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Research Report

The use of Instagram by gynecologic oncology providers as a patient education tool for patients at high-risk of gynecologic cancer

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ABSTRACT

Social media outlets have increased in popularity within the last decade and are influencing the ways in which patients interact with the healthcare system. The objective of this study is to examine the presence of gynecologic oncology divisions on Instagram and to analyze the content of their posts. Secondary objectives included examining and analyzing the use of Instagram as a tool for patient education among people at increased genetic risk of gynecologic cancers. Seventy-one NCI-Designated Cancer Centers, their gynecologic oncology divisions and hereditary gynecologic cancer related posts were searched on Instagram. Content was reviewed and authorship was analyzed. Of the 71 NCI-designated Cancer Centers, 29 (40.8 %) had Instagram accounts, whereas, four (6 %) gynecologic oncology divisions had Instagram accounts. The search of the seven most common gynecologic oncology genetic terms yielded 126,750 posts with the majority under BRCA1(n = 56,900) and BRCA2 (n = 45,000) followed by Lynch syndrome (n = 14,700) and hereditary breast and ovarian cancer (n = 8,900). In terms of authorship, 93 (66 %) of all top 140 posts were written by patients, 20 (14.2 %) were written by health care providers and 27 (19.3 %) were written by "other." This study highlights the lack of presence of divisions of gynecologic oncology at NCI-designated Cancer Centers on Instagram but does demonstrate the existence of active discussion on hereditary gynecologic cancers on Instagram by patients.

1. Introduction

Instagram is a visual-based social media platform that has more than 1 billion monthly active users, making it the third most popular social media network (Suciu, 2020). Instagram users can post photos, videos/reels, slideshows, stories, and live stream content (Panahi et al., 2016). It is notable because of its popularity (versus Twitter with 330 million active users) (Panahi et al., 2016; Park et al., 2018) ease of access to public posts (versus Facebook with member restricted access to groups), and organization of search results or posts by hashtag (versus TikTok, which provides a curated result report by user search history). Daily Instagram use among adults in the US is reported as 63 %, with 59 % of users visiting the site or mobile application at least once per day (Pew Research Center). Specifically, for individuals between the ages of 18–49 years-old, 81–83 % are using Instagram daily (Pew Research Center). While Instagram may have initially served as a social platform to connect individuals to each other, its use has expanded to many other domains including health care. A survey of adults in the United States revealed that 80 % of internet users search online for health information, and with the expansion of social networking sites, the use of social media for health information has (Social media).

As a method of physician communication and a tool for patient education, social media platforms have been demonstrated in the literature to be successful and effective (Campbell et al., 2016). A qualitative study interviewing 24 physicians sources social media including staying connected with colleagues, reaching out and networking with the wider community, sharing knowledge, engaging in medical education, benchmarking and branding (Panahi et al., 2016). A prior study among cancer patients and providers noted that health care professionals used Twitter, whereas patients and caregivers were more likely to use Instagram as their social media platform of choice (Rahimy et al., 2021). Despite the presence of Society of Gynecologic Oncology (SGO) on Instagram and numerous published studies examining the presence of gynecologic oncologists on other social media platforms, including Twitter and Facebook, data on gynecologic oncology presence on Instagram is lacking. To our knowledge, this is the first study to examine gynecologic oncology presence on Instagram and to discuss the content present on this social media platform. Given the large number of

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individuals using Instagram as a source for health care information and the platform's popularity with younger adults, Instagram has the potential to be an important resource for raising awareness for people at increased genetic risk of gynecologic cancer, thereby encouraging them to assess their risk sooner, in time for them to take preventative action.

The objectives of this study are twofold: to examine the presence of gynecologic oncology divisions on Instagram and analyze the content of their posts, and to assess the use of Instagram as a tool for patient education among people with genetic predisposition to gynecologic cancer.

2. Methods

This was a cross-sectional observational study using data available on Instagram. This study was exempt from our institution's institutional review board according to our institution's guidelines, as data on Instagram are in the public domain. Our methods using hashtag search and analysis were adapted from previously published literature by Park and colleagues (Park et al., 2018).

The 71 NCI-Designated Cancer Centers and their gynecologic oncology divisions were searched on Instagram. The search was performed using the name of cancer center as an institution independently and then in a gynecologic oncology context. This was cross referenced to NCI-Designated Cancer Centers' obstetrics and gynecology department Instagram accounts. Once a social media account was identified, information about the number of followers and posts was recorded. Each post was then qualitatively reviewed on the basis of content and divided thematically into categories including marketing, patient education and awareness, patient engagement, and recruitment.

Posts related to gynecologic specific hereditary cancer syndromes were identified by searching the seven most common hashtags in familial disease in gynecologic oncology field based on SGO genetics fact sheet (https://www.sgo.org/resources/genetics/): Hereditary Breast and Ovarian cancer (HBOC), Lynch syndrome, BRCA1, BRCA2, MLH1, MSH6 and EPCAM, cross-referenced with the Joint Statement on Gynecologic Social Media Ontologies (https://www.sgo.org/news/joint-statement-on-gynecologic-social-media-ontologies/). Other instagram hashtags were searched including MSH6, PMS2, BRIP1, RAD51D and RAD51C but did not result with significant posts. Instagram automatically creates a "top" set of posts based on highest engagement levels. Engagement level is determined by a private Instagram algorithm incorporating but not limited to the number of comments and "likes" on a photo, the amount of time post was viewed, and following to follower ratio. These hereditary cancer terms were searched on May 1, 2021 by S. H. The gathered top 20 posts per term as determined by Instagram's internal algorithm were subsequently analyzed for authorship and content type. Authorship was determined by examining credential information displayed on account profile or linked website and subsequently sorted into the following categories: health professionals, patients and other. Each post was qualitatively reviewed and divided thematically into the following categories: patient education, patient experiences, outreach and community building, and advertisement. Posts were excluded for unknown authorship type, non-English language content, duplicate posts, and if unrelated to gynecologic oncology (Fig. 1). The authorship and content analysis was performed by S.H and reviewed by S.V.B. The most common authorship and content was determined by greatest number of posts associated per respective category. Quantitative review consisted of descriptive statistics.

3. Results

Of the 71 NCI-designated Cancer centers, 29 (40.8 %) had Instagram accounts with a range of 17–101,000 followers, whereas four (6 %) gynecologic oncology divisions had Instagram accounts, with number of followers ranging from 60 to 219. Of the 29 NCI-designated cancer centers on Instagram, 89.7 % (N = 26) used their account as marketing

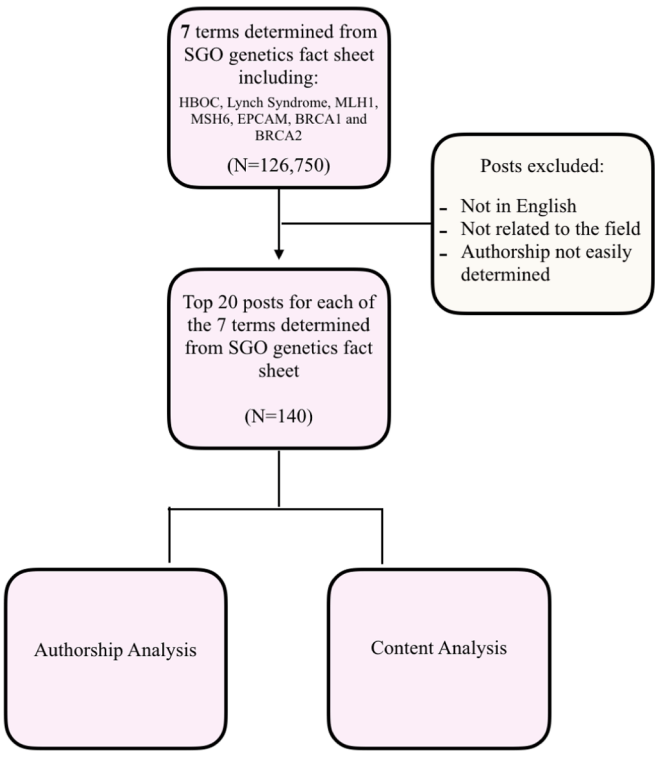

Fig. 1.

platform, 65.5 % (N = 19) used to promote patient education and awareness, and 48.2 % (N = 14) used for patient engagement and no cancer center used it for staff recruitment. Among the four gynecologic oncology divisons' Instagram accounts, the majority of accounts (N = 3) were used for fellowship recruitment.

The search of the seven most common gynecologic oncology genetic terms yielded 126,750 posts on Instagram. The tags which yielded the most results included BRCA1 (n = 56,900) and BRCA2 (n = 45,000) followed by Lynch syndrome (n = 14,700) and hereditary breast and ovarian cancer (n = 8,900). Content of the top 140 posts (top 20 per term) across all tags was analyzed with 44.2 % (n = 62) categorized as being related to patient education and awareness, 58.6 % (n = 82) as patient experience, 32.9 % (n = 46) as outreach and community building and 4.3 % (n = 6) as advertisements. When analyzing the content of specific tags, 95 % of the posts with BRCA1 and 90 % of the posts tagged as BRCA2 were categorized as patient experience. The tags with highest posts categorized as patient education and awareness were MLH1 and EPCAM with 75 % (n = 15) in each of those categories. Outreach and community building were highest for MSH6 with 60 % (n = 12) posts in that category (Fig. 1).

In terms of authorship, 93 (66 %) of all top 140 hereditary gynecologic oncology posts were written by patients, 20 (14.2 %) were written by health care providers and 27 (19.3 %) were written by "other." When looking at each individual tag, most posts written by patients were about their personal experiences. The tag with most authorship by patients was "BRCA1" (95 %, n = 19) of all top posts. The tag with most posts written by healthcare professionals was "MLH1" with 40 % (n = 8) of the posts written by genetic counselors, nurse practitioners, and physicians (Fig. 2).

4. Discussion

As gynecologic oncologists, we can improve outcomes for our patients by both increasing their ability to access gynecologic oncologists and raising their awareness of the importance of gynecologic cancer risk assessment. Social media, and specifically, Instagram, is an ideal

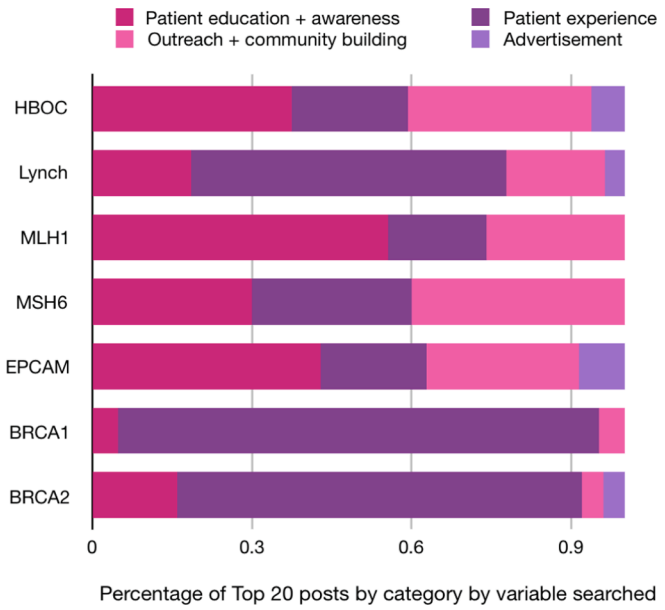

Fig. 2. Percentage of top 20 posts by category and by variable searched.

platform for achieving both of these goals. Knowledge of what information, or misinformation, is exchanged among patients can help healthcare professionals improve patient care and education. Because posts on these platforms are easily accessible to millions of potential patients across the globe, it is prudent that high quality information be more prevalent. The aim of this cross-sectional study was to provide an initial description of gynecologic oncology divisions on Instagram as well as a descriptive analysis of posts regarding genetic predisposition to gynecologic cancer.

We have found a lack of presence and an underutilization of Instagram by gynecologic oncology divisions at NCI-designated Cancer Centers. Only four of the 71 gynecologic oncology divisions had Instagram accounts, with the majority using the platform for fellowship recruitment. Our secondary outcome pertains to Instagram posts about hereditary gynecologic cancers; identifying patients at an earlier age with increased genetic risk affords more opportunity for genetic testing and taking action based on these results. Our descriptive analysis demonstrates that two thirds of the posts regarding hereditary gynecologic cancer were written by patients, with almost half of the posts about patient education, awareness and personal experience. Only a minor percentage of all posts were written by healthcare professionals.

The lack of gynecologic oncology healthcare professionals on Instagram and the large number of posts presented on these topics present a missed opportunity to reach our patients. There are limited published studies which examine the use of social media in health care and even fewer within the field of obstetrics and gynecology.

In a review of the literature, other gynecologic surgery subspecialties have examined the use of Instagram as a patient outreach platform demonstrating the popular use by patients and the lack of health provider presence (Sinha et al., 2021; Carlson et al., 2020; Qin et al., 2020). In the paper by Sinha et al, the majority of invasive gynecologic surgery Instagram posts were authored by patients about endometriosis and discussed personal experience with a lack of healthcare professional presence (Sinha et al., 2021). In the reproductive endocrinology and infertility field, there was a difference in content in posts authored by physicians compared to patients with the majority of posts authored by patients to publicly display their experience[8*] In other medical oncologic fields, studies have further examined the use of social media as a form of support and encouragement for patients and as a tool for recruitment for clinical trials, all illustrating Instagram as a potentially powerful tool to reach our patients (Attai et al., 2015; Pase et al., 2018).

In 2016, the American College of Obstetricians and Gynecologists (ACOG) published a commentary on the use of social media in regards to power morcellation, hysteroscopic tubal sterilization and mesh procedures in urogynecology. Through this piece, ACOG encouraged physicians to be present and active participants on social media to ensure the spread of evidence-based medicine to help patients make informed decisions about their healthcare (Tracy et al., 2016). Despite this statement, in alignment with other studies in gynecologic subspecialties (Rahimy et al., 2021; Sinha et al., 2021; Carlson et al., 2020; Qin et al., 2020), our study demonstrates only a small fraction of gynecologic oncologists utilize their expertise as a professional presence on Instagram. Studies examining hereditary cancers have been mainly conducted on twitter, demonstrating that most twitter posts were focused on resource sharing with individuals showing their personal stories and testimonials about experience with HBOC and LS (PM ID: 32415453).

While there is a lack of professional presence on social media, almost 90 % of all physicians do use social media for personal uses. A study by Truong M et al, notes that the lack of physician presence on social media has been attributed to lack of familiarity, apprehension regarding legal repercussions, concern about privacy infringement of the individuals or patients and vulnerability of intellectual property (Tracy et al., 2016). While there is certainly room to optimize the potential use of Instagram as a powerful platform to reach patients, the question remains as how to engage gynecologic oncology professionals in a fruitful discussion via Instagram. Knowledge of the content of information can help healthcare professionals improve patient care and education. Further studies should analyze and examine patient awareness and education based on gynecologic oncology healthcare professionals on Instagram and the possible impact their presence may have on patient outcomes.

Strengths of this study include it being the first to examine the utilization of Instagram within the field gynecologic oncology. Limitations to the study design include the inherent biases of a cross-sectional design including the subjective nature of social media. Data may be biased due to the importance of collecting data within a 24-hour period,8 as new content can outrank a previously popular post. In addition, the search terms queried were limited to only a few terms; thus, other posts relevant to this study may not have been included. The results may be further skewed as only publicly accessible posts were analyzed, and medical professionals may have more private settings. Furthermore, the sources of information may be unreliable because those who contribute may not publicly self-identify as a healthcare professional or, vice versa, may misidentify themselves as more knowledgeable than what is true.

Overall, this study highlights the lack of gynecologic oncology division presence on Instagram but demonstrates the existence of active patient-driven Instagram discussion on hereditary predisposition to cancers. Professional health care provider involvement in social media may lead to improvement in patient education, physician-patient relationships, genetic testing in gynecologic cancer and ultimately cancer prevention.

CRediT authorship contribution statement

Holtzman: Conceptualization, Data curation, Formal analysis, Project administration, Writing - original Draft, writing- review & editing. **Carr:** Conceptualization, Writing- original draft. **Zeligs:** Conceptualization, writing - original draft. **Blank:** Conceptualization, Data Curation, Formal analysis, Writing - original draft, writing - review & editing.

Declaration of Competing Interest

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

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Condensation

There is a lack of Gynecologic Oncology providers on Instagram and the majority of content on this social media platform is written by patients about patient experiences.

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