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# Images Published by Cancer Patients in Social Media and Their Reception: A Systematic Review

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#### **Abstract**

This paper presents a systematic review of the discourses that emerge from the study of cancer images posted by patients and caregivers on Instagram, Imgur, Pinterest, Twitter and Facebook. It presents the types of images that posters use to visualise cancer and how they are perceived by viewers. Results indicate that three factors affect visibility and engagement: (a) the framing, (b) the purpose, and (c) the emotions portrayed. They also show that viewers prefer images that (a) show the patient improving their condition through treatment, (b) tell a personal story and (c) take on an optimistic tone. This type of image reflects the common idea of the cancer patient as a survivor, which is particularly visible in breast cancer posts. For patients faced with uncertainty, fear or frustration, the standardisation of survivorship images may challenge identity-formation and create a sense of isolation. However, we also find that patients who use photographs to express negative emotions (such as sadness or frustration) are met with emotional support from viewers. Our findings show that, beyond virality and standardised discourses, visual social media and photography can provide a positive venue for the communication of more diverse cancer experiences from patients and caregivers.

#### Highlights

- Social media-cancer is a rich field, but little attention has been given to the specific role of images.
- Current studies are divided between the biomedical and social approaches, making it challenging to establish a conversation.
- Few of the published papers use images to communicate their results, despite studying visual communications.
- Images that show cancer as a journey are met with positive reactions in most social media.
- Images that provide general information about cancer perform best on Twitter and Pinterest.
- Social media favours positive emotions, but negative emotions also find home and support.
- Mixed methods can help predict the (algorithmic) performance of images while also accounting for their individual perception.
- Situating social media images of cancer in three discursive lines may help predict their impact.

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#### Introduction

With World Breast Cancer Awareness month in October and the Movember movement in November, the last quarter of the year sees scores of cancer-related news and posts in social media. Users publish messages and images to support patients, share experiences of treatment, or participate in fund-raising campaigns for cancer research. During these months, thousands of images mention breast cancer, a site that achieves high levels of engagement on Twitter, Instagram and Facebook (Vraga et al., 2018), as well as on Imgur (Hale et al., 2020). Other cancer sites, such as skin cancer, also receive attention (Banerjee et al., 2018).

The study of social media as a space for cancer communication has grown in recent years. Post metadata, their features, the level of engagement with them, and the discourses they create have been subject to numerous studies. Systematic reviews in this area have analysed the psychosocial impact of social media (Skrabal Ross et al., 2020), their usefulness for clinical trials (Reuter et al., 2018), or their measurable effects on health outcomes (Chou et al., 2020). Overall, research shows that social media help communicate cancer prevention and screening measures, support patients during treatment, and provide psychosocial and informational support to patients and caregivers (Attai et al., 2015; Chou et al., 2020).

This paper taps into an emerging area in the literature: the use of photographic images in social media to communicate cancer. The systematic review covers three databases (PUBMED, SCOPUS and Web of Science) and 17 years of publications (from 2004 to 2021). Papers are assessed first on six criteria, related to language, access and whether the paper attempts an analysis of images related to cancer in social media. Papers that pass these first criteria are then reviewed in-depth to determine whether they focus on still images, whether they address social media and content

analysis of said images, whether they evaluate cancer discourses as generated by patients, and whether they put forward a clear method for their analysis. The final sample consists of 16 papers that have been found to study photographic and visual representations of cancer on Instagram, Twitter, Facebook, Pinterest and Imgur. All of them make their methods explicit and analyse the discourses that result from the images studied, their captions, and the comments they receive.

A review of the 16 papers reveals that cancer images in social media move along three discursive lines. The first line is drawn between images that present their poster's journey through cancer (episodic framing) and images that discuss cancer information generally (thematic framing). The second line is drawn between images that visualise positive emotions (hope, joy) and those that present negative emotions (fear, uncertainty). Lastly, the third line reviews whether images take on a "me" framing (focusing on the poster's experience of cancer and how they perceive it) and those that take a "you" framing (calling the viewer to action, highlighting the consequences of cancer, or advocating for change in the public health system). These three lines highlight the challenges and opportunities for both health communicators, practitioners, and patients in using photographs to discuss cancer in social media. They also carry implications for prevention and screening efforts.

The review is divided into four general sections. It first presents the problem addressed, previous research done on the topic, and the goals of the paper. The Methodology section outlines the search queries, the search and inclusion criteria, and the process to store and analyse the papers obtained. The Results section presents the findings: number of papers filtered and selected, their characteristics, and how the three discursive lines appear in the sample. This section also discusses the engagement that the different discourses lead to, where available. Lastly, the Discussion reviews the

implications of the results obtained, as well as options for future research.

#### **Problem Statement and Goals**

Since the 1970s, the study of public discourses of cancer has been a fruitful field. Susan Sontag discussed cancer as "the master illness" (Sontag, 1978). Along with the work of feminist writers like Audre Lorde (1980), Sontag's critique of the discourse of restitution gave shape to a new understanding of this group of illnesses. At the time, researchers and activists questioned the usefulness of referring to patients as "fighters", challenged the use of visual tropes such as the pink ribbon, and highlighted the risks of using cancer awareness campaigns for commercial purposes (King, 2008).

Media representations of breast cancer have received great academic attention in the past decades, which has crossed over to other cancer sites. Today, an enhanced understanding of the informational and support needs of cancer patients has enabled advances in psychosocial attention. It has also impacted the way cancer is communicated and increased the uptake of screening and prevention messages.

In the early 2000s, the rise of social media platforms came with new opportunities and challenges for cancer communication. While social media have enhanced patients' agency to discuss their illness, they also appear to favour carefully curated contents (Tifentale & Manovich, 2018), which may force users into adopting aesthetic and cultural patterns that do not always conform with the reality of cancer. Further, while the hashtag-based design of platforms like Instagram makes browsing and categorising posts easier, they have also made some cancer sites (such as breast cancer) and discourses (such as survivorship) more visible than others (Bell, 2014).

Importantly, social media posts discussing health have been found to contain significant volumes of misinformation. Wang et al. (2019) illustrate how posts discussing health often contain fake or inaccurate facts, especially around infectious diseases and cancer prevention. Suárez-Lledo & Álvarez-Gálvez (2021) note that cancer-related topics such as the HPV vaccine are particularly affected, as misinformation is liked and shared more than accurate medical information. Extant research also suggest that social media amplifies the search for unproven, alternative treatment, unsupervised advice, and false promises on prevention (Delgado-López & Corrales-García, 2018; Wilner & Holton, 2018). Wang et al.

explain that viewers need certainty and reassurance, which misinformation sometimes provides.

Despite their limitations, social media have also been shown to play a positive role in cancer survivorship, prevention, and screening. In 2007, a study of online communities (blogs and forums at the time) found that these platforms help increase social interaction, interpersonal trust, and social support for patients (Beaudoin & Tao, 2007). Since then, numerous studies have approached social media and its role in cancer support.

From the perspective of patients, Instagram, Facebook, or Twitter enhance the relationship with health practitioners (Gentile et al., 2018). They also facilitate the understanding and management of symptoms (Bender et al., 2013), provide clarity and support through the different phases of treatment (Attai et al., 2015; Banerjee et al., 2018), support the building of communities of exchange (Zade et al., 2017), and alleviate the feeling of loneliness during and after treatment (Hale et al., 2020; Skrabal Ross et al., 2020).

From the perspective of practitioners, mobile health technologies and social media can be sued to engage participants in clinical trials (Gentile et al., 2018), to increase participation in cancer screening (Ruco et al., 2021), and to support awareness-raising on preventive measures (Brinker et al., 2017).

Systematic reviews in this area reveal a divide between the biomedical sciences and the social/communication sciences, however. Biomedical research often looks at the impact that the use of social media has on health, from a quantitative approach. Meanwhile, the social and communication sciences lean on qualitative methods to explore the affordances of social media and how they affect the psychosocial needs of patients, as well as the impact of visual elements in prevention campaigns.

Thus, reviews in the biomedical fields often take issue with the lack of hard evidence in the social sciences. An example is the review by McAlpine et al.: while they affirm that social media appear to have a "mildly positive effect" on cancer patients, they also highlight how "the vast majority [of papers studied] report only simple qualitative analysis". This is found to limit their capacity to lead to measurable health outcomes (McAlpine et al., 2015, p. 293). Similar concerns are raised in Koskan et al. (2014) and can be seen in systematic reviews across different cancer sites, be it breast cancer (Falisi et al., 2017), colorectal cancer (Pellino et al., 2017) or prostate cancer (Pyle et al., 2021). Despite the challenges in establishing a clear correlation between health

improvements and social media usage, it has been observed that social media does increase the uptake of preventive measures (Han et al., 2018) and the likelihood of screening (Döbrössy et al., 2020).

On the other side of the spectrum, social scientists highlight how biomedical studies neglect the non-medical aspects of treatment, "leaving survivorship to the wayside" (Cherian et al., 2020, p. 16). Through qualitative approaches, their work addresses the effects of misinformation on patients (Delgado-López & Corrales-García, 2018; Wilner & Holton, 2020), the adoption of social discourses on illness and how they relate to user agency (Stage, 2019a, 2019b), and how social media can increase the participation of underrepresented groups (Pailler et al., 2020; Rivera et al., 2021). In sum, they find that social media "can create a space to share, comment and discuss health information" (Moorhead et al., 2013, p. 9). The finding comes with a warning, however: social media is useful when research goes beyond commonly studied platforms, when it includes the perspectives of underprivileged groups, and when it expands the reach of study to cancer sites that are less present in public communications (Grant & Hundley, 2008; Hale et al., 2020; Macdonald et al., 2018).

Despite the advancements in the study of the cancersocial media nexus, a gap remains in knowledge when it comes to where images fit in that discussion. This paper aims to obtain a picture of the topic, drawing the number of academic papers that have been dedicated to it and their main conclusions to facilitate discussion across fields.

### **Approaching Images in Social Media**

The emergence of patient-produced photographs of cancer around the 1980s provided a new layer of information and meaning-creation for patients, one that commercial and medical representations did not enable (Pardo, 2019). Where the latter presented images of patients that were often stigmatising (íbid.), visual auto-pathographies (Hawkins, 1999) enhanced the self-expression and self-tracking of patients and raised public awareness on the consequences of cancer. The photographic camera has allowed patients to see themselves, negotiate their identity, and understand their emotional responses to the illness (Capewell et al., 2020). It has also served as a tool for activism. While Audre Lorde's Cancer Journals used text to challenge cancer stereotypes, Jo Spence, Matuschka, or Hannah Wilke used their cameras to the same end (Gómez-Arrieta & Silva-Salazar, 2017).

Cancer photographs taken by patients and caregivers reflect the "here and now", an instant in the journey of illness as seen by those who live through it. As Sontag put it, photographs are a "way of dealing with the present" (2008, p.130). For people that live with cancer, dealing with the present may entail showing the effects of chemotherapy, expressing hope for restitution through a thumbs up, showing gratefulness to their caregivers as they embrace them, or showing the physical and emotional toll when they simply do not have the strength to get out of bed. Through the camera, patients "deploy normality", coexist with their illness, reflect on what they may have left behind, and normalise life with illness in the eyes of the viewer (Plage, 2021).

By 2010, the arrival of visual social media (such as Instagram or the now-extinct Vine) added new elements to this function of self-presentation. While platforms launched in the early 2000s like SmugMug, PhotoBucket, or Flickr prioritised storage and artistic expression, these new applications focused on the immediacy of smartphone photography. Instagram's launch in 2010 was a milestone in this regard (Leaver et al., 2020). It enabled people with an iPhone (later, with an Android smartphone too) to capture the world around them and to share it instantaneously with a global audience. Eventually, it would become one of the fastest growing social media (Pew Research Center, 2019), and other networks would incorporate its approach to photography to their design. Today, posts that are accompanied by an image are known to achieve higher levels of engagement in all the major platforms (Miller et al., 2019), and images have become ubiquitous in social media.

Photographs do not exist in isolation in these platforms, however, not even in visual social media. They coexist with audio, video, text, polls, and other interactive elements. Users add text (both to the captions and to the image itself), hashtags, filters and enhancements to guide the perception of their post, deploying the anchorage function that Barthes outlined already in the 1970s (Barthes, 1977, p.40). Further, the grid layout and the infinite feeds of Instagram, Pinterest or 9Gag perform a relay function (Barthes, 1977), engaging the viewer in a continuous visual discourse that tells a story and propagates a message. Applied to cancer, these two functions (anchorage and relay), along with Instagram's algorithms that prioritise the best-performing posts, lead to the creation of social discourses of cancer (Stage, 2019b, p. 272): images that are socially recognised as representative of this group of illnesses.

Admittedly, visual social media cannot be taken as "photographic truth" in cancer communication. For one, Instagram users are selective in what they share, as they seek to conform to aesthetic and cultural expectations (Leaver et al., 2020, p. 44). Typically, this leads to curated photographs. Benefiting from the stillness of photography, users may take tens of different versions of any given image before they finally share their preferred version. Some apps and smartphones can even facilitate that process with algorithms that choose the "best" of the roll. Meanwhile, filters, captions, and text overlays not only anchor the images, but serve to shape their aesthetics and motivate responses (Manovich, 2017).

For researchers, visual social media provide a unique opportunity, as images posted there are accompanied by elements that facilitate their use as data. Likes, comments and shares can be incorporated into content analysis to evaluate the perception of certain elements or discourses. With cancer images in social media, researchers can conduct both quantitative and qualitative analysis (Stage, 2018, p. 16), addressing not only the visual elements but also their accompanying text and the reaction from viewers.

When it comes to their interpretation, Barthes (1977) provides a fitting framework for visual analysis with the distinction between denotation and connotation. Overall, denotation refers to identifying what is in the picture, with little to no interpretation, and with no reference to supporting documents such as captions. Individuals, objects, and environments are part of this level. A denotative analysis indicates there is a person, a building, or an animal in the frame, without identifying them by name.

Connotation goes a step further by interpreting and naming each of those denotative elements and situations, sometimes helped by captions or comments: a person becomes a specific celebrity or a cancer patient; a building becomes a museum, a library, or the city council, for instance.

These two levels of visual study, denotation and connotation, are expanded with Panofsky's (1991) framework for iconology. Panofsky spoke of the primary subject (the elements in the image; equivalent to denotation), the secondary subject (what the elements in the image are meant to represent; equivalent to connotation) and the intrinsic meaning. Some authors refer to this latter level as "ideological"

analysis (Rodríguez & Dimitrova, 2011). It evaluates the social messages of an image and what it can tell us about its context. Engaging in this level of analysis helps understand the context that has led to the production of an image, the ideas that it portrays, and what their producers try to tell us about the world. For instance, through ideological analysis we can identify that a pink ribbon is a symbolic representation of support to cancer patients. Descriptions, captions and comments are common resources to support this task.

Lastly, there are other components of image semiotics, mainly those relating to modality and framing. At this level, framing is understood as the position and composition of elements in the image: assessing the relationship between the subjects pictured and how they are presented to the viewer, whether there are elements in the image that are more salient than others, or whether the photographer uses visual devices to highlight the subject. Issues related to thematic and episodic framing (which are explained in detail in further sections) may also be explored here. Meanwhile, image modality refers to visual devices that regulate the "realness" of an image: the use of black and white, extreme saturation, filters or strong lighting, for instance, are elements that make images appear stylised and thus further from reality (see Kress & van Leeuwen, 2010).

Applying visual analysis should enable a deeper understanding of images in social media. To our purpose, it can reveal patterns in our social imagination of cancer. While previous research has highlighted the scarcity of this type of analysis in visual social media (Highfield & Leaver, 2016), the social media-cancer nexus has seen some progress. Kearney et al. (2019) reviewed the representation of the HPV vaccine on Instagram and how viewers reacted to different images; Ketonen & Malik (2020) implemented a machine-learning method to identify and characterise vaping posts on Instagram; Banerjee<sup>1</sup> et al. look at representations of tanning on Pinterest (2019) and how they affect the perception of skin cancer. For cancer screening and health messaging, images have been shown to increase recall and information uptake (Houts et al., 2006). However, our review has found few papers that engage in a discussion of visual representations of cancer as produced by patients or caregivers. Thus, there is a gap in understanding how people

<sup>&</sup>lt;sup>1</sup> Banerjee's and Hay's work on skin cancer and social media, although it does not fit within the specific scope of this review, is one of the more revealing accounts of how social media can affect patients by imposing normative discourses of survivorship.

who live through cancer imagine the illness and their life with it. To our knowledge, no systematic review has been conducted on this topic before, either.

We believe that a systematic review has the potential to identify key papers and open new venues of research into cancer narratives, strengthening future work. It may discover patterns of image creation and engagement that could explain if (or why) social media favours certain cancer sites and discourses, evaluate the functions of images in social media for cancer patients, or expand the discussion from cancer sites more typically studied (such as breast cancer) to other cancer sites.

### Methodology

This systematic review combines existing approaches for qualitative and quantitative systematic reviews (Pardal-Refoyo & Pardal-Peláez, 2020; Petticrew & Roberts, 2006). From question formulation to report write-up, each step in the process is detailed below.

The Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) statement (Moher et al., 2009; Page et al., 2021) is followed to report on the total number of papers considered for review and the selection process. The PRISMA flowchart can be found in the Results section for a quick picture of the process followed.

# Understanding of "Photographic Images"

"Photographic images" are understood as still images that may or may not include text, drawings, or other visual elements outside of traditional photography. This allows for the inclusion of memes, informational posters, and infographics, all of which are widely used online. This review does not include video or other moving image formats, since these contain narrative elements that are unique to them and outside the scope of this work.

# Understanding of "Social Media"

This review uses Sloan and Quan-Haase's definition of social media:

"web-based services that allow individuals, communities, and organizations to collaborate, connect, interact, and build a community by enabling them to create, co-create, modify, share, and engage with user-generated content that is easily accessible." (Sloan & Quan-Haase, 2016, p. 23)

Mentions to broader online communities (such as forums or blogs) are also considered, to avoid missing papers that consider the visual discourses in patient-generated images of cancer online. Conversely, the broader discussion of cancer photography, outside social media, informs the aim of the paper but is not considered for the results, as the research is interested in the nexus that exists between social media and photography.

#### **Research Questions**

An overall question was formulated:

How do peer-reviewed papers address the use of patient-generated photographic images in social media to discuss cancer?

The overall question would later be expanded to include images posted by caregivers, too, given their central role in cancer care and support.

In addition, several questions are considered to guide the systematic review of results:

- 1. What are the methodological approaches applied?
- 2. What use do patients make of photographic images in social media?
- 3. Which types of engagement do the photographs posted achieve?
- 4. What are the common discourses and consequences that emerge from the papers?

# **Search Strategy**

#### Research dates

To be considered for this review, papers must be published between 1 January 2004 and 11 November 2022. 2004 was selected as the start date since it was the year Facebook was launched. Searches were conducted on 11 November 2022.

### Paper sources

Three databases were searched: SCOPUS, Web of Science and PUBMED. Only papers published in peer-reviewed journals were considered for review. Other sources, such as books, inform the research but fall outside the scope of the review—future work may look to these sources to expand the validity of this work.

#### **Platforms Considered**

Initially, only Facebook, Instagram, and Twitter, as the three largest social media platforms, were considered for research. After a first round of searches, several platforms stood out as potentially relevant and were included in the study: Pinterest, Imgur, 9Gag, Reddit, TikTok and SnapChat.

#### **Search Queries**

Two groups of search queries were defined for each database. Wildcards were used to allow for more results.

- 1. **General searches** that combine social media, visual elements, *and* cancer:
  - a. PUBMED: (("Social media") AND ((Photogra\*)
    OR (imag\*) OR (visual\*)) AND ((cancer)
    OR (tumor))) AND (("2004/01/01"[Date Publication]: "2022/11/11"[Date Publication]))
  - b. SCOPUS: (TITLE-ABS-KEY ("social media")

    AND TITLE-ABS-KEY (cancer OR tumor) AND

    TITLE-ABS-KEY (photogra\* OR imag\* OR

    visual\*)) AND PUBYEAR > 2003
  - c. Web of Science (with manual selection of dates: 01/01/2004 to 11/11/2022): ALL=("social media") AND ALL=(photogra\* OR visual\* OR imag\*) AND ALL=(cancer OR tumor)
- 2. **Platform-specific searches**, substituting the term "social media" for either "Instagram", "Facebook" or "Twitter".
  - a. In a second round, additional searches were conducted for the terms "selfie" and "health communication", as well as for additional platforms (Pinterest, Imgur, Reddit, 9Gag, Tiktok and Snapchat)

To expand the reach of the search queries, papers were added to the sample through a snowball approach by reviewing the reference lists of papers selected for full-text reading. Snowballing has been shown to be an efficient way to achieve relevant results that may escape automated searches (Greenhalgh & Peacock, 2005).

# Exclusion criteria, high level (before full-text reading)

Papers were first considered on an abstract and title level. Titles that suggested a review of social media, photography and cancer advanced to the next round. For those that passed this initial review, six sequential exclusion criteria were defined, where passing one criterion allowed the paper to be considered for the next one:

- Language: only papers in Spanish, English or Portuguese were considered.
- Accessibility: only papers that could be accessed through the library services available to the authors were considered.
- 3. **Social media:** only papers that explicitly discuss social media.
- 4. **Health:** only papers that explicitly address health-related topics.
- 5. Cancer: only papers that explicitly address cancer.
- 6. **Images:** only papers that explicitly discuss images.

All papers that passed these six criteria were downloaded and stored for full-text reading. This included 62 papers in total, deemed to be representative of the nexus social media-cancer-image nexus.

# Exclusion criteria, low level (after full-text reading)

For papers that passed the high-level criteria, an additional round of exclusion was implemented. This is a more detailed round, where papers are excluded if:

1. Images are only partially discussed. Images are not discussed as a core part of the study. Instead, papers commonly utilise a quantitative approach that solely mentions that an image is present in a post. Thus, images are considered in the results, but researchers do not engage with the contents of said images nor their effect.

- Focuses on video, not still, photographic images.
   These are mainly papers that focus on YouTube or TikTok, and typically deal with audio transcripts.
   Moving images include elements of rhythm and montage that merit their own analysis.
- 3. Social media is not the object of the study but used as a tool to connect with patients. This includes clinical trials that are disseminated via social media, or which use photographic applications to simulate changes in the user's body if they do not engage in preventive behaviour. These papers are relevant for cancer prevention and screening, but do not focus on patient- or caregiver-generated discourses of cancer.
- 4. The paper analyses text, not images. The paper uses text analysis as its primary method. While images may be mentioned, they are not analysed individually nor collectively.
- Cancer is not the focus. The paper might mention elements related to cancer or analyse environmental factors such as smoking or tanning, but cancer is not its primary focus, which means a discourse of cancer cannot be extracted.
- 6. Social media discourse as generated by patients is not analysed. These papers typically look at images posted by health practitioners or organisations, analysing their quality, or instead discuss image-analysis methods to diagnose cancer. Sometimes they engage in a review of an organisation's campaign. While relevant, these papers fall outside the scope of our review as they do not address patient-generated visual discourses of cancer. Where papers were found to focus on cancer discourses as generated by caregivers, they were considered for full analysis.
- 7. **Method is unclear.** These are often abstracts without an accompanying paper, conference presentations, or papers that have unclear sources.

Figure 1 shows the papers that were removed from the review according to these criteria, a total of 46 papers.

### **Data Management and Analysis**

References were downloaded from each database into the free and open-source library management software Zotero,

using its version 6.0.0. For those that passed a title review, abstracts were exported to an Excel file, where each paper was reviewed for the six high-level criteria. Papers that passed said criteria were then downloaded in full (in PDF format) into Atlas. Ti Qualitative Data Analysis (version 22), a commercial software that allows for the qualitative analysis of textual and visual documents and helps finding connections between them. The PDF files were read in detail and coded in Atlas. Ti, where they were also reviewed for the seven low-level criteria.

#### **Search Results**

The search queries implemented returned a total of 1247 papers. We removed 528 duplicates, and 24 additional records were added through snowballing, making for a total of 743 records for title and abstract review. The PRISMA flowchart in Figure 2 visualises the different steps.

Most of the papers rejected (435) do not study social media, despite being returned by the queries. Of those that do address social media, many either do not focus on cancer (117) or do not study images (114). We found 20 papers in the sample that do not mention social media in their title or abstract but refer to "blogs" or forums". None of them were found to conduct a visual discourse analysis or image content analysis. It thus appears that, despite social media-cancer being a rich field of study, visual representations of the illness by patients or caregivers remain an area to be explored.

All records identified were either in Spanish, English, or Portuguese, and only two records could not be accessed through the university library services by the authors. The two of them were messages from the editors of a journal and were thus not pursued further.

Finally, 62 papers passed all initial exclusion criteria and were downloaded for full-text reading. Of these, 58 were in English and 4 in Spanish; none were in Portuguese. While the 62 were relevant for the broader approach of this review, only 16 of them passed the low-level exclusion criteria. We find that the criteria established for this review are a rare occurrence in the literature. Where they address cancer and social media, papers tend to treat images as a sidenote, mentioning that an image is present in the post but not performing image content or discourse analysis. In some cases, the papers analyse the texts that accompany an image (be it captions or comments), but do not conduct visual content analysis. We understand that the lack of a deeper

Figure 1. Papers removed after full-text reading and the criteria that motivated their exclusion

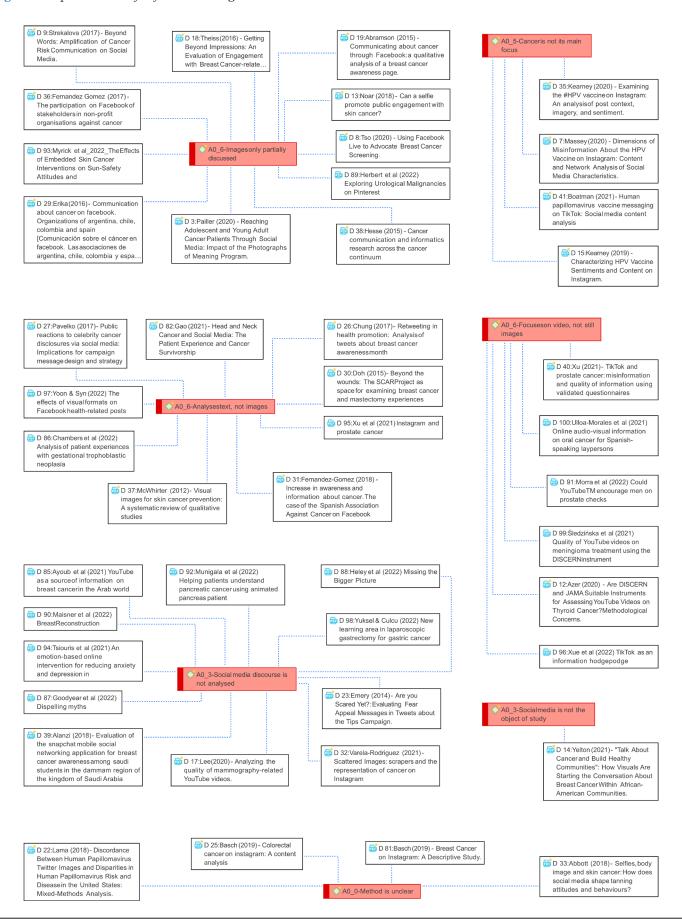
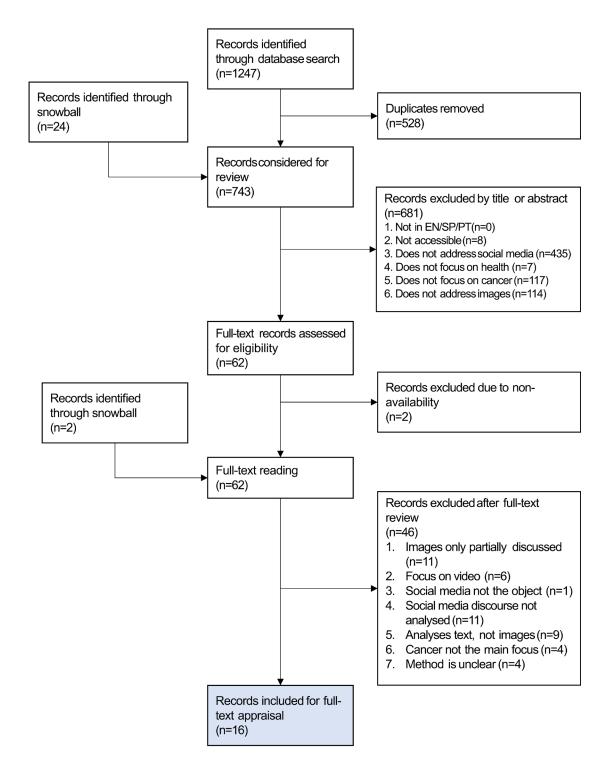


Figure 2. PRISMA Flowchart



engagement with the images might be due to the complexity of image analysis as a technique, something that is explored later in this review.

Therefore, the final sample for review is made of 16 papers, which are found to be representative of the study of visual discourses of cancer in visual social media as generated by patients and caregivers. All of them are evaluated on the method they use and the cancer sites they represent, how they approach visual analysis, and the discourses that emerge from them.

A table is provided in annexes that details the 16 papers, the number of images they review, their methods

to obtain images and to code them, and the cancer sites they focus on.

# Methodologies used and cancer sites represented

The method implemented in each paper is assessed on a qualitative-quantitative continuum, annotated on Atlas.Ti, along with the tools used and their coding process. Similarly, the cancer sites they address are also noted in the table in annexes.

### Visual analysis and image aesthetics

Information is collected on whether the papers attempt to conduct a visual analysis as per Barthes's (1977), Panofsky's (1991), Kress & van Leeuwen's (2010) or Rodriguez & Dimitrova's (2011) frameworks. These four models aim to evaluate the process of meaning-making in photographs through the use of distinct subjects, light sources, and composition, as well as external elements like text. Papers may adapt these frameworks or apply them indirectly.

#### Extracting common discourses

The extraction of common discourses was developed through meta-ethnographic synthesis (Noblit & Hare, 1999; Sandelowski & Barroso, 2007; Thorne et al., 2004), following three distinct phases of coding.

First, each paper was thematically coded (Thomas & Harden, 2008) using Atlas.Ti. This method entails the in-depth reading of each paper and the verbatim coding of their findings and core ideas. The result is a number of quotations from each paper.

Second, each of these quotations was re-read and reinterpreted by both authors, who then summarised and clustered them into general statements. Statements take the shape of a single phrase that seeks to encapsulate the findings expressed in the larger quotations. This allowed the authors to analyse and compare different statements.

Thirdly, statements were compared and clustered into analytical hierarchies, which were compared with one another. Each paper's context was considered for this, with several rounds of review conducted.

Given the diversity in methods and approaches present in the papers, a certain degree of "translation" (Britten et al., 2002) had to be performed to draw codes adequate both for qualitative and quantitative research. Some of the hierarchies, such as "cancer as a journey" were already present in the literature, while others were developed inductively based on our findings. Similar approaches have been followed in previous research to categorise the experiences of cancer patients and relatives participating in psychosocial interventions (Hoeck et al., 2017) and to evaluate the sources of cancer-related fear (Vrinten et al., 2017).

Take the following three quotations as an example:

"[...] posts that explicitly pushed back against conventional notions of health and beauty were not nearly as prominent, let alone popular, as those that focus on a return to a pre-cancer state [...]" (Cherian et al., 2020, p. 12)

"The smooth overlap between the happiness and loving optimism expressed and produced through sharing treatment metrics is based on a general cultural prioritization of restitution narratives [...]" (Stage, 2019a, p. 90)

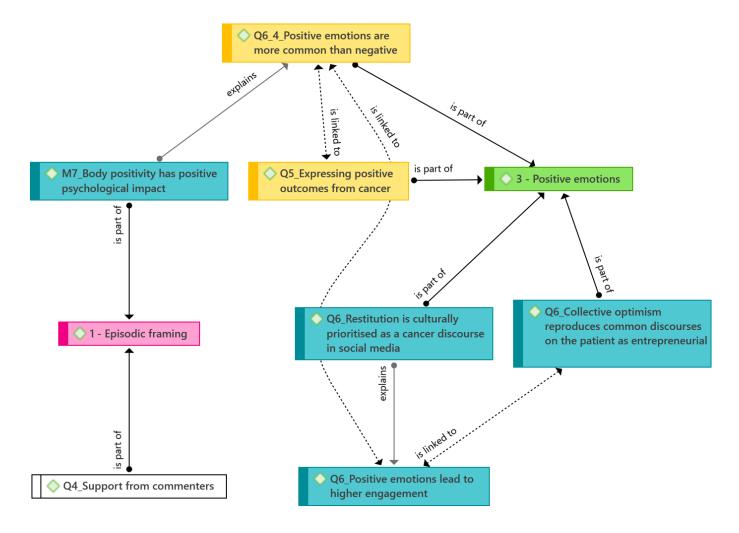
"[...] posters who positively reappraised their situation increased their likelihood of receiving informational support." (Hale et al., 2020, p. 10)

Through context, the three of them could be traced to the narrative of restitution, whereby a cancer patient expresses their hope to regain health. Jointly, the quotations appear to reflect a cultural tendency to prioritise this narrative in social media. In consequence, the following statement was formulated:

"Restitution is culturally prioritised as a cancer discourse in social media."

Deeper reading reveals that, apart from being linked to the use of episodic framing (where cancer is described as a journey), this prioritisation appears linked to at least two facts. First, viewers empathise more easily with positivity. Second, posters appear more approachable when they express optimism. Through clustering, the authors traced this and other statements to the broader hierarchy of positive emotions, as visualised in Figure 3.

This form of coding relies on the interpretation and reflexivity of the researcher. To limit the risk of bias, both reviewers discussed each code to ensure they were interpreted the same way and that the text included was indeed a good match for the code.



**Figure 3.** The coding process to obtain the "Positive Emotions" hierarchy

#### Results

# Representation of Cancer Sites

The representation of cancer sites in the sample echoes some of the trends observed in the literature. Most papers (10) focus on breast cancer. Coincidentally, these include some of the most qualitative studies, which engage deeply with the images and the discourses that they create. Two papers study skin cancer, specifically melanoma, and engage with the representation of the actual cancer in the images. One paper discusses ovarian cancer through the qualitative analysis of a single profile, while the rest address cancer more generally.

#### Methodological Approaches

Most of the papers in the final sample (15) are in English; one is in Spanish. Papers focus on Instagram (6),

Pinterest (4), Facebook (2), Imgur (1), a combination of Facebook, Instagram and Twitter (1), and a combination of Twitter and Instagram (1). Methodologically, two of them engaged participants in a survey and interview or performed keyword-based searches with them; four observed specific profiles over an extended period; and the rest (10) conducted hashtag or keyword-based searches to identify images mentioning different cancer sites or cancer-related phrases.

The papers can be divided in two groups depending on their approach to image coding and discourse analysis. On the one hand, four papers (Gupta, 2022; Stage, 2019a, 2019b; Tetteh, 2021) implement an in-depth, qualitative study of Instagram profiles. This results in a thorough analysis of discursive practices in the images and the reactions that they prompt. Three of these, Gupta's and both of Stage's, show some of the images studied within the paper and engage in an analysis of their content, facilitated by the informed consent

of the research subjects. Images and text are weaved together, creating a conversation between visual and textual exposition.

On the other hand, seven papers (Cho et al., 2018; Henderson et al., 2021; Ma & Yang, 2022; Miller et al., 2019, 2020; Park et al., 2019; Varela-Rodríguez & Vicente-Mariño, 2021b) deploy a methodology that leans on quantitative approaches. They conduct content analysis to measure the presence of certain elements in the images and how they affect engagement metrics. Of these, only Varela-Rodríguez & Vicente-Mariño include images in their papers (either non-identifiable or posted by a public organisation or business), while most do not offer visual support to the text.

Somewhere in between are Cherian et al. (2020), Gürtler et al. (2022), Hale et al. (2020), Rivera et al. (2021), and Wilner & Holton (2020). These five papers implement what could be characterised as a mixed-methods approach: they perform content analysis, measure engagement, and provide a review of discursive practices in the photographs. Rivera et al. and Wilner & Holton use some images to communicate their results.

It should be noted that, despite quantitative approaches being more common in the sample, most if not all the papers incorporate notions of qualitative analysis. They do so by reviewing the presence of narrative resources or models, like the Health Beliefs Model, and by making use of traditionally qualitative methods such as Grounded Theory to code the images manually.

One of the papers, by Varela-Rodríguez & Vicente-Mariño, makes use of automated image-analysis, and it does so only to extract their leading colours using scripts on the open-source image analysis software ImageJ.

# Visual Analysis and Image Aesthetics

All papers conduct visual analysis, adapting elements of different frameworks such as Barthes's image rhetoric (1977), Kress & van Leeuwen's visual grammar (2010), Panofsky's iconological analysis (1991) or Rodríguez & Dimitrova's visual framing (2011). Gürtler et al. (2022) adapt a framework developed by Acal-Díaz (2015). While none of the other papers make their visual analysis method explicit, they all address at least at one of four levels: denotation, connotation, ideology or image semiotics.

When it comes to denotation, all papers discuss the items contained in the images: specific colours, the presence of people or nature, or the picturing of medical equipment, for instance. Six papers provide a full list of the items they analyse, although they do not differentiate between denotative and connotative elements. Cherian et al. (2020) note the presence of individuals and nature while they also distinguish patients, friends and doctors. Miller et al. (2020) indicate the presence of adults and their demographic characteristics (such as their apparent gender or the colour of their skin). Henderson et al. (2021) note the "individual profile race" as well as elements that reveal cancer treatment (chemotherapy equipment, scars, or surgeries). Park et al. (2019) annotate the picturing of male, female, white and non-white individuals. Rivera et al. (2021) identify whether the image discusses food/diet, alcohol, obesity or tobacco, as well as specific cancer sites. Cho et al. (2018) collect the emotions portrayed in the images.

Across the 16 papers, denotative elements are extended into connotation: selfies are discussed as patient representations; groups of people are interpreted as support groups, celebrities are named; pink ribbons are interpreted as awareness ribbons, images of medical equipment are transformed into chemotherapy sessions, and smiles are coded as positive emotions. Papers also use connotative analysis, often supported by image captions and comments, to categorise and cluster posts.

Other semiotic elements are considered through a discussion of framing, mainly, both in terms of episodic-thematic framing and in terms of where each element in the image is located (Henderson et al., 2021; Miller et al., 2020). While not widely addressed, image modality is discussed in two of the papers, which consider the use of colour and black and white to convey emotions (Park et al., 2019; Varela-Rodríguez & Vicente-Mariño, 2021). Filters, lighting or subject distance are not present, however, while composition is discussed in Stage (2019a; 2019b) and Tetteh (2021).

Lastly, ideological analysis is presented through elements of the health beliefs model (Cho et al., 2018; Park et al., 2019), misinformation (Rivera et al., 2021; Wilner & Holton, 2020); different types of social support (Hale et al., 2020); or different social cancer discourses (Cho et al., 2018; Varela-Rodríguez & Vicente-Mariño, 2021). Qualitative papers (Gupta, 2022; Stage, 2019a, 2019b; Tetteh, 2021) put emphasis on this level, engaging in a discursive analysis of what social media images can do for cancer discourse and for patients' identities.

#### **Three Discursive Lines**

The perception and impact of cancer images is found to depend on their framing, on the emotions they portray, and on their purpose. All papers engage in the discussion of at least one of these three factors, which allows us to draw three distinct discursive lines.

First discursive line, framing: episodic vs thematic. This line situates images between the poles of episodic and thematic framing. While episodic images visualise cancer as a journey through (and after) diagnosis and treatment, thematic framing refers to images that contain general information about cancer (Hale et al., 2020; Henderson et al., 2021, p. 2; Miller et al., 2019). These two poles, common in communication studies (Reese et al., 2001) receive various names in the papers studied: for instance, Stage includes "self-measurement" images as episodic (Stage, 2019a), Cherian et al. (2020) and Tetteh (2021) speak of "cancer journeys", while Ma & Yang (2022) do not explicitly refer to episodic framing but speak of narrative and exemplars in both text and images.

#### Second discursive line, emotion: positive vs negative.

This line is drawn to locate images between the poles of positive and negative emotions. Images that visualise positive emotions, such as hope, generate different responses from viewers than those that visualise negative emotions, such as fear (Cherian et al., 2020; Hale et al., 2020; Henderson et al., 2021; Stage, 2019a). Drawing a line between these two poles highlights the importance of emotions in social media photographs of cancer. The line appears more clearly in papers that study episodic images, while it does not appear to be as relevant for more neutral, thematic images.

Third discursive line, purpose: addressing the self or the other. As an extension of the episodic-thematic continuum, this third line situates images between two poles that we have called "me" and "you" messaging. It emerges from papers that pay closer attention to educational images (Hale et al., 2020; Park et al., 2019; Rivera et al., 2021), but is also present in qualitative inquiries into patient identities (Gupta, 2022; Stage 2019a; 2019b). This discursive line distinguishes two types of images: those that aim to visualise the posters' experience of cancer, and those that explicitly intend to change the viewers' attitude towards cancer. "Me" images thus tell the poster's story: through them, patients and caregivers maintain a visual diary, share a moment in treatment, or represent the changes they observed in their

bodies. In other words: "this is *my* cancer", "this is how *I* have changed" or "this is who *I am*". "Me" images engage the viewer in the experience of cancer through the eyes of the poster.

Conversely, "you" images are explicitly directed towards the viewer. They aim to educate viewers about cancer, whether it is through the discussion of healthy diets, by reminding them to get checked by a doctor, or by advocating for more research. Thus, "this is what *you* should do". "You" images seek an attitudinal change with regards to cancer in the viewer and sometimes contain cues to action. While this and the first line are sometimes equivalent, they are distinctly identifiable in the sample, as episodic images can be both "me" and "you" framed.

Table 1 illustrates the angles and poles visible in each paper, which are discussed in detail in the following pages.

# First Discursive Line, Framing: Cancer as a Personal Story or a General Theme

# A personal story (episodic framing): tracking progress on treatment and visualising the journey

In the papers reviewed, some patients use images to keep a "diary" of their cancer experience. Their photographs log their progress, celebrate milestones, or count down to their next chemotherapy session. Others present the evolution of a loved one or a relative through treatment. Authors describe this type of image as one with an episodic framing, where posters "present an issue by offering a specific example or experience (e.g., a firsthand narrative about one's cancer journey) [...]" (Miller et al. 2019, p. 51).

The use of episodic framing is common in social media, where "the lay public decides what to express and share about their cancer experiences" (Cho et al., 2018, p. 8).

On Instagram, this type of image helps patients engage in "self-measurement" (Stage, 2019a). They use visual resources to point to an upcoming treatment session and to track their progress on the road to recovery:

The term 'self-measurement' refers both to measurements initiated by the poster (e.g. by posting a picture of hair measurement) and processes of measurement initiated by others (e.g. the medical system) that are articulated or visualized by the patient on the profile. (Stage, 2019a, p. 78)

**Table 1.** Discursive lines that can be inferred from each paper

	Framing: Cancer as a general theme or as a personal story		Emotion: An affective line between optimism and fear		Purpose: Addressing the self or the other	
	Thematic	Episodic	Negative	Positive	"Me"	"You"
Cherian et al. (2020)	YES	YES	YES	YES	YES	NO
Cho et al. (2018)	NO	YES	YES	YES	YES	YES
Gupta (2022)	NO	YES	YES	YES	YES	NO
Gürtler et al. (2022)	YES	NO	YES	YES	NO	YES
Hale et al. (2020)	YES	YES	YES	YES	NO	YES
Henderson et al. (2021)	YES	YES	YES	NO	YES	YES
Ma & Yang (2022)	YES	YES	YES	YES	NO	YES
Miller et al. (2019)	YES	YES	NO	NO	NO	YES
Miller et al. (2020)	YES	YES	NO	NO	YES	YES
Park et al. (2019)	YES	NO	NO	NO	NO	YES
Rivera et al. (2021)	YES	NO	NO	NO	YES	YES
Stage (2019a)	NO	YES	YES	YES	YES	NO
Stage (2019b)	NO	NO	YES	YES	YES	NO
Tetteh (2021)	NO	YES	YES	YES	NO	NO
Varela-Rodríguez & Vicente-Mariño (2021)	NO	YES	NO	NO	YES	NO
Wilner & Holton (2020)	YES	NO	NO	NO	NO	YES

Stage (2019a, p. 88) illustrates this framing with an image posted by one of his informants. In the image, the patient, with a shaved head, is shown in hospital. With a broad smile, her fingers signal the number nine, an allusion to the ninth session of chemotherapy they are pictured at. The caption, accompanied by a smiling emoji, mentions they are looking forward to finishing treatment, with three more sessions to go.

Patients appear to post this type of image regularly, often including quantifiable elements to indicate progress: hair (and its loss), medical equipment, fingers forming a number that indicates how many chemotherapy sessions are left... Together, they build the "journey" of cancer (Cherian et al., 2020), a collection of "small stories" (Stage, 2019b) that are presented by a single user but given meaning to in

cooperation with commenters, likers, and followers. Episodic framing also appears to serve a therapeutic function:

Describing cancer as a journey [...] has been argued to minimize feelings of guilt or failure that are implicitly felt by those who conceptualized themselves as 'fighters' or 'warriors' if treatment is ineffective. (Cherian et al., 2020, p. 9)

On Facebook, Ma & Yang (2022) describe the use of exemplification, which can be linked to episodic framing. Exemplars in images present relatable, personal stories and specific events that resonate with viewers. They find that this type of image intensifies emotional responses and motivates behavioural intentions (fbid., p. 132).

Typically, and across the platforms studied, reactions to episodic framing take on a positive tone, whereby commenters encourage the poster to "keep going" and show their appreciation. This is particularly so when the post shows signs of progress and a return to "normality" after cancer. Stage calls this an "affective tailwind": a feedback loop whereby images aligned with the survivorship discourse generate positive reinforcement that, in turn, motivates users to continue deploying said discourse (Stage, 2019a, p. 89). The tailwind extends to caregivers, family members, and generally any user who shares the cancer story of their loved ones (Hale et al., 2020).

Episodic images in the shape of journeys are most common and most successful on Instagram (Cherian et al., 2020; Henderson et al., 2021; Tetteh, 2021), where a closer relationship between posters and viewers is common. On this platform, episodic framing also appears to lead to higher levels of engagement (Henderson et al., 2021, p. 5). This type of image is not as common on Twitter or Pinterest, where posters favour images rich in information and with a thematic framing (Cherian et al., 2020; Miller et al., 2019).

Interestingly, the use of episodic images on Imgur contains traits that are not reported for other platforms. Here, photographs that discuss the cancer of another person or of their pets are more common than self-referential images (Hale et al., 2020, p. 6). In fact, when patients post their own stories of cancer on Imgur, they receive less supportive comments than when they post those of a loved one (human or otherwise). Regardless, episodic images appear to retain their affective tailwind against thematic publications (Hale et al., 2020, p. 7).

Hale et al. discuss whether this effect may just reflect viewers' familiarity with the situation pictured. Those who have not experienced cancer themselves may still empathise with the emotional toll that it takes to have someone close to you undergo cancer treatment or being ill. Further, the design of Imgur around pseudonymity is appears to favour anonymous stories of cancer, which may further limit the use episodic framing. Lastly, Imgur is geared around "posts [that] are generally brief and humorous" and the fact that users tend to it for distraction does not favour the use this framing (Hale et al., 2020, p. 10).

# A general theme (thematic framing): communicating facts and calling for action

On the opposite pole of this line are images that do not visualise cancer as an individual's journey, but instead present

information specific to a cancer site, its treatment, its prevention, or its symptoms:

[...] a thematic pin may provide a summary of mammography screening guidelines. (Miller et al. 2019, p. 53)

This thematic framing seems more common on Twitter (Cherian et al., 2020) and on Pinterest (Miller et al., 2019; 2020). Thematic images lean on factual content, make intensive use of text, and provide rich, often external information to viewers. A common example are the guidelines and general recommendations given in breast cancer images (Gürtler et al., 2022; Miller et al., 2019).

The risk of misinformation hovers over thematic images, as they often contain inaccurate information and exaggerated claims (Gürtler et al., 2022, p. 157; Wilner & Holton, 2020, p. 303). This risk is compounded by the fact that thematic images on Instagram, Pinterest and Facebook are often posted by individuals, and not by health organisations (Henderson et al., 2021; Miller et al., 2019; Rivera et al., 2021). For Miller et al. (2019) this is an opportunity for more, better cancer communication and education:

[...] the breast cancer conversation currently present on Pinterest contains more than just superficial content and inspirational images, and provides support for Pinterest as a possible channel for promulgating health education and promotion. (Miller et al., 2019, p. 565)

When it comes to the reception of thematic images, results seem inconclusive. Information-heavy posts achieve higher shares on Pinterest, where they are perceived positively (Miller et al., 2019, 2020; Park et al., 2019). It also seems that the inclusion of text within the image facilitates their uptake on Facebook (Ma & Yang, 2022).

However, thematic framing on Instagram leads to lower engagement (Henderson et al., 2021; Stage, 2019a). In fact, images that visualise cancer or which discuss its negative effects (both of which are described as important elements of the Health Beliefs Model) seem to decrease the number of likes on this platform (Cho et al., 2018).

This difference in perception is seen to be related to the different affordances of these applications. While Instagram is used to build deeper connections with others, Pinterest appears as a resource to obtain and organise information.

On Facebook, users react positively to thematic images posted by sources they trust. That is regardless of whether they consider the source knowledgeable or simply because they feel close to them, culturally or socially (Rivera et al., 2021). Viewer-engagement on Facebook is also facilitated by narrative and exemplar elements, such as personal stories that highlight the risks of cancer-related behaviours like drinking alcohol (Ma & Yang, 2022). Thus, episodic and thematic framings work together.

Meanwhile, on Imgur factual information appears to decrease engagement and support, especially when it is not accompanied by identifiable people in the image (Hale et al., 2020). Again, exemplars and personal messages appear to support the social impact of thematic images.

The thematic frame is highlighted by papers that study prevention and screening campaigns, and by those that review the presence of the Health Beliefs Model, such as Cho et al. (2018) or Miller et al. (2019; 2020). They find that thematic images do not always come accompanied by a cue to action, an important component to motivate preventive behaviour. Instead, fear-invoking images of the consequences of cancer or miracle-diets may be presented, both of which are often ignored by viewers (Miller et al., 2019, p. 56) and limit the impact of this framing.

# Second Discursive Line, Emotion: An Affective Line between Optimism and Fear

# Positive emotions: celebrating milestones and the hope for restitution.

Positive emotions are a staple of the cancer survivorship discourse, where the patient is shown as hopeful, strong, and willing to "fight". In social media, they often take the shape of hope, strength, joy and bravery (Cho et al., 2018; Henderson et al., 2021).

In the sample, optimism is visually contrasted with signs of treatment and cancer symptoms. In a picture shown by Stage (2019b, p. 278), an Instagram user who has undergone a double mastectomy sunbathes with a lush lawn behind her. Her smile and her skin, lit and tanned by the sun, contrast with the visible scars left by the intervention. The patient reflects on this contrast in the caption while she reaffirms her identity and highlights the positive aspects of no longer having breasts. Stage discusses the impact of this optimistic framing, and notes that 7 out of the 10 most-liked posts in

this patient's feed were images showing her "bare-chested, with one or two breasts removed, while smiling" (2019b, p. 278).

Visualising restitution is arguably one of the functions of social media most visible across the sample. Gupta (2022), Stage (2019a, 2019b) and Cherian et al. (2020) describe how cancer patients picture themselves as hopeful and optimistic in their fight towards regaining the normality that cancer has taken away from them. Bodies become the canvas for such a struggle, contrasting the impact of cancer with smiles, grimace and other elements that reveal posttraumatic growth (Cherian et al., 2020) or even renewal through cancer (Stage, 2019a). When posters stay hopeful, some viewers appreciate it with their likes.

Positive images are thus often intertwined with episodic framing and are used to celebrate milestones in treatment and share moments of joy. Patients invite their followers to join in celebration and accompany their hope for a return to life as it was before cancer. This type of framing is reminiscent of the survivorship discourse, which presents patients as brave and positive fighters. This discourse is salient on key dates such as World Breast Cancer Day (Cherian et al., 2020). It is sometimes found to promote a normative discourse on femininity, using the female body to get attention and showing highly stylised images of young and healthy women (Gürtler et al. 2022, p. 157-158).

The results of positive framing vary depending on the platform. Conducting a large-scale study, Cho et al. (2018, p. 9) find that it does not increase the number of likes on Instagram, while Stage's (2019b) study of a patient's feed signals that positivity does seem to increase likes. On Instagram and Twitter, Cherian et al. (2020) find that positive framing performs best when it challenges dominant discourses, showing that cancer patients can also be happy and self-ful-filled despite their illness.

Once again, Imgur is in stark contrast with the other platforms: despite taking on a positive attitude to coexist with cancer or regain normality, patients who share optimism on this platform are met with fewer and less supportive comments than those sharing negative emotions. Hale et al. speculate that this difference may be due to the fact that audiences on Imgur are often unfamiliar with the poster, and thus do not feel attached to their story (Hale et al., 2020):

Agentive problem solving and positive reappraisal indicate a positive or healthy transformation in the poster's mindset (e.g.,"I have decided to take charge and try something new"; "I have now developed a new outlook on life") and thus could have more impact for familiar and intimate audiences, which are more likely to provide empathic support [...]. Hale et al. 2021, p. 10

The key seems to lie not on the specific emotion visualised, but on whether the image presents a positive outlook towards being cured and whether it highlights the positive outcomes and *learnings* from cancer (Cho et al., 2018; Hale et al., 2020). Why? Perhaps because viewers believe that posters who share these perspectives are more open to feedback and support, or because such attitudes are culturally more acceptable and a better fit to the economy of social media:

The ability to transgress the hardships of illness and insist that the present and future is a space for self-cultivation and struggle aligns more effectively with the attention economy of social media, where affective clicking motivates further visibility. (Stage, 2019a, p. 96)

Regardless of their effect on viewers, positive framing is discussed in the papers as therapeutic for posters, as long as they are not forced to fit a discourse that is not aligned with their own experience and they feel like they have the space to share negative emotions, too (Cherian et al., 2020; Tetteh, 2021).

## Negative emotions: expressing fear and uncertainty

The visualisation of cancer inevitably carries negative emotions, either because patients and caregivers need to express their fear, anger and frustration or because these may be used as a device to deter consumers from engaging in cancer-related behaviours. The papers studied consider negative emotions through the depiction of fear, anger and sadness (Cho et al., 2018, p. 4), as well as through the sharing of fear-invoking images. They also discuss images that explicitly mention the possibility of death and the fragility of life.

In some cases, negative emotions result in comments that show compassion and empathic support, strengthening the use of social media for community-building. This is particularly so for Imgur, where negative images seem to be expressed more often than in other platforms (Hale et al., 2020, p. 10).

On Instagram, images with negative emotions achieve fewer likes but unlock conversations. Especially when they have a close relationship with the poster, viewers respond to this type of image with more comments (Cho et al., 2018, p. 9):

While the 'most liked' list primarily consists of posts that present news of progression that can be supported, the 'most commented' list also consists of posts that present news of progress being threatened or stalled. (Stage, 2019b, p. 280)

The role of negative emotions challenges dominant discourses, particularly the discourse of survivorship. Patients turn to crude images to establish visual contrast with commercial images that show them as heroic, beautiful and optimistic (Gupta, 2022; Gürtler, 2022). While they may limit the reach of the image, negative emotions help patients feel accompanied and validated. The experience of celebrities and influencers is particularly impactful here. Reviewing Elly Mayday's images of ovarian cancer, Tetteh reflects on how her images in the hospital, bruised and with multiple syringes connected to her body, brought the restitution narrative to question:

Given such a cultural context, it is particularly imperative that Elly did not hide some of these personal details about her ovarian cancer experience and by that, forced society to make space for and consider these not-too-pleasant experiences as legitimate part of the ovarian cancer experience. (Tetteh, 2021, p. 10)

When faced with this type of image, more graphic and less positive in nature, viewers on Instagram may take one of two routes. Some may look away, or even unfollow the poster, as was the experience of Mayday; others offer what Stage defines as "supportive disalignment", helping the poster re-focus their attention on the positive and giving them hope for the future:

If posts divert from the desired narrative over a period of time, it can be argued that the poster is forced to engage in acts that reposition the overall story he or she hopes to tell in the future. (Stage, 2019b, p. 281)

On Twitter, patients choose to "emphasize the difficulties [...] that are often glossed over" (Cherian, 2020, p. 11) in cancer communications. On Pinterest, where thematic images are more common, negative emotions are expressed through fear images, meant to motivate behavioural change.

Overall, papers argue that enabling the expression of negative emotions is important to ensure a more inclusive representation of cancer online (Cherian et al., 2020, p. 12; Varela-Rodríguez & Vicente-Mariño, 2021b, p. 15), especially for cancer sites that have been subject to gendered and romanticised representations in popular media, such as breast cancer (Gupta, 2022; Gürtler, 2022; Tetteh, 2021). However, the use of these emotions comes at a cost, typically with lower engagement and, consequently, visibility:

[T]he women who post about [triple negative breast cancer] may be aware of the lower engagement with posts that may appear negative, therefore opting to potentially mask their real feelings by posting content that provides a silver lining in a negative post. (Henderson, 2020, p. 6).

# Third Discursive Line, Purpose: Addressing the Self ("Me") or the Other ("You") in Cancer Images

# "Me": defending and reassessing identity and normalising cancer

Across the papers, photography is understood as a tool for self-expression, which patients use not only to communicate with others but to better understand themselves. Cancer is a profoundly life-altering illness, which entails a change in identity for patients (Gupta, 2022, p. 222). Social media images allow them to express themselves, visualise their relationship with cancer, and perform their persona. The "meyou" discursive line evaluates this function by reviewing the purpose and the 'addressee' of the image: is the image meant to express my experience and represent me, as the poster, or is it meant to inspire a change in attitude from you, the viewer? It is often the case that the answer lies somewhere in between both poles.

When it comes to forming and affirming the self ("me"), posting a photograph on social media can help regaining a sense of certainty and challenge the aggression of cancer (Gupta, 2022, p. 218). Stage (2019a) outlines two functions for Instagram pictures in this regard. The first is that of

self-tracking: episodic images, typically in sequence, that help patients keep a visual diary and monitor their own progress.

The second function is simply for patients to see how their body changes, without necessarily establishing a conversation with other images. Stage refers to this as "self-experimentation" (Stage, 2019a, p. 78); Gupta speaks of performed patienthood, a form of self-negotiation that often involves a disconnection between the self and the body. Cancer is an invasive illness that affects patients' perception of themselves: the loss of hair and weight, and they transformation of their capacities is a traumatic process. The photographic camera and the reactions from viewers help patients regain agency and control over their own image (Gupta, 2022, p. 222; Cherian et al, 2020, p. 8). Posting images to social media also lets them reflect on their personal relationships (Tetteh, 2021, p. 11) and create their own definition of cancer (Cho et al., 2018, p. 2).

Across the spectrum, "me" images see patients taking the lead in shaping their own understanding of what being a patient means. While these photographs may have an implicit function to inform others, they are self-expressing at their core. Cho et al. (2018, p. 9) find that this is particularly true for images with positive emotions on Instagram, which help modify the posters' beliefs and keep them in high spirits. Similar findings are made by Cherian et al.:

[T]he most popular posts represented the line between treatment and survivorship as a return to previous appearance and functional status, with many posts emphasizing "#thisisme". (Cherian et al., 2020, p. 10)

On Imgur, "me" images present the poster through agentive problem-solving or positive re-appraisal, expressing a change in attitude or a new outlook on life (Hale et al., 2020, p. 10).

Through this line, posters establish a visual conversation with leading social discourses, and evaluate how these fit into their own experience. Sometimes, they adopt the survivor or warrior identity. Other times, they reject that identity and present themselves as vulnerable and afraid, accepting that cancer is a life-long illness (Gupta, 2022, p. 225). Often, positive emotions help counter the visual impact of cancer symptoms and consequences, allowing the poster to be more than a patient:

[P]osts contrast scarring and hair loss, which are conventionally depicted as tragic, with smiles and hopeful expressions

that call into question the experience of cancer treatment as unremittingly negative. (Cherian et al., 2020, p. 11)

The embodiment of cancer is another crucial part of self-negotiation in "me" images. Typically, auto-pathographies visualise identity through aesthetic or bodily changes over time. It is common for patients to use "dramatic before-and-after images contrasting the aesthetics of treatment and post-treatment" (Cherian et al., 2020, p. 12). But patients also use these images to dissociate and abstract themselves from the illness:

Hair becomes the most visible platform for this contestation where the affective tensions between the I (the embodied self) and the It (the physiology of cancer, its own life force) becomes most pronounced. (Gupta, 2022, p. 222)

"Me" images are thus a constant negotiation between the poster's desired identity, the actual content of the image, and how followers react to them, which in turn further reinforces or challenges the poster's desired identity (Stage, 2019b, p. 276).

Engagement with this type of image appears to be high on Imgur, especially when there are people in the frame (Hale et al., 2020), and on Instagram (Cho et al., 2018; Tetteh, 2021). When posted by trusted community leaders, "me" images are also effective on Facebook (Rivera et al., 2021).

For posters who transform their social media into a visual diary of cancer, "me" images come with costs, too. When treatment is complete, they may experience what Stage (2019b) calls a "crisis of tellability": should I continue posting images? How will my identity change now that I am cured? What is my relationship with my followers after treatment?

We have not found specific mentions to "me" framing on papers dedicated to Pinterest. However, given that thematic images are more common there than episodic photographs, and given the use of Pinterest for "visual curation" (Park et al., 2019, p. 9), we may speculate that "me" images are not common on this platform.

#### "You": education and activism

Opposite to self-expressive photographs are images that focus on the viewer and contain cues to action. Admittedly, this could appear as just another term for thematic framing, yet episodically framed images may also fit within this category. A selfie showing progress in treatment and explicitly asking the viewer to get checked by a doctor would be episodic and "you" framed.

"You" images call others to action, raise awareness on prevention, and try to motivate screening. Typically, they also contain information about the negative consequences of cancer. These are, for instance, posters and infographics, or images that make a personal appeal to viewer's responsibility and self-care (often in captions). In the sample, they are discussed in relation to the Health Beliefs Model and to misinformation on cancer prevention.

"You" images are important to increase the perception of self-efficacy amongst viewers (Gürtler et al., 2022; Ma & Yang, 2022; Miller et al., 2019, p. 56) and to motivate preventive behaviours. In their review of breast cancer communications on Pinterest, Miller et al. (2019) find that thematic images rarely contain such cues. Park et al. (2019, p. 7) find that, on Pinterest, "you" messaging works best when it contains people in frame, explanatory texts, and rich information. Meanwhile, images that discuss cancer as a threat are often ignored on this platform:

Messages that contain primarily perceived threat components (i.e., severity and susceptibility) are more likely to result in people ignoring the message and not adhering to the recommendation. (Miller et al., 2019, p. 56).

Rivera et al. (2021) find that, on Facebook, viewers do engage with this type of content if they are connected to the person or group who posted it, or when shared by a respected figure, suggesting that personal ties lead to higher trust in the content posted. On Imgur, calls for check-ups or screening led to lower support and engagement, as they are perceived as an intrusion into a moment of browsing that should be fun and relaxed (Hale et al., 2020, p. 10). On Instagram, "you" images are not often accompanied by constructs of the Health Belief Model (Henderson et al., 2021); when they are, they reduce the likelihood for engagement (Cho et al., 2018). It thus appears that "you" images face resistance across the platforms studied.

The framing of "you" messages is also affected by the high prevalence of misinformation in cancer images online. Wilner & Holton (2020) find that more than half of the posts on Pinterest that contained information about breast cancer also contained misinformation, typically through

exaggeration, which may further limit the impact of this type of image. This risk is only higher given the absence of health organisations from platforms like Pinterest (Miller, 2019; 2020) or Facebook (Rivera et al., 2021), and given the misalignment of cancer prevention contents with medical recommendations (Gürtler et al., 2022).

#### Discussion

The study of social media images that visualise cancer remains a field in development. While many papers deal with text and even video transcript in social media, few—to the author's knowledge, as few as 16—attempt an image content or discourse analysis. Yet relevant results can be extracted from them.

# On the Representation of Cancer Sites

The fact that breast cancer has more presence in the sample is explained by the great amount of work done since the 1970s to raise public attention on its prevalence and the importance of research and prevention. While they are no strangers to criticism (see, for instance, Bell, 2014; Sweeney & Killoran-McKibbin, 2016), breast cancer awareness campaigns have activated multiple mechanisms for attention in popular media, developed a clear visual identity, built successful messages of resilience and survivorship, and achieved the support of large businesses. Breast cancer has thus been put at the centre of public awareness on cancer generally and, consequently, users today are relatively comfortable sharing contents that mention this site. As a result, images of breast cancer are commonplace in social media, especially in the month of October.

In addition, breast cancer has been subject to numerous studies on representation, and special attention has been given to the importance of communities of patients. While similar studies have been conducted for other sites, the volume of papers remains low in comparison (Koskan et al., 2014). The sheer number of breast cancer images in social media dwarves other cancer sites (Varela-Rodríguez & Vicente-Mariño, 2021b), while the widespread use of visual tropes that are easy to identify (such as pink ribbons) may further compound its higher visibility. In addition, cancer sites that affect primarily women appear to be more visible in social media overall, which Cherian et al. interpret

as a consequence of "the norms surrounding masculinity that deter disclosure, even in private" (Cherian et al., 2020, p. 11).

#### On Method

The difference between qualitative and quantitative approaches leads to different results in the analysis. Quantitative studies provide an answer to a question of "what": what do posters share to visualise cancer, and what is the engagement with such posts? In contrast, qualitative studies provide answers to "how": how do patients present themselves and their illness, and how does that affect others? Where the former fall short in capturing the experiences of individual patients, the latter tend to look at common suspects and achieve results with limited significance for other sites. Bridging the two approaches can help facilitate a communication of cancer that is impactful and inclusive.

Inspiration may be sought in existing work on cancer prevention, where visual communication of smoking, vaping, tanning or the HPV vaccine have received more attention. These are fields where even machine learning algorithms have been used in conjunction with qualitative methods. Admittedly, detecting a cigarette or a syringe in an image may be easier than detecting a visual representation of cancer, which is a general term that is compounded by multiple illnesses, emotions, and life experiences.

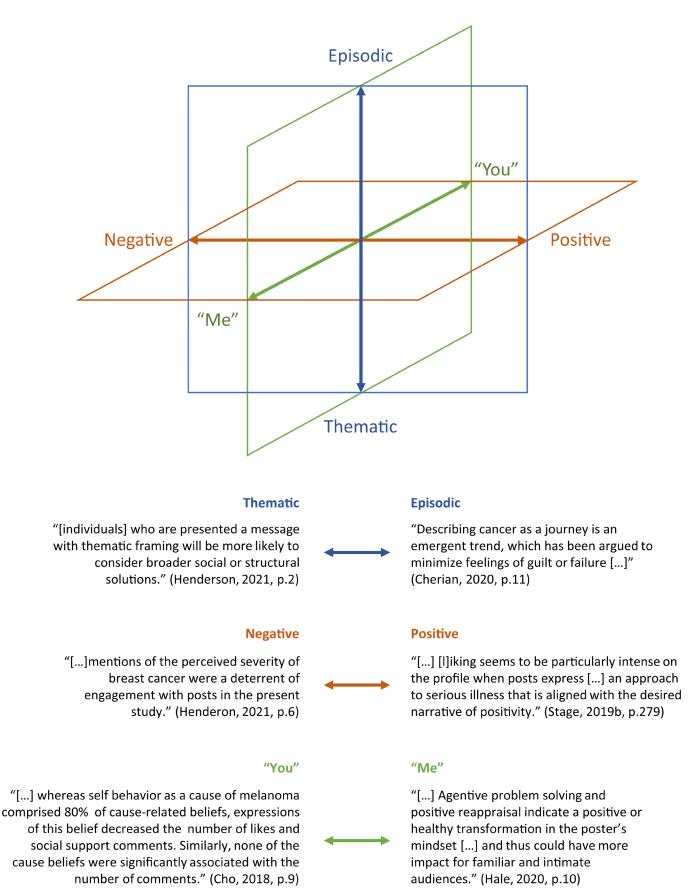
Further developing the three discursive lines identified in this meta-synthesis may serve as a starting point. At the very least, they could guide the design of cancer communications by helping to predict some of the impact that images may have on viewers, and on the patients and relatives who posted them, too.

#### **Three Discursive Lines**

Figure 4 condenses the three discursive lines that emerged in this paper. They translate into a three-dimensional plot where images could be located—not without some difficulty. Images may be more episodic, "me" framed and positive, or the complete opposite.

The first line, episodic vs thematic framing, can be used to understand patient messaging and psychosocial needs. Their use and impact seem to be tied to platform affordances: thematic framing is well-received in social media that are not based on interpersonal connections but rather on browsing

Figure 4. The three discursive lines for images of cancer in social media that emerge from a meta-synthesis of the 16 papers studied



and collecting content (such as Pinterest and Imgur). They are also received positively on Facebook when the poster is a trusted organisation or a closer acquaintance. Conversely, episodic framing has a measurable impact on Instagram, where viewers follow the experience of their friends or of the people they admire (celebrities, influencers), and where they are actively encouraged to comment and like.

The second discursive line, between positive and negative emotions, returns inspiring results. Part of the literature is critical of the social media economy, arguing that it puts pressure on patients to share a specific discourse (that of survivorship) that favours positive images (Stage, 2019a; Henderson et al., 2021). Images where patients count down to life as it was before cancer, show a thumbs up from their chemotherapy session, or appear in frame with scars and a smile do reflect a push towards restitution. Indeed, positive emotions are more often expressed across all social media studied. The design of social media platforms is also shown to favour unobtrusive cancer sites that permit visuallyappealing images, sites that are well-known, and privileged groups, with higher technological competencies or generally more representation in social media (Miller et al., 2019; Park et al., 2019; Rivera et al., 2021; Stage, 2019b). Symptomatic of this, argues Stage (2019a), is how viewers react to posts outside dominant discourses on Instagram. When a post shows fear or uncertainty, commenters redirect them to a socially desirable narrative of cancer: they reassure posters and encourage them to stay hopeful. Tetteh (2021) echoes these observations, while Varela-Rodríguez & Vicente-Mariño (2021b) provide some quantitative support by visualising the unequal distribution of cancer sites on Instagram.

However, results also show that social media can offer a positive space for the broader spectrum of emotions associated with cancer (Cho et al., 2018; Hale et al., 2020; Park et al., 2019). On Instagram, Pinterest and Imgur, negative emotions and even the discussion of mortality have a space, and images that make use of them are met with supportive, reassuring, and compassionate comments. Cho et al. (2018) demonstrate that negative emotions are better at generating comments (thus conversation), while Hale et al. (2020) show how commenters offer compassion to posters who are sharing their anxiety over treatment. For patients, this means that, even if they do not align with survivorship or if they struggle with the social imperative to remain optimistic, and even if their images may not reach the influential status of

more positive ones, they can find support in social media. Importantly, however, this may be true for well-represented groups, while underrepresented peoples continue to swim against the tide (Rivera et al., 2021).

This second discursive line (positive vs negative emotions) is important to achieve a more inclusive representation of cancer. It may facilitate the inclusion of underprivileged groups and give visibility to lesser-known cancer sites, while speaking to patients beyond standardised discourses.

For cancer screening and prevention, the use of negative emotions should be approached carefully. By favouring images that insist on the physical and emotional consequences of cancer, such as fear-invoking photographs, campaigns could run the risk of falling into shock advertisement. They may also stigmatise patients. An example may be found in anti-to-bacco campaigns: while the use of shock images may have deterred consumption, it may have also contributed to placing blame on lung cancer patients (Riley et al., 2017).

It is also important to note that discourses by patients who feel represented in scars and other bodily manifestations of cancer are not representative of all cancer experiences. Popular imagery, especially around breast cancer, made a positive move towards the 1990s by incorporating more diverse groups and reducing the blame on patients (Andsager et al., 2001). Building a more representative image of cancer does not entail going back to images where cancer is only visible as scars or trauma, but instead creating a space that allows for the representation of the broad spectrum of cancer experiences, whether those imply visualising hope or fear, or both.

Lastly, the third discursive line ("me" vs "you") establishes that posts framed through "me" messaging (sharing personal experience) are effective on Instagram and Imgur. They are amplified when posted by celebrities who are vocal about their cancer, which can create an image of cancer that is closer to the broader reality of the illness. Meanwhile, "you" messages remain ever-important for screening and prevention, as well as for informational support to patients. They are most impactful on Pinterest or Twitter, while they struggle to become visible on Instagram or Imgur.

# An Image of Cancer in Social Media... without Images?

A final consideration, one that is striking to us as authors, is how images are absent from the majority of the 16 papers

studied. Only 6 of them use images from their samples to communicate results.

Most of the papers point to ethical challenges to explain the absence of images. Social media studies undertake an analysis of data that is often disjointed and great in scale, which makes it complex to obtain consent. Further, the images studied are, after all, deeply personal, and there are few mechanisms to deidentify them as one could do with quotations from an interview. One method is used by Varela-Rodríguez and Vicente-Mariño, who collapse together the images in their study so that they are virtually impossible to identify but retain some information (mainly colour). Stage, on the other hand, uses sample images that are perfectly identifiable, having obtained informed consent from his research subjects to do so.

There are also technical challenges to obtaining images, as social media platforms limit access for researchers. In addition, reproducing social media images, although public in the sense that they are available to public viewers, leads to a legal dead-end that is yet to be resolved. This is a recurring challenge in social media studies, and it is even more pressing for the obtention, storing and study of images (see Varela-Rodríguez & Vicente-Mariño, 2021a).

That said, all the papers studied engage in a generous, in-depth analysis of images, either quantitatively or qualitatively. Yet we cannot help but wonder if accompanying said analysis with sample images could strengthen their results.

# **Implications for Further Research and Future Developments**

The implications of this research are several. Firstly, we have established that images in social media are an important vehicle for sense-making, identity-formation, and community-building for cancer patients. Researchers will find a fruitful field here. Before that, however, more work is needed to develop methods for social media image analysis. In particular, the automation of some of this work (both in terms of image-download and image-processing) can help (see Varela-Rodríguez & Vicente-Mariño, 2021a). There are important technical and ethical considerations to bear in mind, including the constant changes in the Terms of Use of social media platforms, the grey area that is social media data ownership and access by researchers, and the challenges

in obtaining informed consent when conducting large-scale studies.

Secondly, challenging the divide between qualitative and quantitative methods and relying on mixed approaches have been shown to be productive. Social media are particularly ripe for this type of work. Future work could explore the use of automated searches that can then be analysed in-depth through interviews and focus groups, similar to the method used by Rivera et al. (2021; 2022). Likewise, reviewing quantitative findings with posters and viewers can provide richer information on user-intention and impact. Social media research thus appears to be a potentially fruitful field to connect the biomedical and social sciences.

Thirdly, multi-platform studies may risk obtaining a biased picture if they neglect the affordances of said platforms. The different expectations users have for each platform may explain the disparities observed on Instagram, Pinterest and Imgur. Future work may look to conduct cross-platform research while being mindful of each platform's audience and functionalities.

Fourthly, researchers studying visual communications should be well-positioned to strengthen their own use of images to reinforce textual narratives. If our object of interest are images, it appears reasonable to use them as part of our communication.

Lastly, the three-dimensional grid we have developed with the three discursive lines may help analyse social media images of cancer qualitatively, while offering some value towards predicting their engagement. Future work may look to validate, modify, or improve these three lines, developing specific criteria for each line and contrasting the engagement for each type of image.

As visual social media continue to grow, it seems reasonable to expect them to continue playing a key role in the communication of cancer. Given their rapid development, it is likely that new papers dealing with the topic are published in the next few years. Future research may also consider works developed in other formats, such as communication campaigns run by cancer organisations, or lager-format books. Academic works like Carsten Stage's *Networked Cancer* are outside the scope of this paper but are an important source of knowledge. Similarly, the work of Stephanie Plage, although not focused on social media, offers great insight into visual cancer discourses by a variety of patients (Plage, 2021).

#### Limitations

This research is limited by the small number of papers available in this field, or, at least, the number of papers we could identify with the queries defined and the resources available. Some relevant documents known to the authors were left out as they were not part of the search or had a format that was not included—most notably Carsten Stage's exploration of the topic in the book Networked Cancer (Stage, 2018). By narrowing the search to very exclusive criteria (journal papers AND images AND cancer AND social media) we have made it possible to undertake a deeper analysis but had to leave out works that we hope to return to in the future.

In addition, the lack of previous systematic reviews on this topic does not allow to build on existing knowledge, but instead generate new ideas that will be tested by time and, surely, need to be updated.

### **Conclusions**

This review presented an in-depth analysis of 16 papers that address the use of images in social media to communicate cancer.

Overall, the papers study at least three discursive lines that are followed by the images in their studies. The first line, between episodic and thematic framing, considers the different impact that images have depending on whether they present cancer as a journey or as an individual topic. Episodic image are individual, personal images, where patients show progress. Thematic images contain text and present general information about cancer or its prevention. Thematic images are more successful on Pinterest or Twitter, while Instagram favours episodic images. Imgur returns interesting results as episodic images often present cancer stories from other people, instead of the poster's.

The second line considers the different impact that positive and negative emotions have on viewers on the different platforms. Positive emotions are found to receive more likes on sites like Instagram, and to be generally more "agreeable" as they align better with dominant discourses. However, negative emotions still have a place in social media, and are met with empathic support and compassionate comments on Imgur or Facebook and are reshared on Pinterest.

Lastly, the third line considers the primary purpose of the images, whether it is to present the poster's experience ("me" images) or to motivate action from the viewer ("you" images). The former seem to perform better on most of the platforms, whereas "you" images are often perceived as intrusive.

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