Quality and Misinformation of Cancer-Related Information on Social Media: A Systematic Review of Literature (2014–2023)

Xue-Jing Liu, Danny Valdez, Maria A Parker, Eric Walsh-Buhi

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Abstract

Background: Social media has become a vital source of cancer-related health information, offering patients, caregivers, and the public a platform for sharing knowledge and experiences. However, concerns regarding the quality, accuracy, and potential misinformation of cancer information on social media persist.

Objective: This study systematically reviewed literature published between 2014 and 2023 evaluating the quality of cancer-related information on social media. It aimed to identify common characteristics of these studies, assess patterns in information quality across platforms and cancer types, and explore factors associated with study outcomes.

Methods: This systematic review searched PubMed, Web of Science, Scopus, and Medline. Studies were included if they analyzed cancer-related social media content and assessed information quality using standardized tools (e.g., the DISCERN tool). Extracted data included study characteristics, social media platform, cancer types, and quality assessment methods. Meta-analysis and ordinal logistic regression analysis were performed to pool findings from multiple studies.

Results: A total of 75 studies were included, covering various a range of social media platforms, such as YouTube, TikTok, Facebook, Twitter, and Reddit. Findings indicated that video-based platforms, particularly YouTube and TikTok, were the most studied but also contained misinformation. Overall, 27% of social media cancer-related content included misinformation, with common false claims regarding alternative treatments and unproven therapies. Studies assessing rare cancers reported lower information quality compared to those focusing on common cancers. Additionally, content from medical professionals was of higher quality but less engaging than user-generated content.

Conclusions: While social media serves as an essential platform for cancer-related health information, concerns remain about misinformation, completeness, and actionability. Future research should prioritize improving information accuracy, leveraging AI for content verification, and promoting authoritative sources to enhance public health outcomes.

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Keywords: Social media, cancer, consumer health information, social communication, misinformation, health literacy, systematic review

INTRODUCTION

Social media has become an indispensable tool for health information and network support, notably among individuals experiencing chronic and terminal health conditions, such as many forms of cancer (1). On Facebook, Instagram, TikTok, YouTube and other platforms, cancer patients, survivors, and caregivers as well as their families are exchanging information (2), seeking external support (3), and sharing personal experiences of cancer (4). Further, among the US adults who report being online almost constantly, specifically on social media (5), 72% report leveraging their preferred platform, and increasingly generative AI, to learn about health conditions diagnosed in themselves and their friends and family (6).

Research shows that turning to online outlets is associated with improved psychosocial outcomes across a range of acute and chronic conditions (7). Research also indicates that access to high-quality information on social media improves health literacy, decision-making, behaviors, and outcomes, as well as healthcare experiences (8–10). Conversely, low quality information can lead people trusting unproven, ineffective, and harmful treatments, as well as fake news, conspiracy theories, and misleading testimonials about "natural" or alternative cures (11). Kington et al. described “high-quality information” as that which is science-based and consistent with the best available evidence at the time (12). Huang et al. (13) identified 15 key attributes of information quality, including accuracy, objectivity, access, completeness, and ease of understanding, among others.

As cancer is a leading cause of death globally and rates increasing (14), discussions about it are widespread on social media (15), making it a target for commercial and political interests (16,17). There are substantial financial incentives to promote treatment (18), and cancer patients, often desperate for hope, are especially susceptible to miracle stories and misleading information circulated on social media (11). Cancer survivors are also at risk of cognitive barriers such as fatigue, memory deficits, and reduced executive function (19,20), which may diminish their ability to critically evaluate the quality of the information they encounter (21). Low-quality information can lure patients into submitting to costly and dangerous treatments, undermining the potential benefits of online support networks (22).

To date, literature reviews using systematic, scoping, and other methods pertaining to cancer content on social media generally point to inconclusive and non-definitive results regarding the quality of information about cancers on social media (15,23,24). A majority of cross-sectional studies assessing the quality of information about cancers on social media report a wide range of quality across platform, content type (i.e., text-based or video-based), and cancer types (25). Differences in studied cancers, platforms analyzed, and the approaches used to rate the quality of information may explain this inconsistency. A critical gap remains the breadth of literature on this topic that directly accounts for (a) a wide variety of cancer types, (b) a multitude of platforms, and (c) differences in findings over time. Social media has evolved enormously in the past two decades. Accounting for factors such as users’ shift in medium preference (text-based versus video-based), and platform changes (Twitter to X, and at the time of writing the potential closure of TikTok) may reveal temporal trends that implicate improvement or worsening of information quality over time.

Purpose

This paper summarizes a systematic review of empirical research studies, published from 2013 to 2023, addressing cancer-related information on social media. In so doing explore the growing phenomenon of people using social media as a cancer-related health information source, trends in specific platform use for cancer-related information seeking, and myriad tools employed to determine the quality of social media cancer-related information across included studies. We explore three research questions (RQs):

RQ1. What are characteristics of cancer-related social media information quality studies and how have these characteristics changed over the study period?
RQ2. What patterns emerge in the findings of social media information quality assessments?
RQ3. What factors are associated with outcomes of cancer-related social media information quality studies, and do these factors vary across platforms, assessment tools, and cancer types?

Findings from this review stand to further support our understanding of social media's role as a cancer-related health information source. The longitudinal nature of our review will also reveal trends in quality assessment studies using social media data and support recommendations for future research on this vital topic.

METHODS

Guidelines and ethical considerations

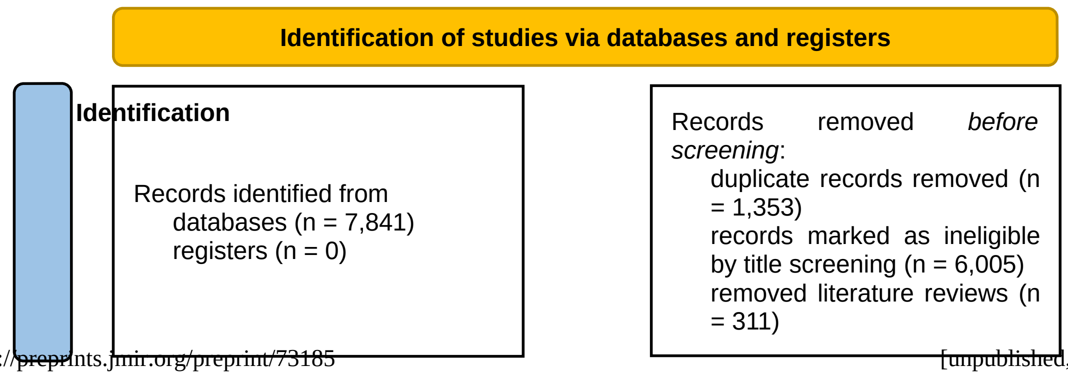
This review was conducted according to the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) guidelines. As a review study of published studies, our research is considered non-human subjects research and exempt from review by an Institutional Review Board.

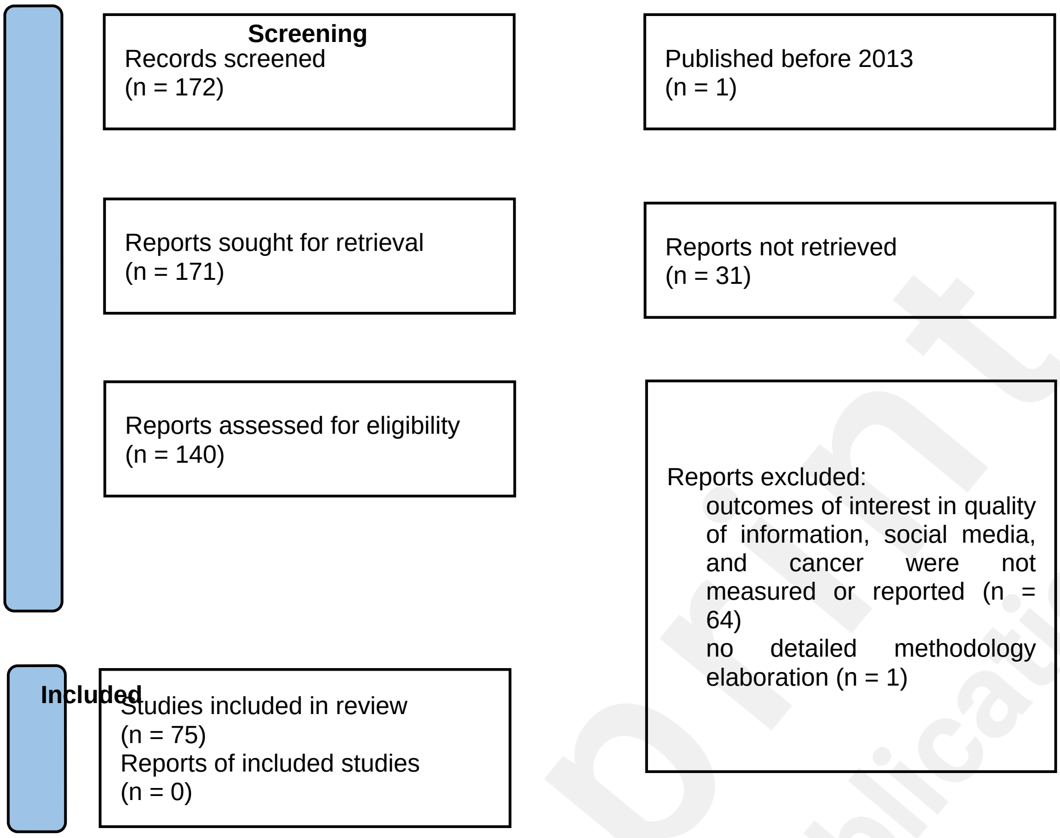
Search strategy

Between January and September 2023, we conducted a systematic literature search on PubMed, Web of Science, Scopus, and Medline using Medical Subject Heading (MeSH) terms "Oncology" and "Social Media" and additional keywords related to "Oncology." These included "cancer" OR "tumor" OR "Neoplasm," "Social Media," including "SM" OR "SoME." We also included in our search articles with specific names of social media platforms (e.g., YouTube, Twitter) AND terms related to "information quality," including "misinformation" OR "disinformation" OR "Fake News." Three researchers (XJL, DV, and EWB) conducted independent examinations of the selection criteria and search terms as well as the records returned by the search. Where necessary, they undertook a discussion of given records for potential inclusion to resolve disagreements by consensus. This search strategy was adapted across all considered research databases. For each included study, we also reviewed the associated reference list to identify other publications that met our criteria and had not yet been included. The complete search terms appear in Appendix Table A.

Our initial search identified 7,841 articles, including (1) 3,002 records from PubMed, (2) 2,033 records from Web of Science, (3) 1,293 records from Scopus, and (4) 1,515 records from Medline. After using a screening process to filter duplicates by title and abstract, 172 potentially eligible papers were left for a further full-text review. Through full-text review, we excluded 97 additional studies for lacking analytic rigor or not including quality of information as the main component of analytic results. Our final sample size comprised 75 individual studies. Figure 1 documents our filtering process according to the PRISMA guidelines (Figure 1).

Figure 1 PRISMA





Selection criteria

We initially included studies if they met three broad categories of inclusion: (1) they contained a synthesis of cancer-related social media data, (2) they used an information quality assessment to rate the quality of data along varying criteria, and (3) they were published in English between 2013 and 2023. Cancer types were defined according to the International Classification of Disease for Oncology. Likewise, we considered three broad categories of social media for inclusion: (1) text and graph-based media, such as Facebook, Instagram, Pinterest, Reddit, Twitter (now X), WeChat, and Weibo; (2) video-based media such as YouTube, TikTok, and Xigua; and (3) generative AI-based media, such as ChatGPT, Chatsonic, Microsoft Bing AI, Perplexity. We included generative AI-based models because they were trained including social media data, and conversations in those AI-chatbox were further used in model training, and they became increasingly critical sources of health related information in the final years of the study period. We only included studies that underwent peer review between 2014 and 2023 and presented empirical qualitative, quantitative, or computational findings. We also excluded articles that did not present original findings, unpublished manuscripts originating from preprint repositories such as arxiv, conference abstracts, narratives, literature reviews, and editorials. Studies were also excluded if they discussed the quality of information but did not elaborate on how it was assessed, for example, without conducting a comprehensive and systematic data collection and analysis, without referring to any scientific quality criteria.

Data Extraction

We extracted the following data from the included studies: (1) author(s), (2) year of publication, (3) journal name, (4) study design (i.e., quantitative, qualitative, or computational), (5) sample size, (6) sample sex/genders, if applicable, (7) study location, (8) post authors' public page category (individual/constitute, non-medical professional/medical professional), (7) social media platform, (8) search strategies used to procure data in each study, (9) cancer types, (10) the language of the original data, (11) the profession of the raters, if applicable, (12) contents of the posts, and (13) study results.

We also considered the information assessment tools used in the included studies, such as the DISCERN (26) tool. We extracted findings for the constructs measured by each tool. In spite of such variation, most considered at least one of the following: (1) overall quality: a holistic assessment of the posts ; (2) technical criteria: an assessment of the layout and functionality of the data; (3) readability and understandability: an assessment of reading and comprehension level; (4) accuracy and misinformation; an evaluation of technical correctness of the content; (5) completeness and coverage: or scope of topics; (6) actionability and usefulness: an assessment of the practical nature of the content; (7) harmfulness: whether the content can cause or promote harm, and (8) commercial bias: evidence of the direct influence of commercial interests. We categorized the 75 studies based on the tools and metrics used to evaluate the quality of information and draw comparisons between studies. All information was maintained in a .csv file for efficient data processing and analysis via Python.

Analyses

Descriptive Analysis. First, we illustrated several granular details for all studies about the search process, rating process, and review process. Second, we documented the frequencies and percentages of all mentioned social media platforms, cancer types, and assessment tools for information quality, as well as changes in those patterns over the study period.

Statistical Analysis. For a single study reporting information quality for stratified groups, such as different posters (e.g., individual/institute/with or without medical professional), content types (e.g., prevention/treatment), or other specified categories, we calculated the pooled mean and pooled standard deviation. For a study that reported a median instead of a mean for a quality indicator, we estimated the mean and standard deviation from the median (27). We standardized quality indicators across different scales by mapping them onto a proportional rate system. For example, a score of 2 in a 1–5 scale system, would be standardized as 40% in the proportional rating system. Then those quality scores are classified as follows: "low quality" for scores within [0%-30%], "median quality" for scores within (30%-70%), and "high quality" for scores within [70%-100%]. For negative indicators (misinformation, harmfulness, and commercial bias), the coding system was the opposite. To categorize the conclusion of each study based on quality indicators used, we adopted the following criteria: The overall conclusion of information in a study was deemed "positive" if it reported more "high quality" than "low quality" results. It was considered "negative" if it reported more "low quality" results than "high quality" results. Studies reporting exclusively "medium quality" results, or equal numbers of "high" and "low quality" results, were classified as "neutral." We then used ordinal logistic regression to estimate the association between social media type, cancer type, and characteristics of studies based on the search, rating, report process, and study conclusions (28). Regression models were weighted by the natural log of each study's sample size (29),since studies on some kinds of platforms, such as Twitter and Reddit, included larger sample sizes than others, such as YouTube.

Meta analysis. We used a meta-analysis of proportions to test the homogeneity of results obtained using the same quality assessment tool. Only results reported by three or more studies using the same tool were included in the analysis. Statistical heterogeneity was assessed via I^2 and Cochran's Q test values, where an I^2 value of 25% represents low heterogeneity, 50% represents moderate heterogeneity, and 75% represents high heterogeneity. Analysis of proportions was pooled with a random-effect model with DerSimonian-Laird intervals when the test of heterogeneity was moderate or high (30). For studies reporting indicators with 0% or 100% estimates, we used the Freeman-Tukey double arcsine transformation to stabilize the variance (31). We calculated 95% confidence intervals with an alpha level of 0.05 to estimate statistical significance.

RESULTS

This review summarizes the body of literature on quality of cancer-related information on social media, published from 2014-2023. A total of 75 published studies met our inclusion criteria. We present our results below in relation to each of our research questions.

RQ1. What are common characteristics of cancer-related social media information quality studies and how have these characteristics changed over the study period?

Table 1 provides a summary of characteristics for included studies, including binary classifications of whether certain characteristics were present or not present. Most studies followed similar practices for search process, including documenting their search period, query terms, the use of more than one search tool, and only considering one social media platform and content in English. Languages represented in the 20 studies that assessed content in languages other than English included Chinese, French, German, Italian, Japanese, and Turkish, while most of these studies addressed content in English. A vast majority of studies used a blinded rating process, documented the number of raters in the study, relied on more than one rater, and defined their rating criteria a priori. Additionally, most studies did not include a rater with a medical background. Most studies reported "views" and liking/unliking behavior. A few tracked posts sharing behavior. A majority of studies did report the poster's identity; those that did address whether the account originated from a person, a medical professional, a medical entity, or others. Almost all studies reported the contents or topics discussed in the included posts.

Overall Study Characteristics

Table 1 Summary of Characteristics of Included Studies (N = 75)

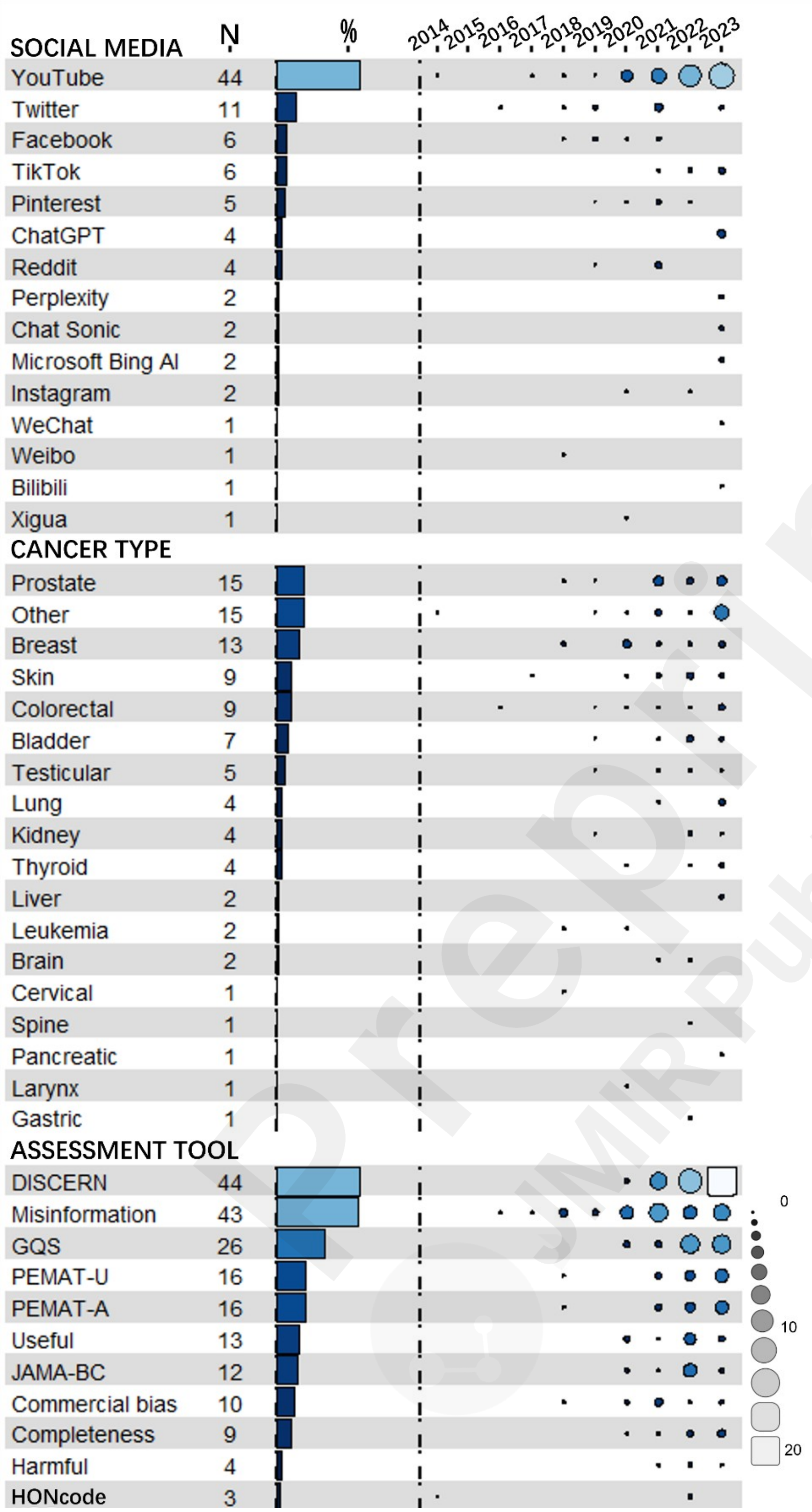
Study characteristics	YES (%)	NO (%)	Other (%)
Search Process			
Date/period mentioned	70 (93.33%)	5 (6.67%)	
Search tools mentioned	69 (92%)	6 (8%)	
More than one search tool used	13 (17.33%)	62 (82.67%)	
Search terms mentioned	73 (97.33%)	2 (2.67%)	
Initial hits reported	41 (54.67%)	34 (45.33%)	
Assessed language other than English	20 (26.67%)	55 (73.33%)	
More than one social media platform examined	8 (10.67%)	67 (89.33%)	
Cancer type more than one	30 (40%)	45 (60%)	
Rating Process			
Raters blinded for the source	2 (2.67%)	73 (97.33%)	
Number of raters reported	66 (88%)	9 (12%)	
More than one rater	69 (92%)	6 (8%)	
Rater independently	38 (50.67%)	37 (49.33%)	
Interrater reliability figures for evaluation determined	34 (45.33%)	41 (54.67%)	
Process graph contained	34 (45.33%)	41 (54.67%)	
Medical professional background for rater	42 (56%)	17 (22.67%)	16 (21.33%)*
A priori criteria defined for quality	14 (18.67%)	52 (69.33%)	9 (12.00%)**
Report Process			

Engagement: view	46 (61.33%)	29 (38.67%)
Engagement: like/unlike	56 (74.67%)	19 (25.33%)
Engagement: forward/share	11 (14.67%)	64 (85.33%)
Engagement: comment	47 (62.67%)	28 (37.33%)
Poster characteristics reported (sex/age/ethnic/country)	17 (22.67%)	58 (77.33%)
Poster identity reported (personal/institute/medical professional)	53 (70.67%)	22 (29.33%)
Contents/topics mentioned	67 (89.33%)	8 (10.67%)

Note. *denotes that raters were authors of the study and it was unclear if they were medical professionals; ** generally mentioned using literature/publication as criteria

Individual Study Characteristics

Figure 2 Frequency of Studies on Information Quality Across Social Media Platforms, Cancer Types, and Assessment Tools (2014–2023)



Note. Global Quality Score (GQS), the Patient Education Materials Assessment Tool - Understandability part (PEMAT-U), the Patient Education Materials Assessment Tool - Actionability part (PEMAT-A), the Journal of the American Medical Association Score benchmark criteria (JAMA-BC), the Health On the Net Foundation has initiated the Code of Conduct (HONcode)

Included Social Media Platforms. Figure 2 highlights the frequency of considered social media platforms and changes in included platforms over time. Twenty articles investigated content from various text and graph platforms, including Twitter (11 studies) (32–42); Facebook (6 studies) (2,32–34,42,43); Pinterest (5 studies) (32–34,44,45), Reddit (4 studies)(32–34,46); Instagram (2 studies)(47,48), and one study each on WeChat (49) and Weibo (50). Fifty-two articles studied video-based media; of these, 44 examined YouTube (51–95), 6 focused on TikTok (96–101), and one study each on Bilibili (98) and Xigua (102). Overall, four articles studied data from generative AI-chatbot media, all of which specifically included ChatGPT (103–106); two studies also included Perplexity, Chatsonic, and Bing AI (105,106).

We also observed changes in included social media platforms over time. In 2014-2016, the number of included social media platforms was relatively narrow, with only two studies investigating content from YouTube and Twitter. The scope expanded in 2018 and 2019, with increased research other text- and graphic-based media, including three Facebook studies, one Pinterest study, one Reddit study, and one Weibo study. From 2020 to 2022, we observed a significant increase in the volume of studies, with 17 YouTube studies, while each of the other text- and graphic-based media platforms maintained approximately 2-3 publications each. In 2023, the trend continued, with video-based media such as YouTube remaining a major focus of cancer information quality studies with 14 studies conducted. This period also marked the emergence of research on generative AI-chatbot media, which was the subject of four studies.

Included Cancer Types. As shown in Figure 2, we captured 17 unique types of cancer within our data with varying levels of emphasis. There were 15 research studied information about prostate cancer (32,34,45,48,62,68,69,71,76,79,99,100,103,105,106); 13 about breast cancer; 9 about skin cancer (33,43,55,59,78,82,85,88,105); 9 about colorectal cancer (32,39,40,53,54,60,93,103,105); 7 about bladder cancer (34,45,72,73,100,103,106); 5 about testicular cancer (34,45,70,81,106); 4 each about lung cancer (32,58,83,95) thyroid cancer (74,84,96,97), and kidney cancer (34,100,103,106); 2 each about liver cancer (65,98), leukemia (2,56) and brain cancer (75,89); and 1 each about cervical (50), gastric (101), larynx (91), pancreatic (64), spine (52) cancers. Another 15 articles were about cancer information in general or did not specify the cancer type (36–38,41,42,46,47,57,63,66,67,80,87,90,104). Several studies were not limited to a single type of cancer but examined multiple types. As a result, those studies were counted more than once.

Included Information Quality Assessments. Figure 2 highlights the presence of formal and informal information quality tools used to evaluate data in a given study. From this table, we observed that a majority of studies used DISCERN, followed by Misinformation, the Global Quality Scale (GQS), and the Patient Education Materials Assessment Tool (PEMAT). Over time, we also observed changes in tool use. In 2014-2019 Misinformation was the most common instrument, used in 10 studies. From 2020 to 2022, we observed further increases in the use of Misinformation and DISCERN, which each appeared in 24 studies. In 2023, the trend continued, with DISCERN maintaining a robust presence, appearing in 20 studies published that year.

Characteristics of Content

Content Distributor Information. Using pooled study data, we identified patterns in content distributors across studies. Among studies that included information on content distributors, we observed a strong presence of surgeons, physicians, endocrinologists, sonographers, radiologists, physiotherapists, and dietitians. YouTube was the most represented social media platform in our review and was the subject of most studies with content distributor information. Studies generally concluded that the most-watched or -

engaged videos originated from such medical professionals. Indeed, medical professionals had posted 80% of top posts about thyroid cancer on TikTok (96,97) and 80% on both spine tumors (52), and hepatocellular carcinoma (65) on YouTube. Medical professionals contributed more than half of the top posts on rectal cancer surgery (53), nutrition (63), the mental health of prostate cancer patients (68), radioactive Iodine therapy (84), and larynx cancer (91) on YouTube. They also contributed more than half on liver cancer (98) and gastric cancer (101) in Chinese on TikTok. In YouTube associated medical institutions posters, such as hospitals, clinics, academic centers, and universities, contributed many top posts in two studies: 92% of top videos on pediatric cancer clinical trials (87) and 54% on Merkel cell carcinoma (88). However, they contributed less than half of posts on other topics. In contrast, two studies of TikTok found that non-medical individuals, including patients and their families/friends, posted over 93% of top videos on gastric cancer in English and Japanese (101) and 83% of prostate cancer videos (99). Non-medical professionals and organizations, such as media agencies and for-profit companies, herbalists, health websites, or health-living vlog channels contributed less than 61.1% of all topics.

***Engagement Data of Video-Based Content*.** When possible, we also used pooled study data to triangulate engagement (watch count, likes/dislikes, and comment counts) of video-based and non-video content. Of the 51 studies involving an analysis of video-based data, we observed a view count ranging from 3 (71) to 11 million (96). The single video with the highest watch count in any of the studies (N=11 million pertained to thyroid cancer and originated from a medical professional (96). Studies reported the highest views for single videos about breast cancer and leukemia on YouTube (56,60,94), each of these exceeded 7 million views. Indeed, the top 50 videos about breast cancer had an average of over 1 million views (51) —double the average for videos on cancer-related food (80). In contrast, videos on prostate cancer (TikTok) and pediatric cancer clinical trials (YouTube) averaged around 2,000 views (87,99).

Likes and commented numbers were lower than viewer numbers, as expected. The most-liked video was a TikTok video on thyroid cancer that garnered 308,000 likes (96,97), followed by a breast cancer YouTube video with 226,000 likes (94). Nutrition and cancer-related videos averaged about 10,000 likes per video (80). The most disliked video was a YouTube video on herbal cancer treatments in Arabic, with an average of 994 dislikes (57). Thyroid cancer videos on TikTok received the most comments, averaging 1,252 comments per video, with the top video amassing over 73,000 comments (96,97). The most-commented nutrition and lung cancer videos each had over 450 comments (80,83). Of non-video entries, the highest engagement was on Facebook, where studies found the highest engagement for sharing information on common cancers, including breast, prostate, colorectal, and lung cancers, as well as dermatological and genitourinary cancers (32–34).

RQ2: What patterns emerge in the findings of social media information quality assessments?

Information Quality Criteria.

Overall quality. Overall quality refers to a holistic assessment of content including its alignment with current scientific standards and whether content achieves educational aims. The most commonly used overall quality assessment tools were DISCERN and GQS. DISCERN, is a 16-question tool evaluating publication reliability, quality of information on treatment choices, and a singular overall quality rating. GQS uses a 5-point Likert scale from poor (=1) to high (=5) quality. Forty-five studies in our sample used DISCERN. Overall, DISCERN scores were higher for content provided by medical individuals and institutions, such as hospitals, National Cancer Institute–Designated cancer centers, physicians, dietitians, and physiotherapists, than their non-professional counterparts

(51,58,59,63,64,70,77,84,89,96,98,100,101,101,102,102). Within these medical groups, hospitals provided higher quality information than health organizations (96), and doctors specializing in modern medicine consistently scored higher than those practicing traditional medicine (98). However, one study on bladder cancer information on YouTube found that content from medical professionals had lower quality scores (73). TikTok videos posted by news agencies outperformed some medical providers; the researchers explained that the quality was better because the content lacked confusing jargon (100). Studies comparing for-profit and non-profit sources yielded mixed results; some found for-profit sources had higher DISCERN scores (58,100), while two studies of content about colorectal cancer on YouTube did not find significant differences (53,54).

Studies using the DISCERN tool identified varying scores along different criteria. Eight studies reported the highest scores for “explicit aims” (55,57,69,77,79,81,87,90), six for “aims achieved” (49,69,77,79,81,89) and four for “benefits of treatments” (57,79,81,87). The most common reason for score deductions was the absence of “additional sources of information”, with seven studies reporting the lowest scores in this area (49,55,59,69,79,81,89). Four studies reported the lowest scores for “describes what would happen if any treatment is not used” (69,77,79,89), while three studies showed the lowest scores for whether “provides information source” (55,59,103). Additionally, two studies each noted the lowest scores for “currency (date) of information” (57,81) (that is, how up to date it is), “reference to areas of uncertainty” (75,77) (that is, the content does not acknowledge extant uncertainties), reporting “risks of treatment,” (87,106) and “quality of life.” (57,106).

Based on DISCERN measurement, a study of gastric cancer TikTok videos found that Chinese videos had significantly higher quality than those in English and Japanese (101). However, comparisons of prostate and thyroid cancer videos on YouTube in English, French, German, Italian, and Turkish revealed no significant differences in overall quality by language (69,84). A study comparing content quality of English-language videos in the United States, Europe, Asia, and Australia found that U.S. videos had the highest quality, Australian videos the lowest, and quality was middling in Europe and Asia (77). A different study found that U.S. videos also had statistically higher quality than those from India, Australia, Brazil, Jordan, Ireland, Czech Republic, and the United Arab Emirates (89).

Three studies comparing generative AI-chatbot media on a range of platforms found that they generally provided moderate to high-quality information (103,105,106). These chatbots frequently cited reputable sources such as the American Cancer Society, Mayo Clinic, CDC, and Cleveland Clinic.

Studies using GQS found that scores were typically higher for videos produced by medical professionals (56,59,63,77,84,98,102) and for-profit medical providers (53,54). For example, content posted by medical providers on YouTube about pediatric cancer clinical trials (87), liver cancer (65), and skin cancer (88) reported GQSs of 4 or higher, indicating good quality. While YouTube videos on Merkel cell carcinoma (88), breast cancer originating from Australia (77), and breast cancer uploaded by medical advertisers on Xigua videos (102) received GQS scores below 2, indicating poor quality,

Technical Quality. Technical quality is the evaluation of disclosure ethics. The commonly used Journal of Medical Association Benchmark Criteria (JAMA-BC) critically assesses web content based on four key "transparency criteria": (1) authorship, (2) attribution, (3) disclosure, and (4) currency. This tool, which has a high score of 4.0, was applied in five studies of YouTube content. The highest JAMA-BC score, 2.6, was reported for spine tumor videos (52), while the lowest score, 1.0, was for nutrition videos posted by independent users (63), indicating minimal adherence to reliability standards. Across included studies, content was rated high for “authorship” when clear information about contributors and their credentials was provided; the “disclosure” and “currency” indicators were rated lowest, reflecting a lack of transparency regarding sponsorship, commercial funding, potential conflicts of interest, and dates of posted and updated information (55,59,78).

Transparency of ethics of shared content was measured using other tools. Three studies used the Health on the Net Foundation Code of Conduct (HONcode) (107), which uses eight constructs: (1) authority, (2) complementarity, (3) privacy, (4) attribution, (5) justification, (6) contact details, (7) financial disclosure, and (8) advertising policy. Studies found that most cancer content videos disclosed authority but few disclosed source information, conflict of interest, financial sources, or advertisement policy (77,90,100). The Quality Evaluation Scoring Tool (QUEST), which was used in one study, measures six aspects of online health information: (1) authorship, (2) attribution, (3) conflict of interest, (4) currency, (5) complementarity, and (6) tone (108). The study using QUEST examined videos about gastric cancer on TikTok and found that Chinese-language videos scored higher than Japanese- and English-language videos (101). Finally, the Audiovisual Quality Score (AQS) assesses the viewability, precision, and editing of audiovisual materials and the study found that larynx cancer videos from university sources showed clearer and more professional editing (91).

Readability and understandability. Readability and understandability are metrics used to determine how effectively audiences can process and absorb information. PEMAT-U is the first part of the PEMAT toolkit to assess the understandability of print and audiovisual materials which consists of 13 questions measuring the understandability of content's language, organization, and visual design (109). Eighteen studies in our sample adapted PEMAT-U scores for online content, with a majority reporting high understandability (above 70%). In general, higher scores were attributed to content with a clear purpose and use of accessible language (57,99); and lower scores were attributed to content that lacked summaries or educational visual aids to help people understand the content (57,59,78,105,106). The highest PEMAT-U score, 88%, was awarded to research on imaging information about prostate cancer on Instagram (48); followed by thyroid cancer videos from TikTok (97). The lowest PEMAT-U scores (below 30%) were found in Arabic-language YouTube videos on herbal cancer treatments (57) and immunotherapy for renal cell cancer and prostate cancers (66). Two studies using PEMAT-U to analyze generative AI chatbot content found medical jargon and concise terminology that may be challenging for lay audiences to understand was common (105,106).

Three studies measuring readability of content used the Flesch-Kincaid scale, which determines the average reading level needed to comprehend a written document on a continuum from 5 (signifying a fifth grade reading level) to 16 (indicating a post graduate reading level). One of these studies examined prostate cancer information on YouTube, reporting a 12th-grade readability level overall (62). The other two focused on generative AI chatbots responding to cancer-related inquiries. Both found that text was at a college-level readability (105,106).

Accuracy and misinformation. Accuracy refers to the extent that information aligns with consensus scientific or medical evidence. Alternative terms used to describe a lack of accuracy sometimes include terms now categorized as having political connotations, including misinformation, misleading content, false claims, and non-evidence-based claims. Most studies did not use a standardized instrument to evaluate accuracy. Rather, content accuracy was assessed by identifying the proportion of content that did not align with scientific standards in each corpus or dataset. In some cases, studies defined criteria in advance to assess accuracy, and in others expert reviewers were utilized to review and classify content.

One study in our sample that analyzed the top 10 most-viewed YouTube videos on THC oil and skin cancer concluded that all 10 contained misleading information (82). Similarly, a study of YouTube videos on radiotherapy and surgery for prostate cancer flagged 76.25% as containing misinformation, with radiotherapy videos demonstrating less misinformation than surgery videos (79). Over half of videos on prostate cancer in Arabic (71), and in English on skin cancer (33), breast cancer (102), immunotherapy for urological tumors (66), and arm and shoulder exercise after breast cancer surgery (92) were identified as having misleading content.

Across studies, the most common type of misinformation involved unproven prevention and treatments. For example, one study on Facebook pages about acute lymphoblastic leukemia found that all references to alternative and complementary therapies were related to unproven treatment options or modalities (2). Similarly, a study on dermatology information reported that 74.2% of content on alternative medicine was imprecise, confusing, or generally misleading (33). On Twitter, “alternative treatments” were often briefly mentioned and then linked to external sources, such as hyperlinks, books, videos, or movies, for further information, without assessing the credibility of those external materials (41).

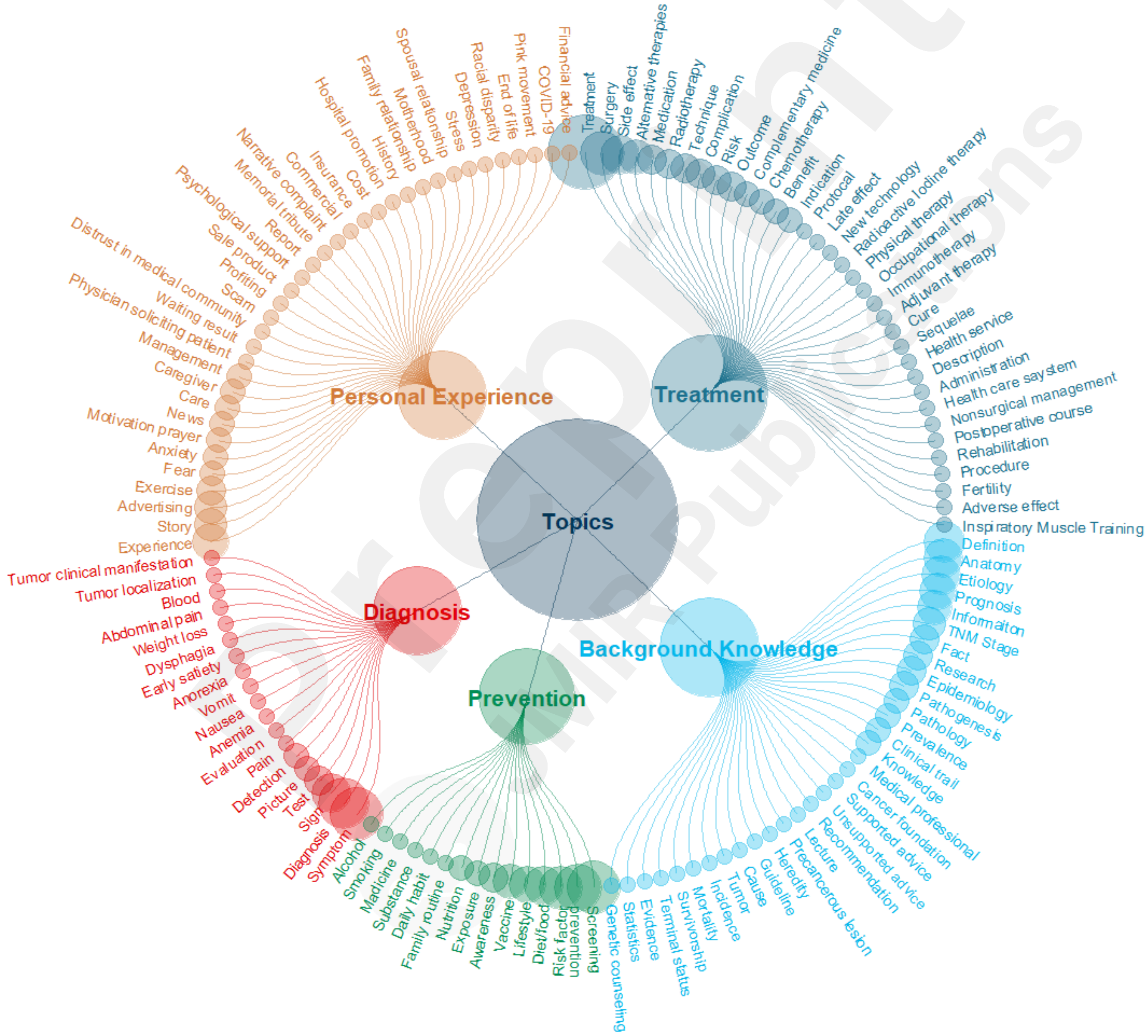
Another common form of misinformation prevalent in the reviewed studies involves overstating the effectiveness of certain foods and supplements in preventing or curing cancer. For example, studies found that 54.9% of misinformation on Pinterest falsely claimed that the Mediterranean diet; supplements, including flaxseed, turmeric, IGF-1, vitamin D, slippery elm, probiotics; specific fruits such as pomegranates; or herbs such as dandelions, minerals, and green tea could prevent or treat cancer, terming them natural remedies, “cancer pills,” and “cures for cancer” (33,44,83,93,94). Studies described cannabis as an alternative cancer treatment on social media like Facebook and Twitter, finding that approximately 43.8% of posts touting it as a cancer cure relied on anecdotal evidence from cancer patients, and more than half use invalid scientific reasoning to support these claims (32,41,42). Approximately 5% of analyzed TikTok videos in a study featured supernatural or heroic powers as potential cancer treatments (100). Other studies describe content touting laetrile and colloidal silver on Twitter despite their potential toxicity and lack of cancer-fighting benefits (41,44), and spiritual healing on Twitter as a means to cure cancer and relieve pain (41). Alternative therapies like acupuncture, chiropractic care, and yoga (41), and escharotic black salve (43) were also mentioned on social media.

Another misinformation category many studies reported was misuse and discrediting of health services. For example, 25% of Facebook posts on acute lymphoblastic leukemia included disapproved treatment protocols and health services (2) and 16.5% of Pinterest pins attacked the accuracy and safety of mammograms, promoted alternatives like ultrasounds or thermography, and spread false information about bioidentical hormones and breast cancer tumors (44). Additionally, a study of generative AI chatbot–produced information on cancer treatment found that 12.5% referenced hallucinated therapies, for example immunotherapy, which was not part of recommended treatment (104), And a study of videos about breast cancer in Arabic found that 42% called for inadequate screening and treatment protocols (86).

The final misinformation category referenced in several studies was the use of outdated information to substantiate claims. This issue was found common in genitourinary cancers on TikTok videos (100). For example, 4.4% of related posts failed to reflect the changes when the American Cancer Society updated its mammogram guidelines (44). Such discrepancies can create confusion and potentially influence audience decision-making (35).

Scope and completeness. Scope refers to the range of topics covered. The figure 3 shows the detected topics that covered in the included studies. The most frequently topic was treatment (50 in total) including details on protocols, medication, surgery, technique, benefits, side effects, health services, and alternative therapies. Background knowledge was the focus of 36 studies and included cancer definitions, pathology, etiology, anatomy, epidemiology, and prognosis. Prevention was the third most common topic in individual research, and it was covered in 35 studies. Prevention broadly refers to methods and actions to reduce cancer risk, such as screening, lifestyle changes, dietary modifications, vaccination, risk factors, and raising awareness. Diagnosis, which was addressed in the focus of 30 studies, refers to identifying cancer through symptoms, tests, staging, and clinical manifestations. Personal experiences and others were the focus of 25 studies, including patient stories, psychological support, relationships, news and emotional aspects such as fear, anxiety, and depression.

Figure 3. Overview of Cancer-related Topics on Social Media Platforms



The completeness assesses how thoroughly health-related content is addressed on social media. Nine studies assessed the completeness of content based on itemizing predefined criteria set within each individual study. One YouTube study used the Sahin critical appraisal tool, which includes 12 questions covering primary, secondary, and tertiary prevention levels for pancreatic cancer (64). Another study employed Hexagonal Radar Charts to illustrate content balance and found TikTok videos about genitourinary cancer contents tended to cover symptoms and examinations well, but not to cover definitions of terms or outcomes well (100). Some studies suggested that information about adverse outcomes should also be included in social media posts for completeness. For example, a study of ChatGPT applied an informed consent measurement (110) to assess responses to queries about urological cancer found that it often omits details on available treatments, risks, complications, and quality-of-life impacts, as well as what might happen if a patient chose not to pursue treatment (103). Another study noted that YouTube videos on surgical treatments for spine tumors provided more information on benefits than on complications or post-treatment sequelae, potentially biasing patients' perceptions (52).

A study of completeness based on creators found that academic-based channels provide more complete information in their videos about colorectal cancer screening than non-profit, for-profit, public spotlight, or health program publishers' channels (54). Completeness also varied by language; a study of videos about gastric cancer posted on TikTok found that Chinese-language videos by educational and health professionals were more comprehensive than their English and Japanese counterparts, but videos provided by individual English-language videos were more complete than Chinese or Japanese videos (101).

Actionability and usefulness. Actionability measures how well information enables individuals to take action based on the information provided; usefulness indicates the extent to which the information benefits personal decision-making processes. The second part of the PEMAT assessment toolkit, PEMAT-Actionability (PEMAT-A), includes four strategies to enhance the actionability of materials, with higher scores indicating greater compliance with more strategies and increased actionability (109). This tool was used in 16 studies included in our sample, 11 of which reported that the content analyzed had poor actionability, with scores below 50%. Common reasons for low scores included missing interpretations of figures and failure to break down actions into clear, manageable steps (59,78). There was some variation by type of cancer. Studies analyzing content about urological and breast cancer on YouTube (66,94) and content about prostate cancer on TikTok (99) found none of the videos were actionable. However, study analyzing testicular cancer YouTube videos yielded an actionability score of 100% (81). Further, studies analyzing prostate cancer videos on YouTube reported 75% actionability (62), in contrast to TikTok videos on the subject, which evidenced no actionability (99).

Fourteen studies assessed the usefulness of information, with four reporting that more than 80% of videos on hepatocellular carcinoma (65) and Merkel cell carcinoma (88), as well as prostate cancer videos in Arabic (71) and gastric cancer videos in Chinese (101) were useful. In contrast, an assessment of TikTok videos about gastric cancer found that only 20.51% of English-language videos and 17.46% of Japanese-language videos were useful (101). Similarly, around 20% of English and Japanese videos on skin, larynx, and gastric cancers were rated as useful (78,91,101). Studies also found variation by type of poster; among YouTube videos on rectal cancer surgery and colorectal cancer screening, approximately 15% of videos by non-profit posters but only 5.39% of videos by for-profit videos posters were deemed useful (53,54).

Harmfulness. Studies evaluating social media content for harmfulness typically considered the following constructs: (1) harmful actions, (2) harmful inaction, (3) harmful interactions, and (4) economic harm. Five studies in our sample presented an "informative harm" assessment by measuring the ratio of harmful messages to positive messages in their respective datasets. The most common harmful factor identified was inaction. For example, information likely to lead to harmful inaction accounted for 73% of harmful information in a study of Japanese tweets (37). Similarly, a study of articles that are widely shared on social media found that a plurality, 31%, of harmful messages urged rejecting conventional cancer treatments in favor of alternatives with no evidence in their favor (32).

In that same study information likely to produce economic harm, such as out-of-pocket costs for unproven treatments or travel, and information likely to lead to harmful actions, such as suggesting potentially toxic tests or treatments, accounted for 27.7% and 17% of harmful content respectively (32). In a study on YouTube videos about basal cell carcinoma, laypersons had posted all harmful messages (59).

Commercial bias. Eight studies included in our sample use commercial bias as a quality criteria by measuring the proportion of content containing material that originated from commercial, for-profit, or agenda-driven posters. On Pinterest, prostate cancer posts showed the highest proportion of pins with commercial bias (14%), followed by bladder (7%) and kidney (1%) cancer (45). Studies of content on video-based platforms reported commercial bias affected 10% to 27.33% (62,76,79,99). Two studies found commercial bias in 13.2% and 17% of popular YouTube videos about bladder cancer (72,73).

Pooled quality results

Table 2. Pooled quality evaluation results using Meta-analysis

Criteria	Indicator	Study Count	Sample Size	Pooled Quality % (95%CI)	p-value	I^2
Overall quality	DISCERN&	44	3701	43.58 (37.80, 49.35)	<0.001	93.22%
Overall quality	GQS*	26	1440	49.91 (43.31, 56.50)	<0.001	90.14%
Technical quality	JAMA-BC	12	746	46.13 (38.87, 53.39)	<0.001	75.29%
Technical quality	HONcode	3	155	49.68 (19.68, 79.68)	<0.001	94.35%
Understandability	PEMAT-U#	16	1453	66.92 (59.86, 73.99)	<0.001	88.69%
Accuracy	Misinformation*	44	345169	27.15 (21.36, 33.35)	<0.001	99.77%
Completeness	Completeness**	8	1036	34.22 (27.96, 40.48)	<0.001	77.08%
Actionability	PEMAT-A*,***	16	1116	37.24 (18.08, 58.68)	<0.001	98.53%
Actionability	Usefulness	13	1427	48.86 (26.24, 71.48)	<0.001	99.38%
Harmfulness	Harmfulness	5	395	21.15 (8.96, 36.50)	<0.001	88.73%
Commercial bias	Commercial bias	11	4432	11.50 (4.71, 20.60)	<0.001	97.22%

Note. * contained papers with indicators reporting 0 or 100%; ** three papers were removed from the meta-analysis because they did not provide the exact score for the indicator; *** one paper was removed from the meta-analysis because it provided a combined score for PEMAT-U and PEMAT-A. The quality of information in different studies in a proportional rating system is shown in Appendix Table B.

Table 2 shows the pooled estimated scores for indicators for different quality criteria measurements. The pooled estimates reported moderate overall quality (DISCERN 43.58%, 95% CI [37.80, 49.35]; GQS 49.91, 95% CI [43.31, 56.50]), and moderate technical quality (JAMA 46.13%, 95% CI [38.87, 53.39]; HONcode 49.68, 95% CI [19.68, 79.68]). About 67% of the information was understandable to viewers (PEMAT-U 66.92, 95% CI [59.86, 73.99]). About 27% of posts contained misinformation (27.15, 95% CI [21.36, 33.35]), 34% of essential topics defined by individual study were covered (completeness 34.22, 95% CI [27.96, 40.48]), less than half of the posts provided actionable message and were considered useful (PEMAT-A 37.24, 95% CI [18.08, 58.68]; usefulness 48.86, 95% CI [26.24, 71.48]). Furthermore, 21% of posts contained harmful messages (harmfulness 21.15, 95% CI [8.96, 36.50], and 11.5% of posts showed evidence of commercial bias (commercial bias 11.50, 95% CI [4.71, 20.60]). The forest plots for each indicator are in Appendix Figures A.1-A.11.

RQ3. What factors were associated with outcomes of cancer-related social media information quality studies, and do these factors vary across platforms, assessment tools, and cancer types?

Factors Impacting Quality Conclusion

Table 3 The association between characteristics of the study and quality conclusion.

Characteristics of Study	Odds Ratio	p-value	95% CI
Social media type (text-based media as ref)			
Video-based	0.02	<0.001	(0.01, 0.12)
Generative AI based	0.70	0.722	(0.10, 5.01)
Cancer type*(common cancer as ref)			
Rare cancer	0.32	0.002	(0.16, 0.65)
Combined cancer	0.04	<0.001	(0.01, 0.14)
Search Process			
Date/period mentioned	1.75	0.517	(0.32, 9.47)
Search tools mentioned	2.01	0.356	(0.46, 8.89)
More than one search tool used	0.30	0.008	(0.13, 0.73)
Search terms mentioned	0.13	0.029	(0.02, 0.81)
Initial hits reported	0.14	<0.001	(0.07, 0.28)
Assessed language other than English	0.35	0.009	(0.16, 0.76)
Sites on more than one social media platform	0.06	<0.001	(0.02, 0.27)
Cancer type more than one	1.41	0.474	(0.55, 3.63)
Rating Process			
Raters blinded for the source	11.16	0.106	(0.60, 207.53)
Number of raters reported	0.02	<0.001	(0.00, 0.14)
More than one rater	5.21	0.093	(0.76, 35.75)
Rater working independently	0.88	0.687	(0.46, 1.67)
Interrater reliability figures for evaluation determined	1.22	0.563	(0.62, 2.43)
Process graph contained	3.06	<0.001	(1.61, 5.79)
Medical professional background for rater (no professional as ref)			
Author as raters	0.43	0.135	(0.14, 1.30)
Professional	0.52	0.256	(0.17, 1.60)
A priori criteria defined for quality (no criteria mentioned as ref)			
Based on literature	2.93	0.041	(1.04, 8.20)
Specific criteria mentioned	0.94	0.878	(0.41, 2.14)
Report Process			
Engagement: view	1.64	0.491	(0.40, 6.70)
Engagement: like/dislike	3.35	0.022	(1.20, 9.38)
Engagement: forward/share	6.17	0.008	(1.61, 23.65)
Engagement: comment	1.97	0.087	(0.91, 4.29)
Poster characteristics reported (sex/age/ethnic/country)	1.51	0.358	(0.63, 3.64)
Poster identity reported (personal/institute/medical professional)	1.81	0.176	(0.77, 4.28)
Contents/topics mentioned	3.77	0.007	(1.43, 9.94)

Note. *Using GLOBOCAN 2020 statistics, we coded the top 10 most common cancers as “common cancer,” and others as “rare cancer” (111).

The ordinal logistic regression analysis identified several factors associated with reporting high-quality conclusions. Video-based media (OR = 0.02), studies on rare cancers (OR = 0.23), and studies on combined cancer types (OR = 0.04) were less likely to yield high-quality conclusions than text-based media and studies on common cancers. Similarly, using multiple search tools (OR = 0.30), mentioning search terms (OR = 0.13), reporting initial hits (OR = 0.14), sourcing content in languages other than English (OR = 0.35), and analyzing multiple social media platforms (OR = 0.06) were negatively associated with quality conclusions. In terms of decisions about what to include in the articles, disclosing the number of raters (OR = 0.02) negatively impacted quality conclusions, while including process graphs (OR = 3.06) and using literature-based assessments (OR = 2.93) were positively associated with the quality of conclusions. Reporting engagement metrics such as likes/dislikes (OR = 3.35), forwards/shares (OR = 6.17), and content/topics mentioned (OR = 3.77) were associated with high-quality conclusions.

DISCUSSION

Our systematic review and meta-analysis offers robust insight into social-media driven information quality studies pertaining to cancer. Our findings showcase a complex and diverse body of literature varying across multiple domains, including, time, platform, quality assessment types, and findings therein. Several important patterns merited further discussion.

Evidence of temporal changes highlights the evolution of social media and cancer content over time.

The studies evidenced clear changes in utilized social media platforms, reflecting availability and popularity of the platform at the time. For example, early in the study period we principally identified studies analyzing YouTube videos. However, in addition to YouTube, and prior to 2021, we also observed greater use of text-based media, including Twitter, Reddit, Pinterest, Facebook and others. Between 2021–2023, a majority of studies shifted solely on video-based platforms, to the exclusion of text-based platforms. The shift in emphasis from text and image to video-based social media largely aligns with US patterns in that a majority of the user-generated social media content created daily since 2021 consists of videos (112,113). It also coincides with changes to data access policies on platforms such as Twitter, now X, which closed its API in 2022 limiting data collection efforts (114). Another important point is that the second and third most popular social media platforms in the United States (Facebook and Instagram, respectively) (112) represented a small proportion of the total number of studies reviewed (6 studies examined cancer information on Facebook and 2 studies on Instagram). This represents a critical gap that warrants further investigation. The other temporal pattern is that the first cancer-related information quality assessment of generative AI content occurred in 2023 (106). In coming years, more studies may consider generative AI content. Future research should compare the quality of information of multiple generative AI platforms and models.

Given the proliferation of video-based social media over time, it is critical to contextualize information quality patterns by cancer type (i.e., text-based and video-based social media). Our findings generally highlight that video-based cancer content is more engaged than text-based content but at notable risk for low quality information. Indeed, our meta-analysis of pooled findings show significantly higher engagement (likes, comments, and shares) for video-based platforms (YouTube and TikTok), which may be due to their general accessibility, visual appeal, or targeted algorithmic marketing. This finding might suggest that cancer-related content on video-based platforms may have greater reach and visibility compared with text-based content, and empirical evidence supports this (51,115). The negative association between video-based platforms and overall information quality (OR = 0.02, p<.001) underscores challenges in content moderation and infoveillance, where prior research suggests that even passive exposure to scientifically unsupported content can undermine sound health decisions.

Reflecting shifts in research priorities and interests, there was change over time in cancer types included in studies.

Between 2014 and 2018, attention to certain cancer types, primarily breast, prostate, skin, and colorectal cancers, began to be more prevalent over this period. These cancers are all highly prevalent in the US and disparities in healthcare seeking, treatment, and outcomes affect all of them (116), which may explain their broad emphasis during this time period.

Studies of these highly prevalent cancers remained prevalent through data collection, but in 2018–2023 we focus on rare, less studied cancers, including gastric, thyroid, and spinal cancers, began to emerge and studies on information about cancer generally or focused on several cancer types became less common.

Cancer types predicted information quality; and recommendations for improving poor information quality on social media are limited.

Studies involving highly prevalent cancers generally scored higher on quality and actionability than other studies involving rarer cancers. For example, one study found that medical professionals' breast cancer YouTube videos scored higher than 50% on DISCERN and another found that prostate cancer TikTok videos that originated from professional sources had observed GQS scores ranging 3.5-4.5 and PEMAT scores for actionability and understandability exceeding 65%. In contrast, information on rarer cancers, including gastric and thyroid, generally had lower information quality scores across metrics, with several studies observing that content in these studies often did not originate from medical professionals, touted unproven medical treatments, largely was not transparent or comprehensive, and relied on anecdotal evidence.

Prior research attributes lower information quality on social media to several factors, including algorithmic amplification of engaged content regardless of the source (117,118), brevity of text and short-form videos limiting content depth (119), and increased content from non-expert creators with no moderation (120). The literature highlights various recommendations for addressing these issues, including improved architecture for detecting and eliminating incorrect content (121), increased mHealth and digital health social media campaigns to promote health literacy (122), and encouraging more medical entities to have a social media presence (122). The success of these strategies is mixed, suggesting further work is needed to address the dichotomous issue of the reach and visibility of video-based cancer information relative to information quality risk. However, with evident proliferation of health content on video-based social media, timely attention to these issues remains a public health priority.

Future information quality assessments using social media data should address a range of questions.

Findings from this review offer three tangible recommendations for future research. First, while it is clear social media information quality assessments is a growing and popular field, there is limited consensus on which information quality assessment is needed relative to the task. Based on our findings, we strongly encourage future researchers conducting such assessments to consider robust and validated tools such as DISCERN, PEMAT U/A, GQS, and the JAMA criteria. Although application of these tools can be time intensive, each provides an evaluation of social media content in several domains simultaneously, ensuring thorough analysis of the data. Further, consistently employing these tools for information quality assessments will allow for robust and streamlined meta-analyses, which would allow for even greater insights than cross-sectional designs alone. However, we also acknowledge that even when these tools are consistently applied, variations in study objectives, social media platforms, and evolving contents may still pose challenges in achieving standardized assessments across different research contexts.

Second, when conducting mHealth or digital health interventions, we advise researchers launching them through video-based apps, such as YouTube and TikTok. Comparing studies consistently revealed greater engagement with data from these sources than text-based sources, regardless of cancer type or account attributes. This directly suggests that the broad access and ease-of-use of these videos may make health-related content more readily accessible to others, regardless of barriers to care. Prior research strongly recommends using innovative strategies such as narrative story telling or personal testimonials to boost engagement. Regardless of the strategies, it is clear from our findings that the shift away from text-based media is not a trend but part of the shifting social media landscape. At the same time, researchers should also remain abreast of new social media trends and adapt accordingly.

Third, video-based mHealth or digital health interventions should be produced by or in partnership with specialists, clinicians, and hospitals. Content posted by professional entities that was analyzed consistently had better information quality across inventories, cancers, and platforms. Although in some cases content by medical professionals was not as well-engaged and content from other accounts, these cases may reflect content posted on text-based platforms where engagement was consistently lower. Specialists with direct expertise in the topic as video protagonists may help extend the credibility of the content and transcend trust barriers for certain topics including vaccinations and routine screenings.

Fourth, our results are only starting to show the emergence of artificial intelligence as a health promotion tool. Professionals in health and medical fields should continue researching generative AI content for information quality.

Limitations

First, while we believe we offered a thorough review of the social media cancer information literature, we were not able to consider other facets that may lead to varying information quality, such as the professional level of raters, content language, nation of origin, and difference criteria in the searching and rating process. As this review focused only on English-language-based studies, similar reviews focusing on studies in other languages (such as Spanish, Arabic, and Chinese) and social media data (such as LinkedIn, Snapchat, and BeReal) are needed. Second, inconsistent nomenclature of certain information quality and measurement used may be driving high levels of heterogeneity in our meta-analysis. For example, the construct “actionability” was sometimes called “usefulness” or “recommendation” depending on the study. This inconsistent nomenclature made it difficult to categorize study findings, which may have resulted in a marginally biased result. Further, even in cases where studies used the same quality assessment, the diversity of platforms, cancer types, and scope of work may have also contributed to higher levels of heterogeneity. As such, pooled findings should be interpreted as indicative rather than definitive. Third, our study is minimally representative of generative AI as an information source. Given its growing popularity and strong body of literature considering generative AI as a health communication tool, we strongly consider further systematic reviews specifically conducting information quality assessments using multiple generative AI tools.

Conclusion

Cancer information on social media had a significant impact on decision-making; we found that high-quality content contributed to informed cancer-related decision-making. However, the quality of this information remained at a moderate to moderate-low level, particularly in terms of overall quality, transparency, understandability, accuracy, actionability, harmfulness, and commercial bias. Our findings indicated that poster identity, medium (text-based or video-based media), and assessments of highly prevalent cancers were statistically significantly associated to higher information quality. Gaps in information quality, which were evident across all studies considered in our review, remain a critical and timely public health issue.

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