

ORIGINAL ARTICLE

## Cancer Types: Their Social Media Coverage, Incidence and Distortion in French-Speaking Countries of the West\*

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*This article investigates the coverage of different types of cancer on two major social networks sites, Facebook and Instagram. A categorical content analysis is performed on a corpus of 2,446 posts collected via a web listening tool on these two social media. The primary objective is to assess the coverage of different types of cancer on these social media. The second objective is to detect any distortions between this social media coverage and the number of new patients (incidence rate) in French-speaking countries of the West in 2020. Our results highlight the predominance of breast cancer coverage (18.3%), pediatric cancer (9.7%), leukemia (4.2%), but also the over-representation of female cancers accompanied by an under-representation of male cancers and urological cancers. Insofar as the efforts of groups defending certain diseases create a considerable impact on social media— and subsequently on the public agenda — it is of paramount importance to draw the attention of policymakers, scientists, and organizations on these representation gaps (distortions), by further engaging, for instance, communities around less visible cancers.*

**Keywords:** Cancer type, Social media, Coverage, Incidence, Distortion

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## Introduction

Social media provide an increasingly significant communication space when it comes to health. The growing importance of social media for various uses such as sharing and searching for health information has been widely explored (see, e.g., Antheunis et al., 2013; Pershad et al., 2018; Smailhodzik et al., 2016), including in the field of oncology (Attai et al., 2016; Gentile et al., 2018). On social media, contents exchanged about cancers can be of different types: campaigns - prevention but also fundraising - advertising, information, marketing, and come from different actors: individuals (including patients), organizations (hospitals, clinics, leagues/associations), companies as well as health professionals.

Even if the term “cancer” entails common characteristics, it, nevertheless, encompasses a wide range of pathologies. The different types of cancer vary from each other, first of all, because they can affect any part of the body, but also because they all have their own risk factors, development prospects, and treatment options (Ligue Contre le Cancer). One out of two new cancer cases occurring in 2020 concerns the following cancers: the skin, prostate, breast, or lung.

Depending on the type of cancer, some internet users will be more or less active on social media, and certain content will be more or less present on these platforms (Gage-Bouchard et al., 2017; Gage & Panagakis, 2012; Loeb et al., 2017; Loeb et al., 2018; Slater et al., 2008; Sugawara et al., 2012).

Regarding the mainstream media, it was indicated that certain types of cancers were much more represented than others, even though, in reality, they did not constitute the most common types of cancer (Hurley et al., 2014; Jensen et al., 2014; Jensen et al., 2010; Slater et al. 2008). This difference between media coverage and the frequency of occurrence of the different types of cancer in the population tends to form an interreality distortion - which we will denote here as “distortion” - in the way individuals perceive the frequency of appearance of different types of cancer (Jensen et al., 2010). These distortions, can, subsequently, have implications on the behavior of individuals, prevention campaigns, or even on research funding (Jensen et al., 2014). Recent studies on media coverage and its influence on public and political agendas have highlighted the influence of social media on this agenda-

setting (see, e.g., Albalawi & Sixsmith, 2015; McCombs, 2005). Thereby, it seems necessary to consider the factor of social media coverage in order to consolidate the previous work on the press and the mainstream media.

On this basis, this article aims to study the frequency of the different types of cancer mentioned on the social network sites Facebook and Instagram, but also to observe whether the coverage of these cancers on these two social media is representative of the number of new patients (incidence) in French-speaking countries of the West.

## **Literature Review**

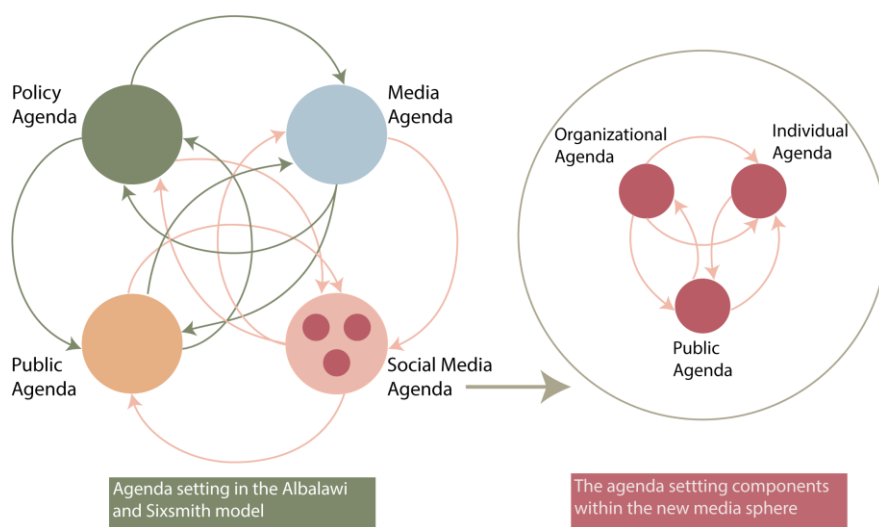
To understand the mutual influence between media coverage of cancers and content on social media on cancers, it is important to look at the mechanism of agenda setting.

### **Agenda setting and the social media agenda**

When the authors McCombs and Shaw introduced the theory of agenda-setting, they explained how the media, through a process of selection and framing of the news, affect the issues in the public mind, but also, how they think about them (McCombs & Shaw, 1972). Rogers and Dearing (1988) consider that agenda-setting is the outcome of the mutual influence of the media agenda, the public agenda, and the political agenda. Each of these agendas constitutes issues and concerns specific to its stakeholders. Within this system, the traditional media are relatively few in number; their programs reach a large audience which significantly influences the public as well as the political agenda (Rogers and Dearing, 1988). Nonetheless, the media landscape is very different in today's digital environment. McCombs has admitted that the internet has created a new configuration within the agenda-setting model (2005, p. 544). At the time of this author's observation, social media did not have yet the importance they have currently acquired. The age of social media has thus decentralized communication

stemming from traditional media (broadcasting) by putting forward the information shared by a network (Zimmerli & Pelletier, 2021).

According to Albalawi & Sixsmith (2015), the social media agenda constitutes a new entity to be taken into account in establishing the agenda-setting. Thereby, the agenda-setting results from a process of influence between the media agenda, the political agenda, the public agenda as well as the social media agenda. Indeed, the interactions occurring between these four spheres can affect each other. For example, several studies have demonstrated the mutual influence between the media agenda and the social media agenda (Bekkers et al., 2011; Sayre et al., 2010). Extending this notion, Albalawi & Sixsmith (2015) argue that the social media agenda also has set its own organization and agenda. The latter is built through almost continuous social interactions between the users of these platforms (Albalawi & Sixsmith, 2015).



*Note:* Based on the scheme of Albalawi and Sixsmith (2015, p.11)

**Figure 1.** Agenda setting model in the age of social media

Regarding health, the individual agenda is set by the personal interests of the patients, their close members, or by ordinary citizens, who share and create health

content on their social media. By diffusing publicly their experiences, questions, or preoccupations on health, individuals, participate, voluntarily or not, in the establishment of the social media agenda, as well as the more general agenda of public debate (Albalawi & Sixsmith, 2015; Feezell, 2017; Han et al., 2019; Sugawara et al., 2012). Literature has already pointed out the importance of patients that rely on social media in order to create communities and support networks with patients affected by the same disease (Broca & Koster, 2011; Gupta & Schapira, 2018). However, the existence of communities of patients is not the same for all medical conditions. While researchers have indicated that even if certain patients - particularly those affected by cancer - have received a significant amount of online support, this is not always the case for any kind of disease or any type of cancer (Gage-Bouchard et al., 2017; Gage & Panagakis, 2012; Loeb et al., 2017; Loeb et al., 2018; Slater et al., 2008; Sugawara et al., 2012). As to the organizational aspect of the agenda, health institutions, associations, and organizations, employ social media to conduct prevention campaigns, fundraising, communicate about an institution or, more broadly to set the public agenda without resorting to traditional media, field journalism (Albalawi & Sixsmith, 2016); this also occurs on the topic of cancer (Cao et al., 2017; Plunkett & Ryan, 2018; Neiger et al., 2013; Nguyen et al., 2013). The public agenda reflects the public interest deriving from the mutual influences of individual and organizational agendas.

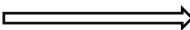
For this reason, the most discussed types of cancers on social media depend on the activity and interests of various users of the network. For instance, if a community of patients engages more actively on a specific type of cancer, the disseminated content will influence the organizational agenda as well as the public agenda of social media. The interactions between these spheres will also impact the three key components of the agenda setting: the media agenda, the public agenda, and the policy agenda (see Figure 1). To put it differently, if certain types of cancer appear much more frequently than others in the social media agenda, then - through the process of mutual influence between the different agendas - this differentiated treatment will be also present in the establishment of the media

agenda, the policy agenda as well as the public agenda. Jensen et al. (2014) have already indicated the influence of the media agenda on the public agenda. In particular, by comparing the perceptions of individuals with the media coverage, they revealed that distortions of perception of the incidences of cancer in relation to real incidences coincided with the media distortions. Individuals' perceptions of the risk and frequency of a type of cancer can be explained by what Fischhoff et al. (1993) refer to as accessibility bias: "a tendency to estimate the frequency of events by the ease with which they are remembered" (p.187). Therefore, the crucial role of social media in the processes of influence between different agendas leads us to enhance the studies on traditional media by focusing this time on social media coverage.

### **Cancer news coverage, distortions and incidence rate**

In an attempt to grasp the visibility of the different types of cancer in the public media space, research studies have mostly been conducted on written press (Freimuth et al., 2006; Greenberg et al. 1979; Jensen et al., 2014; Jensen et al., 2010; Stryker et al., 2007), occasionally on newspapers addressed to specific audiences (Cohen et al., 2008; Stryker et al., 2007), or even on a corpus of multiple traditional media (Slater et al., 2008). A few years later, Hurley et al. (2014) examined the different types of cancer mentioned on the web by centralizing his approach on online information websites (Google News, Yahoo! News, CNN, etc.). Even if the main field of study for all these researches has been conducted in the United States, some studies carried out in China (Cai et al. 2008; Peng & Tang, 2010), in Japan (Miyawaki et al., 2017), or Canada (Hoffman-Goetz & Freidman, 2005) have yielded results with many similarities. Indeed, these authors note that the most publicized cancers concern breast, lung, female and male reproductive systems. To a lesser extent, colon cancers and leukemias also appear in the most publicized cancers (Table 1).

**Table 1.** Ranking of cancer types by authors who studied the distortion in the cancer news coverage

Authors	Sample of Newspapers	Most coverage  Least coverage				
		1	2	3	4	5
Greenberg et al. (1979)	Highest circulation newspapers US	Breast	Lung	Bladder Kidney	Bone Muscle	Blood Leukemia
Freimuth et al. (2006)	Highest circulation newspapers US	Lung	Breast	Female reproductive	-	-
Hoffman-Goetz & Freidman (2005)	Mainstream and ethnic Canada	Breast	Prostate	Leukemia Lymphoma	Colon	Lung
Stryker et al. (2007)	Ethnic US	Breast	Prostate	Colon	Lung	Female reproductive
Cohen et al. (2008)	Mainstream and ethnic US	Breast	Prostate	Colon Rectum	Lung Bronchus	Melanoma
Slater et al. (2008)	Local and national media outlet <sup>a</sup> US	Breast	Colon	Prostate	Lung	Brain
Cai et al. (2009)	Local and national China	Breast	Lung	Liver	Leukemia	Gastric
Jensen et al. (2010)	Highest circulation newspapers US	Breast	Lung	Male reproductive	Colon	Blood Leukemia
Miyawaki et al. (2017)	Highest circulation newspapers Japan	Lung	Leucemia	Breast	Liver	Colon

*Note:* Based on the comparison of content analysis (top five cancers) made by Jensen et al. (2014, p.612). a Includes newspapers, news magazines, and television newscasts.

Despite the studies carried out in North America on English-speaking corpora and those from the Asian continent, there is a substantial lack of current research on the French-speaking side on this subject. Besides, the importance of the uses of social media in relation to health and their impact on the establishment of the

public agenda leads us to extend this research on the different types of cancer initially carried out on the so-called traditional media by applying them to a French-speaking corpus drawn from Facebook and Instagram. The objective is to determine the French-speaking coverage of the types of cancer mentioned on these social media. For this reason, this study asks the following research question:

RQ1: With what frequencies different cancer types are mentioned on Facebook and Instagram?

Among the studies that have analyzed the media coverage of different types of cancer, some of them have delved deeper into the analysis by comparing this media coverage with the incidence rate of these types of cancers; all of them recognize the existence of distortions (Freimuth et al., 2006; Greenberg et al., 1979; Jensen et al., 2010; Miyawaki et al., 2017; Slater et al., 2008). Indeed, the results of these studies point out the phenomena of over- or under-representation - respectively called "media amplification" or "media attenuation" in reference to Combs and Slovic (1979 - of certain types of cancer in media compared to their incidence rate (Jensen et al., 2014). Also, researchers have indicated that media coverage of cancer types reflects more closely incidence rates than death rates (Cohen et al., 2006; Slater et al., 2008)

From 1979 to 2010, studies conducted on US media outlets have strived to indicate the over-representation of breast cancer and leukemia, but also the under-representation of cancers of the male reproductive system as well as lymphomas. This news distortion (Jensen et al., 2014) of media coverage has evolved over time, with certain types of cancer moving from over- to under-represented, such as cancers of the female reproductive system. While coverage of cancer types has been little analyzed online so far, to our knowledge, it has never been studied under the prism of social media. Indeed, studies associating cancer with social media have generally focused on content generated on a particular type of cancer or communities created around specific hashtags, often on Twitter (see, e.g., Feliciano et al., 2020; Himelboim & Han, 2014; Loeb et al., 2018; O'Hanlon, 2019; Sugawara et al., 2012). This study focuses on the

frequency of the different types of cancer in correlation with the most popular social media of today, Facebook and Instagram. Indeed, Facebook is the most widely used social network in the world, with 2,740 million active users. According to a survey of Statista, Instagram is deemed the 4th most popular social network in the world (2021). The results are similar in a European context, as Drahošova & Balco (2017) stated, Facebook, used by 89.20% of Europeans, and Instagram, used by 48.60% of Europeans, are among the three most consumed social media in Europe.

Considering that social media have an impact on the establishment of the public agenda, it seems essential to delve into this theme. This study, therefore aims, to answer the following questions:

RQ2: Are the most mentioned types of cancer on Facebook and Instagram also the most common in the population? If distortions are detected between social media and reality, what types of cancers are involved and how significant this gap with reality is?

## Methodology

### Sample and procedure

Aiming to answer these research questions, using the Mention web listening tool, a corpus of 3,288 French-language Facebook and Instagram posts was collected. Data collection took place over 2 periods of 4 days: from 4 to 7 June 2020 and from 10 to 13 August 2020. Two distinct periods were randomly selected from the available results thus limiting the bias inherent in the choice of a single period. The number of days was chosen so as to obtain a substantial corpus for the analysis. Furthermore, the main days of prevention of various cancers have consciously been avoided. Finally, the collection of publications via the Mention tool on these two social media can be merely achieved on public pages on Facebook, and Business accounts on Instagram: for reasons of protection of the private sphere. This research, therefore, does not include posts created from private accounts.

The web listening tool was configured by a Boolean query developed from a rigorous selection of keywords related to cancer. The wide variety of use of the word "cancer" on social media denotes minimizing as much as possible the "pollution", for example by removing anything within the purview of astrology. A pre-test carried out on the first body of entries (N = 250) helped refine the initial Boolean query.

Thereafter, with the aim of comparing the types of cancers mentioned in French-speaking publications on social media with the actual incidence of different cancers, the corpus was sorted manually; only publications from French-speaking countries in the West, i.e., France, French-speaking Switzerland, Belgium, Luxembourg, and the region of Quebec in Canada, have been retained. They have emerged from our corpus as the main countries publishing French-language content about cancer. Publications from French-speaking countries in Africa have been withdrawn from the corpus because these publications were less numerous compared to those from Western geographic areas, but also because the varying incidence of cancer types was significantly different from that of the countries retained for our analysis. The geographical origin of the publication was sourced from information diffused on the Facebook page or the Instagram account of the transmitter of the message.

Data cleansing was performed on the entire corpus, in order to remove duplicates on the same social media; publications that were no longer present at the time of the analysis, or even cancers that occurred in an animal. In addition, only the content that was directly visible on social media was analyzed. The final corpus is composed of 2,446 publications (Table 2).

**Table 2.** Composition of the corpus of Facebook and Instagram publications (after sorting)

	Period 1	Period 2	Total
Facebook	1101	945	2046
Instagram	204	196	400
Total	1305	1141	2446

*Note:* Period 1 = from 04.06.20 to 7.06.20. Period 2 = from 10.08.20 to 13.08.20.

As this study deals with the discussion of cancer on social media, we chose to select the two platforms most used by our study population and to process them together.

## Variables

Categories have been constructed on the basis of the 36 types of cancer identified via a reference site in the fight against cancer (Ligue Contre le Cancer). From this point, a series of keywords has been identified for each type of cancer. The categories listed were submitted and corrected by an expert in the field, the head of the oncology department of the Geneva University Hospitals (Gage-Bouchard et al., 2018; Tapi Nzali et al., 2017). The entire corpus was then sorted through content analysis in order to identify the types of cancer mentioned in each post.

If a cancer type was mentioned even once, the post was then classified in the corresponding category; even if the entry of this type appeared merely via the logo of the owner's Facebook page/Instagram account, via a hashtag, or even if the entry of a particular type of cancer was evident through an image or a video. Furthermore, if more than one type of cancer was mentioned, then the publication could be classified into more than one category. Whereas, if there was no precise indication of cancer type, but the word "cancer" in general was merely mentioned, the post was classified under the category "General cancer". The 2,446 publications of the corpus generated 2,680 categorizations.

## Intercoder reliability

As the two researchers of this study conducted the post classification, Krippendorff's Alpha reliability test was carried out on a sample of 20% of the total publications (507 entries). This coefficient allows measuring the agreement between two reviewers during a content analysis (Krippendorff, 2011). Hence, an alpha index ( $\alpha$ ) was calculated for each type of cancer in order to test and validate the conducted categorizations. An index equal to 1 signifies a degree of perfect agreement between researchers (Krippendorff, 2011).

## Results

Nearly half of the categorizations (46.8%) concern cancer disease in general, without specifying a specific type of cancer.

### RQ1: Frequency of the types of cancer mentioned

The RQ1 aims to find out how often different types of cancer are mentioned on Facebook and Instagram. Table 3 shows the classification of the different types of cancer identified according to their frequency of occurrence in the studied corpus.

**Table 3.** Ranking of cancer types according to their social media presence (Facebook, Instagram), as well as the Krippendorff's alpha index associated with each type

Rank	Cancer type	N = 2680	Cancer coverage in Social Media in %	$\alpha$
1	Breast cancer	490	18.3	0.96
2	Pediatric cancer	261	9.7	0.90
3	Leukemia	112	4.2	0.97
4	Skin cancer	104	3.9	0.96
5	Brain cancer	75	2.8	0.95
6	Lung cancer	53	2.0	1
7	Colon cancer <sup>a</sup>	48	1.8	1
8	Lymphoma	41	1.5	0.93
9	Prostate cancer	34	1.3	0.95
10	Cervix uteri cancer	33	1.2	1
11	Ovarian cancer	29	1.1	0.86
12	Corpus uteri cancer	19	0.7	N/A
13	Liver cancer	19	0.7	1
14	Pancreatic cancer	14	0.5	1
15	Thyroid cancer	12	0.4	N/A
16	Stomach cancer	11	0.4	N/A
17	Oral cavity cancer	11	0.4	0.80
18	Eye cancer	10	0.4	N/A
19	Esophageal cancer	9	0.3	1
	Other <sup>b</sup>	42	1.6	1
	No site mentioned	1255	46.8	0.92

*Note:* N/A = when the number of occurrences of this type of cancer in the sample was not sufficient to calculate a Krippendorff's alpha.

<sup>a</sup> Colon cancer = it includes cancer of the colon, rectum, and anus. <sup>b</sup>Other = Bone cancer (8), Myeloma (7), Blood cancer (6), Bladder cancer (6), Testis cancer (4), Kidney cancer (3), Penis cancer (3), Soft tissue cancer (2), Bowel cancer (1), Gallbladder cancer (0), Larynx cancer (0), and Mesothelioma (0).

The six most mentioned types of cancer on Facebook and Instagram are breast cancer (18.3%), pediatric cancer (9.7%), leukemia (4.2%), skin cancer (3.9%), brain cancer (2.8%), and lung cancer (2.0%). All other cancer types were categorized in less than 2% of the publications, representing a categorization number equal to or less than 54 out of 2,679. Breast and pediatric cancer, as well as leukemia, represent nearly one-third (32.2%) of all categorizations.

Table 3 shows that the category "Other" includes 12 types of cancer with a very low number of entries (less than 9), indicating that these are very little discussed in the internet public sphere (Papacharissi, 2002).

## **RQ2: Distortion between social media and reality and difference score**

RQ2 aims to detect interreality distortions between social media and reality, but also to quantify them. In order to achieve this, the types of cancers listed according to their frequency of appearance on social media (cancer coverage in social media) were compared to the classification of their incidence (as a reminder, the number of new cases) in 2020, in the countries selected for the study. The incidence, prevalence, and mortality rates stem from the database of the International Agency for Research on Cancer (2021) which allows a targeted comparison of the posts of Facebook and Instagram corpus within the geographical zone under study.

**Table 4.** List of cancer types according to their social media presence, compared to incidence rank, prevalence and mortality in 2020

<b>Cancer type</b>	<b>Cancer coverage in social media (rank)</b>	<b>Incidence rank</b>	<b>Prevalence rank</b>	<b>Mortality rank</b>
Breast cancer	1	3	3	3
Pediatric cancer	2	N/A	N/A	N/A
Leukemia	3	11	11	8
Skin cancer	4	1	1	16
Brain cancer	5	16	15	10
Lung cancer	6	4	5	1
Colon cancer	7	5	4	2
Lymphoma	8	7	7	9
Prostate cancer	9	2	2	5
Cervix uteri cancer	10	21	21	19
Ovarian cancer	11	19	18	14
Corpus uteri cancer	12 <sup>a</sup>	12	10	17
Liver cancer	12 <sup>a</sup>	13	16	6
Pancreatic cancer	14	10	12	4
Thyroid cancer	15	9	8	24
Stomach cancer	16	14	17	11
Oral cavity cancer	16	N/A	N/A	N/A
Eye cancer	18	N/A	N/A	N/A
Esophageal cancer	19	18	20	13
Bone cancer	20	N/A	N/A	N/A
Myeloma	21	15	14	15
Blood cancer	22	N/A	N/A	N/A
Bladder cancer	22	6	6	7
Testis cancer	24	23	22	30

Kidney cancer	25	8	9	12
Penis cancer	25	30	29	29
Soft tissue cancer	27	N/A	N/A	N/A
Bowel cancer	28	N/A	N/A	N/A
Gallbladder cancer	29	28	30	26
Larynx cancer	29	22	23	22
Mesothelioma	29	25	27	20

*Note:* N/A = As the different types of cancer vary from one typology to another, it was not possible to make a comparison for cancers including the N/A statement.

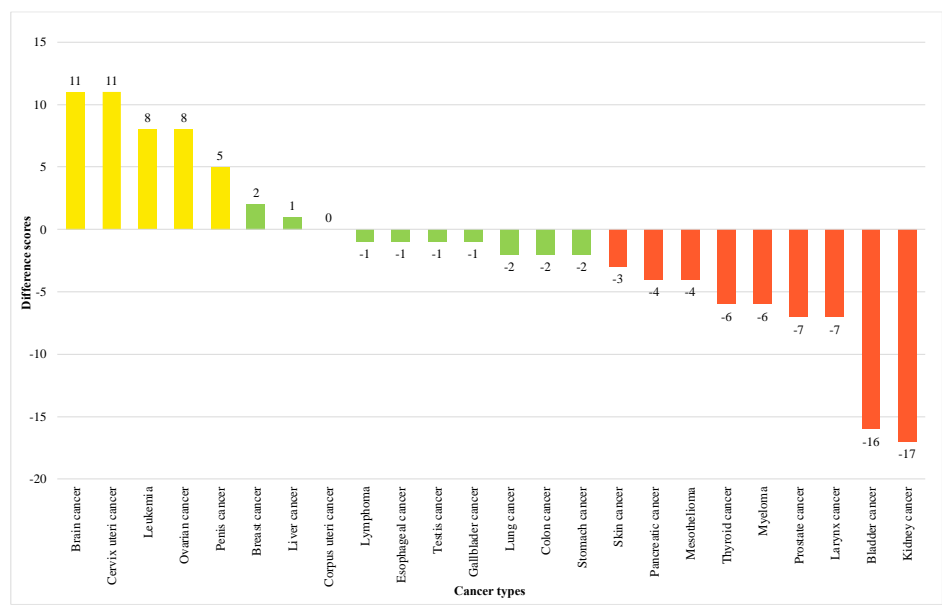
a We applied the same classification number when the number of posts was the same. For example, Corpus Uteri Cancer and Liver Cancer both contain the same number of publications.

The analysis of Table 4 reveals that ten types of cancer benefit from an adequate representation between the frequency with which they are mentioned on social media and their actual incidence in the same year: breast cancer (+2), liver cancer (1), corpus uteri cancer (0), lymphoma (-1), esophageal cancer (-1), testis (-1), gallbladder (-1), lungs (-2), colon (-2) and stomach (-2).

However, it is also possible to observe two types of distortions between reality and social media. The first type, over-representation, concerns brain cancer (+11), cervix uteri (+11), leukemia (+8), ovarian cancer (+8) as well as penis cancer (+5). The second type of distortion, the under-representation is observed in the case of kidney cancer (-17), bladder cancer (-16), larynx cancer (-7), prostate cancer (-7), myeloma (-6), thyroid cancer (-6), mesothelioma (-4), pancreatic cancer (-4) and skin cancer (-3).

These cases of distortions of reality do not display all the same degree of severity. Indeed, Figure 2 shows the greater or lesser importance of the distortion: a difference score was calculated between cancer coverage in social media and their actual incidence (interreality distortion). The cases of over-representation are indicated in yellow (difference score of +3 and more), while in red are portrayed the cases of under-representation (difference score of -3 or less). The intermediate cancers, illustrated in green and placed in the middle of the scale of

values (difference score equal to or between +2 and -2), indicate an absence of distortion.



**Figure 2.** Difference score between cancer coverage in social media and incidence rank

Kidney cancer and bladder cancer present alarming levels of interreality distortion, assuming that under-representation is more dangerous to individuals than over-representation. However, as we have seen previously, over-representation can also be problematic. Brain cancer and cervical cancer are the most affected by this over-exposure on social media. Explanatory paths are proposed below to clarify the existence of these distortions.

## Discussion

### The predominance of breast cancer coverage

Our results indicate that breast cancer is the most-talked-about type of cancer on Facebook and Instagram (18.3% and 1st in the ranking); in the continuity of previous works (see, e.g., Cai et al., 2008; Jensen et al., 2010; Slater et al., 2008) which, even though performed mainly on newspapers, place this cancer at the top of the cancer types mentioned. In this analysis, this cancer has an adequate representation in relation to its incidence rather than an over-representation as it has been identified within the press. It is also noteworthy that breast cancer is the most diagnosed cancer in women. In fact, nearly one in four (24.2%) cases of cancer detected in women worldwide are affected particularly by this type of cancer (International Agency for Research on Cancer, 2021). In addition, numerous studies have highlighted the existence of a large community of patients formed by advocacy or mobilization groups around this cancer (Slater et al., 2008). Still very active today, the strong online engagement of these communities contributes to the visibility of this cancer (Loeb et al., 2017; O'Hanlon, 2019; Seale et al., 2006).

### An over-representation of female cancers to the detriment of male cancers

The strong coverage of breast cancer on social media joins that observed more generally for female cancers. Indeed, our results highlight a high presence of cancers of the female reproductive system (cancer of the cervix, ovary, and uterus) as well as a major over-representation for cancers of the cervix uterus (+11) and ovary (+8). Conversely, prostate cancer is little and even under-represented (-7) on the social media under study. This result coincides with Vagra et al. (2018), who demonstrated an over-representation of female cancers compared to male cancers. It also further underlines a distortion from reality, since over the course of a lifetime, one in two men is at risk of developing cancer, whereas this is the case for one in three women (Frost et al., 2014). This distortion can be explained by two

main factors. First of all, we must bear in mind the greater use of social media by women than by men (Bender et al., 2021; Kimbrough et al., 2013) as well as the over-representation of women in online participation in support groups (Nikoloudakis et al., 2018). As mentioned previously in the case of breast cancer, this distortion can also be explained by the mobilization of associations and institutions in charge of health against female cancers (Slater et al., 2008). This prevalence of attention to female cancers rather than male cancers is long-standing, since historians have shown that from the onset of this disease, it is perceived as mainly affecting women. Despite the current evidence of high incidence rates of cancer among men, female cancers retain a major place on the public health agenda. The evolution of treatments and screening over time for gynecological cancers (Hurley et al., 2014; Moscucci, 2016), but also the latest advances in terms of HPV vaccination help explain the over-representation of cervical cancers observed (Wenjia et al., 2020).

Our results show the need to communicate more about prostate cancer (-7). The communication efforts of advocacy groups and associations around this cancer are recent; this observation is consistent with that of Loeb et al. (2017), who report a considerable delay in the promotion of awareness surrounding this male cancer. After studying the two months of the year devoted to breast cancer and then to prostate cancer on Twitter, these authors noticed a significant difference both in the amount of messages exchanged over these two periods and in the type of transmitters: mainly patients in the first case, and doctors or influencers specializing in the issue, in the second (Loeb et al., 2017). Certain societal factors, such as social stigma, can influence this lack of digital voice among patients with prostate cancer and, more generally, male cancers.

### **High visibility of pediatric cancer**

This study also shed light on the significant place pediatric cancer occupied on social media. It constitutes the second most common type of cancer in our corpus. Additionally, it is important to underline that two of the over-represented cancers

in our corpus, brain cancer (+11) and leukemia (+8), are the two types of cancer that affect mostly children (Ligue Contre le Cancer, 2021). Compared with previous studies usually focused on traditional media, leukemias have always appeared as over-represented cancers; stressing the existence of a strong community around this disease (Jensen et al. 2010; Sugawara et al., 2012). As for the strong presence of pediatric cancer on social media, we can state several explanatory factors. In the corpus analyzed, we noticed that opening a public page on social media allows family or relatives to share their experiences, emotional fatigue, mobilize funds or acquire online support. Gage-Bouchard et al. (2017) also observed a plethora of Facebook pages launched by hospitals or charities offering information and resources related to pediatric cancer. Moreover, glioblastoma - a subtype of brain cancer that particularly affects children - is talked about a lot due to its extremely aggressive nature, often considered the most deadly.

Another explanatory factor, concerning not only childhood cancers, is the creation of a brain tumor social media hashtag (#BTSM), induced by the successful example of the breast cancer social media hashtag (#BCSM), managed to bring currently together a large community (Feliciano et al., 2020). Brain cancer is also heavily mentioned when it comes to radiation emitted by cell phones, and even more so in current debates around 5G (Service de recherche du Parlement européen, 2019). Regarding leukemia, as the treatment period for this disease can be quite long, patients have the time to engage in a discourse about it on social media (Sugawara et al., 2012).

### **The importance of preventing skin cancer**

The fourth most-mentioned cancer (3.9% of categorizations), skin cancer, is heavily present on social media. The corpus of our study takes place over a summer period, which probably contributed to its strong evocation, despite this fact; this cancer presents a reality score of -3, signifying that it is slightly under-represented compared to its real impact. To understand the very high incidence

rate of this type of cancer, it should be stated that it includes not only melanoma-type cancers but also non-melanoma-type cancers. The former are very severe but less frequent, whereas the latter are less dangerous but extremely frequent. Totalling these two forms of cancer up increases their incidence rate: 80% were non-melanoma type of cancers while the remaining 20% concerned melanoma (International Agency for Research on Cancer, 2021). Insofar as the main cause of occurrence of this cancer derives from ultraviolet radiation, strong prevention activities have been implemented especially through social media, a suitable means of transmitting messages to the younger generation. The prevention of skin cancer is also widely exploited for commercial purposes, for example, by cosmetic companies.

### **An under-representation of urological cancers**

Our results reveal a strong under-representation for kidney cancer (-17), bladder cancer (-16), and to a lesser extent for prostate (-7). This result corresponds to that of Loeb et al. (2018) who highlighted the presence of a few tweets on Twitter concerning urological cancer. Provided that the incidence of the latter is lower than for other cancers, there is a significant gap in our analysis between the reality and the online presence of kidney and bladder cancers, also observed in the study of Sugawara et al. (2012). Worth mentioning that some cancers are less "attractive" than others when it comes to communicating with visuals (Slater et al., 2008); this phenomenon is probably further reinforced on social media (Harcup & O'Neill, 2017).

### **Almost half of the time, no cancer site is mentioned**

This analysis also enabled us to notice the importance of addressing cancer disease in general (46.8%) without referring to a specific type of cancer. This result is consistent with findings of Miyawaki et al. (2017) on a Japanese corpus - half of the articles dealt with the disease in general, without focusing on a particular type

of cancer - and that of Cohen et al. (2008) on a corpus of US news journals where almost 30% dealt with cancer in general.

## Limitations

Despite the many contributions of this study, limitations should be stated. Data ownership regulations did not allow us to access the accounts and private pages of Facebook and Instagram users; for this reason, only public Facebook pages and Business Instagram accounts were taken into account, favoring possibly the content of brands and organizations at the expense of private users. Additionally, the two selected periods take place during summer, which has increased publications related to skin cancer, even though the prevention days have been avoided. The results could be slightly enhanced by the COVID-19 pandemic. However, in the corpus, the theme of COVID emerges when it comes to cancer in general (6% of the category “no site mentioned”) in order to evoke the problems of the patients in their diagnosis or treatment of cancer or their illness during a pandemic period. Finally, the classification of cancer sites varies substantially depending on the institution. This categorization draws on the typology of the Swiss cancer league, validated by the Head of the Oncology Department at HUG, which has proven to be particularly suited to our corpus. In fact, as for the publications observed, the types of cancer were more often designated according to their physiological location than by their scientific name. Hence, the choice of this classification was made on that basis. However, the used incidence rates were based on another typology, that of the International Agency for Research on Cancer (IARC); the comparison with our results was not always possible.

## Conclusion

Thanks to the wide interactivity offered by social media (Zimmerli & Pelletier, 2022) and to the tools facilitating its promotion such as hashtags, we have noticed

that certain cancers, such as breast cancers, leukemias or cancers in children generate strong online engagements which translate into the development of important communities. Composed of professionals, but above all of patients and relatives of patients, these social networks (in a non-digital sense) constitute themselves a "network therapy", a "medicine" (Coeira, 2013). Conversely, cancers of the male reproductive system and urological cancers struggle to unite these communities and suffer from poor online representation. Considering the positive impact of these communities, it seems important to deploy means of communication capable of developing these public spaces of digital expression, particularly by liberating the voice of men on this disease.

Insofar as the efforts of disease advocacy groups have a strong impact on social media - which then influences public agenda-setting (Albalawi & Sixsmith, 2015) - but also because there are tangible effects of mobilizations on the funds allocated to research (Best, 2012), it seems essential to draw the attention of policymakers, scientists, and organizations on these interreality distortions. Considering that certain cancers are more likely to be mentioned on social media, it is necessary to raise awareness about the incidence of these different pathologies, rendering the information as precise as possible, for instance by avoiding talking about cancer in general.

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## Supplementary material

### Boolean query

The Boolean query is: cancer OR cancers OR leucémie OR leucemie OR leucemies OR leucémies OR tumeur OR tumeurs OR mélanome OR mélanomes OR melanome OR melanomes OR lymphome OR lymphomes OR myélome OR myélomes OR myelome OR myelomes OR "maladie de hodgkin" OR "maladies de hodgkin" OR mésothéliome OR mésothéliomes OR mésotheliome OR mésotheliomes OR mesotheliome OR mesotheliomes OR mesothéliomes OR mesothéliome OR carcinome OR carcinomes OR sarcome OR sarcomes OR glioblastome OR glioblastomes OR gliome OR gliomes OR méningiome OR meningiome OR méningiomes OR meningiomes OR thymome OR thymomes OR adénocarcinome OR adenocarcinome OR adenocarcinomes OR adénocarcinomes OR médulloblastome OR medulloblastome OR médulloblastomes OR medulloblastomes OR épéndymome OR ependymome OR épéndymomes OR ependymomes OR craniopharyngiome OR craniopharyngiomes OR neuroblastome OR neuroblastomes OR rhabdomyosarcome OR rhabdomyosarcomes.

### Content analysis guide on cancer types (in french)

Bladder cancer - *Cancer de la vessie : vessie*

Blood cancer - *Cancer du sang : sang*

Bone cancer - *Cancer des os : os, osseux, ostéosarcome*

Bowel cancer - *Cancer de l'intestin : intestin, intestin grêle, carcinoïde*

Brain cancer - *Cancer du cerveau : cerveau, cérébral, glioblastome, gliome, méningiome*

Breast cancer - *Cancer du sein : sein, mammaire*

Cancer of the anus - *Cancer de l'anus : anus, anal, anale*

Cervix uteri cancer - *Cancer du col de l'utérus : col, cervical*

Colon cancer - *Cancer du côlon : côlon, gros intestin, colorectal, rectum*

Corpus uteri cancer - *Cancer de l'utérus : utérus, utérin, endomètre*

Esophageal cancer - *Cancer de l'oesophage : oesophage, oesophagien*

Gallbladder cancer - *Cancer de la vésicule : vésicule, voie biliaire*

Kidney cancer - *Cancer du rein : rein, rénal, rénaux*

Larynx cancer - *Cancer du larynx : larynx*

Leukemia - *Leucémie : leucémie*

Liver cancer - *Cancer du foie : foie, hépatocellulaire, cholangiocarcinome intrahépatique*

Lung cancer - *Cancer du poumon : poumon, bronchique, bronche*

Lymphoma - *Lymphome : lymphome, hodgkin, hodgkinien*

Mesothelioma - *Mésothéliome : mésothéliome, plèvre, pleural*

Myeloma - *Myélome : myélome, plasmocyte, plasmocytome, Kahler*

Oral cavity cancer - *Cancer de la cavité buccale : bouche, cavité buccale, buccal*

Ovarian cancer - *Cancer de l'ovaire : ovaire, ovarienne*

Pancreatic cancer - *Cancer du pancréas : pancréas, pancréatique*

Pediatric cancer - *Cancer chez l'enfant : enfant, infantile, pédiatrique, médulloblastome, épendymome, craniopharyngiome, neuroblastome, rhabdomyosarcome*

Penis cancer - *Cancer du pénis : pénis*

Prostate cancer - *Cancer de la prostate : prostate, prostatique*

Skin cancer - *Cancer de la peau : peau, mélanome, basocellulaire, spinocellulaire, cutané, carcinome*

Soft tissue cancer - *Cancer des tissus mous : tissus mous*

Stomach cancer - *Cancer de l'estomac : estomac, gastrique*

Testis cancer - *Cancer du testicule : testicule*

Thyroid cancer - *Cancer de la thyroïde : thyroïde*

## Disclosure statement

The authors declare that there is no conflict of interest.

## Data availability statement

There is a data set associated with this paper (that can be provided by the authors).