3%)
Other/Unknown	45 (16.1%)
Country of Post	**No. of Posts (%)**
USA	51 (18.2%)

UK	16 (5.7%)
Others [a]	18 (6.4%)
Unknown	194 (69.5%)
Other Characteristics	**No. of Posts (%)**
Overperforming Status	110 (39.4%)
Medical Theme Present	97 (34.7%)
Advertising Present [b]	52 (18.6%)
Type of Post – Album [c]	70 (25.1%)

a: Canada, Mexico, Ireland, Sweden, The Netherlands, South Africa, India, Australia, and New Zealand
b: Advertisements included podcasts, blogs, supplements, hyperbaric oxygen therapy, health coaching services, money donation accounts, and products from online shops such as "tubie" supplies and chronic illness pins/stickers/graphic tees/books.
c: Albums are posts that contain multiple photos.

Qualitative Analysis

Photos

Out of the 260 posts with photos analyzed (Table 2), 27 (10%) were in a healthcare setting and 49 (19%) contained medical equipment. Among the posts featuring medical equipment, 10 posts depicted invasive devices, primarily IVs and feeding tubes, while 39 posts showcased non-invasive equipment, mainly mobility aids. Support animals, such as dogs, cats, and stuffed animals, were present in 34 posts (13%), often with captions written from the perspective of the support animal. The number of people in the photos ranged from 0 to 5, with a mode of 0 and a median of 1.

Hashtags

A total of 5454 hashtags across the 279 posts were analyzed for conditions and medical interventions (Table 2, conditions and interventions mentioned in 10 or more posts; Supplemental Table 1, full list of hashtagged conditions and interventions). Among the analyzed posts, 232 posts (83%) contained hashtags referencing specific medical conditions with 107 different conditions identified. Additionally, 57 posts (20%) contained hashtags referencing medical interventions, with 28 different interventions identified.

Table 2. Content of the Photo and Hashtag analysis

Photo Analysis	No. of Posts n=260
Location of Photo	**260 (100%)**
Healthcare setting (i.e., clinic or hospital)	27 (10.4%)
Non-healthcare setting (i.e., home, outdoors [a])	199 (76.5%)

Location indeterminate (i.e., art, slides)	34 (13.1%)
Medical Equipment	**49 (18.8%)**
Invasive medical equipment [b]	10 (3.8%)
Non-invasive medical equipment [c]	39 (15%)
Hashtag Analysis	**No. of Posts** **n=279**
Condition [d]	232 (83.2%)
Chronic Pain	101 (36.2%)
Fibromyalgia	56 (20.1%)
Autoimmunity	38 (13.6%)
Ehlers-Danlos syndrome	38 (13.6%)
POTS	36 (12.9%)
Anxiety	31 (11.1%)
ME/CFS	27 (9.6%)
Dysautonomia	25 (9.0%)
Depression	22 (7.9%)
Endometriosis/Adenomyosis	21 (7.5%)
Gastroparesis	20 (7.2%)
Inflammatory Bowel Disease	20 (7.2%)
Arthritis	15 (5.4%)
Headache	14 (5.0%)
Lupus	13 (4.7%)
Multiple Sclerosis	12 (4.3%)
PTSD	11 (3.9%)
Lyme Disease	10 (3.6%)
Medical Intervention	57 (20.4%)
Mobility Aids	25 (9.0%)
Medications	16 (5.7%)
Invasive Procedures	15 (5.4%)
Feeding Tubes	11 (3.9%)

a: including nature, yards, neighborhoods, and cities.

b: including PIVs, PICCs, Ports, feeding tubes.

c: including medications, bandages, blood vials, mobility aids (canes, wheelchairs, walkers), compression socks, hospital beds, hospital gowns, telemetry wires, nasal cannulas, oxygen tanks, diagnostic images, and visual symptoms of illness.

d: 107 different conditions were identified. Conditions that were mentioned in ten or more

posts are listed.

Captions

Content analysis of the captions revealed four major categories: 1) Medical Experiences, 2) Illness Journey, 3) Connection, and 4) Non-illness Experiences (Table 3). The Medical Experiences category encompassed content related to specific medical encounters, diagnostic testing, and medical treatments. The Illness Journey category explored the impact of chronic illness on daily life, including the ways in which other people misunderstood their conditions, the concept of "invisible illness," and the promotion of products related to their illnesses. Invisible illness is a phrase used to raise awareness and highlight the unique struggles faced by individuals whose conditions may not be immediately apparent to others. The Connection category highlighted relationships established among individuals with chronic illnesses, the support received from both human and non-human sources, and advice for those without chronic illnesses to foster empathy and understanding. Finally, non-illness experiences include food, art, and activities. Excerpts from the full list of categories and codes (Supplement Table 2).

Table 3. Caption categories, codes, and example excerpts

Category	Code and description	Excerpt from post
Medical Experience	**Complications** – Sharing experiences of disease/ treatment complications	"... Operation was successful except for the surprise blood transfusion and accidental cut of my bowel. ..."
	Diagnostic testing – Experiences with testing	"... Yet another set of invasive inquiries into my body to figure out **why my uterus is a battlefield**. ..."
	Medical encounter – Referencing specific medical appointments or hospitalization	"... I usually don't get too nervous about doctor appointments. After all, I've had plenty of practice! But today is my second tilt table test. I've been waiting over a year for this appointment, and now that it's here, my stomach is in knots. ..."
	Negative – Experiences with healthcare providers/ institutions that are negative	"... Every time I'd leave a doctor's office after a new autoimmune disease diagnosis, I felt utterly defeated. I felt like my body hated me & was completely against me. ☺ I was told I'd always be overweight, always have pain, always be sick & never have children. FINALLY I said enough is enough! Doctors are just people like you & I and why was I taking a persons opinion as gospel?! ..."
	Positive – Experiences with healthcare providers/	"... My POTs diagnosis changed my life and I am thankful for the doctor who caught the pattern in

Category	Code and description	Excerpt from post
	institutions that are positive	my symptoms. …"
	Treatment – Describing upcoming treatment plans or treatment experiences	"… So, next steps are having 18 more blood tests pending, the anemia will be treated by a hematologist with parenteral iron, esomeprazole may help with the ulcerations, and I'll have to wait a couple weeks for the final [verdict] and treatment with the gastroenterologist. …"
Illness Journey	**Experience** – Describing experiences related to/ resulted from chronic illnesses	"… A few years ago I could barely make it through a (then) 40 minute class period without needing the bathroom or without being so sick I actually asked a student to run class for me while I sat in a corner and supervised, trash can nearby and doubled over in pain. …"
	Advocacy/Awareness – Encouraging self-advocacy or attempting to increase awareness of a disease	"… You know your body best! If you think something is wrong - fight for answers! You might just [surprise] yourself and change YOUR life! "
	Misunderstood – Experiences of their illnesses being misunderstood	"… I've never been one to go to the hospital unless made to. I hate them. The medical gaslighting, the toxic hate for chronic pain patients. The misinformation of Ehlers-Danlos syndrome (of lack of knowledge all together). It's scary. …"
	Invisible illness – Focusing on the fact that illnesses exist even though signs/ symptoms are not obvious	"… chronic INVISIBLE illness exists at ALL moments. There is not ONE moment off. However, those moments can look very different from the outside especially to those who lack the knowledge and understanding. …"
	Advertisements – Promoting products, services, or activities related to chronic illness	" Note to the medical community: Every new diagnosis should come with a link to your illness-specific shirt from @spooniesistershop 👕 …"
Connection	**People with chronic illness** – Online or in person relationships or messages to other people with chronic illness	"… I [am] extremely [lucky] to have been blessed to have met many others with rare and/or chronic illnesses, however me and @megsmiracles have became super close ! Mainly due to similar diagnosis of #stiffpersonsyndrome , #mthfrgenemutation and many others, but also because of our

Category	Code and description	Excerpt from post
		perseverance to help others not fall into the "broken health care system" …"
	Support creature – Relating to support animal or object (i.e., stuffed animal).	" Being an emotional support frog can be hard work, especially when your human has a chronic illness. …"
	People without chronic illness – Experiences with and advice to people without chronic illness	"… Don't be one of those sideline judges. We know most of you don't understand. But we would love it if you could just try. Try to understand. For one day walk in our shoes. One day see through our eyes. …"
	Religion – Sharing religious belief and interaction with their religious god.	"… I find myself a lot of times just breaking down completely when I try to pray. I may only get out the words "Jesus, help me" as the extent of my "prayer". And for a while I was embarrassed. I thought, how is God supposed to help me if I can't even give Him a real prayer asking for the things I need? …"

Quantitative Analysis

The bivariate logistic regression (Table 4) showed that posts had a statistically significantly higher odds of overperforming, or receiving more attention based on likes and comments, if they contained a longer caption (OR 2.727, 95% CI: 1.352, 5.499), medical theme (OR 2.025, 95% CI: 1.224, 3.349), photo with invasive medical equipment (OR 6.526, 95% CI: 1.357, 31.382), or medical experience (OR 1.831, 95% CI: 1.078, 3.11). Medical theme was a summary variable that included posts that had photos with medical equipment, photo in a medical location, and/or a caption containing the theme medical experience. During multivariate regression analysis, the calculations were controlled for presence of people in the photo, type of post, number of hashtags, caption length, number of conditions hashtagged, gender, and number of followers. After controlling for these variables, caption length (OR 2.438, 95% CI: 1.047, 5.674), medical theme (OR 1.854, 95% CI: 1.004, 3.421) and photos with invasive medical equipment (OR 6.187, 95% CI: 1.16, 32.991) remained statistically significant.

Table 4. Odds ratio bivariate and multivariate analyses

Variable	Bivariate OR (95% CI)	Model 1 OR (95% CI)	Model 2 OR (95% CI)	Model 3 OR (95% CI)
People Present in Photo	1.511 (0.9, 2.537)	1.208 (0.655, 2.227)	1.181 (0.645, 2.162)	1.195 (0.647, 2.207)
Type of Post (Photo vs Album)	1.653 (0.957, 2.856)	1.47 (0.763, 2.831)	1.496 (0.778, 2.875)	1.315 (0.673, 2.566)

Hashtag: Quartile 2 vs 1	1.333 (0.68, 2.612)	1.527 (0.663, 3.518)	1.503 (0.655, 3.448)	1.874 (0.789, 4.446)
Hashtag: Quartile 3 vs 1	1.379 (0.706, 2.693)	2.156 (0.918, 5.066)	1.955 (0.844, 4.528)	2.296 (0.961, 5.484)
Hashtag: Quartile 4 vs 1	1.24 (0.62, 2.481)	1.136 (0.464, 2.782)	1.055 (0.435, 2.558)	1.24 (0.494, 3.113)
Caption Length: Quartile 2 vs 1	1.304 (0.637, 2.668)	1.186 (0.496, 2.836)	1.167 (0.493, 2.767)	1.137 (0.475, 2.721)
Caption Length: Quartile 3 vs 1	1.875 (0.929, 3.783)	2.048 (0.868, 4.829)	2.112 (0.902, 4.948)	2.145 (0.909, 5.064)
Caption Length: Quartile 4 vs 1	*2.727 (1.352, 5.499)	2.02 (0.846, 4.824)	*2.438 (1.047, 5.674)	2.179 (0.925, 5.135)
Number of Condition: 3-4 vs 1-2	0.874 (0.479, 1.596)	0.591 (0.288, 1.211)	0.655 (0.324, 1.325)	0.628 (0.307, 1.284)
Number of Condition: 5+ vs 1-2	0.876 (0.451, 1.703)	0.646 (0.298, 1.404)	0.748 (0.352, 1.591)	0.731 (0.34, 1.571)
Gender: Male vs Female	0.267 (0.057, 1.249)	0.292 (0.057, 1.502)	0.27 (0.054, 1.354)	0.279 (0.056, 1.391)
Gender: Other vs Female	0.543 (0.27, 1.091)	0.404 (0.127, 1.285)	0.39 (0.123, 1.239)	0.425 (0.134, 1.345)
Number of Followers: Quartile 2 vs 1	1.061 (0.541, 2.083)	0.955 (0.416, 2.191)	0.983 (0.432, 2.236)	1.051 (0.456, 2.422)
Number of Followers: Quartile 3 vs 1	0.942 (0.478, 1.856)	0.852 (0.366, 1.984)	0.813 (0.352, 1.88)	0.868 (0.371, 2.034)
Number of Followers: Quartile 4 vs 1	0.907 (0.458, 1.795)	0.741 (0.309, 1.781)	0.727 (0.305, 1.733)	0.788 (0.327, 1.899)
Medical Theme Summary[a]	*2.025 (1.224, 3.349)	*1.854 (1.004, 3.421)	-	-
Photo with Non-Invasive Medical Equipment	1.213 (0.609, 2.414)	-	*1.005 (0.474, 2.134)	-
Photo with Invasive Medical Equipment	*6.526 (1.357, 31.382)	-	-	*6.187 (1.16, 32.991)
Photo in Medical Location	1.248 (0.559, 2.788)	-	-	-
Medical Experience	*1.831 (1.078, 3.11)	-	-	-
Condition Discussed	1.737 (0.977, 3.091)	-	-	-
Support Object	0.697 (0.324, 1.498)	-	-	-
Non-Illness Related Content	0.664 (0.393, 1.121)	-	-	-
Advertisement	0.7 (0.37, 1.323)	-	-	-

[a]Summary variable that includes photo with medical equipment (invasive or non-invasive), photo in a medical location, and/or a caption containing the category Medical Experience.
*Statistically significant odds ratio with 95% confidence interval

Discussion

Principal Results

This mixed-methods study aimed to examine the content of Instagram posts related to chronic illness and investigate whether medical-related posts garner more attention. The results shed light on an intriguing phenomenon with far-reaching implications. We found that medical content, including captions discussing medical encounters, photos taken in medical settings, and images featuring medical equipment, significantly outperformed posts without such content (Figure 4 for example posts). This indicates that chronic illness-related posts with medical content receive more attention, potentially leading to reinforcement of the observed behaviors through two mechanisms. First, content creators may attempt to reproduce this engaging content to maintain popularity online. Second, exposure to the online social environment may normalize or popularize these behaviors and result in mimicking of such content, particularly among adolescents.

Figure 4. Examples of photo themes identified include healthcare setting, invasive medical equipment, non-invasive medical equipment, and advertisements.

Adapted Instagram posts created using Shutterstock photos.

The prominence of posts featuring photos with invasive medical equipment is particularly concerning. Our study revealed that posts featuring such equipment had over six times higher odds of overperforming, indicating a worrisome trend. This finding suggests the inadvertent promotion of invasive medical procedures as visible signs of illness. Additionally, it raises the possibility that individuals who view these posts may seek out such procedures to gain popularity, fit in with peers, or due to a genuine belief that they are necessary, which may contribute to the overmedicalization of chronic illness. Adolescents, particularly those with self-perceived health issues, are likely to be the most vulnerable to this content as they navigate their understanding of their own health. Anecdotal evidence further supports this potential impact, as the first author has cared for multiple adolescent patients who have requested invasive medical procedures based on what they have seen online. This observation underscores the influence that attention-generating posts can have on shaping patients' health-

related decisions and behaviors.

Posts with medical content may receive more attention for a variety of reasons. These experiences may be perceived as more authentic, captivating, and unique, leading to greater interest and credibility within the chronic illness community. Furthermore, such posts may provide a sense of visibility and validation for individuals with chronic illness, who often grapple with being misunderstood by doctors and individuals without similar health conditions. This is particularly relevant in the context of the theme of "invisible illness" that emerged during our analysis. The concept of invisible illness highlights the idea that individuals can have chronic illness even when they appear healthy, further contributing to their feelings of being misunderstood. When the validation of invisible illness experiences is combined with attention-generating posts featuring medical content, the potential influence of this content may be further amplified.

In addition to the overperformance of medical-related posts, our study also revealed another concerning finding, the prevalence of advertisements within Instagram posts related to chronic illness. Approximately one in five posts advertised products ranging from health coaching services to personal Etsy shops. While it is not surprising considering the role of social media influencers in product marketing, the presence of advertisements in posts related to chronic illness raises ethical questions. It brings into focus the potential influence of commercial interests on health-related information disseminated on Instagram. Posting about chronic illness on Instagram may offer individuals opportunities for secondary gain, enhancing their credibility and legitimacy when marketing illness-related products.

Limitations

This study has several limitations that should be considered. First, the data collection was conducted on a single day, potentially biasing the results towards events such as awareness weeks. However, our analysis did not aim to generalize findings about specific diseases, but rather to capture broader themes related to awareness. Second, convenience sampling was employed due to the large volume of posts and continuous content creation. While convenience sampling may introduce bias, the study employed a "most recent" search strategy to include the most up-to-date and relevant posts. Clear demographic details were not available for all posts, but the focus was on content rather than the demographics of the creators, as adolescents are the ones who consume the most online content regardless of the demographics of the content creator. Last, we were unable to access private accounts or posts, but the study still captured a wide range of experiences within the online chronic illness community.

Comparison with Prior Work

While scientific research in this area is limited, our study is consistent with previous findings that people are sharing their medical experiences online. Moreover, our study revealed that medical content, especially invasive medical equipment, attracts more attention. This supports reports from journalists and other media of the potential for mimicking behavior, which can lead to overmedicalization and unnecessary procedures.

Conclusions

Our findings, even with the limited number of posts reviewed, have already generated insights with significant implications, particularly for adolescents within the chronic illness community. They emphasize the importance of further examining this phenomenon through additional data collection and monitoring this trend over time to determine whether this type of post becomes more frequent due to the attention these posts receive. Furthermore, the impact of social media on adolescents' perceptions, beliefs, and health-related decision-making should also be studied to assess the potential for overmedicalization fueled by attention-generating posts and the commercialization of chronic illness-related content. By better understanding these issues, we can strive for a healthier online ecosystem that supports individuals with chronic illness while mitigating the risks of misinformation, unnecessary medical procedures, and the commodification of health experiences.

Conflict of Interest

None declared.

Abbreviations

IV: intravenous line
PICC: peripherally inserted central catheter
OR: odds ratio
CI: confidence interval

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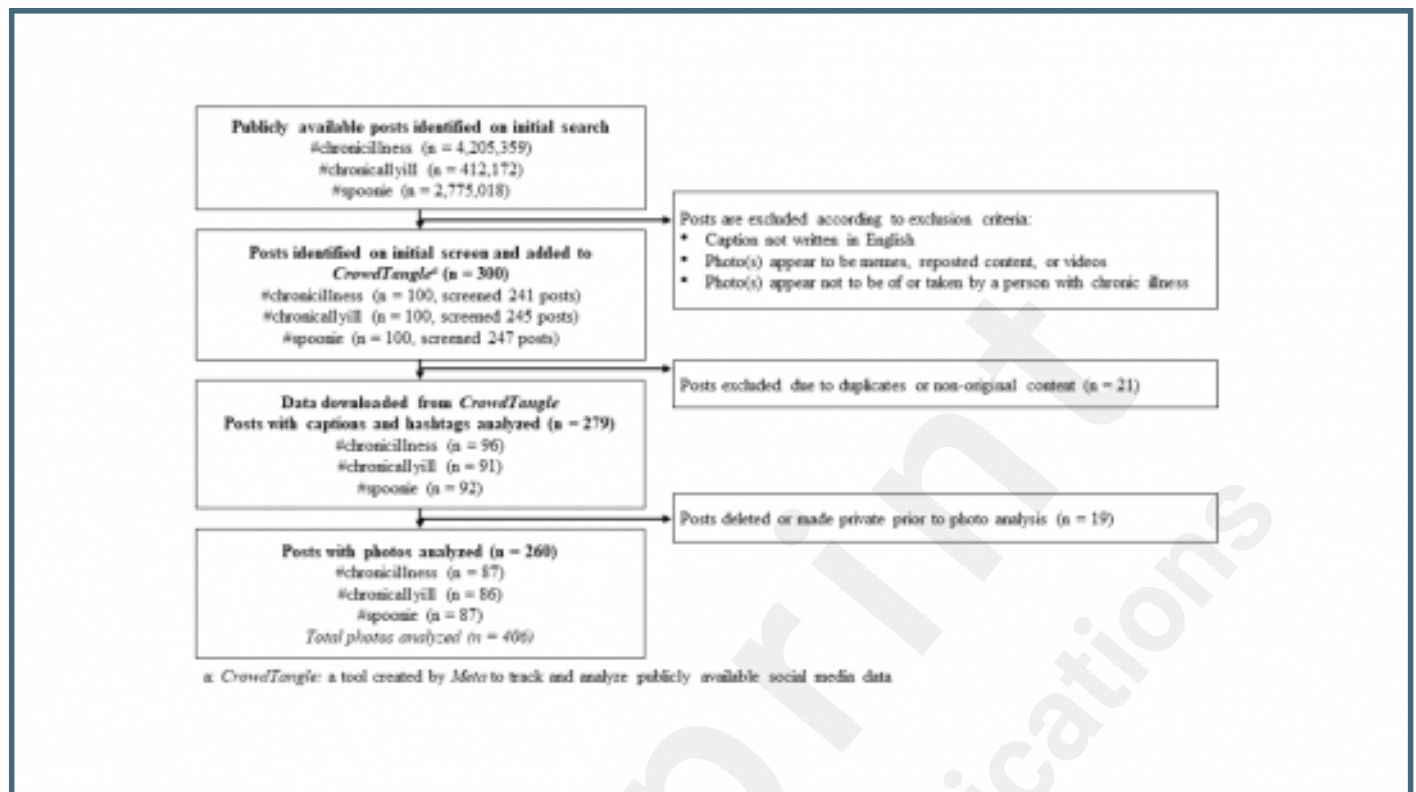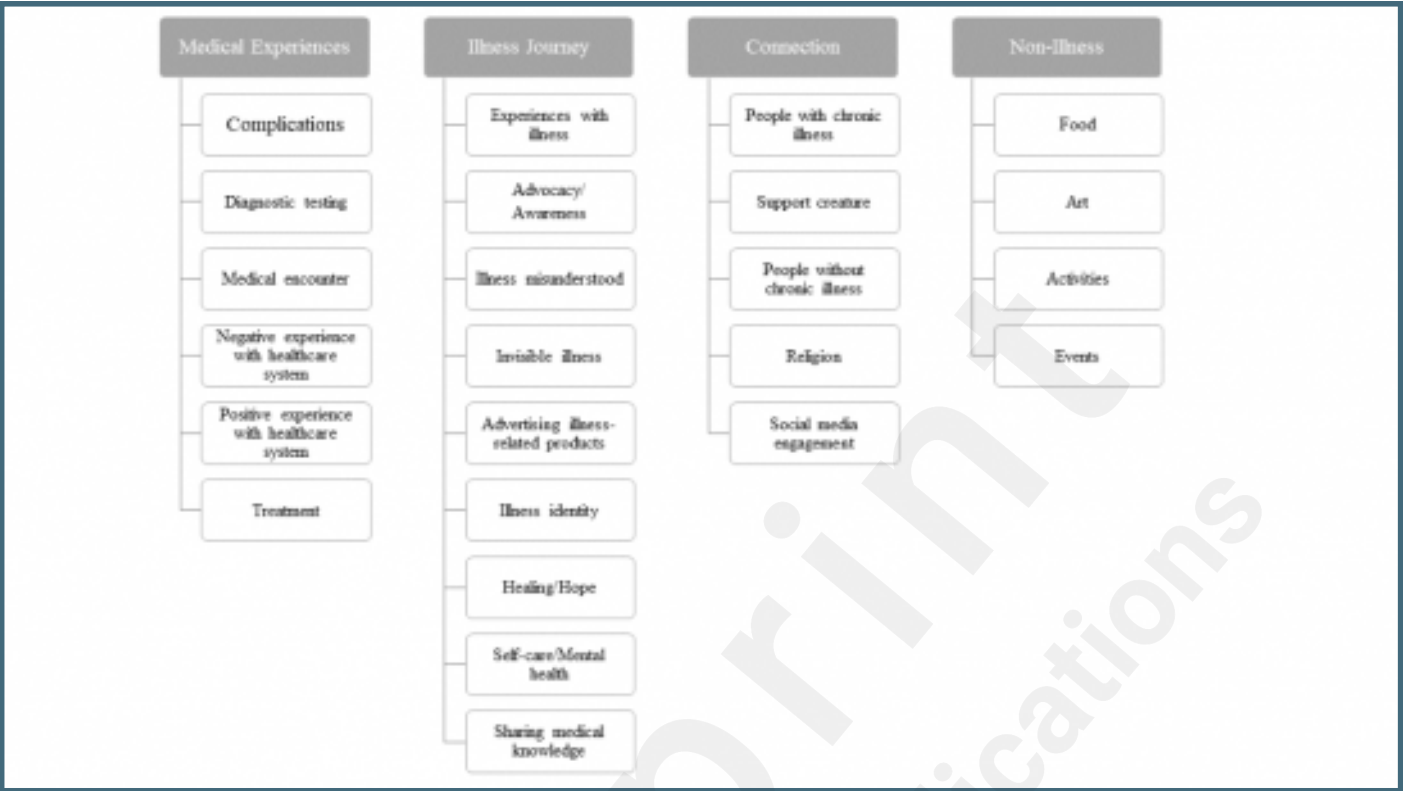
Supplementary Files

Figures

Example Instagram post with the analyzed components of the post identified.
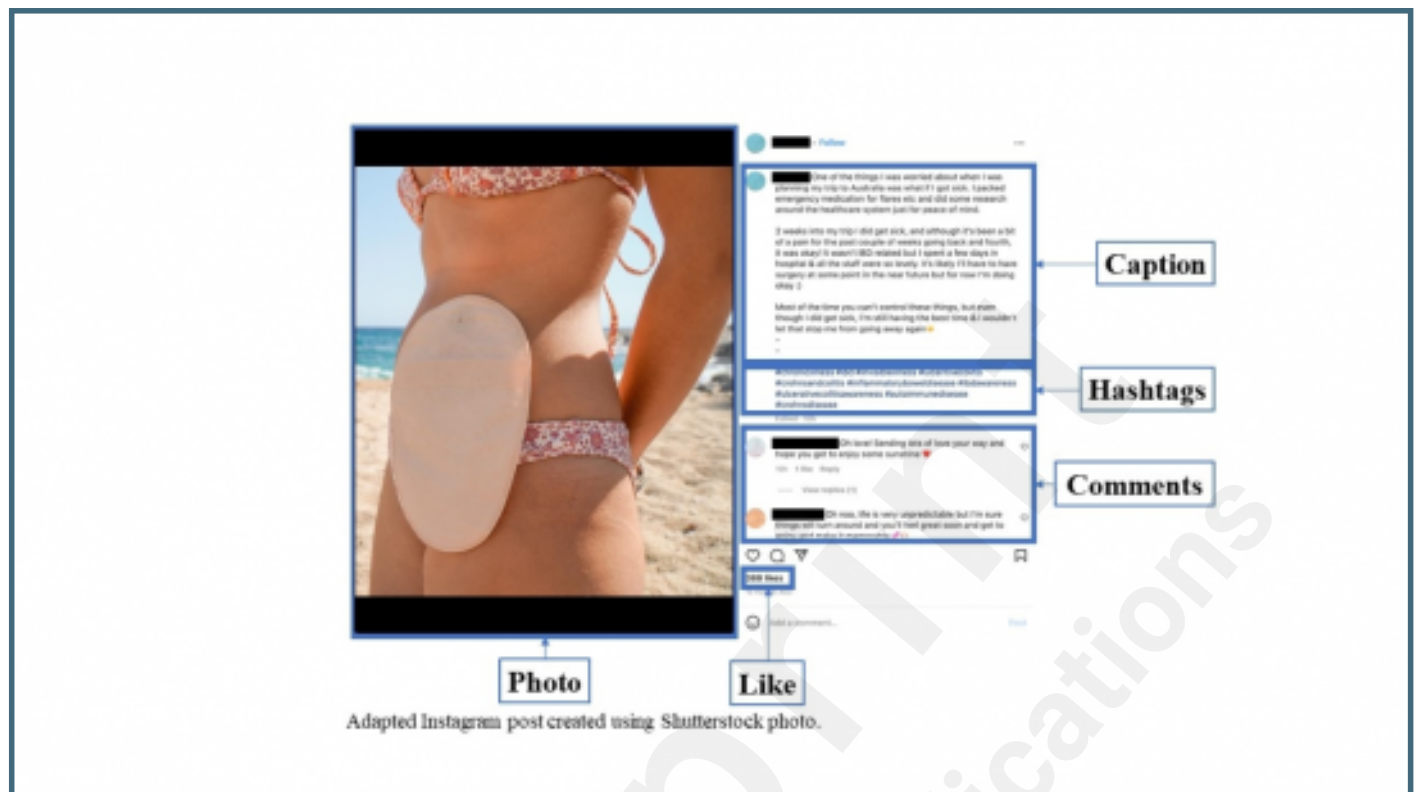
Adapted Instagram post created using Shutterstock photo.

Flowchart explaining the post selection process and inclusion/exclusion criteria.

Caption categories and codes.

Examples of photo themes identified include healthcare setting, invasive medical equipment, non-invasive medical equipment, and advertisements.

Adapted Instagram posts created using Shutterstock photos.

Multimedia Appendixes

Supplementary Table 1, Full list of hashtag conditions and interventions. Supplementary Table 2, Full list of categories and codes with excerpts from post.
URL: http://asset.jmir.pub/assets/24c409d9eb625982ff2ba4aae0902874.docx

TOC/Feature image for homepages

Screenshot of current number of posts under the hashtag Chronicillness.