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TESIS DOCTORAL:

**The Shape of Cancer: Socialisation and Visual
Representations of the Illness on Instagram**

(ES) La Forma del Cáncer: Socialización y
Representación Visual de la Enfermedad en
Instagram

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THE SHAPE OF CANCER: SOCIALISATION AND VISUAL REPRESENTATION OF THE ILLNESS ON INSTAGRAM

La Forma del Cáncer: Socialización y Representación Visual de la Enfermedad en Instagram

Before reading

In my late-teens and early-20s, I would spend hours editing photographs, scanning my drawings to outline them on my computer, and writing down all the ideas that crossed my very emotional mind. My eyes, often glued to a screen, avoided the deep stare of my piling homework. My head, always at risk of taking “the shape of the screen” according to my mother, gave little thought to the future.

As life took me in the direction of work and adulthood, I began to think of all those hours as wasted, little more than a hobby with no structure and with no purpose other than to avoid my obligations. I would think back of the things that I used to write and draw with a touch of embarrassment.

Yet here we are today, after countless hours in front of a screen, submitting a PhD thesis charged with emotion and where images and feelings have played a central role.

These last two-and-a-half years as a PhD student have been challenging. Researching at night while keeping a full-time job, I have often found myself thinking “what is the purpose?”. I would like to take this opportunity to thank all the people who have helped me keep going.

Miguel Vicente, my PhD Director, for your diplomacy, patience, and continued efforts to make this thesis possible. You have shown me that this work is only the starting line of a lifelong process of learning.

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Gonzalo and Isabel, my parents, for accompanying me my whole life and for giving me your everything so that I could continue studying and growing.

And Elisa Nerea, my wife. It is impossible to list the myriad things I am thankful to you for. You have taught me everything I now know about myself. Thank you also to your parents and your brother for their care and support through these two long years.

It is entirely possible that, in the future, as I look back at this thesis, I will feel that familiar touch of embarrassment. No doubt, I will have missed something, misunderstood an important idea, taken the wrong steps. For now, I hope you enjoy reading it and that the mixed methods I use lead to new knowledge and ideas. More than anything, however, I hope it does justice to the people whose lives I try to portray.

Abstract (EN)

Social media platforms like Instagram are a source of information and support for cancer patients. On this platform, millions of images shared by patients, organisations and the general public give shape to the social imagination of one of the most feared illnesses around the world.

This thesis proposes a method to identify and obtain images of cancer from Instagram, a social media that in 2022 remains nearly inaccessible to research. Through a transdisciplinary lens, it combines the sociology of everyday life, visual sociology and methodologies from social media analysis to discover visual patterns in the images and find alternative discourses.

The results show the variety of visual resources that patients use to communicate their illness and support the construction of their identity. They also show how Instagram's economy of affection favours the publication of positive images, aligned with the discourse of survivorship, while they hamper the expression of other experiences. It concludes with the proposal for a new regime in the communication of cancer, based on the concept of socialisation.

Resumen (ES)

Las redes sociales visuales como Instagram son una fuente de información y apoyo para pacientes de cáncer. En esta red, millones de imágenes compartidas por pacientes, organizaciones y por el público general configuran la imaginación social de una de las enfermedades más temidas en todo el mundo.

Esta tesis plantea una metodología para extraer y estudiar imágenes de esta red, prácticamente inaccesible para la investigación en 2022, y para su codificación. A través de un enfoque transdisciplinar, combina la sociología de la vida cotidiana, la sociología visual y las metodologías del análisis de redes sociales para descubrir patrones visuales en las imágenes de cáncer e identificar discursos alternativos.

Los resultados muestran la variedad de recursos visuales que utilizan los pacientes de cáncer para comunicar su enfermedad y apoyar un proceso de construcción de la identidad. Muestran también cómo la economía afectiva de esta plataforma favorece la publicación de imágenes positivas y alineadas con el discurso de la supervivencia, mientras que supone un reto para visibilizar otras experiencias. Concluye con la propuesta de un nuevo modelo de comunicación sobre cáncer, basado en el concepto de la socialización.

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Structure of this thesis

This thesis is submitted as a PhD Thesis by Publication, in accordance with Article 4.1. of the “Normativa sobre Presentación y Defensa de la Tesis Doctoral” at the University of Valladolid. It is composed of the following academic publications:

1. Varela-Rodríguez, M., & Vicente-Mariño, M. (in press). Images published by cancer patients in social media and their reception: A systematic review. *Review of Communication Research*.
2. Varela-Rodríguez, M., & Vicente-Mariño, M. (2021). Imágenes desgarradas: El uso de scrapers en investigación social en Instagram sobre cáncer. *Cuadernos.Info*, 49, 72–97. <https://doi.org/10.7764/cdi.49.27809>
3. Varela-Rodríguez, M., & Vicente-Mariño, M. (2021). Whose cancer? Visualising the distribution of mentions to cancer sites on instagram. *Journal of Visual Communication in Medicine*, 1–17. <https://doi.org/10.1080/17453054.2021.1964356>
4. Varela-Rodríguez, M., & Vicente-Mariño, M. (2022). Llorar fotografías: Análisis de contenidos y discursos visuales sobre el cáncer en las fotografías de Olatz Vázquez en Instagram. *Revista Española de Sociología*, 32(1), Article 1. <https://doi.org/10.22325/fes/res.2023.149>

This accompanying document offers an overview of the conceptual framework, the methodology, the thematic linkages between the papers presented, and the logic followed throughout the process, as well as a series of conclusions. Following the visual spirit of the thesis, the text is accompanied by a series of visualisations that encapsulate the main points made in each chapter.

For ease of reference, each paper is referred to by its short name:

1. Systematic review
2. Scattered Images
3. Whose Cancer
4. Crying Photographs

1. Introduction

The four papers that compose this thesis evaluate the role of social media images in the building of a social discourse of cancer. Submitted as a PhD Thesis by Publication, the methods and frameworks of visual sociology, the sociology of everyday life, and social media analysis are incorporated into the research.

This document will guide the reader through the work undertaken, beginning with an introduction that is followed by an outline of the research objectives. The conceptual and theoretical frameworks are then discussed. Before presenting the four papers, methodological and ethical issues are discussed. The document concludes with a review of the implications for future work.

1.1. Where does this thesis come from?

The work submitted herewith grows from a mixed soil, made of four areas of personal, academic, and professional interest.

Firstly, the thesis incorporates a life of contact with the world of health. Medical sciences have been present throughout my life. I remember watching my father's computer screen as he edited images of his and his team's latest surgery for an upcoming presentation. At home, we were often reminded of the importance of personal responsibility to prevent illness: to avoid lung cancer, do not smoke; to avoid colon cancer, make sure to eat plenty of vegetables; to avoid skin cancer, apply sunscreen. I also remember my father's call for our public health system to be more humane, egalitarian, and closer to the patient.

My wife's experience as a psycho-oncologist has also influenced my work greatly. Sheltered from the cold fog of November in a local café, we argued about how anxious cancer patients must feel when they are presented with discourses of cancer that do not align with their experience.

The thesis collects these two experiences and translates them into an understanding of health as a social objective and responsibility, instead of just a personal task.

Secondly, the work that I present throughout these pages is based on my academic and professional experience. Fifteen years that, much like the contents on Instagram, reveal a series of patterns underneath a blanket of chaos. At the age of 17, I enrolled in a bachelor's degree in Sociology at the University of Salamanca. My only hope was to follow in the footsteps of my siblings, all of whom had already graduated from university. I quickly realised that I had no interest in Economics or Political Sciences, both close disciplines to Sociology that made my first years as a student quite miserable. I was, however, interested in learning how different social groups give symbolic meaning to their daily lives, and how conflict and inequality are given shape. At 21, I enrolled in a Master's Programme in Peace and Development Work at Linnaeus University, in Sweden. A year later I found myself as an intern at a peace mediation NGO in Brussels, where my dread for political analysis came back to haunt me.

In 2014, a project financed by the United Nations Development Programme allowed me to explore the role of social media in conflict. From then on, I have been learning how these media give shape to our identity, bring us closer to our loved ones, and sometimes keep us apart from each other.

In 2019, I stepped back into a university faculty, this time to offer guidance to students who already had a much clearer sense of purpose than I ever did. My experience in Kosovo, Ukraine or Ivory Coast would allow me to teach in a Master's Programme in International Relations and reveal that sociology was in fact the common thread between everything I had done. A sociology of everyday life and of social media.

These experiences are brought into my thesis through the exploration of everyday life sociology and the use of communication sciences. I evaluate how cancer patients give meaning to their daily lives through social media and how, in doing so, they contribute to building a social image of the illness.

Thirdly, this thesis would not have materialised without my lifetime obsession with photography. At 15, I grabbed my uncle's ages-old iron camera to take portraits of my friends—at least that was the purpose. Looking back at those pictures, I find images of trashcans, plastic bags, twisted branches, broken windows, or abandoned cars. It was only around 2017 that I understood my fixation with these “ugly” features of our lives. I came to accept it as an impulse to document the things that often stay in the fringes. To pursue it further, I took a loan so I could enrol in a Master's Program in Photojournalism and Documentary Photography at the University of Arts London while I continued working full-time. The final Project for that MA was the steppingstone for this thesis, which incorporates photography as the object of my study.

Lastly, this work stems from my teenage years. I was born into the *millennial* generation, with the Power Rangers on TV and my big box of cereals as a child but, more importantly, with my Fotolog account as a teenager. Fotolog was a proto-social-media that was widely popular in Spain and Spanish-speaking countries in the early 2000s. Those of us who lived through our teen years in that era were pioneers (not by choice) of what is today a key feature in the lives of millions of people: the daily use of social media to build friendships and, sometimes, to maintain rivalries. In a world that was not yet worried about privacy or disinformation, Fotolog was exciting and simple, but it already highlighted some of the dynamics that dominate our online interaction today: virality, posing, affects. That network, almost an ancestor to Instagram, allowed users to publish one photograph per day, which in turn could receive up to 10 comments from other users. Reaching those 10 comments on your publication was an achievement you could feel proud of; being one of the 10 commenters in a friend's publication was an obligation you could not avoid.

In March 2020, I formally enrolled in the Doctorate in Transdisciplinary Research in Education program at the University of Valladolid. Only a couple of weeks later, the world came to a halt. The COVID-19 and the ensuing State of Alarm

locked me in my room in Valladolid, from where I have developed most of this thesis. The pandemic came to underline the importance of the four areas above: images, fundamental in an era of disinformation and paranoia; social media, key to keeping us connected and (dis)informed; sociology, without which we could never have understood the unequal distribution of the illness; and, of course, the need for a health system that treats its patients as more than just statistics.

Together, health, the sociology of everyday life, photography and social media are the basis of the thesis here presented.

2. Objectives

This thesis responds to some questions while it raises others on the role that visual social media have in the communication of health. It stems from two basic questions:

- How do we imagine cancer on Instagram?
- How does Instagram affect the creation of a social discourse of cancer?

To find an answer to these questions, five objectives were drawn:

1. **To build a methodology** for the extraction of images from Instagram and their reproduction, so that visual sociology may be applied to social media.
2. **To identify visual patterns** in cancer images on Instagram through image analysis, so that we may evaluate the presence of dominant features.
3. **To evaluate the impact of the economy of affection** in the representation of cancer on Instagram and in the formulation of visual discourses on this illness.
4. **To unearth alternative visual practices**, located at the fringe of dominant social media discourses, so that we may contrast them with the “standard” image of cancer.
5. **To analyse the implications** of Instagram cancer images for health education.

2.1. Linkages between papers

The specific objectives above translate into four papers, each one with a different focus: a theoretical paper, a methodological paper and two results papers (quantitative and qualitative, respectively).

The **first paper**, ‘**Systematic Review**’ (Varela-Rodríguez & Vicente-Mariño, in press) responds to the fourth and fifth objectives and provides the theoretical backbone for the thesis. It presents a systematic review of the literature through

metasynthesis (Carrillo-González et al., 2007). Specifically, it reviews papers focused on images posted by cancer patients in social media. The first steps taken towards this thesis suggested that this is a field with limited scientific production—the systematic review confirms that. Only sixteen papers were found to study the nexus between social media and cancer, addressing the topic from diverse disciplines, ranging from health studies to communication sciences and feminist theory. The results from their review reveal three axes where images of cancer shared on social media can be traced. The first axis is drawn depending on the framing of the image (episodic or thematic); the second axis considers the type of emotion that the image portrays (positive or negative); the third axis addresses the purpose of the image (to motivate an attitudinal change in viewers, or to represent the identity of the poster).

The **second paper**, ‘**Scattered Images**’ (Varela-Rodríguez & Vicente-Mariño, 2021a) focuses on the first objective. It presents a methodology to obtain and analyse images from Instagram. One of the most populated and active social media, Instagram remains nearly impossible to study going into 2023. The doors to this network (known as APIs, short for Application Programming Interfaces) were closed following the Cambridge Analytica scandal, forcing academics to adapt. While some have accepted the limited sample that CrowdTangle¹ provides, others advocate for the violation of Instagram’s Terms of Use by using automated tools (Bruns, 2019; Rogers, 2018). This paper explores the use of one such tool, known as *scrapers*, that allows researchers to conduct large-scale searches based on keywords and to download the results. The paper was presented at the 2020

¹ CrowdTangle is a service provided by Meta Platforms, Inc. (the company we used to know as Facebook, Inc.) that allows access to public data from Facebook or Instagram for research. It has limitations, especially with regards to Instagram: CrowdTangle only provides access to profiles with more than 50,000 followers and to verified profiles (Fraser, n.d.). That gives us as skewed sample, equivalent to reviewing influencer profiles, far from representing the average user. In addition, the requirement to access this platform change rapidly, making for an unstable research environment (see Bruns, 2019).

Technological Ecosystems for Enhancing Multiculturality conference (Varela-Rodríguez & Vicente-Mariño, 2020), earning the Best Presentation award in its branch.

The research continues with a quantitative exploration in the **third paper**, ‘**Whose Cancer**’ (Varela-Rodríguez & Vicente-Mariño, 2021b), which addresses the second and third objectives of the thesis. It evaluates the unequal representation of different cancer sites on Instagram, collecting data on the number of images that mention keywords related to breast, pancreatic, and lung cancer, among others. It also reviews the potential correlation between online visibility and epidemiological indicators, such as incidence and mortality. Results suggest that breast cancer is ten times more likely to be mentioned on Instagram than the next cancer site, and that there is no seeming correlation with its epidemiology.

Lastly, the **fourth paper**, “**Crying Photographs**” (Varela-Rodríguez & Vicente-Mariño, 2022) adopts a qualitative approach to study the images shared by Olatz Vazquez, a Spanish journalist, during her treatment of a stomach cancer. It addresses the second and third objectives. Taking from the visual analysis described by Rodríguez & Dimitrova (2011) and Kress & van Leeuwen (1996), it presents a dialogue with Olatz’s images. Most of her photographs are in black and white, outside the traditional image of cancer on Instagram. The result is a series of discourses that Olatz used to represent cancer, herself, and her social environment. Figure 1 collects the different objectives and the papers that address them.

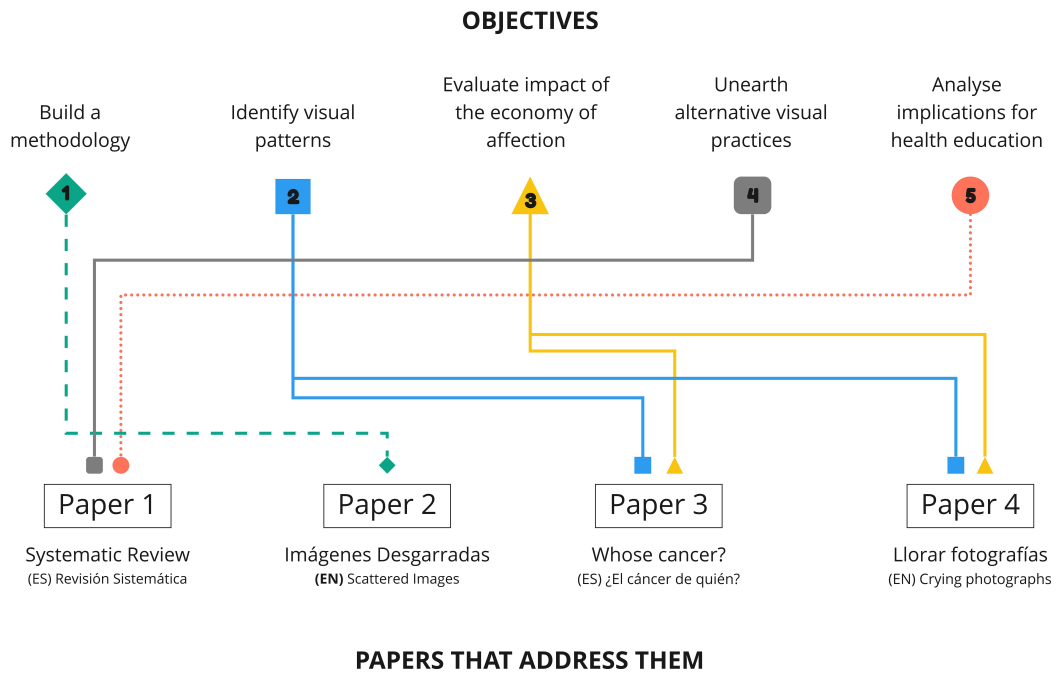


Figure 1. Objectives and papers that address them

3. Theoretical framework

Approaching images in social media through the social sciences means diving into a world of interpretations and ambivalence. This thesis balances two distinct disciplines: the sociology of everyday life—or “Third Sociology” in the words of Piotr Sztompka (2008)—and visual sociology. It also addresses the study of affects.

3.1. Social media, part of everyday life

Beginning with the first of the two disciplines, the papers here presented approach a **sociology preoccupied** with human action in collective spaces. For Sztompka, this Third Sociology descends from the abstract level of macro-sociological issues to the individual’s daily life. It is a science interested in what “really” happens in human society (2008, p. 3), and which uses numerous information sources, including visual tools: photographs in traditional media, photojournalism, found photography, ads, billboards (2008, p. 3)... and social media.

Within the sociology of everyday life, we find some of the concepts that best describe social reality on Instagram: the concepts **space and moment** by Henri Lefebvre, and the idea of **performance** by Erving Goffman.

Lefebvre’s work is extensive, but his understanding of everyday life can be summarised in the following lines:

[...] 'what is left over' after all distinct, superior, specialized, structured activities have been singled out by analysis, must be defined as a totality [...] superior activities leave a 'technical vacuum' between one another which is filled up by everyday life. (Lefebvre, 1991, p. 97).

The time and space of everyday life are thus made of instants where nothing remarkable happens, as extended by Highmore (2011, p. 3). Moments of transition between events, like the ones we live during our daily commute, or while we wait for someone, and which are often characterised by a stable rhythm set by

socioeconomic dynamics, such as work or urban life (Lefebvre, 2004). When routine and rhythm are interrupted, we experience **arrhythmia**: an uncomfortable disconnect that pushes us into seeking normality once again.

What could be more disrupting, more arrhythmic, than an illness as serious as cancer? Carsten Stage, one of the leading researchers in the everyday life of cancer, reflects on this as he argues that cancer patients often use social media as a means to regain some sense of normality (Stage, 2018, pp. 165–175). Connecting with other patients, sharing images, or celebrating progress can help patients gain a new rhythm in their daily life. In the process, they build a discourse of cancer.

Approaching social media through everyday life implies not only reviewing the contents we share, but also the contents we **consume, where we consume them, and how they affect to the way we present ourselves in society**. It thus implies understanding that social media are a stage (Goffman, 1959) where images are the lead actor.

Discussing the invasive nature of the photographic camera, Susan Sontag describes photography as a violation of intimacy, where we see the person in a way they have never seen themselves (2017, p. 24). Conversely, photography in social media is an opportunity to present ourselves exactly how we see ourselves—or, at least, how we want others to see us. We furnish our surroundings (Walsh & Baker, 2017, p. 5), use filters, write lengthy descriptions, and overlay texts that guide the interpretation of the image shared (Storey, 2014, p. 96). In Goffman's terminology, social media are our opportunity to play our best role.²

² In her 2015 *Excellences & Perfections* project, the Argentinian artist, Amalia Ulman, demonstrated the performative nature of Instagram. Throughout the duration of the project, she built a fake identity as a social media influencer, using photomontages that showed her (fake) life and hustle towards stardom in Los Angeles. Shortly before announcing that her influencer life was but an artistic lie, she had amassed close to 100,000 followers. In 2016, *The Telegraph* labelled her work as the first masterpiece in the era of Instagram (Sooke, 2016)

Thus, in communication sciences it is common to read reflections about the **performative nature** of social media. But on platforms like Instagram, users are not in full control of their performance. While social media allow us to present ourselves in a favouring light, they also introduce a series of mediative agents, third parties that guide us in our quest to find our best image (Hogan, 2010). Selection algorithms and the economy of affection help us get a sense of what is desirable online, and favour the building of “personas”, profiles that aim to fit in what is expected of us (Merunková & Šlerka, 2019). Why else, if not to guide their interpretation, would we use hashtags when posting a selfie (Walsh & Baker, 2017)? Why else would we present ourselves as more extraverted and agreeable online than in “real” life (Attrill, 2015; Harris & Bardey, 2019)?

Ambiguous as they are, social media require that we learn from classic sociology, too. Lindgren (2020) applies the concepts of ambivalence by Robert Merton and Max Weber’s ideal types to explain the anxiety we feel when faced by millions of images that represent everything we wish we could be. Through this lens, interaction in social media becomes a process whereby we constantly construct meaning and negotiate our identity.

3.2. Visual sociology in the era of social media

“The omnipresence of cameras persuasively suggests that time consists of interesting events, events worth photographing.” (Sontag, 2008, p. 8)

The study of photographic images and social sciences share their origins. Towards the end of the 1830s, with the first daguerreotypes and Comte’s definition of sociology, two disciplines were born that shared an ambition to explore, represent and—sometimes—advance society (Becker, 1974; Harper, 1988).

Documentary photographers were amongst the first to marry the two disciplines. Early in the 20th Century, the topics of sociology and anthropology were given new

shape by photographers who hoped to document the living conditions and the everyday life of those around them. Post-depression poverty in the USA was the subject of Dorothea Lange's work; Lewis Hine portrayed child labour and helped put an end to it; Diane Arbus gave new meaning to the social understanding of beauty, and explored issues of marginalisation; Robert Frank explored issues of belonging and identity; Rene Burri photographed conflict and the role of political personalities in it; Walker Evans pictured daily social interaction; Paul Strand reflected the power relationship between peasants and the leadership. In Spain, Cristina García Rodero, Piedad Isla, Carlos Pérez Siquier, Ramón Masats or Xavier Miserachs adopted this same impulse after 1950. AFAL, one of the collectives and magazines that pioneered documentary photography in Spain, referred to a new impulse to "win the streets" and capture humanity (Fuster Pérez, 2008, p. 91).

All of these photographers made of their work a tireless search for the roots of inequality and the place of the individual within society. They used some of the methods of social sciences and shared its ambition for an objective representation of life (Becker, 1974; Harper, 1988; Pauwels, 2015).

Towards the end of the 1960s, access to photographic cameras was democratised, colour printing was cheaper than ever, and the Vietnam War was on millions of TVs, magazines and newspapers. Photography and sociology came even closer (Berger, 2016; Sontag, 2017). The camera became a way for sociologists who rejected dominant paradigms in social research and theory to find their way into social studies (Harper, 1988, p. 59). Slow but steady, visual information became crucial for social research. The foundation of the International Visual Sociology Association in 1981 formalised a relationship that today permeates the study of images in our field (Harper, 1996; Pauwels, 2015).

From its roots, this new **visual sociology** incorporates the interpretive tradition of Max Weber, and brings new methods to understanding the point of view from both the photographer and the photographed (Harper, 1988, p. 66). It is well-aware that there is no image without interpretation: each photograph is built through the

photographer's perspective on the world around them. The things we choose to picture, how we choose to frame them, and which elements we leave out of frame are consequences of our worldview. This may be the reason why, as argued by Pauwels (2015), Caulfield (1996), Gold (2011) or Harper (2000), visual sociologists eventually favoured the use of found images instead of the production of new photographs in its methods.

In 2022, social media is a key source of said found images, Instagram in particular.

Instagram is a platform that belongs to Meta Platforms Inc., the former Facebook Inc. Launched in 2010, Instagram arrived at time a when visual social media platforms (those that prioritise the sharing of images over text) were growing rapidly. Facing competitors like Flickr or Hipstamatic, Instagram made a winning argument: it proposed an application that allowed users to share photographs instantaneously with a broad community of users, from the comfort of their phones. It removed the process of mediation that comes with uploading pictures to a computer and favoured spontaneity (Leaver et al., 2020, p. 10). Today, Instagram is one of the most recognisable services in the online world, and has been growing steadily for years (Pew Research Center, 2019).

In 2022, Instagram is governed by a series of algorithms that determine which images are shown to each user depending on the time of day, the impact of the images (measured as likes and comments, among others), and the user's network of contacts. At the core of the platform was the aim to facilitate the relationship between users and the world around them through images. Since its inception, Instagram has helped users shape the way they are perceived by others, too (Tembeck, 2016). Back in 2010, it did so with a series of filters that made images more attractive, often with a retro look; today, multimodal communication (videos, images, texts and interactive contents) and a full-scale economy of *influencers* have led to the carefully planned contents that we see online.

The Systematic Review contained in this thesis, discusses how complex it is to use Instagram in social research, both for ethical and technical reasons. Whether Instagram images posted in public profiles are indeed public (and thus subject to observation) is a heated discussion, especially in the field of political studies. Existing ethical guidelines on the use of social media data for research are sometimes vaguely formulated, and open more questions than they give answers (see for instance Townsend & Wallace, 2016). Besides, the Terms of Use change rapidly and constantly, which makes for an even more volatile research environment.

And yet, despite the challenges, looking at Instagram can help identify dominating and non-mainstream discourses, as I hope to demonstrate throughout the four papers in this thesis.

3.3. Social discourses of cancer and their affects

Cancer is loaded with metaphors and affects. Whether it is as a battle, a race or a journey, the iconography of cancer is full of evocative images. Even its etymology, as explained by Mukherjee (2014) draws the image of an invader that weighs on the carrier's body throughout their treatment.

This thesis does not develop a typology of the discourses of cancer. Instead, it is focused on the one that is perhaps most visible in European societies: **the discourse of survivorship**. To understand it, we ought to take a short tour back to the early 20th century with Maren Klawiter (2008). The author discusses two regimes (or stages) in the social understanding of cancer: medicalisation and biomedicalization. This thesis will extend said stages into a new regime of **socialisation**.

Beginning with the first regime, in the early 20th century, cancer patients assumed their patient role (Parsons, 1976), obedient and subjected to the clinical gaze as they were. Medical doctors were cold and distant. In the **medicalisation** regime, patients ought to trust in medicine, be cured, and return to their duties as soon as possible.

They received limited information about their diagnosis and treatment, if any, particularly if they were women suffering from breast cancer (Klawiter, 2008, p. 279). The public image of cancer was that of a curable disease, a temporary inconvenience that patients fought against thanks to the wonders of medicine. Women who underwent cancer treatment concealed its consequences and tended to their symptoms in private. Women who chose not to do so were shunned. This discourse, which furthered the understanding of illness as a moral failure, reached its peak before the 1970s, when social movements (particularly feminist movements) began to question its moral imperatives (King, 2008; Lorde, 1980; Sontag, 1978).

Between the 1970s and the 1990s, the public discourse of cancer grew to include not only diagnosed patients, but also anyone who may be diagnosed in the future. In the case of breast cancer, that meant the inclusion of all women as risk subjects (Klawiter, 2008). In this new **biomedicalisation** regime, the focus was on prevention, lifestyles, and screening. Through large-scale campaigns, this regime improved knowledge about the illness and strengthened prevention efforts. It also improved the information received by patients, who gained more agency in their own treatment (K. Bell, 2014, p. 58).

In parallel, a new discourse emerged in the cultural imagination to describe patients, who were now presented as heroes (Broom et al., 2019, p. 1582). The **discourse of survivorship** showed people with cancer (especially breast cancer patients) as tireless fighters who did everything they could against their illness, and who smiled along the way. In the public image, the cancer battle was fought and won by the optimistic patient. In addition to medicine, cancer was now fought with attitude and lifestyles.

The survivorship discourse is reflective of the narrative of restitution developed by Frank (1998, 2013). For him, the restitution plot is the most recognisable and dominant narrative in cancer discourses. It tells a linear story that goes from health to sickness and back to health. It reflects “a ‘natural’ desire to get well and stay well” (Frank, 2013, p. 78), distancing the patient from illness as something transitory.

It is not a coincidence that survivorship and prevention appear together in the cultural and medical imagination. The biomedicalisation regime appeared at a time when neoliberal politics spread (Navarro, 2009, p. 425), emphasising lifestyle and personal responsibility to avoid health issues. By the early 2000s, new healthcare models focused on being proactive and placing the patient at the centre of medical programming, such as the P4 model, based on prediction, personalisation of care, prevention, and the participation of patients (Hood & Friend, 2011). Health is celebrated as a personal undertaking, while environmental factors take the backseat (Sweeney & Killoran-McKibbin, 2016). For people who suffer from cancer, the transition into this understanding of health has sometimes been translated into a need to adopt an entrepreneurial attitude towards their diagnosis and treatment (Stage, 2018). With the development of individual well-being as a concept, health becomes something malleable, which we can influence. For some authors, this understanding of health can perpetuate illness as moral failing (K. Bell, 2010; Brenner, 2016; King, 2008; Sulik, 2011).

Health then makes it into the commercial arena, in the shape of lifestyles, healthy diets and other formulae that promise a future free of illness (Lupton, 1994, p. 85). In particular, breast cancer becomes the “poster child” of cause marketing, as explained by Barbara Brenner, director of Breast Cancer Action over 15 years and a critical voices in this field (King, 2008; Pool, 2011). Campaigns against this type of cancer grow in popularity, adopt the pink ribbon as their symbol, use metaphors of heroism to refer to patients, and develop the idea of the breast cancer survivor as a fighter, someone brave who smiles in the face of adversity (K. Bell, 2014; Little et al., 2002). Interestingly, they do not favour a discussion on the environmental factors known to be related to cancer, such as inequality; instead, they put their focus on personal responsibility and research.

To be fair, we now ought to take a step back: the neoliberal discourse of health has also been met with criticism. In parallel to the adoption of survivorship by businesses and the media, activists and researchers have been directly opposed to its

standardisation since at least the 1970s. Photographers like Jo Spence or Hannah Wilke, whose work is discussed later in this thesis, were among the most vocal. Critics of the discourse of survivorship denounce a “full-fledged religion” where cheerfulness is mandatory (Ehrenreich, 2001, p. 50) and highlight the social pressure that it imposes on patients (Broom et al., 2019). They also question the commercial use of awareness-raising campaigns (King, 2008; Sulik, 2011) and the normalisation of the feminine, triumphant, happy and healthy patient against any other experiences (Kaiser, 2008, p. 80).

From an empirical point of view, research shows that the discourse of survivorship can have negative effects on patients. For instance, for people suffering from terminal cancer, who cannot “win” in the popular sense, pressure to conform to the cultural image of a cancer survivor is an important stress factor (Park & Blank, 2012, p. 414). Similarly, survivorship has been shown to create an illusion of control (Ruthig et al., 2012, p. 1255) that can push some patients into neglecting their emotions and into adopt ingroles and attitudes that are not adaptive to their prognosis (Broom & Kenny, 2020; Willig, 2011). Cultural insistence on the triumphant cancer patient increases ambivalence, too (Merton & López Muñoz, 1980; Pertl et al., 2014). It has also been shown that survivorship campaigns neglect social inequality, portraying younger, whiter, and wealthier women (Macdonald et al., 2018; Rivera et al., 2021), while feeding gender stereotypes (K. Bell, 2014; Lupton, 1994, p. 84; Sweeney & Killoran-McKibbin, 2016, p. 458).

So, against the criticism, does cancer survivorship prevail as a discourse? Based on the literature review, it seems like it does. It appears to have permeated the social imagination of cancer (see the Systematic Review and Crying Photographs). Through what Katherine Bell calls a process of “breast-cancerisation”, mainstream representations of the breast cancer patient have spread to all other cancer sites. Awareness campaigns and the pink ribbon have become so common that we almost expect them, while we neglect or ignore images of cancer situated outside the common image. In other words, survivorship has become part of our everyday life.

3.4. From medical photography to auto-pathographies

Loaded with symbolic meaning as it is, cancer discourse has been accompanied by images that are now commonplace in social and traditional media. Perhaps the most common picture of cancer in popular culture is that of a woman with a scarf on her head, an image of the restitution narrative. All papers included in this thesis reflect on the photographic practices around the illness, especially on *Crying Photographs*.

While there are historical records of patient-driven accounts of cancer since at least the 19th century (Meek, 2017), research often points to the work of Jo Spence, Matuschka and Hannah Wilke between the 1970s and the 1990s as a departure from traditional photography and into a new image, owned by patients. Through their visual accounts of their cancer treatment, the three photographers offered an image that was radically different from that of medical and commercial photography. Theirs are crude and explicit photographs, charged with an activist intention to show cancer for what it is and to question social imperatives. *Crying Photographs* presents a brief review of their work and its relevance.

Modern documentary photographers have followed on Spence's, Matuschka's and Wilke's footsteps to present stories of cancer owned by the patient or their loved ones:

- 'The Battle we Didn't Choose' is the work of Jennifer and Angelo de Merendino (2013). It documents Jennifer's breast cancer, covering all phases of treatment. The title already points to its intention to offer an image that is in stark contrast with survivorship imagery.
- 'The Faces of Cancer' (G. Bell, 2018) is a long-term project in which the British photographer shares portraits of cancer patients across the United Kingdom. Bell highlights the therapeutic function of photography and discusses how her camera has allowed her to connect and relate to other patients.

- ‘Reality Trauma’, by Carly Clarke (Jarvis, 2019), is a visual diary that covers their diagnosis and treatment of a Hodgkin Lymphoma.
- ‘The Family Imprint’, by Nancy Borowick (Borowick & Estrin, 2017), portrays the experience of their parents through their simultaneous cancers, covering their everyday life.
- ‘This is Documentary’, by Jennifer Keenan (2015), follows a young couple, Josh and Jenna, after Josh’s diagnosis of a glioblastoma, a type of brain cancer.

These projects share the common objective to tell a story of cancer to the rest of the world. Four of the five listed are composed of black and white portraits that focus on showing detail and emotion. In their description, photographers often refer to the intention to visualise the whole experience of cancer, to show the patients’ courage in the face of mortality, and to inform others about treatment. In all of them, the camera is used to raise awareness and show the “reality” of the illness.

This thesis is not focused on documentary photography, but instead reflects on a type of image that shares its intention: **visual auto-pathographies** (Couser, 2011). Auto-pathographies, more broadly, are stories of illness told by the people who suffer from them. An iconic example in cancer are the Cancer Diaries by Audre Lorde, in which she narrates her experience of breast cancer, opposes the use of breast prosthesis, and reflects on the aesthetic imperatives that weigh on women who have undergone a mastectomy (Lorde, 1980).

Applied to photography, **visual auto-pathographies are thus photographs taken by patients to represent their own illness**. The practice has grown since the 1970s and is now seen as a tool to improve patient agency, to give voice to caretakers, and to promote patient-owned accounts (Pardo, 2019, p. 28). The pain and the changes that their bodies suffer makes it challenging for cancer patient to recognise themselves (Wilde, 2003), turning their bodies into strangers (Lindwall & Bergbom, 2009). Photographing the body, picturing their ill faces in the mirror, or

showing the scars of an intervention help patient reclaim their bodies (Bolaki, 2011). Visual auto-pathographies also reconsider the self and extend it beyond the body and into the patient's surroundings (McGavin, 2014; Yardley, 2013).

Researchers have approached visual auto-pathographies of cancer through both quantitative and qualitative lenses. In social media, the work of Carsten Stage (2018, 2019a, 2019b) is a prime example of qualitative research; outside social media, Stefanie Plage (2019, 2020, 2021, 2022) offers an in-depth review of how the photographic camera can help lung cancer patients find meaning and direction. Both Stage's and Plage's work informs this thesis, particularly the Systematic Review and Crying Photographs.

In the quantitative realm, research tends to focus on the elements shown in cancer images, the keywords that accompany them, or how the images are shared. Papers that follow this path find that cancer images often show white women who express positive emotions (Cho et al., 2018; Henderson et al., 2021; Rivera et al., 2021). They reveal an existing visual consensus (Storey, 2014), too: most images present socially appropriate ideas of cancer, aligned with the discourse of survivorship and similar to those used in commercial magazines (Andsager et al., 2001; Grant & Hundley, 2008).

On Instagram, research has shown that the image of cancer is often episodic: most posts visualise a "journey" through the illness (Reisfield & Wilson, 2004) and reflect on the "teachable moments" that cancer can bring (K. Bell, 2012). Patients picture themselves counting down to the end of their treatment; incorporate visual elements that bring them back to life before cancer (such as hair growth); and offer a visual contrast between the signs of treatment and their positive attitude (Cherian et al., 2020).

Survivorship images are not all there is to cancer photography on Instagram, however. As shown in Crying Photographs, alternative discourses (Ucok, 2007) are used to visualise the symptoms of this illness and to debate some of the social assumptions around it. These often take the shape of the chaos narrative described

by Frank (Frank, 2013, pp. 97–113): patients visualise the possibility of life never returning to normality and push against the expectation of restitution and the ideal patient. Their stories also reflect on the materiality of illness, reaching beyond their bodies to touch their social context, the institutions around them, and even their physical space (Yardley, 2013).

Some users tend to Instagram to renegotiate their identity as more than “just” a patient, questioning their capacity to “keep going” as expected in mainstream discourses, and not shying away from shocking images. At times, they use images to dissociate from cancer and visualise it as something outside their self (Gupta, 2022).

Sometimes, patients also deploy Frank’s quest discourse, where cancer is met “head on: they accept illness and seek to use it” (Frank, 2013, p. 115). Stage (2018) highlights how Instagram is a positive space for this.

By deploying the quest and chaos narratives, social media users that visualise cancer create new **affective spaces**. In the public eye, patients who opt for the visual discourse of chaos may appear as “bad patients”, “not interested in marching forward [and] not invested in life at any cost” (Steinberg, 2015, p. 135). Quest narratives seem to lead to supportive comments and significant impact online.

Olatz Vazquez’s story, in *Crying Photographs*, is an example of both the chaos and quest narratives: she met her changed body, reflected on mortality, and used her illness to advocate change in the public health system.

3.5. Instagram and the affects of health imagery

As discussed in the Systematic Review and on *Whose Cancer*, social media are an important means for cancer patients to obtain information about the illness (Hawkins et al., 2008). They also help understand and manage symptoms (Bender et al., 2013), build communities (Moorhead et al., 2013), and strengthen emotional support (Attai et al., 2015; Hale et al., 2020; Skrabal Ross et al., 2020). In particular, Instagram has

been found to facilitate the representation of people with lesser-known cancer sites (Noar et al., 2018; Stage, 2019a; Tetteh, 2021). Meanwhile, visuals are well-established as a successful vehicle to ensure that health information is both understood and retained (Houts et al., 2006). Beyond these functionalities, perhaps to be expected of a visual platform, Instagram is a field where affects can morph the identity and the emotional well-being of patients.

Affects can be understood as socially constructed emotions, often linked to cultural patterns, which are assigned to social events, groups, and attitudes. A term coined by Sara Ahmed, the **affective economy** refers to the process by which certain affects can be created and exploited (Richard & Rudnyckyj, 2009, p. 62) by social actors. Through media and political messaging, affects can be made to “stick” in society—when an affect becomes “sticky”, it becomes part of the emotional baggage of a large social group. Sticky affects are difficult to change given how deeply rooted they become. A clear example of this process is how the media and certain political actors used xenophobic messaging and demonisation to build an image of Islam as a threat to American society after the 9/11 attacks.

In social media, affects and their economy operate more subtly. They appear linked to a psychological need for emotional wellbeing. Seeking such wellbeing, users on sites like Instagram connect with other users and organisations who promote an image that aligns well with their own cosmology (Murphy, 2018). They favour emotions that are more adaptive to their needs, while avoiding images that sit uncomfortably in their emotional baggage, a process that appears to be reinforced by recommendation algorithms.

In the communication of cancer, the affective economy appears to have favoured the use of images aligned with survivorship. Motivational images that show the cancer patient as a fighter seem to perform notably better and to be prioritised by posters and commenters. Stage’s research shows that breast cancer patients tend to Instagram to escape from the fear and uncertainty that come with cancer diagnosis (2018, 2019a). If they picture themselves as vulnerable or scared, other users quickly

bring them back to the survivorship discourse, reassuring them that everything will be okay and that they “can do it” (Stage, 2018; Tetteh, 2021). Next time, when they picture themselves as hopeful and optimistic, their followers react with more likes and supportive comments.

Steadily, this **affective tailwind** (Stage, 2019a, p. 89) motivates users to continue posting positive images, creating an affective space that Instagram integrates into its design through its prioritisation algorithms. Eventually, a “black box” is built: a standardised set of emotions that are expected when visualising cancer on Instagram, and which does not allow for the healthy expression of other feelings (Bösel, 2020).

3.6. Connecting the dots: theoretical linkages between the papers

The four papers presented in this thesis draw a path that integrates everyday life sociology, visual sociology, and digital sociology. Each paper addresses the three disciplines differently, however.

The Systematic Review dives into the functions of social media for health communication more broadly and pays attention to how visual auto-pathographies are used in social media. It underlines risks of social media disinformation while addressing the division between quantitative studies and qualitative research.

Scattered Images builds on the assumptions of visual sociology and incorporates some of its methods to analyse images. It discusses existing methods and their limitations, especially as applied to Instagram. The use of computational tools is reviewed as a potential way to bridge some of the existing gaps.

Based on the method developed in the second paper, Whose Cancer centres its theoretical discussion on the use of social media by cancer patients specifically, and how it can affect their emotional wellbeing. It discusses the role of Instagram images in social research, with particular attention to quantitative approaches, and considers some of the theoretical explanations that have been given to the overrepresentation of breast cancer.

Lastly, *Crying Photographs* builds on qualitative work to approach image analysis. Based on a review of previous work on visual cancer discourse, it deals with issues of perception, the different meanings that may be implied in the use of certain elements in the image, and how affects influence the representation of different cancer sites.

Through the four papers, social media are understood as key component of everyday life. Figure 2 on the next page summarises the main theoretical standpoints in the thesis.

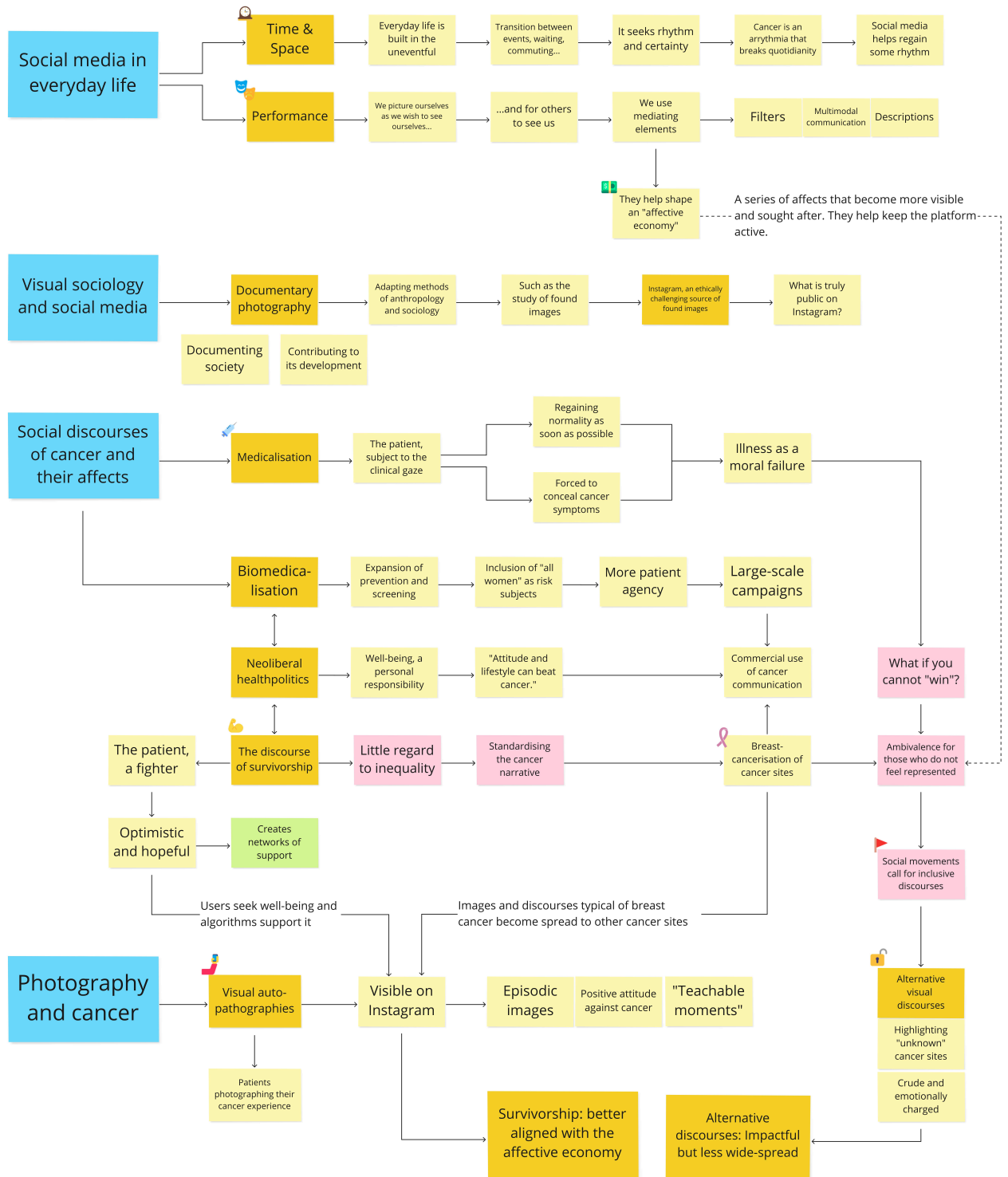


Figure 2. The theoretical standpoints of this thesis and its transdisciplinary backbone

4. Methodology and process

While each paper details its specific method, this section summarises some of the main methodological and practical considerations throughout the research.

4.1. Social media research as methodological “bricolage”

Part of the challenge in approaching social media from a research lens stems from their very definition. This thesis follows the definition given by McCay-Peet & Quan-Haase:

[...] 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. (McCay-Peet & Quan-Haase, 2016, p. 23)

By extension, visual social media are here understood as **those where visual contents are the primary form of communication**. Based on this understanding, each paper constructs its method through a process of “bricolage”, reinventing and adding new components from different theoretical and methodological fields as new challenges arise (Lindgren, 2020, p. 30).

The components of this bricolage seek to respond to four main challenges: how to obtain images for their study; how to treat said images; how to interpret their meanings; and how to use images to communicate the results.

Obtaining the images

Instagram is a vast platform, where millions of images coexist. Given the objective of this thesis to evaluate the presence of standardised visual discourses of cancer and to discern the representation of different cancer sites, it was clear from the beginning that some kind of automation would be necessary. Described in *Scattered Images*, the method to obtain images begins with the observation of selected profiles to

identify cancer-related keywords. A Python code was then developed based on a series of pre-existing programs to accelerate the search and obtention of metadata.

Treating the images

Contrary to text analysis, where texts may be modified or masked, altering an image often implies removing its basic information—on the other hand, not altering it could expose the identity of the poster and thus put them at risk. This fact hampers the use of images in social media research, which to date continues to be limited. The work of Lev Manovich (2018b) is a successful example of how social media images can be used while avoiding their individual identification: thousands of photographs can be merged together in large-scale polar graphs that reveal visual patterns while making it impossible to discern any of them individually. This method was applied to *Whose Cancer*.

Analysing the images

Particularly complex was the task of studying and interpreting the images obtained. While the study of texts in social media has seen great progress in the last decade, the coding and analysis of photographs remains a controverted and underdeveloped area. There are promising examples, however. Apart from Manovich's work, image analysis has shown potential in the study of health communication (Hale et al., 2020; Tetteh, 2021); in political communication (Filimonov et al., 2016); or in the study of social movements (Bogerts, 2022; Doerr et al., 2015; Rossi et al., 2022).

Close to the aim of this thesis, the Systematic Review reveals both quantitative and qualitative efforts to study images in patient-driven cancer communication. Instead of opting for one or the other approach, this thesis seeks to bring them together, developing coding processes that are both inductive and deductive. These are based on a combination of principles and frameworks developed by Barthes (1977); Berger (2016); Panofsky (1970, 2004); Rodríguez & Dimitrova (2011); Rose (2016) and Kress & van Leeuwen (1996). The method for image interpretation is described in detail in *Whose Cancer* and *Crying Photographs*.

Visualising the results

As a visually-driven thesis, all papers sought to use images to communicate its results. However, using social media images is not an easy route to take, hurdled by ethical and technical challenges. Photographs on Instagram often contain elements that make it possible to identify the user who shared them, putting them at risk. On the other hand, obtaining permission to reproduce said images is only possible in studies that are more limited in scope—for research conducted on thousands of images, it is virtually impossible.

The four papers in this thesis, and the text that connects them, use different resources to bypass these challenges. The aim is to facilitate the comprehension of the thesis through visual means. Thus, the Systematic Review makes use of diagrams that summarize the main results. These are based on the PRISMA framework (Moher et al., 2009), but also on the authors' own proposals. Scattered Images also incorporates visual elements, albeit simpler ones such as histograms and one image that is a collage of multiple breast cancer-related photographs. Meanwhile, Whose Cancer presents a series of polar graphs, a resource observed in the work of Lev Manovich (2020) and which allows for the inclusion of thousands of images and their organisations based on quantitative and qualitative categories. Lastly, Crying Photographs uses images from Olatz Vazquez's profile, having obtained the informed consent of its administrators to reproduce them.

With a method and theory built from different disciplines, being able to connect and represent ideas simply was crucial. For this, I make use of diagrams based on dialogue mapping methodologies (Conklin, 2006). Dialogue mapping is primarily a method for facilitation, but it also excels at visualising key ideas in a text or conversation. By applying an approach close to thematic coding (Thomas & Harden, 2008), it helps see the connections between thematic areas. A similar approach is applied to pedagogic materials, such as Hernández-Sampieri and Fernández-Collado's seminal book on research methodology (2014).

Lastly, I use outlines to represent some of the images observed in social media, a method that has shown great potential in political communication (Trillò et al., 2021; Trillò & Shifman, 2021), and image montages to condense the portraits of over 60 cancer patients observed on Instagram.

Throughout the identification, treatment, coding and visualisation of the images, the principle of “theoretical sensitivity” as described by Lindgren (2020) is applied. Aware that photographs are never aleatoric nor a perfect representation of reality, all papers seek to offer theoretical considerations that sit outside the study of social media (whether they come from documentary photography, health studies, or feminist studies), adding to the transdisciplinary nature of this thesis.

4.2. Ethical challenges in online research

Interpreting images from social media is high-voltage. Social media are volatile and sometimes hostile to research, with constant changes to their terms of use. Legally, approaching this topic entails taking one of two paths: either accepting the limitations imposed by Meta, or breaking the rules (Bruns, 2019).

Beyond the legal hurdles, however, the path to studying social media images is also covered in ethical gaps. The observation of public profiles in social media bears the debate on what is *truly* public, and to which degree can we engage with the contents that we see. Some of the standards applied in current research date back to 2012, a time where the legal and cultural context of social media was entirely different from today’s. Markham & Buchanan’s guidelines developed for the Association of Internet Researchers (2012) are often cited in the literature, but they date to a time where the Cambridge Analytica scandal had not happened and privacy laws were exponentially more relaxed.

In 2017, Markham & Buchanan (2017) themselves reflected on how challenging it is to propose specific guidelines to online research, and updated their proposal. Among their recommendations was that of considering that social media subjects

are *constantly* exposed to the risk of being identified through their contents, and to ponder whether such identification could entail physical, economic, or psychological risk. Both of Markham & Buchanan’s guidelines (from 2012 and 2017) have been applied to this thesis, along with considerations offered by other authors on the treatment of selfies and medical imagery (McGill, 2020; Nguyen et al., 2018). Image IDs were removed from the download process—they were instead assigned randomly generated numbers to help work with them. Photographs with sensitive content of any kind were removed (including those where people who appeared underage were pictured). All images were stored in a protected drive. When visualisations were used, they only showed fractions of the images.

In *Crying Photographs*, the informed consent of Olatz Vazquez’s profile administrators was obtained to both conduct the study and to use some of the images. Beyond this, it was deemed unnecessary to obtain further permissions and ethical clearance for the production of this thesis.

Figure 3 reflects the components of the methodology and how they connect with each other.

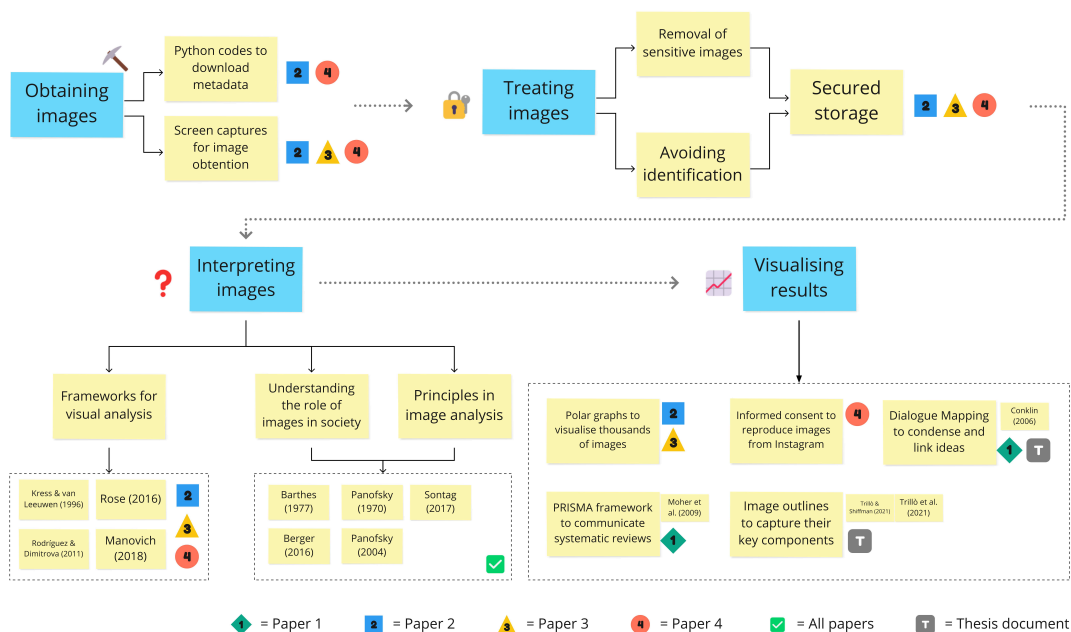


Figure 3. Methodological components of the thesis

5. Published papers

5.1. Paper 1: Systematic Review

Varela-Rodríguez, M., & Vicente-Mariño, M. (in press). Images published by cancer patients in social media and their reception: A systematic review. *Review of Communication Research*.

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Received: 11 January 2022


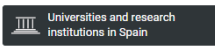
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Spain 	Social Sciences └ Communication		5
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1 **Images published by cancer patients in social media and their reception: a**
2 **systematic review**

3 *Interest groups: Visual Communication Studies; Health Communication*

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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.

Keywords

Visual sociology; Health Communication; Cancer Photography; Public understanding of science; Discourse analysis

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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

90 With World Breast Cancer Awareness month in October and the Movember movement in

91 November, the last quarter of the year sees scores of cancer-related news and posts in social media.

92 Users publish messages and images to support patients, share experiences of treatment, or

93 participate in fund-raising campaigns for cancer research. During these months, thousands of

94 images mention breast cancer, a site that achieves high levels of engagement on Twitter, Instagram

95 and Facebook (Vraga et al., 2018), as well as on Imgur (Hale et al., 2020). Other cancer sites, such

96 as skin cancer, also receive attention (Banerjee et al., 2018).

97 The study of social media as a space for cancer communication has grown in recent years. Post

98 metadata, their features, the level of engagement with them, and the discourses they create have

99 been subject to numerous studies. Systematic reviews in this area have analysed the psychosocial

100 impact of social media (Skrabal Ross et al., 2020), their usefulness for clinical trials (Reuter et al.,

101 2018), or their measurable effects on health outcomes (Chou et al., 2020). Overall, research shows

102 that social media help communicate cancer prevention and screening measures, support patients

103 during treatment, and provide psychosocial and informational support to patients and caregivers

104 (Attai et al., 2015; Chou et al., 2020).

105 This paper taps into an emerging area in the literature: the use of photographic images in social

106 media to communicate cancer. The systematic review covers three databases (PUBMED, SCOPUS

107 and Web of Science) and 17 years of publications (from 2004 to 2021). Papers are assessed first

108 on six criteria, related to language, access and whether the paper attempts an analysis of images

109 related to cancer in social media. Papers that pass these first criteria are then reviewed in-depth to

110 determine whether they focus on still images, whether they address social media and content

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

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

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

134 **Problem statement and goals**

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

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

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

154 Importantly, social media posts discussing health have been found to contain significant volumes
155 of misinformation. Wang et al. (2019) illustrate how posts discussing health often contain fake or
156 inaccurate facts, especially around infectious diseases and cancer prevention. Suárez-Lledo &

157 Álvarez-Gálvez (2021) note that cancer-related topics such as the HPV vaccine are particularly
158 affected, as misinformation is liked and shared more than accurate medical information. Extant
159 research also suggest that social media amplifies the search for unproven, alternative treatment,
160 unsupervised advice, and false promises on prevention (Delgado-López & Corrales-García, 2018;
161 Wilner & Holton, 2018). Wang et al. explain that viewers need certainty and reassurance, which
162 misinformation sometimes provides.

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

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

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

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

184 Thus, reviews in the biomedical fields often take issue with the lack of hard evidence in the social
185 sciences. An example is the review by McAlpine et al.: while they affirm that social media appear
186 to have a “mildly positive effect” on cancer patients, they also highlight how “the vast majority
187 [of papers studied] report only simple qualitative analysis”. This is found to limit their capacity to
188 lead to measurable health outcomes (McAlpine et al., 2015, p. 293). Similar concerns are raised in
189 Koskan et al. (2014) and can be seen in systematic reviews across different cancer sites, be it breast
190 cancer (Falisi et al., 2017), colorectal cancer (Pellino et al., 2017) or prostate cancer (Pyle et al.,
191 2021). Despite the challenges in establishing a clear correlation between health improvements and
192 social media usage, it has been observed that social media does increase the uptake of preventive
193 measures (Han et al., 2018) and the likelihood of screening (Döbrössy et al., 2020).

194 On the other side of the spectrum, social scientists highlight how biomedical studies neglect the
195 non-medical aspects of treatment, “leaving survivorship to the wayside” (Cherian et al., 2020, p.
196 16). Through qualitative approaches, their work addresses the effects of misinformation on patients
197 (Delgado-López & Corrales-García, 2018; Wilner & Holton, 2020), the adoption of social
198 discourses on illness and how they relate to user agency (Stage, 2019a, 2019b), and how social
199 media can increase the participation of underrepresented groups (Pailler et al., 2020; Rivera et al.,
200 2021). In sum, they find that social media “can create a space to share, comment and discuss health

201 information” (Moorhead et al., 2013, p. 9). The finding comes with a warning, however: social
202 media is useful when research goes beyond commonly studied platforms, when it includes the
203 perspectives of underprivileged groups, and when it expands the reach of study to cancer sites that
204 are less present in public communications (Grant & Hundley, 2008; Hale et al., 2020; Macdonald
205 et al., 2018).

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

210 **Approaching images in social media**

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

221 Cancer photographs taken by patients and caregivers reflect the “here and now”, an instant in the
222 journey of illness as seen by those who live through it. As Sontag put it, photographs are a “way

223 of dealing with the present” (2008, p.130). For people that live with cancer, dealing with the
224 present may entail showing the effects of chemotherapy, expressing hope for restitution through a
225 thumbs up, showing gratefulness to their caregivers as they embrace them, or showing the physical
226 and emotional toll when they simply do not have the strength to get out of bed. Through the camera,
227 patients “deploy normality”, coexist with their illness, reflect on what they may have left behind,
228 and normalise life with illness in the eyes of the viewer (Plage, 2021).

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

240 Photographs do not exist in isolation in these platforms, however, not even in visual social media.
241 They coexist with audio, video, text, polls, and other interactive elements. Users add text (both to
242 the captions and to the image itself), hashtags, filters and enhancements to guide the perception of
243 their post, deploying the anchorage function that Barthes outlined already in the 1970s (Barthes,
244 1977, p.40). Further, the grid layout and the infinite feeds of Instagram, Pinterest or 9Gag perform
245 a relay function (Barthes, 1977), engaging the viewer in a continuous visual discourse that tells a

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246 story and propagates a message. Applied to cancer, these two functions (anchorage and relay),
247 along with Instagram’s algorithms that prioritise the best-performing posts, lead to the creation of
248 social discourses of cancer (Stage, 2019b, p. 272): images that are socially recognised as
249 representative of this group of illnesses.

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

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

264 When it comes to their interpretation, Barthes (1977) provides a fitting framework for visual
265 analysis with the distinction between denotation and connotation. Overall, denotation refers to
266 identifying what is in the picture, with little to no interpretation, and with no reference to
267 supporting documents such as captions. Individuals, objects, and environments are part of this

268 level. A denotative analysis indicates there is a person, a building, or an animal in the frame,
269 without identifying them by name.

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

273 These two levels of visual study, denotation and connotation, are expanded with Panofsky's (1991)
274 framework for iconology. Panofsky spoke of the primary subject (the elements in the image;
275 equivalent to denotation), the secondary subject (what the elements in the image are meant to
276 represent; equivalent to connotation) and the intrinsic meaning. Some authors refer to this latter
277 level as "ideological" analysis (Rodríguez & Dimitrova, 2011). It evaluates the social messages of
278 an image and what it can tell us about its context. Engaging in this level of analysis helps
279 understand the context that has led to the production of an image, the ideas that it portrays, and
280 what their producers try to tell us about the world. For instance, through ideological analysis we
281 can identify that a pink ribbon is a symbolic representation of support to cancer patients.
282 Descriptions, captions and comments are common resources to support this task.

283 Lastly, there are other components of image semiotics, mainly those relating to modality and
284 framing. At this level, framing is understood as the position and composition of elements in the
285 image: assessing the relationship between the subjects pictured and how they are presented to the
286 viewer, whether there are elements in the image that are more salient than others, or whether the
287 photographer uses visual devices to highlight the subject. Issues related to thematic and episodic
288 framing (which are explained in detail in further sections) may also be explored here. Meanwhile,
289 image modality refers to visual devices that regulate the "realness" of an image: the use of black

290 and white, extreme saturation, filters or strong lighting, for instance, are elements that make images
291 appear stylised and thus further from reality (see Kress & van Leeuwen, 2010).

292 Applying visual analysis should enable a deeper understanding of images in social media. To our
293 purpose, it can reveal patterns in our social imagination of cancer. While previous research has
294 highlighted the scarcity of this type of analysis in visual social media (Highfield & Leaver, 2016),
295 the social media-cancer nexus has seen some progress. Kearney et al. (2019) reviewed the
296 representation of the HPV vaccine on Instagram and how viewers reacted to different images;
297 Ketonen & Malik (2020) implemented a machine-learning method to identify and characterise
298 vaping posts on Instagram; Banerjee¹ et al. look at representations of tanning on Pinterest (2019)
299 and how they affect the perception of skin cancer. For cancer screening and health messaging,
300 images have been shown to increase recall and information uptake (Houts et al., 2006). However,
301 our review has found few papers that engage in a discussion of visual representations of cancer as
302 produced by patients or caregivers. Thus, there is a gap in understanding how people who live
303 through cancer imagine the illness and their life with it. To our knowledge, no systematic review
304 has been conducted on this topic before, either.

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

¹ 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.

310 **Methodology**

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

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

318 **Understanding of “photographic images”**

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

324 **Understanding of “social media”**

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

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

330 Mentions to broader online communities (such as forums or blogs) are also considered, to avoid
331 missing papers that consider the visual discourses in patient-generated images of cancer online.

332 Conversely, the broader discussion of cancer photography, outside social media, informs the aim
333 of the paper but is not considered for the results, as the research is interested in the nexus that
334 exists between social media and photography.

335 **Research questions**

336 An overall question was formulated:

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

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

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

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

346 **Search strategy**

347 ***Research Dates***

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

351 *Paper sources*

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

356 *Platforms considered*

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

360 *Search queries*

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

363 1. **General searches** that combine social media, visual elements, *and* cancer:

364 a. **PUBMED:** *((("Social media") AND ((Photogra*) OR (imag*) OR (visual*))) AND*
365 *((cancer) OR (tumor))) AND ((("2004/01/01"[Date - Publication] :*
366 *"2022/11/11"[Date - Publication]))*

367 b. **SCOPUS:** *(TITLE-ABS-KEY ("social media") AND TITLE-ABS-KEY (cancer*
368 *OR tumor) AND TITLE-ABS-KEY (photogra* OR imag* OR visual*))*
369 *AND PUBYEAR > 2003*

370 c. **Web of Science** (with manual selection of dates: 01/01/2004 to 11/11/2022):

371 *ALL=("social media") AND ALL=(photogra* OR visual* OR imag*) AND*
372 *ALL=(cancer OR tumor)*

373 2. **Platform-specific searches**, substituting the term “social media” for either “Instagram”,
374 “Facebook” or “Twitter”.

375 a. In a second round, additional searches were conducted for the terms “selfie” and
376 “health communication”, as well as for additional platforms (Pinterest, Imgur,
377 Reddit, 9Gag, Tiktok and Snapchat)

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

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

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

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

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

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

398 For papers that passed the high-level criteria, an additional round of exclusion was implemented.

399 This is a more detailed round, where papers are excluded if:

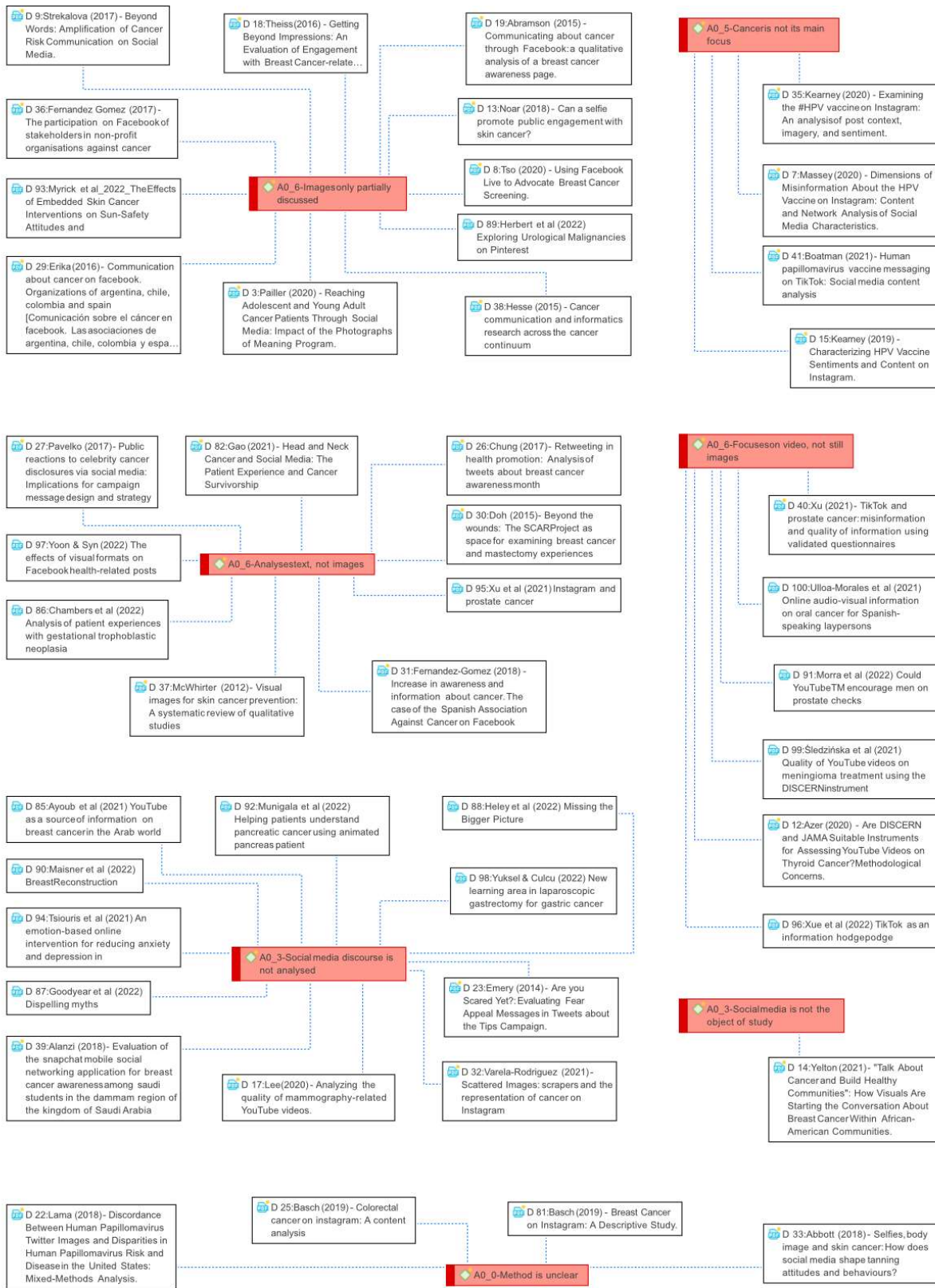
- 400 1. **Images are only partially discussed.** Images are not discussed as a core part of the study.
401 Instead, papers commonly utilise a quantitative approach that solely mentions that an image
402 is present in a post. Thus, images are considered in the results, but researchers do not
403 engage with the contents of said images nor their effect.
- 404 2. **Focuses on video, not still, photographic images.** These are mainly papers that focus on
405 YouTube or TikTok, and typically deal with audio transcripts. Moving images include
406 elements of rhythm and montage that merit their own analysis.
- 407 3. **Social media is not the object of the study** but used as a tool to connect with patients.
408 This includes clinical trials that are disseminated via social media, or which use
409 photographic applications to simulate changes in the user's body if they do not engage in
410 preventive behaviour. These papers are relevant for cancer prevention and screening, but
411 do not focus on patient- or caregiver-generated discourses of cancer.
- 412 4. **The paper analyses text, not images.** The paper uses text analysis as its primary method.
413 While images may be mentioned, they are not analysed individually nor collectively.
- 414 5. **Cancer is not the focus.** The paper might mention elements related to cancer or analyse
415 environmental factors such as smoking or tanning, but cancer is not its primary focus,
416 which means a discourse of cancer cannot be extracted.

417 6. **Social media discourse as generated by patients is not analysed.** These papers typically
418 look at images posted by health practitioners or organisations, analysing their quality, or
419 instead discuss image-analysis methods to diagnose cancer. Sometimes they engage in a
420 review of an organisation’s campaign. While relevant, these papers fall outside the scope
421 of our review as they do not address patient-generated visual discourses of cancer. Where
422 papers were found to focus on cancer discourses as generated by caregivers, they were
423 considered for full analysis.

424 7. **Method is unclear.** These are often abstracts without an accompanying paper, conference
425 presentations, or papers that have unclear sources.

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

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428

429

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

430 **Data management and analysis**

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

439 **Search Results**

440 The search queries implemented returned a total of 1247 papers. We removed 528 duplicates, and
441 24 additional records were added through snowballing, making for a total of 743 records for title
442 and abstract review. The PRISMA flowchart in Figure 2 visualises the different steps.

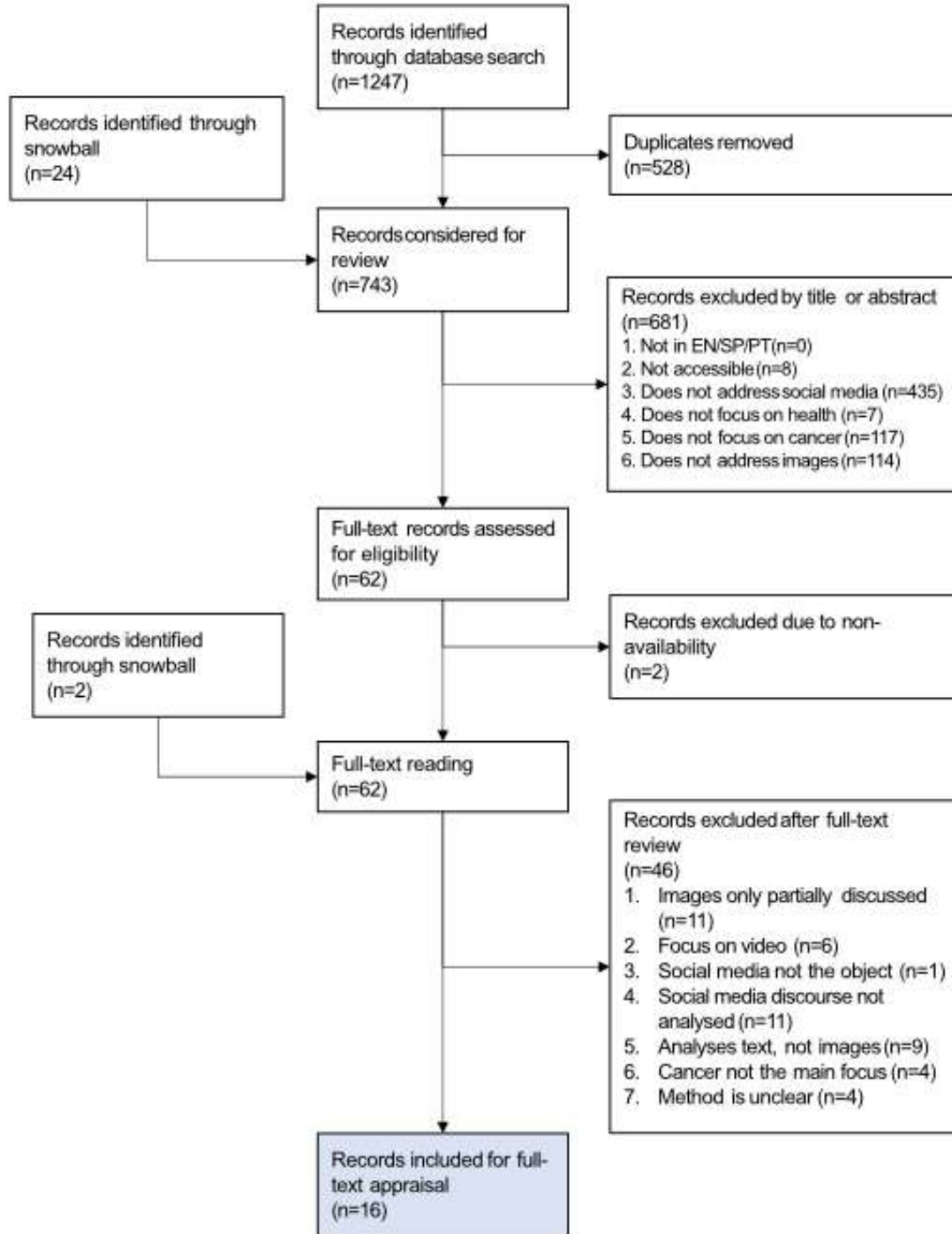


Figure 2. PRISMA Flowchart

443

444

445 Most of the papers rejected (435) do not study social media, despite being returned by the queries.

446 Of those that do address social media, many either do not focus on cancer (117) or do not study

447 images (114). We found 20 papers in the sample that do not mention social media in their title or

448 abstract but refer to “blogs” or forums”. None of them were found to conduct a visual discourse
449 analysis or image content analysis. It thus appears that, despite social media-cancer being a rich
450 field of study, visual representations of the illness by patients or caregivers remain an area to be
451 explored.

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

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

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

469 A table is provided in annexes that details the 16 papers, the number of images they review, their
470 methods to obtain images and to code them, and the cancer sites they focus on.

471 ***Methodologies used and cancer sites represented***

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

475 ***Visual analysis and image aesthetics***

476 Information is collected on whether the papers attempt to conduct a visual analysis as per Barthes's
477 (1977), Panofsky's (1991), Kress & van Leeuwen's (2010) or Rodriguez & Dimitrova's (2011)
478 frameworks. These four models aim to evaluate the process of meaning-making in photographs
479 through the use of distinct subjects, light sources, and composition, as well as external elements
480 like text. Papers may adapt these frameworks or apply them indirectly.

481 ***Extracting common discourses***

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

485 First, each paper was thematically coded (Thomas & Harden, 2008) using Atlas.Ti. This method
486 entails the in-depth reading of each paper and the verbatim coding of their findings and core ideas.

487 The result is a number of quotations from each paper.

488 Second, each of these quotations was re-read and reinterpreted by both authors, who then
489 summarised and clustered them into general statements. Statements take the shape of a single

490 phrase that seeks to encapsulate the findings expressed in the larger quotations. This allowed the
491 authors to analyse and compare different statements.

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

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

502 Take the following three quotations as an example:

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

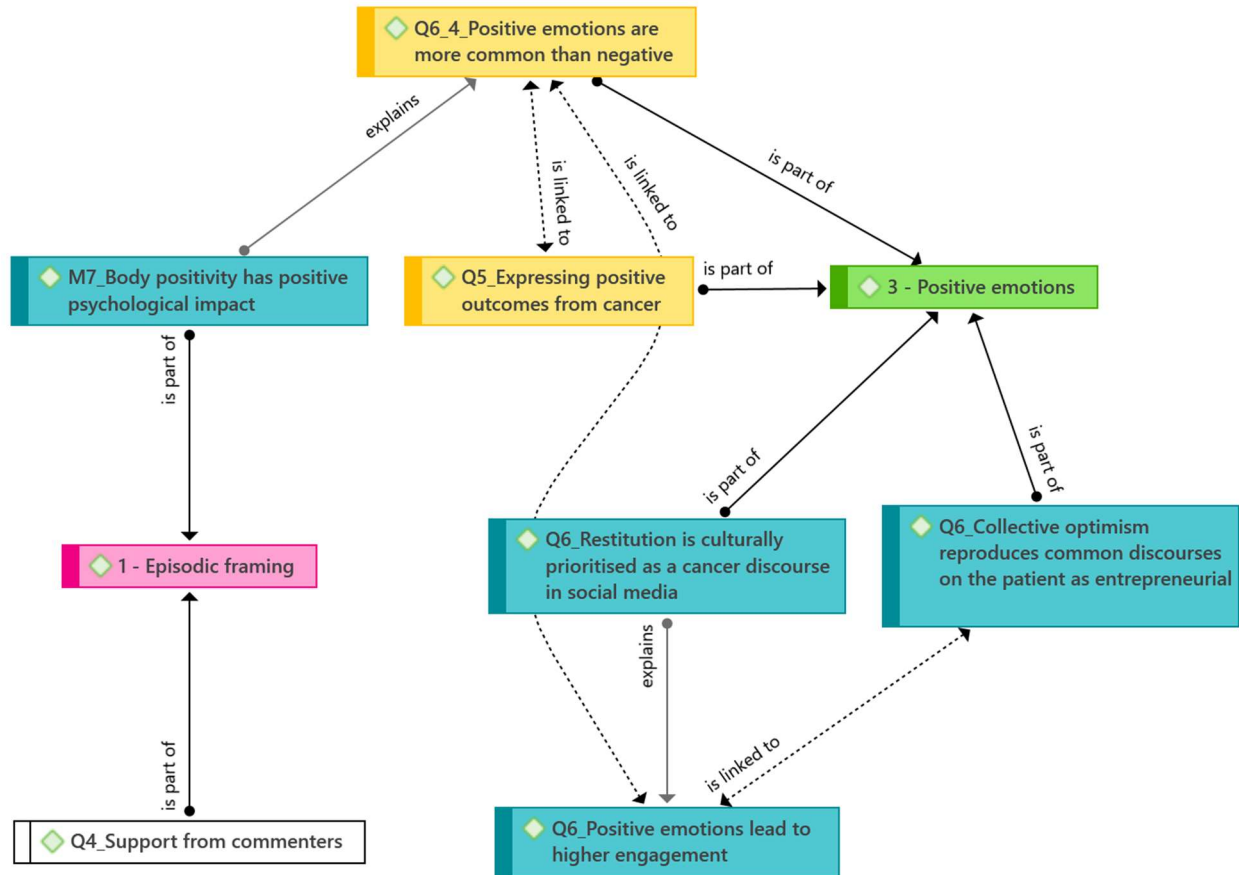
506 *"The smooth overlap between the happiness and loving optimism expressed*
507 *and produced through sharing treatment metrics is based on a general cultural*
508 *prioritization of restitution narratives [...]" (Stage, 2019a, p. 90)*

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

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

515 *“Restitution is culturally prioritised as a cancer discourse in social media.”*

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



521

522

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

523

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.

526

Results

527

Representation of cancer sites

528

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

531

532 cancer in the images. One paper discusses ovarian cancer through the qualitative analysis of a
533 single profile, while the rest address cancer more generally.

534 *Methodological approaches*

535 Most of the papers in the final sample (15) are in English; one is in Spanish. Papers focus on
536 Instagram (6), Pinterest (4), Facebook (2), Imgur (1), a combination of Facebook, Instagram and
537 Twitter (1), and a combination of Twitter and Instagram (1). Methodologically, two of them
538 engaged participants in a survey and interview or performed keyword-based searches with them;
539 four observed specific profiles over an extended period; and the rest (10) conducted hashtag or
540 keyword-based searches to identify images mentioning different cancer sites or cancer-related
541 phrases.

542 The papers can be divided in two groups depending on their approach to image coding and
543 discourse analysis. On the one hand, four papers (Gupta, 2022; Stage, 2019a, 2019b; Tetteh, 2021)
544 implement an in-depth, qualitative study of Instagram profiles. This results in a thorough analysis
545 of discursive practices in the images and the reactions that they prompt. Three of these, Gupta's
546 and both of Stage's, show some of the images studied within the paper and engage in an analysis
547 of their content, facilitated by the informed consent of the research subjects. Images and text are
548 weaved together, creating a conversation between visual and textual exposition.

549 On the other hand, seven papers (Cho et al., 2018; Henderson et al., 2021; Ma & Yang, 2022;
550 Miller et al., 2019, 2020; Park et al., 2019; Varela-Rodríguez & Vicente-Mariño, 2021b) deploy a
551 methodology that leans on quantitative approaches. They conduct content analysis to measure the
552 presence of certain elements in the images and how they affect engagement metrics. Of these, only

553 Varela-Rodríguez & Vicente-Mariño include images in their papers (either non-identifiable or
554 posted by a public organisation or business), while most do not offer visual support to the text.

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

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

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

567 **Visual analysis and image aesthetics**

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

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

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

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

596 Lastly, ideological analysis is presented through elements of the health beliefs model (Cho et al.,
597 2018; Park et al., 2019), misinformation (Rivera et al., 2021; Wilner & Holton, 2020); different
598 types of social support (Hale et al., 2020); or different social cancer discourses (Cho et al., 2018;
599 Varela-Rodríguez & Vicente-Mariño, 2021). Qualitative papers (Gupta, 2022; Stage, 2019a,
600 2019b; Tetteh, 2021) put emphasis on this level, engaging in a discursive analysis of what social
601 media images can do for cancer discourse and for patients' identities.

602 **Three discursive lines**

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

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

615 **Second discursive line, emotion: positive vs negative.** This line is drawn to locate images
616 between the poles of positive and negative emotions. Images that visualise positive emotions, such
617 as hope, generate different responses from viewers than those that visualise negative emotions,

618 such as fear (Cherian et al., 2020; Hale et al., 2020; Henderson et al., 2021; Stage, 2019a). Drawing
619 a line between these two poles highlights the importance of emotions in social media photographs
620 of cancer. The line appears more clearly in papers that study episodic images, while it does not
621 appear to be as relevant for more neutral, thematic images.

622 **Third discursive line, purpose: addressing the self or the other.** As an extension of the
623 episodic-thematic continuum, this third line situates images between two poles that we have called
624 “me” and “you” messaging. It emerges from papers that pay closer attention to educational images
625 (Hale et al., 2020; Park et al., 2019; Rivera et al., 2021), but is also present in qualitative inquiries
626 into patient identities (Gupta, 2022; Stage 2019a; 2019b). This discursive line distinguishes two
627 types of images: those that aim to visualise the posters’ experience of cancer, and those that
628 explicitly intend to change the viewers’ attitude towards cancer. “Me” images thus tell the poster’s
629 story: through them, patients and caregivers maintain a visual diary, share a moment in treatment,
630 or represent the changes they observed in their bodies. In other words: “this is *my* cancer”, “this is
631 how *I* have changed” or “this is who *I am*”. “Me” images engage the viewer in the experience of
632 cancer through the eyes of the poster.

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

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

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

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

642 **First discursive line, framing: cancer as a personal story or a general theme**

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

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

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

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

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

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

665 Patients appear to post this type of image regularly, often including quantifiable elements to
666 indicate progress: hair (and its loss), medical equipment, fingers forming a number that indicates
667 how many chemotherapy sessions are left... Together, they build the “journey” of cancer (Cherian
668 et al., 2020), a collection of “small stories” (Stage, 2019b) that are presented by a single user but
669 given meaning to in cooperation with commenters, likers, and followers. Episodic framing also
670 appears to serve a therapeutic function:

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

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

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

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

691 Interestingly, the use of episodic images on Imgur contains traits that are not reported for other
692 platforms. Here, photographs that discuss the cancer of another person or of their pets are more

693 common than self-referential images (Hale et al., 2020, p. 6). In fact, when patients post their own
694 stories of cancer on Imgur, they receive less supportive comments than when they post those of a
695 loved one (human or otherwise). Regardless, episodic images appear to retain their affective
696 tailwind against thematic publications (Hale et al., 2020, p. 7).

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

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

705 On the opposite pole of this line are images that do not visualise cancer as an individual's journey,
706 but instead present information specific to a cancer site, its treatment, its prevention, or its
707 symptoms:

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

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

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

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

724 When it comes to the reception of thematic images, results seem inconclusive. Information-heavy
725 posts achieve higher shares on Pinterest, where they are perceived positively (Miller et al., 2019,
726 2020; Park et al., 2019). It also seems that the inclusion of text within the image facilitates their
727 uptake on Facebook (Ma & Yang, 2022).

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

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

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

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

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

750 **Second discursive line, emotion: an affective line between optimism and fear**

751 *Positive emotions: celebrating milestones and the hope for restitution.*

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

755 In the sample, optimism is visually contrasted with signs of treatment and cancer symptoms. In a
756 picture shown by Stage (2019b, p. 278), an Instagram user who has undergone a double

757 mastectomy sunbathes with a lush lawn behind her. Her smile and her skin, lit and tanned by the
758 sun, contrast with the visible scars left by the intervention. The patient reflects on this contrast in
759 the caption while she reaffirms her identity and highlights the positive aspects of no longer having
760 breasts. Stage discusses the impact of this optimistic framing, and notes that 7 out of the 10 most-
761 liked posts in this patient’s feed were images showing her “bare-chested, with one or two breasts
762 removed, while smiling” (2019b, p. 278).

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

770 Positive images are thus often intertwined with episodic framing and are used to celebrate
771 milestones in treatment and share moments of joy. Patients invite their followers to join in
772 celebration and accompany their hope for a return to life as it was before cancer. This type of
773 framing is reminiscent of the survivorship discourse, which presents patients as brave and positive
774 fighters. This discourse is salient on key dates such as World Breast Cancer Day (Cherian et al.,
775 2020). It is sometimes found to promote a normative discourse on femininity, using the female
776 body to get attention and showing highly stylised images of young and healthy women (Gürtler et
777 al. 2022, p. 157-158).

778 The results of positive framing vary depending on the platform. Conducting a large-scale study,
779 Cho et al. (2018, p. 9) find that it does not increase the number of likes on Instagram, while Stage’s

780 (2019b) study of a patient's feed signals that positivity does seem to increase likes. On Instagram
781 and Twitter, Cherian et al. (2020) find that positive framing performs best when it challenges
782 dominant discourses, showing that cancer patients can also be happy and self-fulfilled despite their
783 illness.

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

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

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

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

803 Regardless of their effect on viewers, positive framing is discussed in the papers as therapeutic for
804 posters, as long as they are not forced to fit a discourse that is not aligned with their own experience
805 and they feel like they have the space to share negative emotions, too (Cherian et al., 2020; Tetteh,
806 2021).

807 *Negative emotions: expressing fear and uncertainty*

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

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

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

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

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

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

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

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

844 On Twitter, patients choose to “emphasize the difficulties [...] that are often glossed over”
845 (Cherian, 2020, p.11) in cancer communications. On Pinterest, where thematic images are more

846 common, negative emotions are expressed through fear images, meant to motivate behavioural
847 change.

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

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

858 **Third discursive line, purpose: addressing the self (“me”) or the other (“you”) in cancer**
859 **images**

860 ***“Me”:* defending and reassessing identity and normalising cancer**

861 Across the papers, photography is understood as a tool for self-expression, which patients use not
862 only to communicate with others but to better understand themselves. Cancer is a profoundly life-
863 altering illness, which entails a change in identity for patients (Gupta, 2022, p. 222). Social media
864 images allow them to express themselves, visualise their relationship with cancer, and perform
865 their persona. The “me-you” discursive line evaluates this function by reviewing the purpose and
866 the ‘addressee’ of the image: is the image meant to express my experience and represent me, as

867 the poster, or is it meant to inspire a change in attitude from you, the viewer? It is often the case
868 that the answer lies somewhere in between both poles.

869 When it comes to forming and affirming the self (“me”), posting a photograph on social media can
870 help regaining a sense of certainty and challenge the aggression of cancer (Gupta, 2022, p. 218).
871 Stage (2019a) outlines two functions for Instagram pictures in this regard. The first is that of self-
872 tracking: episodic images, typically in sequence, that help patients keep a visual diary and monitor
873 their own progress.

874 The second function is simply for patients to see how their body changes, without necessarily
875 establishing a conversation with other images. Stage refers to this as “self-experimentation”
876 (Stage, 2019a, p. 78); Gupta speaks of performed patienthood, a form of self-negotiation that often
877 involves a disconnection between the self and the body. Cancer is an invasive illness that affects
878 patients’ perception of themselves: the loss of hair and weight, and they transformation of their
879 capacities is a traumatic process. The photographic camera and the reactions from viewers help
880 patients regain agency and control over their own image (Gupta, 2022, p. 222; Cherian et al, 2020,
881 p. 8). Posting images to social media also lets them reflect on their personal relationships (Tetteh,
882 2021, p. 11) and create their own definition of cancer (Cho et al., 2018, p. 2).

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

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

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

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

899 *[P]osts contrast scarring and hair loss, which are conventionally depicted as*
900 *tragic, with smiles and hopeful expressions that call into question the*
901 *experience of cancer treatment as unremittingly negative. (Cherian et al.,*
902 *2020, p. 11)*

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

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

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

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

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

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

925 ***“You”: education and activism***

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

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

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

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

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

952 The framing of “you” messages is also affected by the high prevalence of misinformation in cancer
953 images online. Wilner & Holton (2020) find that more than half of the posts on Pinterest that
954 contained information about breast cancer also contained misinformation, typically through
955 exaggeration, which may further limit the impact of this type of image. This risk is only higher
956 given the absence of health organisations from platforms like Pinterest (Miller, 2019; 2020) or
957 Facebook (Rivera et al., 2021), and given the misalignment of cancer prevention contents with
958 medical recommendations (Gürtler et al., 2022).

959 **Discussion**

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

964 **On the representation of cancer sites**

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

974 In addition, breast cancer has been subject to numerous studies on representation, and special
975 attention has been given to the importance of communities of patients. While similar studies have
976 been conducted for other sites, the volume of papers remains low in comparison (Koskan et al.,
977 2014). The sheer number of breast cancer images in social media dwarves other cancer sites
978 (Varela-Rodríguez & Vicente-Mariño, 2021b), while the widespread use of visual tropes that are
979 easy to identify (such as pink ribbons) may further compound its higher visibility. In addition,
980 cancer sites that affect primarily women appear to be more visible in social media overall, which
981 Cherian et al. interpret as a consequence of “the norms surrounding masculinity that deter
982 disclosure, even in private” (Cherian et al., 2020, p. 11).

983 **On method**

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

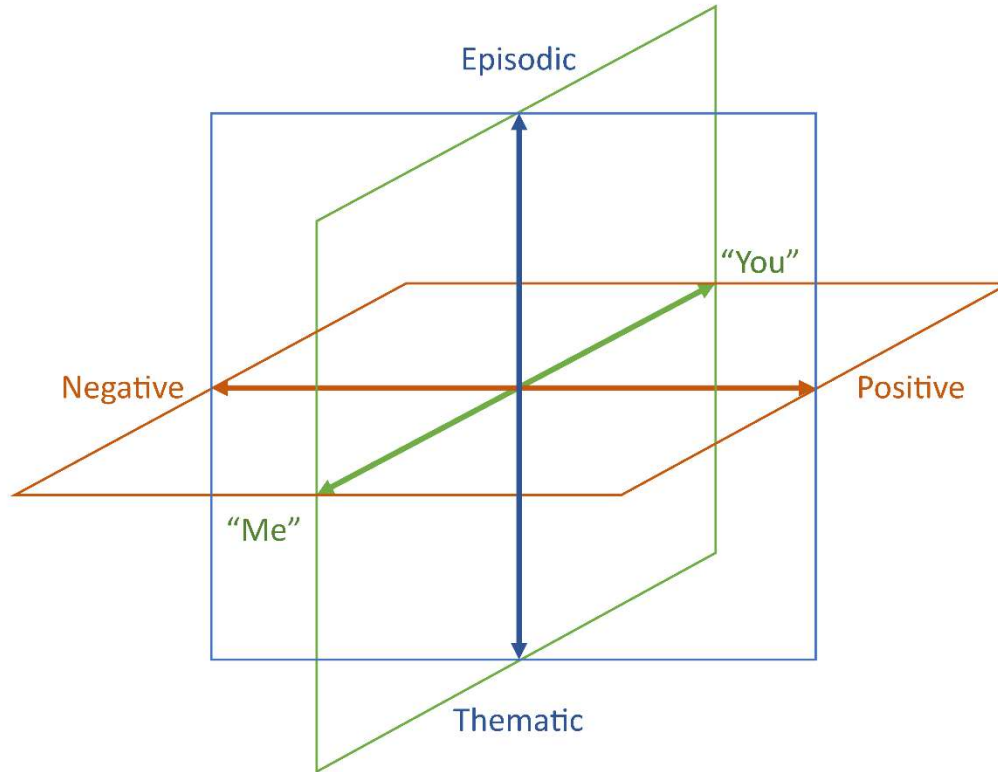
992 Inspiration may be sought in existing work on cancer prevention, where visual communication of
993 smoking, vaping, tanning or the HPV vaccine have received more attention. These are fields where
994 even machine learning algorithms have been used in conjunction with qualitative methods.
995 Admittedly, detecting a cigarette or a syringe in an image may be easier than detecting a visual

996 representation of cancer, which is a general term that is compounded by multiple illnesses,
997 emotions, and life experiences.

998 Further developing the three discursive lines identified in this meta-synthesis may serve as a
999 starting point. At the very least, they could guide the design of cancer communications by helping
1000 to predict some of the impact that images may have on viewers, and on the patients and relatives
1001 who posted them, too.

1002 **Three discursive lines**

1003 Figure 4 condenses the three discursive lines that emerged in this paper. They translate into a three-
1004 dimensional plot where images could be located—not without some difficulty. Images may be
1005 more episodic, “me” framed and positive, or the complete opposite.



<p>Thematic</p> <p>"[individuals] who are presented a message with thematic framing will be more likely to consider broader social or structural solutions." (Henderson, 2021, p.2)</p>	<p>↔</p>	<p>Episodic</p> <p>"Describing cancer as a journey is an emergent trend, which has been argued to minimize feelings of guilt or failure [...]" (Cherian, 2020, p.11)</p>
<p>Negative</p> <p>"[...]mentions of the perceived severity of breast cancer were a deterrent of engagement with posts in the present study." (Henderon, 2021, p.6)</p>	<p>↔</p>	<p>Positive</p> <p>"[...] [l]iking seems to be particularly intense on the profile when posts express [...] an approach to serious illness that is aligned with the desired narrative of positivity." (Stage, 2019b, p.279)</p>
<p>"You"</p> <p>"[...] whereas self behavior as a cause of melanoma comprised 80% of cause-related beliefs, expressions of this belief decreased the number of likes and social support comments. Similarly, none of the cause beliefs were significantly associated with the number of comments." (Cho, 2018, p.9)</p>	<p>↔</p>	<p>"Me"</p> <p>"[...] Agentive problem solving and positive reappraisal indicate a positive or healthy transformation in the poster's mindset [...] and thus could have more impact for familiar and intimate audiences." (Hale, 2020, p.10)</p>

1006

1007

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

1008

16 papers studied.

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1009 The first line, episodic vs thematic framing, can be used to understand patient messaging and
1010 psychosocial needs. Their use and impact seem to be tied to platform affordances: thematic
1011 framing is well-received in social media that are not based on interpersonal connections but rather
1012 on browsing and collecting content (such as Pinterest and Imgur). They are also received positively
1013 on Facebook when the poster is a trusted organisation or a closer acquaintance. Conversely,
1014 episodic framing has a measurable impact on Instagram, where viewers follow the experience of
1015 their friends or of the people they admire (celebrities, influencers), and where they are actively
1016 encouraged to comment and like.

1017 The second discursive line, between positive and negative emotions, returns inspiring results. Part
1018 of the literature is critical of the social media economy, arguing that it puts pressure on patients to
1019 share a specific discourse (that of survivorship) that favours positive images (Stage, 2019a;
1020 Henderson et al., 2021). Images where patients count down to life as it was before cancer, show a
1021 thumbs up from their chemotherapy session, or appear in frame with scars and a smile do reflect a
1022 push towards restitution. Indeed, positive emotions are more often expressed across all social
1023 media studied. The design of social media platforms is also shown to favour unobtrusive cancer
1024 sites that permit visually-appealing images, sites that are well-known, and privileged groups, with
1025 higher technological competencies or generally more representation in social media (Miller et al.,
1026 2019; Park et al., 2019; Rivera et al., 2021; Stage, 2019b). Symptomatic of this, argues Stage
1027 (2019a), is how viewers react to posts outside dominant discourses on Instagram. When a post
1028 shows fear or uncertainty, commenters redirect them to a socially desirable narrative of cancer:
1029 they reassure posters and encourage them to stay hopeful. Tetteh (2021) echoes these observations,
1030 while Varela-Rodríguez & Vicente-Mariño (2021b) provide some quantitative support by
1031 visualising the unequal distribution of cancer sites on Instagram.

1032 However, results also show that social media can offer a positive space for the broader spectrum
1033 of emotions associated with cancer (Cho et al., 2018; Hale et al., 2020; Park et al., 2019). On
1034 Instagram, Pinterest and Imgur, negative emotions and even the discussion of mortality have a
1035 space, and images that make use of them are met with supportive, reassuring, and compassionate
1036 comments. Cho et al. (2018) demonstrate that negative emotions are better at generating comments
1037 (thus conversation), while Hale et al. (2020) show how commenters offer compassion to posters
1038 who are sharing their anxiety over treatment. For patients, this means that, even if they do not align
1039 with survivorship or if they struggle with the social imperative to remain optimistic, and even if
1040 their images may not reach the influential status of more positive ones, they can find support in
1041 social media. Importantly, however, this may be true for well-represented groups, while
1042 underrepresented peoples continue to swim against the tide (Rivera et al., 2021).

1043 This second discursive line (positive vs negative emotions) is important to achieve a more
1044 inclusive representation of cancer. It may facilitate the inclusion of underprivileged groups and
1045 give visibility to lesser-known cancer sites, while speaking to patients beyond standardised
1046 discourses.

1047 For cancer screening and prevention, the use of negative emotions should be approached carefully.
1048 By favouring images that insist on the physical and emotional consequences of cancer, such as
1049 fear-invoking photographs, campaigns could run the risk of falling into shock advertisement. They
1050 may also stigmatise patients. An example may be found in anti-tobacco campaigns: while the use
1051 of shock images may have deterred consumption, it may have also contributed to placing blame
1052 on lung cancer patients (Riley et al., 2017).

1053 It is also important to note that discourses by patients who feel represented in scars and other bodily
1054 manifestations of cancer are not representative of all cancer experiences. Popular imagery,

1055 especially around breast cancer, made a positive move towards the 1990s by incorporating more
1056 diverse groups and reducing the blame on patients (Andsager et al., 2001). Building a more
1057 representative image of cancer does not entail going back to images where cancer is only visible
1058 as scars or trauma, but instead creating a space that allows for the representation of the broad
1059 spectrum of cancer experiences, whether those imply visualising hope or fear, or both.

1060 Lastly, the third discursive line (“me” vs “you”) establishes that posts framed through “me”
1061 messaging (sharing personal experience) are effective on Instagram and Imgur. They are amplified
1062 when posted by celebrities who are vocal about their cancer, which can create an image of cancer
1063 that is closer to the broader reality of the illness. Meanwhile, “you” messages remain ever-
1064 important for screening and prevention, as well as for informational support to patients. They are
1065 most impactful on Pinterest or Twitter, while they struggle to become visible on Instagram or
1066 Imgur.

1067 **An image of cancer in social media... without images?**

1068 A final consideration, one that is striking to us as authors, is how images are absent from the
1069 majority of the 16 papers studied. Only 6 of them use images from their samples to communicate
1070 results.

1071 Most of the papers point to ethical challenges to explain the absence of images. Social media
1072 studies undertake an analysis of data that is often disjointed and great in scale, which makes it
1073 complex to obtain consent. Further, the images studied are, after all, deeply personal, and there are
1074 few mechanisms to deidentify them as one could do with quotations from an interview. One
1075 method is used by Varela-Rodríguez and Vicente-Mariño, who collapse together the images in
1076 their study so that they are virtually impossible to identify but retain some information (mainly

1077 colour). Stage, on the other hand, uses sample images that are perfectly identifiable, having
1078 obtained informed consent from his research subjects to do so.

1079 There are also technical challenges to obtaining images, as social media platforms limit access for
1080 researchers. In addition, reproducing social media images, although public in the sense that they
1081 are available to public viewers, leads to a legal dead-end that is yet to be resolved. This is a
1082 recurring challenge in social media studies, and it is even more pressing for the obtention, storing
1083 and study of images (see Varela-Rodríguez & Vicente-Mariño, 2021a).

1084 That said, all the papers studied engage in a generous, in-depth analysis of images, either
1085 quantitatively or qualitatively. Yet we cannot help but wonder if accompanying said analysis with
1086 sample images could strengthen their results.

1087 **Implications for further research and future developments**

1088 The implications of this research are several. Firstly, we have established that images in social
1089 media are an important vehicle for sense-making, identity-formation, and community-building for
1090 cancer patients. Researchers will find a fruitful field here. Before that, however, more work is
1091 needed to develop methods for social media image analysis. In particular, the automation of some
1092 of this work (both in terms of image-download and image-processing) can help (see Varela-
1093 Rodríguez & Vicente-Mariño, 2021a). There are important technical and ethical considerations to
1094 bear in mind, including the constant changes in the Terms of Use of social media platforms, the
1095 grey area that is social media data ownership and access by researchers, and the challenges in
1096 obtaining informed consent when conducting large-scale studies.

1097 Secondly, challenging the divide between qualitative and quantitative methods and relying on
1098 mixed approaches have been shown to be productive. Social media are particularly ripe for this

1099 type of work. Future work could explore the use of automated searches that can then be analysed
1100 in-depth through interviews and focus groups, similar to the method used by Rivera et al. (2021;
1101 2022). Likewise, reviewing quantitative findings with posters and viewers can provide richer
1102 information on user-intention and impact. Social media research thus appears to be a potentially
1103 fruitful field to connect the biomedical and social sciences.

1104 Thirdly, multi-platform studies may risk obtaining a biased picture if they neglect the affordances
1105 of said platforms. The different expectations users have for each platform may explain the
1106 disparities observed on Instagram, Pinterest and Imgur. Future work may look to conduct cross-
1107 platform research while being mindful of each platform's audience and functionalities.

1108 Fourthly, researchers studying visual communications should be well-positioned to strengthen
1109 their own use of images to reinforce textual narratives. If our object of interest are images, it
1110 appears reasonable to use them as part of our communication.

1111 Lastly, the three-dimensional grid we have developed with the three discursive lines may help
1112 analyse social media images of cancer qualitatively, while offering some value towards predicting
1113 their engagement. Future work may look to validate, modify, or improve these three lines,
1114 developing specific criteria for each line and contrasting the engagement for each type of image.

1115 As visual social media continue to grow, it seems reasonable to expect them to continue playing a
1116 key role in the communication of cancer. Given their rapid development, it is likely that new papers
1117 dealing with the topic are published in the next few years. Future research may also consider works
1118 developed in other formats, such as communication campaigns run by cancer organisations, or
1119 larger-format books. Academic works like Carsten Stage's *Networked Cancer* are outside the scope
1120 of this paper but are an important source of knowledge. Similarly, the work of Stephanie Plage,

1121 although not focused on social media, offers great insight into visual cancer discourses by a variety
1122 of patients (Plage, 2021).

1123 **Limitations**

1124 This research is limited by the small number of papers available in this field, or, at least, the number
1125 of papers we could identify with the queries defined and the resources available. Some relevant
1126 documents known to the authors were left out as they were not part of the search or had a format
1127 that was not included—most notably Carsten Stage’s exploration of the topic in the book
1128 *Networked Cancer* (Stage, 2018). By narrowing the search to very exclusive criteria (journal
1129 papers AND images AND cancer AND social media) we have made it possible to undertake a
1130 deeper analysis but had to leave out works that we hope to return to in the future.

1131 In addition, the lack of previous systematic reviews on this topic does not allow to build on existing
1132 knowledge, but instead generate new ideas that will be tested by time and, surely, need to be
1133 updated.

1134 **Conclusions**

1135 This review presented an in-depth analysis of 16 papers that address the use of images in social
1136 media to communicate cancer.

1137 Overall, the papers study at least three discursive lines that are followed by the images in their
1138 studies. The first line, between episodic and thematic framing, considers the different impact that
1139 images have depending on whether they present cancer as a journey or as an individual topic.
1140 Episodic image are individual, personal images, where patients show progress. Thematic images
1141 contain text and present general information about cancer or its prevention. Thematic images are
1142 more successful on Pinterest or Twitter, while Instagram favours episodic images. Imgur returns

1143 interesting results as episodic images often present cancer stories from other people, instead of the
 1144 poster's.

1145 The second line considers the different impact that positive and negative emotions have on viewers
 1146 on the different platforms. Positive emotions are found to receive more likes on sites like
 1147 Instagram, and to be generally more “agreeable” as they align better with dominant discourses.
 1148 However, negative emotions still have a place in social media, and are met with empathic support
 1149 and compassionate comments on Imgur or Facebook and are reshared on Pinterest.

1150 Lastly, the third line considers the primary purpose of the images, whether it is to present the
 1151 poster's experience (“me” images) or to motivate action from the viewer (“you” images). The
 1152 former seem to perform better on most of the platforms, whereas “you” images are often perceived
 1153 as intrusive.

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5.2. Paper 2: *Imágenes desgarradas* (Scattered Images)

Varela-Rodríguez, M., & Vicente-Mariño, M. (2021). Imágenes desgarradas: El uso de scrapers en investigación social en Instagram sobre cáncer. *Cuadernos.Info*, 49, 72–97. <https://doi.org/10.7764/cdi.49.27809>

Language: Spanish (translation into English annexed)

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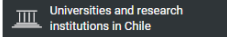
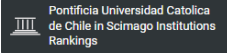
Accepted: 19 April 2021

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Indexed in: Scopus – Scimago SJR; Clarivate Analytics – Emerging Sources Citation Index (ESCI); Sistema Regional de Información en línea para Revistas Científicas de América Latina, el Caribe, España y Portugal (Latindex); Scientific Electronic Library (SciELO); Directory of Open Access Journals (DOAJ); Red Iberoamericana de Innovación y Conocimiento Científico (REDIB); Dialnet; Red de Bibliotecas Universitarias y Científicas Españolas (REBIUN); Citas Latinoamericanas en Ciencias Sociales y Humanidades (CLASE); Clasificación Integrada de Revistas Científicas (CIRC); European References Index for the Humanities and Social Sciences (ERIHPLUS).

Scimago-SJR magazine details as of 22 September 2022

Cuadernos.info 			
COUNTRY	SUBJECT AREA AND CATEGORY	PUBLISHER	H-INDEX
Chile 	Social Sciences └ Communication └ Library and Information Sciences	Facultad de Comunicaciones de la Pontificia Universidad Católica de Chile 	11
PUBLICATION TYPE	ISSN	COVERAGE	INFORMATION
Journals	07193661, 0719367X	2013-2021	Homepage How to publish in this journal dgrassau@uc.cl

5.3. Paper 3: Whose cancer?

Varela-Rodríguez, M., & Vicente-Mariño, M. (2021). Whose cancer? Visualising the distribution of mentions to cancer sites on Instagram. *Journal of Visual Communication in Medicine*, 1–17. <https://doi.org/10.1080/17453054.2021.1964356>

Language: English (translation into Spanish not available)

Received: 20 March 2021

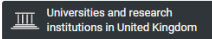
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Scimago: Q1 (Visual and Performing Arts)

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Scimago-SJR magazine details as of 22 September 2022

Journal of Visual Communication in Medicine			
COUNTRY	SUBJECT AREA AND CATEGORY	PUBLISHER	H-INDEX
United Kingdom 	Arts and Humanities ↳ Visual Arts and Performing Arts Health Professions ↳ Health Professions (miscellaneous)	Informa Healthcare	16
PUBLICATION TYPE	ISSN	COVERAGE	INFORMATION
Journals	17453054, 17453062	1978-2021	Homepage How to publish in this journal c.d.erolin@dundee.ac.uk

5.4. Paper 4: *Llorar Fotografías* (Crying Photographs)

Varela-Rodríguez, M., & Vicente-Mariño, M. (2022). Llorar fotografías: Análisis de contenidos y discursos visuales sobre el cáncer en las fotografías de Olatz Vázquez en Instagram. *Revista Española de Sociología*, 32(1), Article 1.

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Scimago-SJR magazine details as of 22 September 2022

Revista Espanola de Sociologia 			
COUNTRY Spain 	SUBJECT AREA AND CATEGORY Social Sciences └ Sociology and Political Science	PUBLISHER Federacion Espanola de Sociologia	H-INDEX 10
PUBLICATION TYPE Journals	ISSN 15782824	COVERAGE 2010-2021	INFORMATION Homepage How to publish in this journal res@fes-sociologia.com

6. Conclusions and implications

Cancer imagination on Instagram resembles a micro-cosmos of social media, an illustration of dynamics that are common to other platforms and other themes: carefully curated self-presentations; the negotiation of identity to adapt to what others expect from us; using social media to challenge dominant discourses; or the feeling of anxiety and uncertainty when we do not feel represented by other people's posts.

The conclusions in the following pages are meant to contribute to the field of cancer communications, but they may serve other areas in social media studies as well.

6.1. On the method to investigate Instagram visuals

This thesis is not the first piece of research to investigate the functions of social media for cancer patients (see Attai et al., 2015; Bour et al., 2021; Laranjo, 2016). It is also not the first one to consider the role of photography in cancer therapy (Plage, 2019, p. see), nor the first to review the visual representation of cancer (see Cho et al., 2018; de Noronha, 2019; McWhirter & Hoffman-Goetz, 2014). It is not even the first to approach cancer content on Instagram (see Henderson et al., 2021; Stage, 2019a; Zade et al., 2017). And yet it is one of the first attempts to thread the line between cancer survivorship, social media, images, and social discourses of illness.

Where a seeming majority of publications focus on either prevention or on the active use of social media by cancer patients, this thesis hopes to contribute a more systemic approach. It looks at how the everyday use of social media can generate a distorted image of cancer, even amongst those who have had no conscious contact with the illness.

This thesis was completed in September 2022. To date, research on cancer imagery in social media remains limited, although promising and clearly growing.

Yet methodological and technical limitations hamper its development: it remains challenging to (1) obtain and treat images, (2) to interpret said images and (3) to do both of those things in a way that is ethical and respectful of the privacy of the users.

When it comes to method and technique, Scattered Images has presented a potential solution. The use of scrapers can accelerate the obtention and treatment of Instagram metadata. It does not, however, make it any easier to actually obtain said images—unless researchers are looking to break the Terms of Use of Instagram. Meta’s own tools, like CrowdTangle, can also be used to obtain a sample of images from user profiles with more than 50,000 followers. Unfortunately, that would be akin to studying influencer profiles, which may skew the sample and favour better-known cancer sites.

Across the thesis, the use of Rodríguez & Dimitrova’s, Kress & van Leeuwen’s, and Rose’s guidelines and techniques have allowed for a detailed study of image content, but they have also proved to be time-consuming. While Instagram’s reality changes at a dramatic speed, with millions of images posted every day, image analysis lags behind. To study such volumes and speed, it seems necessary to build bridges across disciplines, similar to the work done by Manovich (2018a). The linking of Social and Information and Communication Sciences could help make image analysis faster, automatically evaluating quantitative elements as well as non-image contents (texts, descriptions, metadata) that can add to their interpretation.

6.2. The affective economy and the shapes of cancer

From crude images that show the wounds of cancer to celebratory photographs of women smiling and flexing muscles, the research here presented has highlighted the many shapes of the illness on Instagram. Images appear to move along a line between shock and romanticism. Yet we cannot conclude that the use of either pole reflects and intention to further the survivorship discourse. Instead, it seems that survivorship simply lends itself better to the affective economy of Instagram.

On this platform, four affective spaces seem to be activated to represent different moments of cancer:

1. **Prevention:** campaigns seeking to increase the uptake of prevention techniques dive into negative emotions, using risk and fear to highlight the possibility and the probability of someday suffering from cancer.³
2. **Research and awareness:** to motivate donations and contributions, commercial images and public campaigns tend to utilise positive emotions, sometimes leaning into stereotyped representations of the cancer patient.
3. **Treatment and support:** positive emotions are used to visualise the patient who undergoes treatment, who is shown fighting and determined to face the threat of illness with optimism.
4. **The consequences of cancer:** patients often use alternative discourses and negative emotions to visualise how cancer has impacted their lives, to highlight the social cost of the illness, or to reflect on the inequalities inherent to public health systems.

Naturally, the four spaces may (and often do) coexist in the same profile. Patients often share photographs where survivorship and alternative discourses are exchanged—Olatz Vazquez’s profile is one example. Sometimes, they may lean into emotions and attitudes that are more aligned with survivorship. Other times, they may lean on anxiety, fear and graphic content. It is the reaction of their environment, and of the Instagram application itself, that is most relevant to the creation of an affective space.

From the research conducted, it appears that positive emotions are favoured by users (and, consequently, by the algorithms), while negative emotions tend to be rejected. Through the research conducted, it seems possible to conclude that positive emotions are met with more likes, while negative emotions are met with comments

³ Symptomatic of this is the fact that cancer is, in 2022, the most feared cause of death (Ipsos MORI, 2021).

and support (Cho et al., 2018; Hale et al., 2020; Stage, 2018, 2019b; Tetteh, 2021). Perhaps positive content lends itself better to virality, while negative content creates communities.

Figure 4, included in the next page, represents the four spaces, using outlines to visualise some of the images that may be associated with each affective space.

Awareness raising campaigns by NGOs and businesses also populate the Meta-owned platform, making use of both stereotyped and alternative discourses. When they seek to motivate attitudinal changes, users appear to ignore or reject them. Sometimes, campaigns have developed such a strong visual identity that they have left behind their original purpose, as is the case of Movember, which has expanded into male health more generally, diluting its cancer prostate messaging.

Across, the breast-cancerisation of cancer discourses seems visible in the papers presented. Whose Cancer concludes that in 2021 there were 10 times more images that mentioned breast cancer on Instagram than the next most-mentioned cancer site (leukemia).

Thus, cancer images on Instagram appear to represent breast cancer mainly, to favour the expression of positive emotions, and to make attitudinal changes difficult.

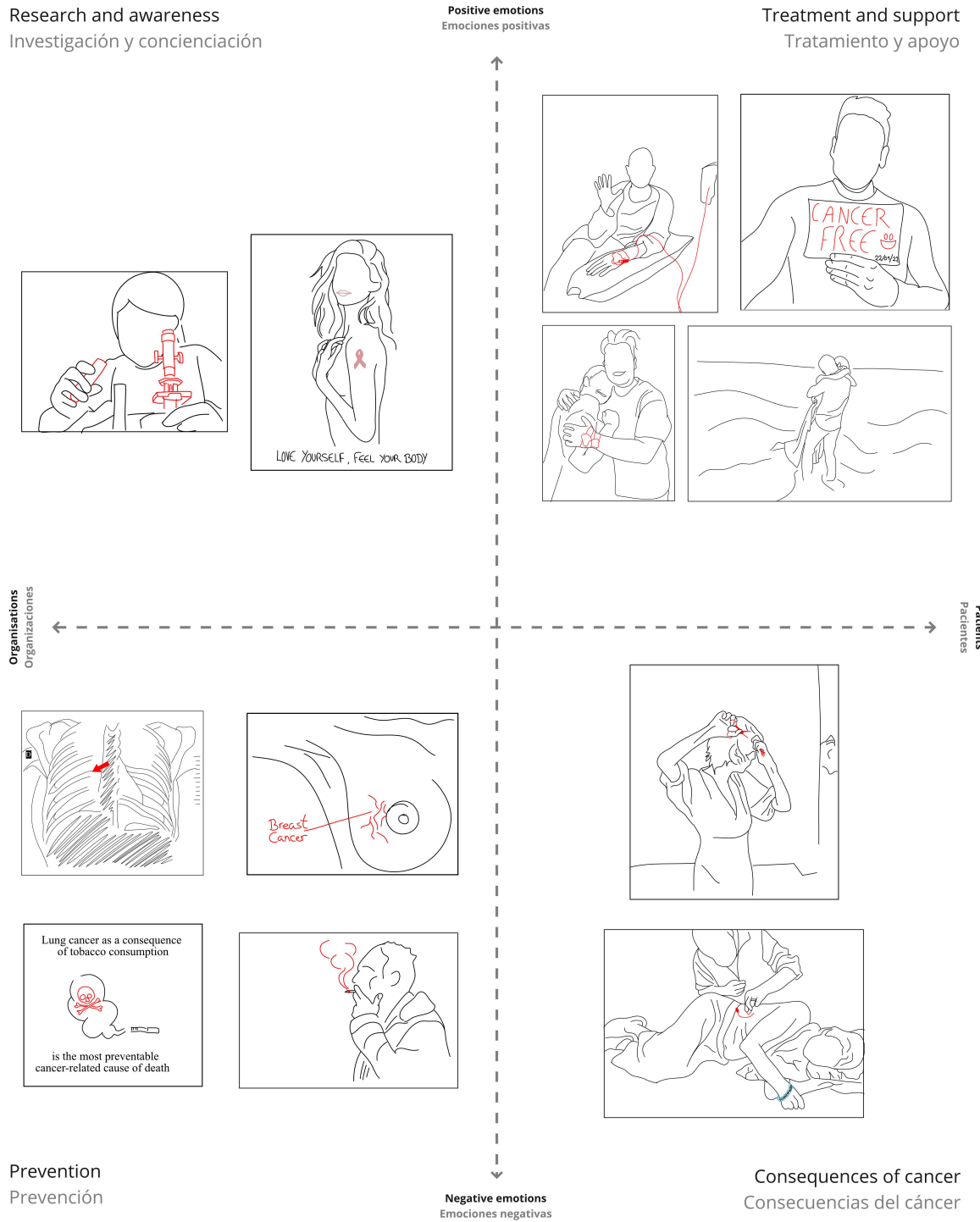


Figure 4. Four affective spaces for cancer images on Instagram. The X axis shows who posts them; the Y axis shows the type of emotions they tend to represent.

6.3. Cancer socialisation in the age of social media

The results of this thesis suggest cancer communications have moved into a new regime. Beyond the medicalisation and the biomedicalisation described by Klawiter, we may now speak of the **socialisation** of cancer. This new paradigm shares some of the dynamics observed in earlier regimes, adding a key new element: the survivorship discourse continues to be dominant, but has now spread into social media, where it is spread and integrated by users. While patients and caregivers deploy different illness narratives, commercial, mass media and social media representations of cancer *socialise* the public in a collective image.

Speaking of socialisation requires looking back into classic sociology, where the concept has a long and complex history. The first mentions to it as a sociological term are often attributed to Georg Simmel (Guhin et al., 2021; Hurrelmann & Bauer, 2018). Socialisation was a key concept in the theory of Émile Durkheim too. Durkheim explained it as a process by which new generations are educated and integrated into the values and norms of their social groups. Through socialisation, institutions built functional members of society, who would otherwise suffer from the anomy of increasingly disconnected and selfish societies (Pietro, 2004; Snarey & Pavkov, 1991).

In functionalist sociology, socialisation was a collective responsibility, but also an individual desire. It bore the promise of more cohesive and positive societies, with members who could thrive within them. In Parson's theory, socialisation thus began in the institutions closest to the individual (such as family), and extended into education and mass media, which provided the necessary moral and cultural backbone by raising children in the values and forms of their context—that is, it *socialised* them (Pietro, 2004, p. 113; Stevens, 2008, p. 106).

The idea came under heavy criticism by the 1970s. Critics asserted that the solidarity principle that was supposed to operate in socialisation was a fallacy. Instead, institutions replicated power structures that benefitted the rich and

privileged, using socialisation to push a hidden agenda. The education system, for instance, helped the powerful remain powerful, while it pushed the underprivileged to the side, blaming them for their failure to adapt to supposedly universal values. Further, the concept negated the individual's capacity to decide upon their lives (their *agency*) and instead built standardised members of society (Guhin et al., 2021; Snarey & Pavkov, 1991).

Despite the criticism, Guhin et al. (2021) show that, outside sociological theory, the term continued to be applied, especially in the sociology of education and in ethnic and racial studies. It is also common to find references to it in the sociology of health and in medical training (Andress & Purtill, 2020; Hansell & Mechanic, 1986; Singh-Manoux & Marmot, 2005; Zempléni, 1988), as well as in political science (Hyman, 1959; McLeod & Shah, 2009). In internet studies, social media platforms are discussed as a key mechanism for *self*-socialisation, a process whereby individuals interiorise the norms of the different social spaces that they choose to inhabit (Anderson & McCabe, 2012; Jensen Arnett, 2015).

This thesis posits that socialisation remains a valid concept in the context of social media visual discourses of cancer. Sandford and Quarmby (2018) and Lindell (2017) demonstrate how the theories of Bourdieu, Goffman, or Berger & Luckmann are visible in platforms like Facebook. In our field of study, we can identify a series of steps that signal how socialisation operates.

First, the design of social media is an apt representation of Bourdieu's idea of *field* (2002). Users (of Instagram or otherwise) inhabit multiple groups and networks, each one with their own space, but all interconnected and porous.

Second, what is adequate and expected within each group (or field) is determined collectively but integrated unconsciously by each individual. Users interiorise visual practices and reproduce them as part of their "cultural" adaption to the field. This is what Bourdieu calls the *habitus*.

Third, deploying the *habitus* correctly rewards users: likes, comments and follows not only result in higher social capital (a form of social influence), but also

provide users with a sense of belonging. This is reflective of the socialisation present in Mead's philosophy (Aboulafia, 2016): in social media, identity is formed by the interplay between independence (which he called the *I* of identity) and the image of us and the expectations that others have from us (which he called the *me*).

Fourth, images are an accessible way to represent the *me* and to pay heed to the habitus of a given group. It has been discussed previously that photographs allow cancer patients to negotiate their identity, to visualise changes in their body, and to dissociate from their illness. They embody identity, and become the material expression of the emotions, discourses, metaphors and cultural norms of each habitus (Gómez Cruz & Lehmuskallio, 2016).

Fifth, the consumption of social media and its algorithms in our everyday life facilitates the integration of certain visual discourses, through a process of habituation (Persson, 2018, p. 129). This makes some images familiar and expected.

Sixth, the borderless design of social media fields enables the spread of discourses from one to another. This results in discourses that are not fully owned by any of the fields, but which are reflected in all of them.

Last, the results obtained in the papers show that visual social media prefers images of cancers that are positive, hopeful and aesthetically pleasing. While users may deploy other discourses of illness in smaller fields, including Frank's chaos narrative, the larger fields are reflective of a standardised discourse of survivorship.

Together, these lead me to believe that the current representation of cancer in visual social media responds to a socialisation dynamic. Whether it is for the greater good as in Durkheim's and Parsons's understanding (perhaps to enable a positive uptake of the illness), or as the consequence of a "hidden agenda" as in the view of their critics is something that can be studied in future works. But recapturing the idea of socialisation may help think more deeply about how we communicate the illness, as well as reclaim a concept that is key to social theory (Guhin et al., 2021).

By asserting that we are now inhabiting a regime of socialisation I do not mean to disregard the agency of cancer patients. Research (my own and previous) shows

that patients do engage in alternative discourses online. It also shows that social media users are receptive to negative images—they, in fact, enable better peer and emotional support (Hale et al., 2020). Instead, speaking of this regime is a way to highlight the challenging environment that patients may face as they turn to social media for information. It also reflects on the likelihood of their social circle feeding them a discourse that is not always adaptive to their prognosis.

In this context, I believe cancer communications ought to be conscious not only of their message, but of the time and space that they occupy in our everyday lives, and of how images may affect the experience of those who suffer from it.

6.4. Where next? Implications for health education

Stemming from the research presented, the implications of this thesis are varied. Firstly, promoting a standardised image of cancer that uses the affective economy of Instagram can promote a more positive and less fearful image of the illness. This might motivate patients and their social circle, providing them with much-needed social support and some emotional well-being, as well as a safe space for patients to tell their story.

Conversely, it can also strengthen the negative aspects of the survivorship discourse: building a false feeling of control; perpetuating the feeling of guilt among patients; ignoring the experiences of patients who suffer from chronic fatigue and other cancer-related symptoms; or neglecting the reality of cancer sites with complicated prognosis. It may also multiply the visibility of better-known cancer sites (such as breast cancer), while ignoring the lesser-known (such as pancreatic cancer). Ultimately, it may create expectations among patients and among their caretakers, that may be challenging to manage. Kaiser (2008) and Pertl et al. (2014) demonstrated that survivorship is a useful discourse for many patients, while it creates a feeling of loneliness among many others.

In parallel to this, user rejection of images that seek to change attitudes is a challenge to health communications, especially to models based on beliefs and participation (Laranjo, 2016). In view of this rejection and the prevalence of positive affects, it seems possible that some of the elements necessary to change health attitudes may become invisible on Instagram.

That being said, there is an important reflection to be made on whether contents on social media ought to become viral to be useful. Fortunately, Instagram allow us to create safe spaces beyond trending topics. Organisations from the Third Sector and public institutions can help promote a healthy use of social media for patients, caretakers, and their relatives. However, engaging with the economy of affection will still be necessary to reach those who currently have no experience of cancer and to build a social image of the illness that allows them to express themselves in a way that is adaptive should they ever experience it. It is **a preventive task**.

Lastly, it should be noted that, although the papers in this thesis sometimes refer to the need to promote a “real” image of cancer, that is no synonym to using shock or crudeness. Shocking images have been used for years to prevent and reduce the consumption of tobacco—sometimes successfully, but also contributing to the stigmatisation of lung cancer patients, as discussed in the first paper. Instead, promoting a real image of cancer means facilitating spaces for the visualisation of different cancer sites; reducing the use of gendered visuals; enabling the communication of negative emotions; and allowing users to show the everyday life that comes with cancer.

Thus, a series of recommendations to visualise cancer in social media in a way that is inclusive and impactful emerge:

1. **Promoting transdisciplinary work**, building on the experience of social sciences to interpret images and discourses of cancer; health sciences, to ensure messaging is aligned with medical knowledge; behavioural sciences to guarantee the emotional well-being of patients; and communication and information sciences, to enable efficient and updated methods.

2. **Expanding academic research on cancer in social media into other cancer sites.** Lesson from breast cancer research could inform investigations into other sites, contributing to more inclusive messaging.
3. **Incorporating methods of visual sociology to visual research online.** The combination of observation and computational analysis with focus groups or photo-elicitation can help understand not only the contents in the images, but the intentions and perceptions of both posters and viewers.
4. **Strengthening the positive aspects of the survivorship discourse.** The creation of safe, online communities or the protection of emotional well-being are important functions for cancer patients, provided the use of language that portrays patients as “fighters” is limited.
5. **Favouring the representation of lesser-known cancer sites** and building on the affective tailwind (in Stage’s terminology) created by projects as impactful as Olatz Vazquez’s.
6. **Supporting Third Sector organisations**, businesses, and public institutions that seek to expand the visual language of cancer beyond common suspects and helping them **deconstruct the “black box” of emotions** generated by decades of survivorship imagery.
7. When it comes to prevention, **reviewing the use of models based on personal responsibility** and healthy habits, so as to avoid stigmatisation and to consider environmental factors.

The wealth of work ahead calls for the inclusion of multiple actors and stakeholders: researchers from the social, health and internet sciences, patients and caregivers, health practitioners, and social media providers. The transdisciplinary approach suggest in Point 1 has been defined as “a way of being” in research, a push to integrate perspectives from as many fields as are relevant, and from the non-academic world, too (Rigolot, 2020).

The fields of health, social and internet studies have returned positive results in applying this perspective. Social and health scientists have implemented such an approach to health programming since the 1990s, enabling projects with a longer lifespan and which integrate new concepts and ideas (Rosenfield, 1992). It is also an important pillar of research on bioethics, where patients' inputs are key to discern medical and socioeconomic needs (Stepke, 2016).

For internet researchers, it has enabled a deeper understanding of what being part of an audience means and where the line between the digital and the physical world can be traced (Hunsinger, 2005, 2008). To continue in this direction, a conversation with providers such as Meta appears necessary. Enhanced transparency on their selection algorithms can also help build affective spaces that are more adaptive to different diagnoses. Just as they demonstrated through the COVID-19 pandemic, platforms like Instagram have the capacity and—hopefully—the willingness to facilitate an online environment that is inclusive and constructive.

In essence, a transdisciplinary response to the socialisation paradigm should seek to give representation to **the many shapes of cancer**.

7. Limitations

Any research that attempts a thematic review of Instagram content exposes itself to high risks. Firstly, it is virtually impossible to draw a global image of the platform, populated by billions of images. From the beginning of the research, this thesis has faced a broad field, where multiple disciplines converge. To reduce the scope and to build achievable objectives, a decision was made to focus on the discourse of survivorship, which reduces the capacity of this work to respond to other discourses.

Importantly, more research may be required to build visual messages appropriate for prevention efforts. Similarly, a systematic definition of the elements that make an image follow the discourse of survivorship may be beneficial.

When it comes to its method, both the analysis and obtention of images from Instagram are risky work. Image analysis, a task that belongs to the world of semiotics, is often challenged by personal interpretation. In future, automatised analysis may help unearth elements in the image that may have been manipulated, which can also help understand the use of image modulation. Similarly, as suggested in the conclusions, contrasting the author's interpretation with that of a focus group will increase the reliability of the work done.

It has been no easy task to develop this thesis during the COVID-19 pandemic. As life returns to normality, and as hospitals recover some of their operational capacities, future research may seek to engage with oncology units and Third Sector organisations to build focus groups and conduct mid- and long-term analysis.

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9. Annexes

9.1. Certificate of acceptance for Paper 1, “Systematic Review”

RcR

Review of Communication Research

Manuscript Acceptance Letter

I am pleased to inform you that two double-blind reviewers have recommended the manuscript titled “**Images of cancer in social media: a systematic review of the literature**” and authored by **Miguel Varela-Rodríguez** and **Miguel Vicente-Mariño** for publication in the forthcoming issue of *Review of Communication Research* (RCR) and that Section Editor Roi Méndez Fernández has decided to accept the manuscript for publication. Congratulations.

Kind regards,



Giorgio De Marchis
Editor, *Review of Communication Research*
Complutense University of Madrid, Spain
For further information, please write to editor@rcommunicationr.org

Madrid (Spain), September 2022

Journal website: <https://www.rcommunicationr.org>

Signed electronically by Dr. Giorgio De Marchis



9.2. Translation into Spanish of the Thesis Document

The following translation into Spanish is provided by the author so as to facilitate the dissemination of the results of this thesis among Third Sector organisations and institutions in Spain. In case any contradiction is detected, the English text shall be given priority.

La Forma del Cáncer: Socialización y Representación Visual de la Enfermedad en Instagram

Traducción al español del compendio

A excepción de los dos artículos publicados en español, esta tesis se ha desarrollado en inglés. Para facilitar su lectura, las próximas páginas incluyen una traducción íntegra del compendio. Lamentablemente, no se incluye una traducción de los dos artículos escritos en inglés, una tarea que espero poder desarrollar en un futuro, con más tiempo y recursos.

Estructura de la tesis

Esta tesis adopta el formato de Tesis Doctoral por Compendio de Publicaciones, de acuerdo con el Artículo 4.1. de la Normativa sobre Presentación y Defensa de la Tesis Doctoral en la Universidad de Valladolid. Incorpora los siguientes artículos publicados en revistas académicas:

1. Varela-Rodríguez, M., & Vicente-Mariño, M. (in press). Images published by cancer patients in social media and their reception: A systematic review. *Review of Communication Research*.
2. Varela-Rodríguez, M., & Vicente-Mariño, M. (2021). Imágenes desgarradas: El uso de scrapers en investigación social en Instagram sobre cáncer. *Cuadernos.Info*, 49, 72–97. <https://doi.org/10.7764/cdi.49.27809>
3. Varela-Rodríguez, M., & Vicente-Mariño, M. (2021). Whose cancer? Visualising the distribution of mentions to cancer sites on instagram. *Journal of Visual Communication in Medicine*, 1–17. <https://doi.org/10.1080/17453054.2021.1964356>
4. Varela-Rodríguez, M., & Vicente-Mariño, M. (in press). Llorar fotografías: Análisis de contenidos y discursos visuales sobre el cáncer en las fotografías de Olatz Vázquez en Instagram. *Revista Española de Sociología*.

Este documento (conocido como “Compendio”) ofrece una visión del marco conceptual, la metodología, y la conexión temática entre artículos, y las conclusiones. La redacción viene acompañada de una serie de visualizaciones que resumen los puntos principales de algunos de los capítulos. El compendio se refiere a cada uno de los artículos por su nombre abreviado:

1. Revisión Sistemática
2. Imágenes Desgarradas
3. El Cáncer de Quien
4. Llorar Fotografías

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1. Introducción

Esta tesis se compone de cuatro artículos que exploran el rol de las imágenes en redes sociales a la hora de construir un discurso social del cáncer. Presentada como Tesis Doctoral por Compendio de Publicaciones, incorpora elementos de la sociología visual, la sociología de la vida cotidiana y el análisis de redes sociales.

Este compendio guía al lector a través del trabajo realizado, empezando con una introducción que la sitúa y que expone su motivación. A continuación, se exponen los objetivos del trabajo y se elabora la contribución de cada artículo a los mismos. La siguiente sección presenta el marco conceptual y teórico común a los artículos presentados. Antes de presentar los cuatro trabajos realizados, se valoran cuestiones metodológicas y éticas, claves para trabajar en las redes sociales, un ámbito rico, pero aún con mucho recorrido por delante. El compendio concluye con una serie de consideraciones e implicaciones para futuras investigaciones.

1.1. ¿De dónde viene esta tesis?

El trabajo que se expone en este documento nace de un sustrato compuesto de cuatro áreas de interés personal.

En primer lugar, la tesis incorpora toda una vida de contacto con las ciencias de la salud. La medicina ha tenido una presencia constante en mi vida. Recuerdo las imágenes de intervenciones quirúrgicas que editaba mi padre en su ordenador antes de acudir a un congreso. En casa, nos recordaban la importancia de la responsabilidad para prevenir la enfermedad: para evitar el cáncer de pulmón, no fumes; para evitar el cáncer de colon, come verduras; para evitar el cáncer de piel, ponte crema solar. También recuerdo las reivindicaciones por un sistema de salud humano, igualitario y cercano al paciente.

Que me haya centrado en el cáncer también se debe a la experiencia de mi esposa, psicooncóloga. En esos momentos de lucidez que facilita la oscuridad de una cafetería en el frío mes de noviembre, reflexionábamos sobre el peso que supone

para los pacientes de cáncer el tener que enfrentarse a los discursos del cáncer en las redes sociales.

La tesis recoge estas experiencias y las traduce en una preocupación por la salud como objetivo y responsabilidad social, no solo como tarea individual.

En segundo lugar, el trabajo se asienta sobre mi experiencia académica y profesional. Son quince años que, tal y como les ocurre a los contenidos de Instagram, revelan patrones bajo un manto de aparente caos. Con 17 años, empecé una Licenciatura en la Universidad de Salamanca (USAL), con la única intención era la de seguir la estela de mis hermanos, ya licenciados. Pronto descubrí que no me interesaban ni el análisis político ni la economía, hermanas cercanas de la sociología y que me hicieron mis primeros años de estudios universitarios bastante incómodos. Sí me interesaba, sin embargo, aprender cómo los distintos grupos sociales dan un sentido simbólico a su día a día, y cómo se generan la desigualdad y el conflicto sociales. Así que a los 21 cursé un Máster en Trabajo de Paz y Desarrollo en la Universidad Lineo en Växjö, Suecia. Un año después me encontré como becario de una ONG especializada en la mediación de paz. De nuevo me enfrentaba a las garras del análisis político.

En 2014, un proyecto financiado por el Programa de las Naciones Unidas para el Desarrollo me permitió aprender sobre el rol de las redes sociales en el conflicto social. Desde entonces, sigo aprendiendo cómo estas redes dan forma a nuestra identidad, nos unen y nos dividen.

En 2019, volví a pisar una universidad, esta vez para orientar a estudiantes que ya tenían un sentido del propósito mucho mayor que el que tenía yo a los 17, a los 21, o a los 29. Mi experiencia en Kosovo, Ucrania o Costa de Marfil me permitiría impartir docencia en un Máster en Relaciones Internacionales y, 12 años después, ver con claridad que la sociología es el hilo conductor entre todo lo que he hecho. Una sociología de la vida cotidiana y de las redes.

La tesis incorpora estas experiencias a través de una exploración de la sociología de lo cotidiano y las ciencias de la comunicación, evaluando cómo el día a día de

pacientes y familiares da forma a una imagen social de la enfermedad, y cómo afecta el entorno digital a sus experiencias.

En tercer lugar, no se entendería este doctorado sin la fotografía. A los 15 años, me eché al hombro una antigua cámara de hierro de mi tío para retratar a mis amigos—al menos esa era la intención. Viendo hoy aquellas fotos, encuentro más imágenes de cubos de basura, bolsas de plástico, ramas torcidas, ventanas rotas o coches abandonados que de personas. Solo en 2017 comprendí que mi fascinación por estas cosas “feas” era un impulso por documentar el mundo en el que vivimos, además de un reflejo de mi propia personalidad introvertida. Me condené a un préstamo bancario para poder cursar un Máster en Fotoperiodismo y Fotografía Documental en la Universidad de las Artes de Londres mientras seguía trabajando a tiempo completo. El trabajo de fin de aquel máster fue el punto de partida para la tesis que hoy deposito, que incorpora la fotografía como objeto de estudio y como reflejo de las dinámicas de construcción de significado social.

Por último, este trabajo crece desde mi adolescencia. Formo parte de la generación *milenial*, con mis Power Rangers en la televisión y mis Choco-Krispies en la merienda a los ocho años, pero, sobre todo, con mi Fotolog a los quince. Quienes pasamos la adolescencia en los primeros 2000 fuimos pioneros (por inercia) de lo que hoy es fundamental en la vida de millones de personas: el uso diario de las redes sociales para construir y mantener amistades... o enemistades. En un mundo que aún no se preocupaba por la privacidad online ni por la desinformación, Fotolog resultaba emocionante y sencillo, pero ya apuntaba las dinámicas que ahora dominan nuestra interacción online: la pose, la viralidad, los afectos. Aquella red, casi precursora de Instagram y con gran presencia en el mundo hispanohablante, permitía publicar una foto al día y recibir hasta 10 comentarios por publicación. Conseguir que tu foto llegase a los 10 comentarios era un logro del que presumir; ser uno de los 10 comentarios en las fotos de tus amigos era una obligación.

En marzo de 2020 formalicé mi matrícula en el Programa de Doctorado en Investigación Transdisciplinar en Educación en la Universidad de Valladolid. Unas

semanas después, el mundo se paró. La COVID-19 y el Estado de Alarma me encerraron en una habitación de mi piso en Valladolid, desde donde he desarrollado prácticamente todo el trabajo. La pandemia ha subrayado la importancia de las cuatro áreas anteriores: la imagen, fundamental en una era de desinformación y paranoia; las redes sociales, claves para mantenernos conectados y también (des)informados; la sociología, sin la que es imposible entender las desigualdades, ya sean las de la pandemia o cualquier otra; y, por supuesto, la centralidad de un sistema de salud que sepa tratar a sus pacientes como algo más que estadísticas.

Juntos, salud, sociología de lo cotidiano, fotografía y redes sociales forman la base de la tesis que ocupa las siguientes páginas.

2. Objetivos

La tesis responde algunas preguntas y plantea otras sobre el rol que tienen las redes sociales visuales en la comunicación en salud. Parte de dos cuestiones básicas:

- ¿Cómo imaginamos el cáncer en Instagram?
- ¿Cómo afecta esta red a la creación de un discurso social sobre la enfermedad?

Para encontrar una respuesta, ha sido preciso definir cinco objetivos específicos:

1. **Desarrollar una metodología** para la extracción de imágenes de Instagram y para su reproducción, de modo que sea posible aplicar la sociología visual en redes sociales.
2. **Identificar patrones visuales** en las imágenes de cáncer en Instagram a través de un análisis de imagen, de manera que se pueda evaluar la existencia de elementos dominantes.
3. **Evaluar el impacto de la economía afectiva** en la representación del cáncer en Instagram y en la formulación de discursos visuales de la enfermedad.
4. **Conocer las prácticas visuales situadas al margen de los discursos visuales de cáncer predominantes**, de modo que se puedan contrastar con la imagen “estándar” del cáncer.
5. **Analizar las implicaciones de los modos de imaginar el cáncer** en Instagram para la educación en salud.

Así, esta tesis traza una hoja de ruta para el uso de imágenes de Instagram en la investigación social en salud, pero busca plantear un proceso que se pueda aplicar a otros ámbitos de las ciencias sociales.

2.1. Relación entre los artículos

Los objetivos específicos se traducen en cuatro artículos, cada uno con un enfoque: un artículo metodológico, uno teórico, y dos de resultados (cuantitativos y cualitativos, respectivamente).

El **primer artículo, “Revisión Sistemática”** (Varela-Rodríguez & Vicente-Mariño, in press a) enfoca los objetivos cuarto y quinto, con una revisión sistemática de la literatura a través de la metasíntesis (Carrillo-González et al., 2007). En concreto, se revisaron artículos dedicados a la imagen autoproducida del cáncer en redes sociales. Los primeros pasos en la investigación sugerían que este es un campo con una producción científica limitada, algo que la revisión sistemática confirmaría. Solo trece artículos estudian la relación entre cáncer e imagen desde ámbitos como las ciencias de la salud, las ciencias de la comunicación o la teoría feminista. Los resultados de su revisión revelan tres ejes en los que es posible situar las imágenes de cáncer que compartimos en redes sociales: según su enfoque (episódicas o temáticas); según el tipo de emoción que buscan reflejar (positivas o negativas); y según su propósito (motivar el cambio de actitudes en quien mira la imagen o construir la identidad de quien la comparte).

El **segundo artículo, “Imágenes Desgarradas”** (Varela-Rodríguez & Vicente-Mariño, 2021a) se centra en el primer objetivo. Presenta una metodología para obtener y analizar imágenes de Instagram. Una de las redes más pobladas y activas, en 2022 Instagram sigue siendo prácticamente inaccesible para la investigación. El cierre de las puertas de acceso a esta red (conocidas como *APIs* – las siglas en inglés para Interfaces de Programación de Aplicaciones) después del escándalo de Cambridge Analytica ha forzado al mundo académico a adaptarse. Mientras unos

aceptan la limitada muestra a la que da acceso la empresa a través de CrowdTangle⁴, otros abogan por violar los términos de uso de la plataforma utilizando herramientas de dudosa ética (Bruns, 2019; Rogers, 2018). Este artículo detalla uno de esos métodos “dudosos”: plantea una investigación basada en palabras clave y fechas a través del uso de los controvertidos *scrapers* (herramientas que extraen el contenido de una página web). Su presentación en el Congreso Technological Ecosystems for Enhancing Multiculturality de 2020 (Varela-Rodríguez & Vicente-Mariño, 2020) fue reconocida con el premio a mejor presentación de su rama.

La investigación avanza con una evaluación cuantitativa en el **tercer artículo**, “**El Cáncer de Quién**” (Varela-Rodríguez & Vicente-Mariño, 2021b), centrado en el segundo y el tercer objetivo de la tesis. Evalúa las menciones en Instagram a distintos tipos de cáncer, recogiendo datos sobre el número de publicaciones que hacen referencia a palabras clave relacionadas con, entre otros, el cáncer de mama, el cáncer de páncreas, o el cáncer de pulmón. Los resultados sugieren que cualquier otro y que no hay correlación aparente entre el número de publicaciones, la mortalidad, la incidencia o la prevalencia.

Por último, el **cuarto artículo**, “**Llorar Fotografías**” (Varela-Rodríguez & Vicente-Mariño, 2022) adopta un enfoque cualitativo para estudiar las imágenes compartidas por la periodista Olatz Vázquez durante su tratamiento de cáncer de estómago. Pone su atención en los objetivos segundo y tercero. Valiéndose del análisis visual descrito por Rodríguez & Dimitrova (2011) y por Kress & van Leeuwen (1996), el artículo establece una conversación con las imágenes de la fotógrafa vasca, situadas fuera de la tradición en redes sociales. La mayoría son

⁴ CrowdTangle es una plataforma proporcionada por Meta Platforms, Inc. (la antigua Facebook, Inc.) que permite el acceso a datos públicos de Facebook o Instagram para la investigación. Especialmente en lo que se refiere a los datos de Instagram, tiene limitaciones importantes: solo proporciona acceso a cuentas públicas con más de 50.000 seguidores y a cuentas verificadas (Fraser, n.d.), lo que construye una muestra sesgada, basada en perfiles influyentes en lugar de perfiles comunes. Por otro lado, los criterios de acceso a esta herramienta cambian con frecuencia (ver Bruns, 2019).

imágenes en blanco y negro, cargadas de una crudeza intencional con las que Olatz buscaba representar la vida tras su diagnóstico. Como resultado, se extraen los modos de representar el cáncer, a la paciente y a su entorno social, y se discute cómo la imagen en redes puede ayudar a construir la identidad y a potenciar el sentido de la agencia ante la enfermedad.

La Ilustración 1 recoge los distintos objetivos y cómo cada artículo los incorpora.

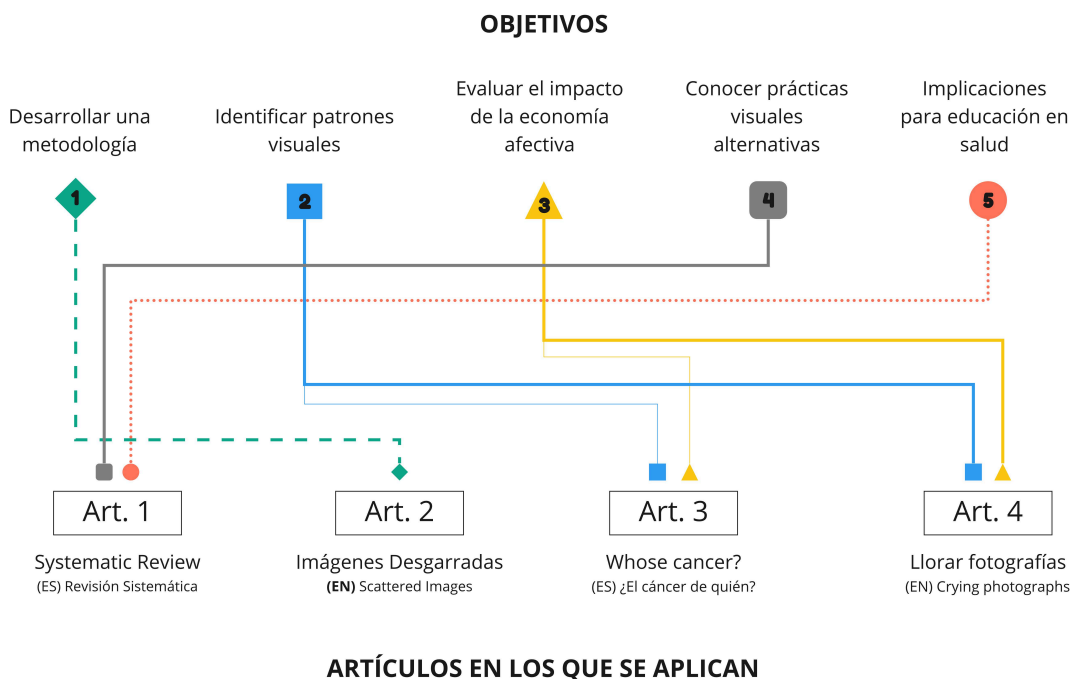


Ilustración 1. Objetivos de la tesis y su incorporación a cada artículo

3. Marco teórico

Acercarse a las imágenes en redes sociales desde las ciencias (también) sociales supone adentrarse en un mundo de interpretaciones y ambivalencias. Esta tesis busca el equilibrio entre al menos dos disciplinas: la sociología de la vida cotidiana—o “Tercera Sociología”, según el sociólogo polaco Piotr Sztompka (2008)—y la sociología visual. También incorpora el estudio de los afectos.

3.1. Las redes sociales, parte de la vida cotidiana

Empezando por la primera de las disciplinas, la tesis aborda una sociología preocupada por la **acción humana** en contextos colectivos. Para Sztompka, esta Tercera Sociología desciende “desde el muy abstracto nivel de los problemas macrosociológicos de los organismos sociales [...] hasta la vida diaria” del individuo. Es una ciencia que se interesa por “lo que realmente ocurre en las sociedades humanas” (2008, p. 3), y que hace uso de las múltiples fuentes de información a disposición de la investigación, especialmente de las herramientas visuales: fotografías de situaciones sociales en los medios, fotoperiodismo, colecciones de imágenes aficionadas, anuncios, carteles (2008, p. 6)... y redes sociales.

En esta sociología encontramos dos de los conceptos que mejor se amoldan a la realidad social en Instagram: los conceptos de **espacio y momento** de Henri Lefebvre, y la idea de **presentación** (*performance*) de Erving Goffman.

El trabajo de Lefebvre es extenso, pero su manera de entender la vida cotidiana se podría resumir en estas líneas:

Lo que resta una vez que todas las actividades distinguidas, superiores, especializadas y estructuradas han sido identificadas [...] Las actividades superiores dejan un vacío técnico que ocupa la vida cotidiana. (Lefebvre, 1991, p. 97 trad. del autor).

El momento y el espacio de la vida diaria son, pues, aquellos instantes en los que no pasa nada reseñable, como extendería Highmore (2011, p. 3). Son los momentos de transición entre eventos, como los que vivimos en el metro o en el autobús, o mientras esperamos a alguien, y que se caracterizan por un ritmo estable, sin sobresaltos, marcado por dinámicas socioeconómicas como el trabajo o la estructura de la vida urbana (Lefebvre, 2004). Cuando esa cotidianidad se rompe, se produce una **arritmia**: un desajuste que nos empuja a buscar la normalidad de nuevo.

¿Y qué mayor desajuste puede haber en la rutina que la enfermedad? Así lo expone Carsten Stage, uno de los investigadores más activos en este campo, y que asegura que los pacientes de cáncer utilizan las redes sociales para intentar volver a la cotidianidad (Stage, 2018, pp. 165–175). Conectar con otros pacientes, compartir imágenes, o celebrar su progreso ayuda a dotar al día a día de los pacientes de un nuevo ritmo social. Y en ese proceso, se construye un discurso del cáncer.

Enfocar las redes sociales desde la vida cotidiana supone estudiar no solo lo que compartimos, sino también los **contenidos que consumimos, dónde los consumimos, y cómo afectan a nuestros roles y a nuestra presentación en sociedad**. Es entender las redes sociales como un escenario (Goffman, 1959) en el que la tiene el papel protagonista.

Reflexionando sobre la función invasiva de la cámara de fotos, Susan Sontag describe la fotografía como una violación de la intimidad de la persona fotografiada, “pues se las ve como jamás se ven a sí mismas, se las conoce como nunca pueden conocerse” (2017, p. 24 trad. del autor). De forma análoga, la fotografía en redes sociales es una oportunidad para vernos exactamente como nos vemos nosotros mismos, o al menos como queremos que nos vean los demás. Por eso adornamos nuestro entorno de forma favorecedora (Walsh & Baker, 2017, p. 5) y utilizamos filtros, descripciones y textos que nos ayudan a orientar la interpretación de la

imagen (Storey, 2014, p. 96). En términos de Goffman, las redes sociales son nuestra oportunidad para desempeñar nuestro mejor papel.⁵

Así, en las ciencias de la comunicación es habitual encontrar reflexiones teóricas y aproximaciones prácticas a la **naturaleza performativa** de las redes sociales. Una *performance* que, por otro lado, no controlamos al 100%: si bien las redes nos permiten presentarnos, nos ofrecen también una serie de **elementos mediadores**, terceras partes que hacen queelijamos y descartemos las imágenes de acuerdo a criterios externos (Hogan, 2010). **Los algoritmos de selección y la economía afectiva** nos hacen intuir qué es y qué no es deseable en las redes, de modo que construimos “personas”, perfiles que buscan adaptarse a lo que se espera de nosotros y que no siempre son coherentes con cómo somos fuera de la pantalla (Merunková & Šlerka, 2019). ¿Por qué utilizamos hashtags cuando compartimos selfis si no es para orientar su interpretación (Walsh & Baker, 2017)? ¿Por qué nos presentamos como personas más extravertidas y amables en el mundo online que en el mundo “táctil” (Attrill, 2015; Harris & Bardey, 2019)?

Ambiguas como son, las redes sociales también requieren que utilicemos conceptos clásicos de la sociología. Así lo hace Lindgren (2020) al aplicar la ambivalencia de Robert Merton y la comprensión y los tipos ideales de Max Weber para explicar la ansiedad que sentimos al enfrentarnos a millones de imágenes que representan todo aquello que querríamos ser. Desde esta óptica, la interacción en redes sociales es un proceso social de construcción constante de significados e, incluso, de crisis de identidades.

⁵ Lo demostró la artista argentina Amalia Ulman en 2014 con *Excellences & Perfections*, un proyecto performativo en Instagram en el que construyó una falsa identidad de *influencer*. Alcanzó los casi 100.000 seguidores con fotomontajes que, supuestamente, la mostraban viviendo una vida en Los Ángeles, antes de anunciar que todo había sido una mentira artística. En 2016, el diario británico *The Telegraph* se preguntaba si el trabajo de Ulman era la primera obra maestra de la era de Instagram (Sooke, 2016).

3.2. La sociología visual ante las redes sociales

“La omnipresencia de las cámaras insinúa de modo persuasivo que el tiempo consiste en acontecimientos interesantes, dignos de fotografiarse.” (Sontag, 2008, p. 8 trad. del autor)

El estudio de las imágenes y las ciencias sociales tienen una relación casi tan antigua como las propias disciplinas. A finales de la década de 1830, con los primeros daguerrotipos y con el trabajo de Comte para definir la sociología, nacen dos disciplinas que comparten la ambición por explorar, representar y, en ocasiones, hacer avanzar a la sociedad (Becker, 1974; Harper, 1988).

Los fotógrafos documentales tuvieron buena mano en este proceso, adentrándose en los métodos y temáticas de la sociología y la antropología a principios del Siglo XX. Más allá de captar momentos históricos o conflictos bélicos, la fotografía buscaba documentar las condiciones y la vida diaria de quienes los habitaban. La pobreza post-depresión en los Estados Unidos según Dorothea Lange; el trabajo infantil retratado por Lewis Hine; los significados sociales de la belleza y la marginación en el trabajo de Diane Arbus; la pertenencia y la identidad sociales reflejadas por Robert Frank; el conflicto y el rol de las personalidades políticas retratadas por Rene Burri; las relaciones sociales cotidianas capturadas por Walker Evans; o las dinámicas de poder y el campesinado que fotografió Paul Strand. En España, Cristina García Rodero, Piedad Isla, Carlos Pérez Siquier, Ramón Masats o Xavier Miserachs adoptaron ese impulso a partir de 1950 por—como rezaba la revista AFAL, pionera en la fotografía documental española—ganar la calle y captar la humanidad que los rodeaba (Fuster Pérez, 2008, p. 91), ya fuese retratando la vida en la montaña palentina, el día a día en las ciudades más grandes, o las fiestas populares.

Se trata de fotógrafos que hicieron de su trabajo una búsqueda incansable de la desigualdad y del lugar del individuo en la sociedad. Lo hacían a través de la

investigación y la ambición por ofrecer una imagen objetiva, casi replicando el método de las ciencias sociales (Becker, 1974; Harper, 1988; Pauwels, 2015).

Hacia finales de la década de 1960, el acceso a las cámaras de fotos se democratiza, la impresión a color se abarata, y la Guerra de Vietnam invade los televisores y las portadas de periódicos y revistas (Berger, 2016; Sontag, 2017). La sociología y la fotografía se acercan más que nunca. La cámara se convirtió en una vía de escape para sociólogos que “rechazaban los paradigmas dominantes en la investigación y la teoría [sociales]” (Harper, 1988, p. 59) y que encontraron en ella un punto de entrada. Poco a poco, lo visual se convertiría en una fuente de información clave para las ciencias sociales. Con la creación de la Sociedad Internacional para la Sociología Visual (*International Visual Sociology Association*) en 1981, se formalizó una relación que hoy permea gran parte del trabajo con imágenes en nuestro ámbito (Harper, 1996; Pauwels, 2015).

Desde sus orígenes, esta nueva **sociología visual** incorpora la tradición interpretativa de Max Weber, y aparece con una serie de nuevos métodos para llegar al punto de vista del sujeto que toma la imagen o que está representado en ella (Harper, 1988, p. 66). Y es que no hay imagen sin interpretación: cada fotografía incorpora una forma de ver el mundo, ya sea en aquello que decidimos capturar o en aquello que dejamos fuera del marco (Becker, 1974; Sontag, 2017). Quizás este sea el motivo por el que, tal y como exponen Pauwels (2015), Caulfield (1996), Gold (2011) o Harper (2000), la sociología visual favorezca el uso de **imágenes encontradas** en lugar de su producción. Y en 2022, las redes sociales son una gran fuente de imágenes encontradas.

Instagram es una red social que forma parte del entramado empresarial de Meta Platforms Inc., la empresa que conocíamos como Facebook Inc. hasta 2021. Nacida en 2010, llegó en un momento en el que las redes sociales visuales (aquellas que priorizaban la imagen por encima del texto) estaban en auge. Aunque se enfrentaba a competidores como Flickr o Hipstamatic, tenía una premisa ganadora: ofrecer una aplicación que permitía compartir imágenes de forma instantánea, desde el móvil,

con una comunidad online, eliminando el proceso de mediación y facilitando la espontaneidad (Leaver et al., 2020, p. 10). Hoy, Instagram es una de las aplicaciones más reconocibles en el mundo digital, y acumula años siendo una de las redes que más rápido crecen (Pew Research Center, 2019).

En 2022, Instagram está gobernada por una serie de algoritmos que determinan las imágenes que se muestran a cada usuario según el momento en que se comparte, su impacto y su red de contactos. La red facilita una relación entre sus usuarios y el mundo a su alrededor, y les brinda la posibilidad de influir sobre cómo son percibidos (Tembeck, 2016). En su origen, una serie de filtros y marcos hacían las imágenes más atractivas; hoy, la comunicación multimodal (vídeos, imágenes, texto y contenidos interactivos) y toda una economía en la que las celebridades se han convertido en *influencers* han dado paso a los contenidos cuidadosamente planificados, dejando de lado la espontaneidad (Leaver et al., 2020).

Tal y como se refleja en la **Revisión Sistemática**, el uso de Instagram para la investigación social es complejo, tanto por cuestiones técnicas como por consideraciones éticas. Si las imágenes de Instagram son públicas o no (por tanto, si pueden verse sujetas a un proceso de observación) es un tema debatido, especialmente en los estudios políticos. Las guías para el uso de este tipo de datos, como la de la Universidad de Aberdeen, suelen ser orientativas (Townsend & Wallace, 2016) y plantean más retos que soluciones. Además, las políticas de acceso a Instagram sufren cambios constantes, lo que la convierte en un ámbito de investigación volátil. Aun así, su uso para evaluar la presencia de discursos visuales, como demuestran los cuatro artículos, es un área con potencial.

3.3. El discurso social del cáncer y sus afectos

El cáncer es una enfermedad que se entiende a través de las metáforas y los afectos. Ya sea como batalla, como carrera, o como viaje, su iconografía está repleta de imágenes evocativas. Su propia etimología, como explica Mukherjee en *El*

Emperador de Todos los Males (2014), nos refiere a la presencia de un invasor que pesa sobre el cuerpo y que arrastramos durante el tratamiento.

Esta tesis no traza una tipología de los discursos modernos del cáncer, sino que se centra en el que quizás es uno de los más reconocibles y extendidos: el **discurso de la supervivencia**. Para entenderlo, es preciso hacer un breve repaso desde principios del Siglo XX, con la ayuda de Maren Klawiter (2008). La investigadora pone el foco sobre el cáncer de mama para distinguir dos regímenes (o etapas) en la comunicación de ese emperador de todos los males: la medicalización y la biomedicalización. En esta tesis, como se verá en las conclusiones, extendiendo estas etapas hasta la **socialización** del cáncer.

Empezamos por el primero. Siguiendo la idea del cáncer invasor, a principios del Siglo XX las pacientes de cáncer asumían el rol social de enfermas (Parsons, 1976) obedientes y sujetas a la mirada clínica ante profesionales médicos distantes. En el régimen de la **medicalización**, los pacientes debían confiar en la medicina para poder volver a sus obligaciones lo antes posible, superando el “bache” de la enfermedad. Recibían poca o ninguna información sobre su diagnóstico o sobre su tratamiento, particularmente si eran mujeres que padecían un cáncer de mama (Klawiter, 2008, p. 279). En la comunicación pública, el cáncer era una enfermedad curable, un inconveniente temporal contra el que peleaban quienes lo padecían, y ante el que solo cabía la respuesta médica. Quienes se sometían al tratamiento debían volver a su vida normal y evitar el juicio social, ocultando cualquier señal de su enfermedad y gestionando los síntomas en privado. Este discurso, hereditario de una forma de entender el cáncer como la consecuencias del fracaso moral de quien lo padece, alcanzó su pico antes de la década de 1970, momento en el que, como se verá más adelante, algunos movimientos sociales (especialmente los movimientos feministas) se levantaron contra él (King, 2008; Lorde, 1980; Sontag, 1978).

Entre 1970 y 1990, el discurso público del cáncer se expandió para incorporar no solo a pacientes diagnosticados, sino a todos aquellos individuos susceptibles de sufrir la enfermedad. En el caso del cáncer de mama, esto supuso la incorporación

de *todas* las mujeres como sujetos de riesgo. En este régimen de **biomedicalización** (Klawiter, 2008), el foco estaba en la prevención, en el estilo de vida y en los cribados. Con grandes campañas de concienciación, este nuevo paradigma mejoró el alcance de la prevención y aumentó el número de diagnósticos. De forma importante, las pacientes de cáncer de mama lograron una mayor agencia en su proceso de diagnóstico y tratamiento, libres del confinamiento informativo al que se veían sometidas a principios de siglo y conscientes de su derecho a la salud (K. Bell, 2014, p. 58).

En paralelo, en el plano cultural emergió un nuevo discurso sobre los pacientes: quienes padecían la enfermedad pasaron de ser víctimas a convertirse en personas heroicas (Broom et al., 2019, p. 1582). En este **discurso de la supervivencia**, las personas con cáncer (especialmente, de mama) aparecen como luchadores que hace todo lo que puede contra él, que lo hacen con alegría y determinación y que, según la imagen pública, *vencen*. El cáncer seguía siendo un invasor al que se expulsaba con la medicina y, ahora, con los buenos hábitos y con la actitud.

El discurso de la supervivencia incorpora la narrativa de la restitución según Frank (1998, 2013). Para él, la historia de la restitución presenta al paciente en una línea que va de la salud a la enfermedad y de vuelta a la salud. Refleja un deseo natural de encontrarse bien (Frank, 2013, p. 78), y distancia al paciente de la enfermedad, que se cuenta como algo transitorio.

La convivencia de la supervivencia y la prevención no es una coincidencia. La biomedicalización aparece al tiempo que las políticas neoliberales en salud pública se extienden (Navarro, 2009, p. 425), incidiendo sobre los hábitos de vida saludables y la responsabilidad individual para evitar los problemas de salud. A principios de los 2000, se refuerza este enfoque proactivo frente a la medicina tradicional (reactiva), con el desarrollo de modelos como el “P4”—basado en la predicción, la personalización del cuidado, la prevención, y la participación de los pacientes (Hood & Friend, 2011). Son modelos que dotan de un nuevo sentido al rol del individuo, ahora situado en el centro no solo de la atención, sino también de la acción. Para el

paciente de cáncer, este paradigma supone, a menudo, adoptar una actitud emprendedora ante su diagnóstico y tratamiento, siendo casi el responsable último de su salud (Stage, 2018). Al incidir en el rol individual, la biomedicalización deja de lado los factores estructurales y ambientales (Sweeney & Killoran-McKibbin, 2016) para celebrar la restitución de la salud como un logro personal, subrayando la responsabilidad de cada uno de nosotros para prevenir el cáncer. Con el desarrollo de la idea del bienestar individual, la salud se convierte en algo maleable y sobre lo que podemos influir siempre que sigamos ciertas pautas. Para algunos autores, es un régimen que perpetúa la enfermedad como un fracaso moral (K. Bell, 2010; Brenner, 2016; King, 2008; Sulik, 2011).

Naturalmente, la salud salta al escenario comercial en forma de estilos de vida, dietas saludables y otras fórmulas para garantizar un futuro sin enfermedades (Lupton, 1994, p. 85). En particular, el cáncer de mama se convierte en el “alumno favorito” del marketing de causa, tal y como explica Barbara Brenner, quien fuera directora de Breast Cancer Action durante 15 años y una de las voces más activas en este ámbito (King, 2008; Pool, 2011). Las campañas contra este tipo de cáncer se popularizan, adoptan el lazo rosa como emblema, utilizan metáforas de heroísmo para referirse a las pacientes y desarrollan la idea de la superviviente de cáncer como mujer luchadora, sonriente, valiente (K. Bell, 2014; Little et al., 2002). Curiosamente, no priorizan factores estructurales como puede ser la desigualdad, sino que se centran en la responsabilidad individual y en la investigación, dejando de lado los factores ambientales.

Siendo justos, es preciso dar un paso atrás: no todo fueron voces a favor de este discurso neoliberal de la salud. También hay voces críticas. En paralelo a la adopción del discurso de la supervivencia en el mundo comercial, desde los primeros 1970 surge un movimiento en oposición directa no al principio de la supervivencia, sino a su estandarización como único discurso público de la enfermedad. La fotografía tuvo, de hecho, un papel fundamental en este proceso, con el trabajo de Jo Spence o Hannahh Wilke que se analiza más adelante. Quienes

critican la supervivencia denuncian una “religión” en la que estar alegre parece obligatorio (Ehrenreich, 2001, p. 50), y enfatizan la presión colectiva que supone para las personas que padecen de cáncer (Broom et al., 2019). Son varias las autoras que se enfrentan al uso económico de las campañas contra el cáncer (King, 2008; Sulik, 2011) y a que se normalice la imagen de la paciente como triunfante, feliz, saludable y femenina, a costa de cualquier otra experiencia (Kaiser, 2008, p. 80).

Las críticas surgen no solo desde un plano ideológico, sino que tienen base en la evidencia, que muestra que el discurso de supervivencia no afecta a todos por igual. Por ejemplo, para pacientes de cáncer terminal, que no pueden “ganar” en el sentido popular, el discurso de la supervivencia supone un factor de estrés (Park & Blank, 2012, p. 414). Asimismo, la supervivencia crea una ilusión de control (Ruthig et al., 2012, p. 1255) que empuja a algunos pacientes a ignorar sus emociones y a adoptar roles y actitudes que no se adaptan a su diagnóstico (Broom & Kenny, 2020; Willig, 2011). El discurso de la supervivencia incrementa la ambivalencia (Merton & López Muñoz, 1980) y la incertidumbre sobre los roles sociales del paciente, especialmente cuando se enfrentan a relatos de la enfermedad que no se corresponden con su experiencia o que incluso la invalidan (Pertl et al., 2014). También niega la desigualdad social, representando mayoritariamente a mujeres blancas, jóvenes y de clase media (Macdonald et al., 2018; Rivera et al., 2021), y a menudo se alimenta de estereotipos de género (K. Bell, 2014; Lupton, 1994, p. 84; Sweeney & Killoran-McKibbin, 2016, p. 458).

Frente a estas críticas, ¿persiste el discurso de la supervivencia en la imaginación social? En base a la literatura revisada, parece que sí, y que se ha infiltrado en las representaciones populares del cáncer (ver, por ejemplo, la Revisión Sistemática y Llorar Fotografías). Además, a través de lo que Katherine Bell llama una “cancer-de-mama-ficación”—una torpe traducción de su *breast-cancerization* (K. Bell, 2014)—el discurso de la supervivencia y el pensamiento positivo se han extendido a todos los tipos de cáncer. Las campañas de concienciación que utilizan los lazos rosas y sus metáforas son tan comunes que casi las esperamos, mientras que

ignoramos o rechazamos las imágenes de cáncer que se sitúan fuera de dicho discurso.

En otras palabras: el discurso de la supervivencia se ha convertido en parte de la vida cotidiana.

3.4. De la fotografía médica a la auto-patografía

Con una carga metafórica tan fuerte, el discurso del cáncer también ha venido acompañado de imágenes que hoy en día reconocemos con facilidad. Quizás la más habitual en nuestra cultura sea la de una mujer con un pañuelo en la cabeza. Todos los artículos incluidos en esta tesis hacen un repaso de las prácticas fotográficas en torno al cáncer, con especial atención en Llorar Fotografías.

Si bien hay registros de relatos de la enfermedad por pacientes de cáncer desde al menos principios del Siglo XIX (Meek, 2017), las investigaciones suelen apuntar al trabajo de Jo Spence, Matuschka y Hannahh Wilke como un distanciamiento de la fotografía de cáncer tradicional. Las tres fueron pacientes de cáncer, y las tres ofrecieron una imagen radicalmente opuesta a la comercial y a la médica. Sus fotos son más crudas y explícitas, y profundamente simbólicas, con una ambición activista, y no esconden las consecuencias del tratamiento. Llorar Fotografías hace un breve repaso de su trabajo.

En la fotografía documental moderna hay numerosos ejemplos de fotógrafos que o bien retratan su propia enfermedad o retratan la de un ser querido:

- “The Battle we Didn’t Choose” es el Trabajo de Jennifer y Angelo de Merendino (2013), que documentaron el cáncer de mama de ella. Cubre todas las etapas del tratamiento, y ya su título (“la batalla que no elegimos”) da pistas de su ubicación contra el discurso de la supervivencia.
- “The Faces of Cancer” (G. Bell, 2018) es un proyecto a largo plazo en el que la fotógrafa británica realiza retratos de pacientes de cáncer por todo Reino

Unido. Subraya la función terapéutica de las sesiones de fotos, y cómo le han permitido conectar y relacionarse con otros pacientes.

- “Reality Trauma”, de Carly Clarke (Jarvis, 2019), es un diario que cubre su diagnóstico y tratamiento de un Linfoma de Hodgkin.
- “The Family Imprint”, de Nancy Borowick (Borowick & Estrin, 2017), cubre la experiencia de sus progenitores a través de los cánceres que padecieron de forma simultánea.
- “This is Documentary”, de Jennifer Keenan (2015), sigue a una joven pareja, Josh y Jenna, tras el diagnóstico de Josh de un Glioblastoma Multiforme, un tipo de cáncer que se origina en el cerebro.

A través de estos proyectos aparece el objetivo común de servir como diario, pero también de presentar la enfermedad al mundo. Cuatro de los cinco proyectos son en blanco y negro, eliminando la información del color y centrándose en el retrato, el detalle y la emoción. En sus descripciones, los autores suelen referirse a la intención de cubrir “toda la experiencia del cáncer”, de documentar el coraje frente a la mortalidad, y de informar a otros pacientes. En todos los casos, la cámara se sitúa hacia el exterior: es decir, las fotografías buscan crear conciencia y enseñar el “lado real” del cáncer.

La presente tesis no se centra en la fotografía documental, sino que pone el énfasis en una práctica que no dista mucho de aquella: **las auto-patografías visuales** (Couser, 2011). Las auto-patografías, en general, son historias de enfermedad contadas por los propios pacientes. Un ejemplo icónico en el cáncer son los diarios de Audre Lorde, en los que narra su experiencia de cáncer de mama, se oponía al uso de las prótesis mamarias, y denunciaba los imperativos estéticos que pesaban sobre ella como mujer mastectomizada (Lorde, 1980).

Aplicado a la fotografía, **las auto-patografías visuales son imágenes que toman los pacientes para representar su propia enfermedad**, un desarrollo que en la segunda mitad del Siglo XX mejoró la agencia de los pacientes y de sus cuidadores,

y que les permitió tomar el control de su imagen (Pardo, 2019, p. 28). A menudo, el dolor y los cambios que sufren los pacientes de cáncer hacen difícil que se reconozcan a sí mismos (Wilde, 2003). Sus cuerpos se convierten en extraños (Lindwall & Berbom, 2009). Fotografiarse a sí mismos frente a un espejo o mostrando sus cicatrices les ayuda a reclamar el cuerpo como suyo (Bolaki, 2011), y a reconsiderar su identidad más allá de sus piernas, sus brazos, su pecho o su cara (McGavin, 2014; Yardley, 2013).

Esta práctica ha sido objeto de estudios en los últimos años, tanto cuantitativos como cualitativos. En este último plano, y en redes sociales, destaca el trabajo de Carsten Stage (2018, 2019a, 2019b); fuera de las redes, nos encontramos con el trabajo de Stefanie Plage (2019, 2020, 2021, 2022). Ambos tienen presencia en los artículos de esta tesis, especialmente en la Revisión Sistemática y en Llorar Fotografías.

Al otro lado del espectro, encontramos los trabajos que, como en *El Cáncer de Quién*, hacen una revisión cuantitativa de la imagen del cáncer en redes sociales. Se centran, por lo general, en los elementos contenidos en las imágenes, las palabras clave que las acompañan, o sus modos de difusión. En general, encuentran que las imágenes de cáncer en redes sociales incluyen, mayoritariamente, a mujeres blancas y jóvenes que expresan emociones positivas (Cho et al., 2018; Henderson et al., 2021; Rivera et al., 2021). Además, parecen revelar un consenso visual (Storey, 2014), utilizando representaciones socialmente apropiadas de la enfermedad, tal y como ocurría en las representaciones comerciales del cáncer en revistas (Andsager et al., 2001; Grant & Hundley, 2008).

En Instagram, las imágenes de cáncer son episódicas, es decir, reflejan un “viaje” a través de la enfermedad (Reisfield & Wilson, 2004). Las fotografías que logran más “me gusta” son aquellas que muestran a sus sujetos sonriendo y reflexionando sobre los momentos de “aprendizaje” (K. Bell, 2012) que el cáncer les ha dado, o apuntando al fin del tratamiento. Incorporan muestras de una vuelta a la normalidad

(como el crecimiento del pelo), y establecen contrastes visuales entre las consecuencias del cáncer y su actitud positiva (Cherian et al., 2020).

Pero, como se elabora en *Llorar Fotografías*, no todas las imágenes de cáncer en Instagram son de supervivencia. Hay quien sigue discursos alternativos (Ucok, 2007). Es habitual ver la narrativa del caos (Frank, 2013, pp. 97-113): pacientes que visualizan la posibilidad de que la vida no vuelva a la normalidad, y que se oponen a la expectativa del paciente ideal que lucha por la restitución. Sus historias incorporan la materialidad de la enfermedad, yendo más allá de sus cuerpos y reflexionando sobre su entorno social, las instituciones que los rodean, y el espacio en el que habitan (Yardley, 2013).

En Instagram, los pacientes fotografían sus síntomas, renegocian su identidad, cuestionan su capacidad para seguir adelante, y construyen una imagen del cáncer que no huye de la crudeza y el shock. A veces, utilizan imágenes que separan el cuerpo de su identidad (Gupa, 2022).

Otros pacientes utilizan la narrativa de la búsqueda, enfrentándose directamente al cáncer y utilizándolo por una causa (Frank, 2013, p. 115). Stage (2018) muestra cómo Instagram es un campo positivo para esta narrativa.

Al hacerlo, generan **espacios afectivos** fuera de los habituales. Al ojo público, las imágenes de caos le resultan imágenes de “malos pacientes”: pacientes que no están interesados en perseguir la vida a cualquier coste (Steinberg, 2015, p. 135). Las imágenes de búsqueda parecen resultar en comentarios positivos y un impacto significativo.

Un ejemplo de ambas, caos y búsqueda, son las fotografías de Olatz Vázquez en *Llorar Fotografías*. Olatz se enfrentó a los cambios y a la mortalidad, y utilizó su enfermedad para reflexionar sobre el sistema de salud.

3.5. Instagram y los espacios afectivos en salud

Como se elabora en la Revisión Sistemática y en El Cáncer de Quién, para los pacientes de cáncer, las redes sociales permiten obtener información sobre la enfermedad (Hawkins et al., 2008); aprender a entender y manejar los síntomas (Bender et al., 2013); construir comunidades de apoyo (Moorhead et al., 2013); o sentirse acompañados (Attai et al., 2015; Hale et al., 2020; Skrabal Ross et al., 2020). En concreto, Instagram facilita la representación de cánceres menos conocidos y proporciona a quienes lo sufren una plataforma de autoexpresión (Noar et al., 2018; Stage, 2019a; Tetteh, 2021). Al mismo tiempo, se ha visto que la información visual mejora la comprensión y la retención de la información sobre salud (Houts et al., 2006).

Más allá de sus funcionalidades y sus usos explícitos, quizás el aspecto más relevante de Instagram sea cómo prioriza unas emociones y actitudes sobre otras a través de los **afectos**: emociones construidas socialmente, a menudo asociadas a factores culturales, y que asignamos a eventos, grupos sociales o actitudes. Un término de Sara Ahmed, la **economía afectiva** se refiere al proceso por el que ciertos afectos se pueden explotar, mitigar, o convertir en parte de la imaginación social (Richard & Rudnykyj, 2009, p. 62). Para Ahmed, los afectos se vuelven “pegadizos” (*sticky affects*) y se convierten en parte del bagaje emocional de un grupo si los agentes sociales más influyentes los utilizan con la suficiente insistencia. Un ejemplo esclarecedor son las dinámicas de demonización y xenofobia que siguieron a los ataques al *World Trade Center* el 11 de septiembre de 2001. Así, en la economía afectiva, las emociones y los afectos se convierten en una mercancía.

Esta economía opera de forma más sutil en redes sociales, donde aparece relacionada con la búsqueda constante del bienestar emocional. Siempre en busca de dicho bienestar, los usuarios de redes como Instagram se presentan bajo una luz favorecedora, protegen su reputación, y conectan con individuos (u organizaciones) que promueven afectos acordes a su forma de entender el mundo (Murphy, 2018). Al mismo tiempo, consumen el ‘yo’ ideal de otros usuarios, se acostumbran a él e

ignoran los contenidos que no apoyan sus necesidades afectivas. Las emociones positivas se “pegan”; las negativas se ignoran.

En la comunicación del cáncer, ese ‘yo’ ideal viene generalmente atado al espíritu de lucha, la inspiración y la motivación, y la esperanza por la restitución. Según las investigaciones de Stage (2018, 2019a), las pacientes de cáncer de mama usan esta red para escapar del miedo y la incertidumbre asociados a la enfermedad, mientras se muestran optimistas y esperanzadas. Si se muestran vulnerables, sus seguidores los devuelven rápidamente al rol de superviviente, recordándoles que saldrán adelante y destacando su capacidad de sobreponerse a las circunstancias (Stage, 2018; Tetteh, 2021).

De esta manera, la comunicación del cáncer en Instagram genera un **rebufo afectivo** (Stage, 2019a, p. 89) que motiva a los usuarios a seguir compartiendo imágenes positivas, y que la propia plataforma integra en su diseño a través de los algoritmos de priorización. Poco a poco, se genera lo que Bösel (2020) llama “cajas negras” de emociones: paquetes de emociones que parecen predeterminados para referirse a ciertos eventos, y que no permiten la expresión saludable de los usuarios.

3.6. Conectando los puntos: conexión teórica entre los artículos

En esta sección, se han expuesto las bases teóricas de la tesis. Los cuatro artículos trazan un camino que incorpora la sociología cotidiana, la sociología visual y la sociología de las redes sociales, si bien es cierto que cada artículo se centra en uno o dos aspectos concretos.

La Revisión Sistemática expone algunos de los postulados de la sociología visual, y, especialmente, explora algunas de las prácticas más comunes en el análisis de imágenes en redes sociales. Hace hincapié en lo limitado de las metodologías disponibles y, especialmente, del trabajo hasta la fecha en Instagram. Desarrolla cuestiones relacionadas con el uso de herramientas computacionales en la obtención y el análisis de imágenes de redes.

Imágenes Desgarradas profundiza en las funciones de las redes en la comunicación en salud, y dedica parte de su atención a las auto-patografías, ofreciendo una reflexión sobre los riesgos de la desinformación sobre la salud en redes sociales. También subraya la división entre los estudios cuantitativos y los cualitativos en la investigación en redes sociales, algo que cobra gran importancia en la metodología de la tesis.

Partiendo del método elaborado en el segundo artículo, El Cáncer de Quién centra su exploración teórica en el uso de las redes sociales por parte de los pacientes de cáncer, y en cómo las imágenes de Instagram pueden ser de utilidad para las investigaciones sociales, mientras destaca los enfoques cuantitativos.

Por último, Llorar Fotografías se centra en las consideraciones cualitativas de la imagen: cómo estudiarla, y cómo afecta a la percepción de visitantes y productores. También hace un repaso de trabajos previos situados al margen de los discursos dominantes, y discute la importancia de los afectos en Instagram.

A través de los cuatro artículos se entienden las redes sociales como un proceso de interacción en la vida cotidiana. La Ilustración 2 resume los principales componentes teóricos de la tesis.

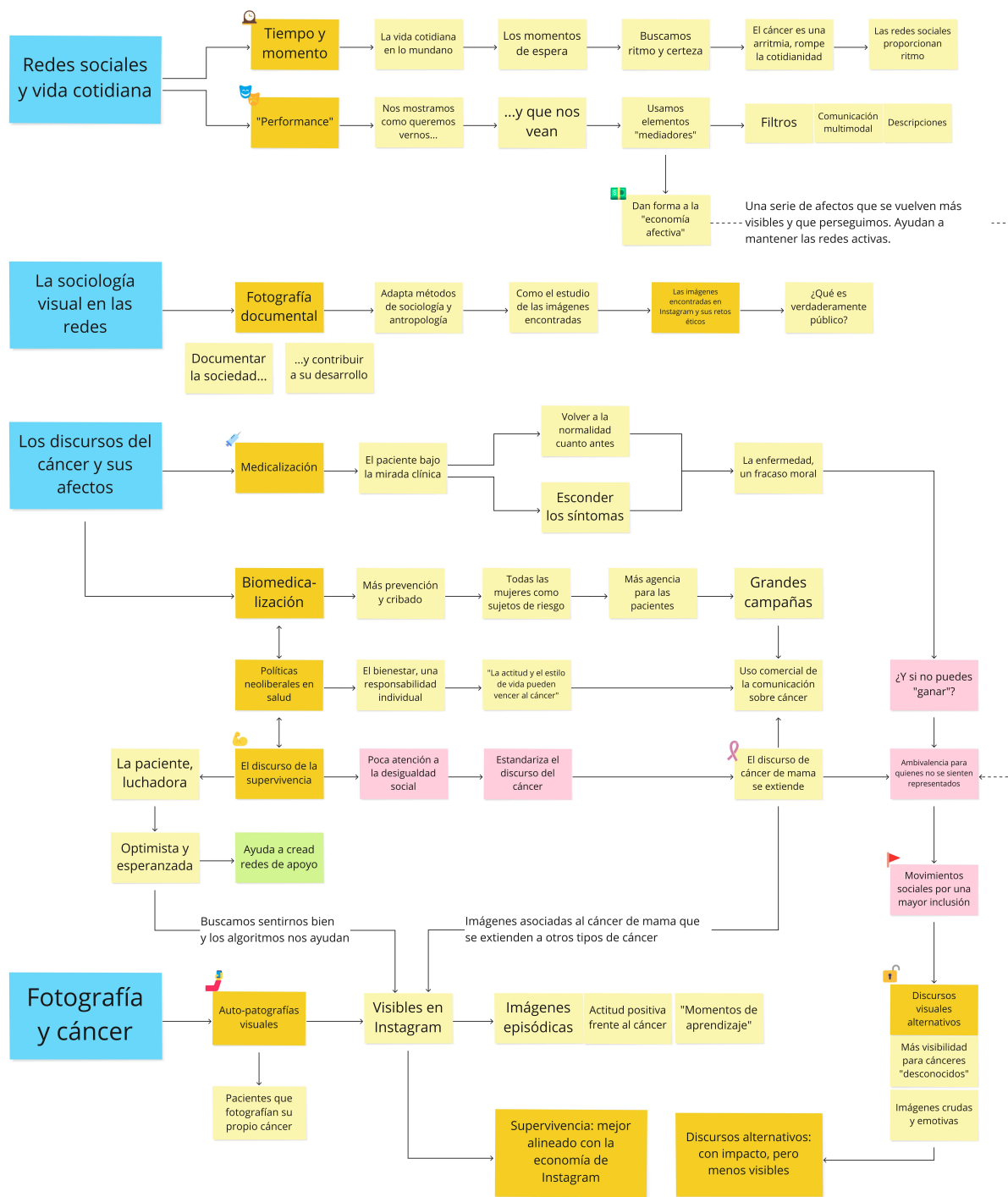


Ilustración 2. Componentes teóricos de la tesis

4. Metodología y proceso de trabajo

Si bien el enfoque metodológico de esta tesis queda resumido en cada uno de los artículos, cabe destacar algunas de las cuestiones principales en esta sección.

4.1. La investigación en redes sociales como “bricolaje” metodológico

Parte de la dificultad de acercarse a las redes radica en cómo las entendemos, con definiciones que cambian con cierta rapidez. En esta tesis, se sigue la definición de las redes sociales que ofrecen McCay-Peet & Quan-Haase:

[...] servicios basados en la web que permiten a individuos, colectivos y organizaciones colaborar, conectar, interactuar, y construir una comunidad a través de la creación, la co-creación, la modificación, el intercambio y la participación de contenido generado por usuarios y fácilmente accesible.

(McCay-Peet & Quan-Haase, 2016, p. 23 trad. del autor)

Por extensión, nos referimos a las redes sociales visuales como aquellas donde los contenidos visuales son el principal modo de comunicación. A partir de esta definición, el método se construye a través de un proceso de “bricolaje”: lo reinventamos e incorporamos elementos de distintas ramas metodológicas en respuesta a cada nuevo reto (Lindgren, 2020, p. 30).

Los componentes básicos de este bricolaje han buscado dar respuesta a cuatro retos fundamentales: cómo obtener las imágenes, cómo tratarlas, cómo interpretarlas, y cómo utilizar imágenes para comunicar los resultados obtenidos.

Obtener las imágenes

En primer lugar, el reto radica en la inmensidad de Instagram, donde habitan millones y millones de imágenes. Puesto que uno de los objetivos de la tesis es evaluar la presencia del discurso de la supervivencia y discernir si existe un desequilibrio entre la representación de distintos tipos de cáncer, se hacía clave construir un proceso que acelerase el trabajo y que no fuese puramente manual.

Descrito Imágenes Desgarradas, el método parte de un proceso de observación de perfiles para identificar palabras clave asociadas al cáncer. Se construyó además un código Python basado en una serie de programas existentes para acelerar el proceso de búsqueda y obtención de metadatos. El método construido permite la obtención de imágenes a través del propio código (de forma automática), pero esto es algo que Instagram no permite en sus términos de uso.

Tratar las imágenes

Al contrario que ocurre con los textos, que se pueden modificar o enmascarar, alterar una imagen supone eliminar sus rasgos básicos; no modificarla podría exponer la identidad de la persona representada. Esto ha hecho particularmente difícil el uso de imágenes para comunicar los resultados. Encontramos inspiración en el trabajo de Lev Manovich (2018b) para *El Cáncer de Quién*, con el uso de gráficos polares que contienen miles de imágenes, imposibles de discernir individualmente, pero con información colectiva.

Analizar las imágenes

Un área de especial complejidad para esta tesis ha sido el estudio de las imágenes obtenidas. Así como el análisis de textos en redes sociales es un área con grandes avances, la codificación de las imágenes sigue siendo un tema controvertido y con escaso desarrollo metodológico. Aparte del trabajo de Manovich, encontramos ejemplos de éxito en el propio mundo de las ciencias de la salud (Hale et al., 2020; Tetteh, 2021); en la comunicación política (Filimonov et al., 2016); o en la estética de los movimientos sociales (Bogerts, 2022; Doerr et al., 2015; Rossi et al., 2022).

En el ámbito de interés para esta tesis, la Revisión Sistemática dos tipos de estudios: los cuantitativos y los cualitativos, con barreras claras entre ambos. En lugar de optar por un camino o por el otro, esta tesis busca su convergencia, desarrollando procesos de codificación de imagen tanto deductivos como inductivos. Están recogidos, fundamentalmente, en *El Cáncer de Quién* y en *Llorar Fotografías*, y combinan principios y marcos de análisis de Barthes (1977); Berger

(2016); Panofsky (1970, 2004); Rodríguez & Dimitrova (2011); Rose (2016) y Kress & van Leeuwen (1996).

Visualizar los Resultados

El uso de materiales gráficos para representar los resultados ha sido clave en el desarrollo de esta tesis. Sin embargo, el uso de imágenes de Instagram dificultades éticas importantes. Las imágenes de redes sociales suelen incluir elementos que podrían facilitar la identificación del usuario que las comparte, lo cual podría suponer un riesgo para ellos. Por otro lado, obtener el permiso de los propietarios de las imágenes para su utilización solo es posible cuando se realizan trabajos con pocos sujetos de estudio—en trabajos que revisan miles de imágenes, es virtualmente imposible.

Los artículos y el propio compendio de esta tesis utilizan distintos recursos para poder utilizar imágenes de forma creativa y que mejore la comunicación de los resultados. La Revisión Sistemática hace uso de diagramas que resumen las conclusiones de la investigación realizada. Están basados en el marco PRISMA (Moher et al., 2009), pero también en propuestas propias del autor. Imágenes Desgarradas también incorpora elementos visuales, si bien se trata de gráficas sencillas como son los histogramas, además de una imagen que muestra fracciones de distintas imágenes de Instagram para destacar sus elementos principales. El Cáncer de Quién utiliza gráficos polares inspirados en el trabajo de Manovich (2020); permiten representar miles de imágenes en base a criterios cuantitativos y categóricos. Por último, para Llorar Fotografías se obtuvo el consentimiento informado de los administradores del perfil de Olatz Vázquez, lo que posibilitó la reproducción de varias de las imágenes.

Con un método y una teoría que vienen de distintas disciplinas, se hacía necesario poder conectar y visualizar las ideas clave de forma sencilla. Para ello, en este compendio hago uso de diagramas basados en las metodologías de mapeado de diálogos (Conklin, 2006). El mapeado de diálogo es, principalmente, un método de

facilitación, pero también muestra resultados excelentes a la hora de condensar y visualizar ideas complejas en un texto o en una conversación. Utilizando un proceso similar a la codificación temática (Thomas & Harden, 2008), el mapeado permite comunicar el enfoque teórico y metodológico en una sola página. Se trata de un enfoque utilizado en los materiales pedagógicos, como por ejemplo el libro sobre metodología de investigación de Hernández-Sampieri y Fernández-Collado (2014).

Por último, utilizo el delineado para destacar los elementos clave en algunas imágenes de Instagram sin utilizarlas directamente, de forma similar a lo visto en trabajos previos sobre la comunicación política (Trillò et al., 2021; Trillò & Shifman, 2021), así como montajes que combinan los retratos de más de 60 pacientes de cáncer, compartidos en Instagram.

A través de estos procesos (identificación, tratamiento, codificación y visualización), se aplica el principio de sensibilidad teórica que expone Simon Lindgren en su obra *Data Theory* (2020). Consciente de que la imagen nunca es aleatoria ni un fiel reflejo de la realidad, se busca en todos los artículos ofrecer interpretaciones teóricas fuera del estudio de las redes sociales, de modo que se pueda construir un puente entre disciplinas.

4.2. Retos éticos de la investigación online

La investigación de imágenes en redes sociales es un campo de alto voltaje. Investigar imágenes de Instagram desde 2018 supone tomar uno de dos caminos: aceptar las limitaciones impuestas por Meta o saltarse las reglas (Bruns, 2019).

Más allá de los términos legales, no obstante, aparecen cuestiones éticas de gran calado. De partida, la observación de redes sociales supone un debate entre qué es y qué no es contenido público. Algunos de los estándares que se aplican hoy en día en la investigación de este tipo tienen más de 10 años (una eternidad en el mundo digital), como la guía desarrollada por la Association of Internet Researchers

(Markham & Buchanan, 2012), publicada en un marco legal y cultural completamente diferente al que habitamos hoy.

En 2017, las propias Markham & Buchanan (2017) reflexionaban sobre la falta de especificidad en la ética en investigación online. Entre sus recomendaciones se encuentra la de considerar la posibilidad de que el sujeto estudiado sea identificado a partir de los contenidos, al tiempo que nos preguntamos si esa identificación podría conllevar un riesgo físico, económico o psicológico. A lo largo de la tesis, se han aplicado medidas para la protección de los datos obtenidos según las recomendaciones de las autoras (tanto de 2012 como de 2017), así como de otros trabajos (McGill, 2020; Nguyen et al., 2018). Los identificadores de las imágenes se han eliminado. Se han retirado las imágenes con contenido sensible de cualquier tipo (incluidas las imágenes en las que pudieran aparecer menores de edad). Todas las imágenes se almacenaron en un dispositivo protegido. Cuando se han utilizado visualizaciones, se han utilizado solo representaciones a muy pequeña escala. En el cuarto artículo se obtuvo el consentimiento informado de sus administradores para la reproducción de las fotografías. Más allá de estas medidas, se consideró que no era necesario obtener permisos adicionales. La Ilustración 3 resume estos aspectos.

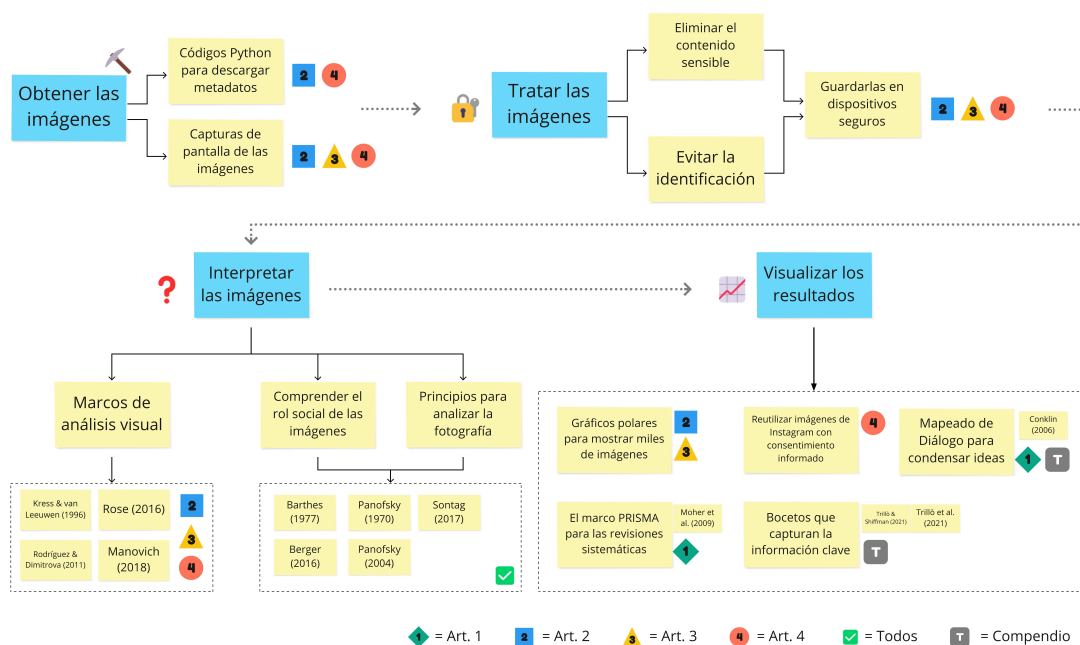


Ilustración 3. Componentes metodológicos de la tesis

5. Artículos publicados

5.1. Artículo 1: *Systematic Review* (Revisión Sistemática)

Varela-Rodríguez, M., & Vicente-Mariño, M. (in press). Images published by cancer patients in social media and their reception: A systematic review. *Review of Communication Research*.

Idioma: Inglés (traducción al español no disponible)

Recibido: 11 de enero de 2022


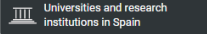
Aceptado: 16 de septiembre de 2022

Publicado: Review of Communication Research (pendiente; ISSN 2255-4165)

Scimago: Q1 (Communication)

Indexada en: SCOPUS – Scimago SJR; Clarivate Analytics – Emerging Sources Citation Index (ESCI); Directory of Open Access Journals (DOAJ); ProQuest

Detalles de la revista en el ranking Scimago-SJR a 22 de septiembre de 2022

Review of Communication Research 			
COUNTRY	SUBJECT AREA AND CATEGORY	PUBLISHER	H-INDEX
Spain 	Social Sciences └ Communication		5
PUBLICATION TYPE	ISSN	COVERAGE	INFORMATION
Journals	22554165	2017-2021	Homepage How to publish in this journal editor@rcommunicationr.org

5.2. Artículo 2: Imágenes desgarradas

Varela-Rodríguez, M., & Vicente-Mariño, M. (2021). Imágenes desgarradas: El uso de scrapers en investigación social en Instagram sobre cáncer. *Cuadernos.Info*, 49, 72–97. <https://doi.org/10.7764/cdi.49.27809>

Idioma: Español (traducción al inglés disponible en anexos)

Recibido: 26 de noviembre de 2020


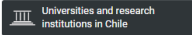
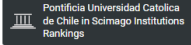
Aceptado: 19 de abril de 2021

Publicado en: Cuadernos.info (Vol. 49; ISSN 0719-367X)

Scimago: Q2 (Communication)

Indexada en: Scopus – Scimago SJR; Clarivate Analytics – Emerging Sources Citation Index (ESCI); Sistema Regional de Información en línea para Revistas Científicas de América Latina, el Caribe, España y Portugal (Latindex); Scientific Electronic Library (SciELO); Directory of Open Access Journals (DOAJ); Red Iberoamericana de Innovación y Conocimiento Científico (REDIB); Dialnet; Red de Bibliotecas Universitarias y Científicas Españolas (REBIUN); Citas Latinoamericanas en Ciencias Sociales y Humanidades (CLASE); Clasificación Integrada de Revistas Científicas (CIRC); European References Index for the Humanities and Social Sciences (ERIHPLUS).

Detalles de la revista en el ranking Scimago-SJR a 22 de septiembre de 2022

Cuadernos.info 			
COUNTRY	SUBJECT AREA AND CATEGORY	PUBLISHER	H-INDEX
Chile 	Social Sciences — Communication — Library and Information Sciences	Facultad de Comunicaciones de la Pontificia Universidad Católica de Chile 	11
PUBLICATION TYPE	ISSN	COVERAGE	INFORMATION
Journals	07193661, 0719367X	2013-2021	Homepage How to publish in this journal dgrassau@uc.cl

5.3. Artículo 3: *Whose cancer?* (¿El cáncer de quién?)

Varela-Rodríguez, M., & Vicente-Mariño, M. (2021). Whose cancer? Visualising the distribution of mentions to cancer sites on instagram. *Journal of Visual Communication in Medicine*, 1–17. <https://doi.org/10.1080/17453054.2021.1964356>

Idioma: Inglés (traducción al español no disponible)

Recibido: 20 de marzo de 2021

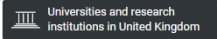
Aceptado: 2 de agosto de 2021

Publicado en: Journal of Visual Communication in Medicine (online; ISSN 1745-3062)

Scimago: Q1 (Visual and Performing Arts)

Indexada en: SCOPUS – Scimago SJR; Clarivate Analytics – Emerging Sources Citation Index (ESCI); Cambridge Scientific Abstracts (CSA); Contents Pages in Education; EBSCO Online; Educational Technology Abstracts; Index Medicus/MEDLINE and Library; Information Science Abstracts (LISA).

Detalles de la revista en el ranking Scimago-SJR a 22 de septiembre de 2022

Journal of Visual Communication in Medicine			
COUNTRY	SUBJECT AREA AND CATEGORY	PUBLISHER	H-INDEX
United Kingdom 	Arts and Humanities └ Visual Arts and Performing Arts Health Professions └ Health Professions (miscellaneous)	Informa Healthcare	16
PUBLICATION TYPE	ISSN	COVERAGE	INFORMATION
Journals	17453054, 17453062	1978-2021	Homepage How to publish in this journal c.d.erolin@dundee.ac.uk

5.4. Artículo 4: Llorar fotografías

Varela-Rodríguez, M., & Vicente-Mariño, M. (2022). Llorar fotografías: Análisis de contenidos y discursos visuales sobre el cáncer en las fotografías de Olatz Vázquez en Instagram. *Revista Española de Sociología*, 32(1), Article 1.

<https://doi.org/10.22325/fes/res.2023.149>

Recibido: 5 de mayo de 2022


Aceptado: 22 de septiembre de 2022

Publicado en: Revista Española de Sociología (Vol. 32, n.1; ISSN 1578-2824)

Scimago: Q2 (Sociology and Political Science)

Indexada en: SCOPUS – Scimago SJR; Clarivate Analytics – Emerging Sources Citation Index (ESCI); Dialnet; EBSCO Online; International Bibliography of the Social Sciences; Fuente Académica Plus; Academic Source Premier; Social Services Abstracts; Worldwide Political Science Abstracts; CARHUS Plus+

Detalles de la revista en el ranking Scimago-SJR a 22 de septiembre de 2022

Revista Espanola de Sociologia 			
COUNTRY	SUBJECT AREA AND CATEGORY	PUBLISHER	H-INDEX
Spain 	Social Sciences └ Sociology and Political Science	Federacion Espanola de Sociologia	10
PUBLICATION TYPE	ISSN	COVERAGE	INFORMATION
Journals	15782824	2010-2021	Homepage How to publish in this journal res@fes-sociologia.com

6. Conclusiones e implicaciones

La representación del cáncer en Instagram parece un microcosmos, una ilustración de dinámicas comunes al uso de las redes sociales: presentarse bajo una luz favorecedora, negociar la identidad para adaptarse a lo que es socialmente deseable, romper con los discursos dominantes, o llenarse de incertidumbre al no verse representado en las publicaciones de otros usuarios.

Las conclusiones presentadas en las próximas páginas se obtienen del análisis de la comunicación visual del cáncer, pero podrían ser aplicables a multitud de campos.

6.1. Sobre la metodología de investigación visual en Instagram

Esta tesis ha planteado una revisión de la presencia del discurso de la supervivencia en las imágenes de Instagram y su encaje con otras formas de entender el cáncer. No es el primer trabajo en acercarse a las funciones de las redes para los pacientes de este tipo de enfermedades (ver Attai et al., 2015; Bour et al., 2021; Laranjo, 2016); tampoco es el primero en considerar el rol de la fotografía (ver Plage, 2019), ni el primero en revisar las prácticas visuales en la comunicación de cáncer (ver Cho et al., 2018; de Noronha, 2019; McWhirter & Hoffman-Goetz, 2014); ni siquiera es el primero en acercarse a Instagram, en concreto (ver Henderson et al., 2021; Stage, 2019a; Zade et al., 2017). Sin embargo, sí es uno de los primeros intentos por encontrar la convergencia entre supervivencia de cáncer, redes sociales, imagen y discurso social de la enfermedad.

Allí donde la mayoría de los trabajos enfocan la mirada sobre las estrategias de prevención o el uso activo por parte de los pacientes, esta tesis busca una visión sistémica, centrándose en cómo el uso cotidiano de redes sociales puede generar una imagen distorsionada del cáncer incluso entre aquellos que no padecen la enfermedad y a los que ni siquiera les toca de cerca.

A fecha de redacción (Septiembre de 2022), las investigaciones sobre la imagen del cáncer en redes sociales son limitadas, aunque prometedoras y en una curva

claramente ascendente. En parte, parece que las limitaciones se deben a las dificultades técnicas y metodológicas para (1) obtener y tratar las imágenes y (2) para interpretarlas. A esto se suman (3) las consideraciones éticas.

Sobre lo primero, la metodología desarrollada en Imágenes Desgarradas permite acelerar el trabajo de obtención de metadatos y su registro. Hace posible identificar el volumen de imágenes compartidas y sus fechas, algo especialmente relevante para trabajar sobre campañas de concienciación, por ejemplo. Sin embargo, no permite acelerar la obtención de las propias imágenes, a no ser que estemos dispuestos a violar los términos de uso de Instagram.

Por otro lado, abandonar el uso de *scrapers* y optar por las herramientas que proporciona Meta, como CrowdTangle, supone centrarse en una muestra de la población de Instagram (cuentas con más de 50.000 seguidores) que difícilmente refleja la realidad social de personas en desventaja o cánceres poco presentes en la imaginación social. Supondría, prácticamente, analizar los discursos visuales de las celebridades y los influencers, algo que tiene utilidad, pero que va en contra del enfoque cotidiano.

En lo que se refiere al análisis de imagen, el uso de los modelos de Rodríguez & Dimitrova, de Kress & van Leeuwen, y de Rose han facilitado un estudio detallado de las imágenes, pero de momento no permite un trabajo lo suficientemente rápido como para poder crear una imagen representativa de la realidad en Instagram. Para ello, parecería necesaria la colaboración entre distintas disciplinas, especialmente entre las ciencias sociales y las ciencias de la comunicación y la información, como hace Manovich (2018a), de modo que se puedan estudiar elementos cuantitativos y no visuales (como los textos y las descripciones) de forma automática.

6.2. Sobre las formas de visualizar el cáncer y la economía afectiva

Desde la imagen cruda que visualiza las heridas de las intervenciones quirúrgicas hasta imágenes de grandes marchas contra el cáncer donde el rosa es el color dominante, son muchas las formas que toma el cáncer en Instagram. Parece, de hecho, que se sitúan en un continuo desde el shock hasta el romanticismo. Aun así, no se puede concluir, a partir de los resultados, que los usuarios sigan conscientemente el discurso de la supervivencia. En su lugar, parece que, simplemente, éste es un discurso que se presta mejor a la economía afectiva de Instagram.

A partir de los resultados y de la revisión de la literatura, parece que conviven cuatro procesos afectivos relacionados con momentos diferentes:

1. **Prevención:** las campañas de prevención generan un espacio afectivo negativo, basado en el miedo y el riesgo, subrayando la posibilidad y la probabilidad de padecer algún tipo de cáncer a lo largo de nuestras vidas.⁶
2. **Investigación y concienciación:** las imágenes comerciales para la concienciación y a favor de la investigación explotan los espacios afectivos positivos y los recursos visuales estereotipados.
3. **Tratamiento y apoyo:** se genera un espacio afectivo positivo para referirse a quienes sufren la enfermedad, destacando su capacidad de lucha, su constancia y su determinación por superar la enfermedad.
4. **Consecuencias del cáncer:** aparecen imágenes alternativas, que gestionan los espacios afectivos negativos al expresar las consecuencias físicas, sociales y económicas del cáncer, y que denuncian las desigualdades del sistema de salud.

⁶ De esta dinámica es síntoma que el cáncer sea hoy en día la enfermedad más temida en todo el mundo (Ipsos MORI, 2021).

Naturalmente, los cuatro espacios coexisten en los perfiles de usuario. Las imágenes de pacientes mezclan la supervivencia con los discursos alternativos. Pero es la reacción de sus seguidores, y de la propia plataforma, lo que da forma a los espacios afectivos. A partir de las investigaciones realizadas, parece que las emociones positivas reciben más “me gusta”, en números significativamente mayores a los comentarios que reciben las imágenes con emociones negativas (Cho et al., 2018; Hale et al., 2020; Stage, 2018, 2019b; Tetteh, 2021). En cierto sentido, parece que las imágenes positivas pueden crear contenido influyente, mientras que las imágenes negativas pueden crear comunidad.

La Ilustración 4, incluida en la siguiente página, resume los cuatros espacios y momentos descritos.

Las campañas de concienciación también pueblan Instagram. Cuando buscan el cambio de actitudes de forma insistente, los espectadores parecen desconectar e ignorarlas. En algunos casos, las campañas han desarrollado una identidad visual tan marcada, que su imagen se ha disociado del cáncer por completo, como es el caso de Movember, una campaña en su origen enlazada al cáncer de próstata, pero hoy utilizada para representar multitud de cuestiones de salud masculina.

Por otro lado, la estandarización del discurso del cáncer de mama es visible en los artículos presentados. El Cáncer de Quién encuentra que en 2021 había al menos 10 veces más imágenes que mencionaban el cáncer de mama que imágenes que mencionen el siguiente tipo de cáncer (la leucemia).

Así, las imágenes de cáncer en Instagram representan mayoritariamente el cáncer de mama, favorecen las emociones positivas, y dificultan el cambio de actitudes.

Research and awareness
Investigación y concienciación

Positive emotions
Emociones positivas

Treatment and support
Tratamiento y apoyo

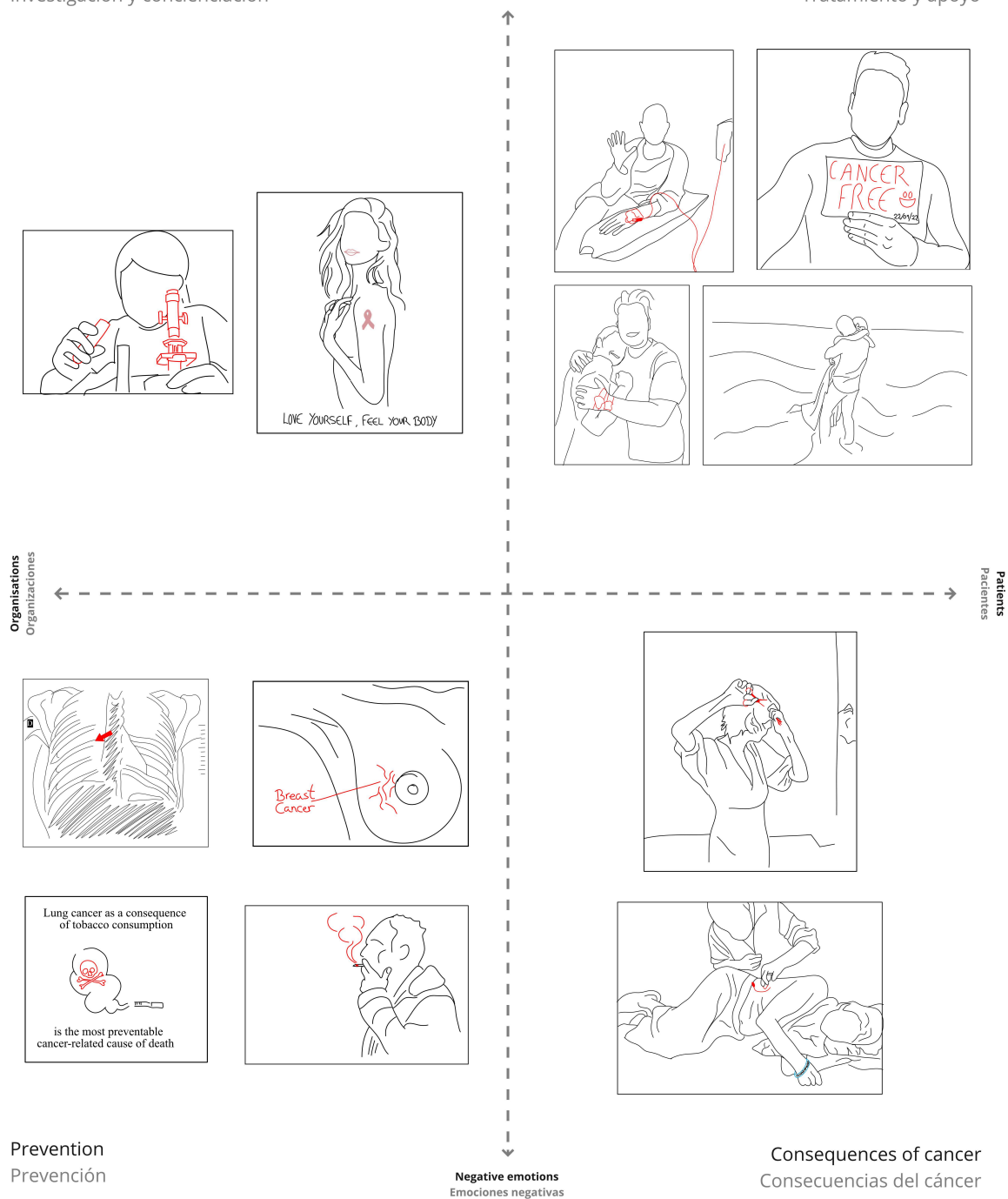


Ilustración 4. Cuatro espacios afectivos en la representación del cáncer en Instagram. El Eje X representa quién las comparte; el Eje Y indica el tipo de emociones que suscitan.

6.3. La socialización del cáncer en la era de las redes sociales

Los resultados de esta tesis sugieren que la comunicación del cáncer se ha movido hacia un nuevo paradigma. Más allá de la medicalización y la biomedicalización que describe Klawiter, podemos hablar de una **socialización** del cáncer. Este nuevo paradigma comparte rasgos con los anteriores, pero añade un elemento clave: el discurso de la supervivencia sigue dominando la imaginación social, pero ahora se transmite y se integra a través de las redes sociales. Si bien quienes padecen la enfermedad pueden utilizar narrativas diversas, los medios sociales y tradicionales *socializan* una imagen estandarizada de la enfermedad.

Para hablar de socialización hay que mirar atrás, hasta la sociología clásica, donde el término tiene una historia larga y compleja. Las primeras menciones como concepto sociológico se atribuyen a Georg Simmel (Guhin et al., 2021; Hurrelmann & Bauer, 2018). La socialización también fue un concepto clave en la teoría de Émile Durkheim—la explicaba como un proceso por el que las nuevas generaciones son educadas e integradas en las normas y valores de sus grupos. A través de la socialización, las instituciones formaban miembros funcionales de la sociedad, evitando la anomia de una sociedad cada vez más desconectada e insolidaria (Pietro, 2004; Snarey & Pavkov, 1991).

Para la sociología funcionalista, la socialización era una responsabilidad colectiva, pero también un deseo individual. Traía consigo la promesa de una sociedad más cohesiva y positiva, en la que los individuos pudieran crecer. Parsons lo entendía como un proceso que empezaba en las instituciones más cercanas a cada miembro de la sociedad (como la familia), pero que continuaba a través de la educación y de los medios. Juntos, proporcionaban un anclaje moral y cultural (Pietro, 2004, p. 113; Stevens, 2008, p. 106).

En los años '70 del siglo XX, la idea de socialización se vio sujeta a numerosas críticas. Los autores contrarios a la sociología funcionalista aseguraban que esa supuesto solidaridad defendida por Durkheim era, en realidad, una excusa para

sostener las estructuras de poder y desigualdad. La socialización beneficiaba a los ricos y poderosos, mientras que dejaba de lado a las personas de clases menos privilegiadas. Más aún, el concepto negaba la capacidad de cada individuo de sobreponerse al sistema en el que nace—es decir, negaba su *agencia* (Guhin et al., 2021; Snarey & Pavkov, 1991).

A pesar de las críticas, Guhin et al. (2021) demuestran que, fuera de la teoría sociológica, el concepto ha tenido acogida, especialmente en la sociología de la educación y en los estudios raciales y étnicos. También es común encontrar referencias en la sociología de la salud (Andress & Purtill, 2020; Hansell & Mechanic, 1986; Singh-Manoux & Marmot, 2005; Zempléni, 1988) y en las ciencias políticas (Hyman, 1959; McLeod & Shah, 2009). En la investigación online, las redes sociales se estudian a menudo como un mecanismo de auto-socialización, el proceso por el que los usuarios van integrando las normas y formas de los grupos que ellos mismos deciden habitar (Anderson & McCabe, 2012; Jensen Arnett, 2015).

Esta tesis defiende que la socialización sigue siendo un término relevante, especialmente en el tema que la atañe. Sandford y Quarmby (2018) y Lindell (2017) muestran cómo las teorías de Bourdieu, Goffman, y de Berger y Luckmann son visibles en las plataformas online. En el campo de la comunicación visual del cáncer, podemos ver cómo opera la socialización en varios pasos.

Primero, el diseño de las redes sociales se asemeja al concepto de *campo* de Bourdieu (2002). Los usuarios (de Instagram o de cualquier otra red) habitan múltiples grupos y redes. Cada uno, con su propio espacio, pero también con fronteras difusas.

Segundo, lo que es adecuado dentro de cada campo se define de forma colectiva y se interpreta individualmente. Los usuarios interiorizan las prácticas visuales, que después reproducen como parte de su adaptación “cultural”. Bourdieu se refería a este proceso como *habitus*.

Tercero, implementar bien el habitus le devuelve una recompensa al usuario: los “me gusta”, los comentarios y los seguidores no solo le otorgan un mayor capital social dentro del grupo, sino que además le proporcionan una sensación de pertenencia. Esto refleja el proceso de formación de la identidad que describía Mead (Aboulafia, 2016): en las redes, la identidad se construye a través de la interacción entre un *yo* independiente y la idea que los demás esperan y nos devuelven de nosotros mismos (lo que Mead llamaba el *mí*).

Cuarto, las imágenes son una forma accesible de acceder al *mí*, pero también de representar el habitus. En los artículos presentados se demuestra cómo las fotografías ayudan a pacientes de cáncer a negociar su identidad, visualizar los cambios en su cuerpo, y disociar de su enfermedad. Las imágenes convierten la identidad en algo visible. También hacen tangibles las emociones, los discursos, las metáforas y las normas culturales de cada habitus (Gómez Cruz & Lehmuskallio, 2016).

Quinto, el consumo diario de redes sociales y sus algoritmos facilitan la integración de los discursos visuales. Los usuarios se habitúan (Persson, 2018, p. 129) a ver ciertas imágenes, y casi las esperan.

Sexto, el hecho de que las fronteras entre campos en redes sociales sean permeables significa que los discursos visuales pueden atravesarlos. Así, se crean discursos que no pertenecen a ningún campo en concreto, pero que están presentes en todos ellos.

Por último, los resultados de esta tesis muestran que las redes sociales visuales prefieren las imágenes de cáncer que son positivas, esperanzadoras, y estéticamente atractivas. Mientras que algunos usuarios utilizan discursos alternativos, como puede ser la narrativa del caos, el campo general de Instagram promueve una imagen estandarizada de la supervivencia.

Juntos, todos estos factores me llevan a pensar que la representación del cáncer en redes visuales responde a una dinámica de socialización, ya sea para generar una imagen más fácil de digerir y que resulten en un mejor pronóstico (como dirían

Durkheim o Parsons) o porque esconden una agenda oculta (como dirían sus críticos). Utilizar esta perspectiva puede ayudarnos a pensar con mayor profundidad sobre las imágenes que empleamos a la hora de comunicar el cáncer—también recupera un concepto, el de socialización, que es clave para la teoría social (Guhin et al., 2021).

Referirse a una socialización del cáncer no debe suponer, sin embargo, obviar la agencia que tienen los pacientes de cáncer. Los resultados de esta tesis muestran que los pacientes sí utilizan discursos alternativos, y que éstos resultan en comentarios de apoyo en redes sociales (Hale et al., 2020). Al contrario, hablar de la socialización del cáncer en redes sociales supone subrayar las dificultades a las que se pueden enfrentar pacientes y cuidadores a la hora de recoger información en redes. También ayuda a reflexionar sobre la posibilidad de que sus círculos sociales, habituados a la imagen de la supervivencia, les transmitan un discurso de cáncer que no se adapta a su pronóstico.

En este contexto, la comunicación visual sobre cáncer debe ser consciente del tiempo y el espacio en el que compartimos y consumimos contenidos. También debe tener en cuenta cómo la imagen que utilizamos para representar la enfermedad puede afectar a la experiencia de quiénes lo padecen, ya sea como pacientes, cuidadores, o supervivientes.

6.4. ¿Hacia dónde vamos? Implicaciones para la educación en salud

Las implicaciones de los resultados en esta tesis son diversas. En primer lugar, promover una imagen estandarizada y que aprovecha los espacios afectivos que mejores resultados obtienen en Instagram puede generar una imagen más positiva del cáncer, que motive al paciente y su círculo social. También puede facilitar la creación de espacios de apoyo, ofrecer bienestar, y ayudar a los pacientes a contar su historia en un entorno seguro.

Sin embargo, también puede potenciar el impacto negativo del discurso de la supervivencia: crear una sensación de falso control y de culpa en los pacientes, ignorar las experiencias de pacientes con fatiga crónica, u ocultar la realidad de cánceres con pronósticos complicados, además de multiplicar la visibilidad de cánceres reconocidos en la sociedad (como el de mama) y la invisibilidad de cánceres desconocidos (como el de páncreas). En última instancia, puede generar expectativas en los pacientes, sus cuidadores y sus seres queridos que después será difícil regular. Kaiser (2008) y Pertl y colegas (2014) demuestran que la insistencia en el discurso de la supervivencia funciona para algunos pacientes, pero genera una sensación de abandono en muchos otros.

En segundo lugar, el rechazo a las imágenes que buscan un cambio de actitudes supone un reto para la educación en salud, especialmente para modelos basados en las creencias sobre la salud y en la participación (Laranjo, 2016). A la vista de este rechazo y de la prevalencia de los afectos positivos, es posible que en Instagram algunos elementos necesarios para el cambio de actitudes, como es la percepción de riesgo, pasen desapercibidos.

Dicho esto, es importante también reflexionar sobre la necesidad (o no) de que los contenidos en redes sean *virales* para ser *útiles*. Afortunadamente, Instagram permite la creación de espacios de intercambio más allá de los contenidos *trending* y de las modas. Para pacientes, cuidadores y círculos cercanos, existe la oportunidad de promover el uso saludable de las redes sociales a través de los servicios de atención al paciente proporcionados por la salud pública y por las organizaciones del tercer sector. Sin embargo, influir sobre la economía afectiva de la supervivencia será clave para alcanzar a quienes no tienen relación directa con el cáncer y para construir una imagen social del cáncer que permita una experiencia adaptativa si llega el momento en que la tengan. Es, pues, una **tarea preventiva**.

Por último, es importante destacar que, aunque los artículos de esta tesis se refieren a la necesidad de promover una imagen “real” del cáncer, esto no es sinónimo de utilizar el shock. Ésta es una estrategia que se ha utilizado en la

prevención y para buscar el cambio de hábitos relacionados con distintos tipos de cáncer, como el tabaquismo. Aunque puede ser una estrategia de éxito, también puede llevar a la estigmatización de los pacientes de cáncer de pulmón, como se discute en la Revisión Sistemática. En su lugar, promover una imagen real del cáncer se refiere a facilitar espacios de comunicación sobre los diversos tipos de cáncer, reducir el uso de elementos visuales con carga de género, posibilitar la comunicación de emociones negativas, y mostrar la cotidianeidad de la enfermedad. Así, surgen una serie de posibles orientaciones para una comunicación educativa en salud en Instagram que tenga impacto y que sea más inclusiva:

1. **Promover el trabajo interdisciplinar**, incorporando las experiencias de las ciencias sociales para interpretar los discursos de cáncer; las de la salud para que los mensajes estén alineados con el conocimiento médico; las del comportamiento, para garantizar el bienestar de los pacientes; y las ciencias de la comunicación, para construir un proceso actualizado y eficiente.
2. **Expandir las investigaciones académicas sobre cáncer en redes sociales a otros tipos de cáncer**. Los aprendizajes de la investigación en cáncer de mama pueden ayudar a alcanzar a los pacientes de otros tipos de cáncer.
3. **Incorporar metodologías de la etnografía y la sociología visual al espacio online**, combinando la observación y el análisis computacional con técnicas como los grupos de discusión o la foto-elicitación, que permiten evaluar la percepción por parte de los espectadores, no solo la intención de los productores.
4. **Reforzar el uso de los aspectos positivos del discurso de la supervivencia**. La creación de comunidades y redes de apoyo para pacientes, o el cuidado del bienestar emocional son funciones importantes que se pueden potenciar si se **limita la insistencia en el lenguaje de superación** y batalla.

5. **Favorecer la representación de tipos de cáncer menos conocidos** con el lenguaje visual de las redes, y aprovechar el rebufo afectivo (una expresión que utiliza Stage) que generan los casos mediáticos.
6. **Apoyar a las empresas y organizaciones colaboradoras** en las campañas contra el cáncer para incorporar discursos visuales del cáncer más allá de los sospechosos habituales, de modo que se pueda **deconstruir la “caja negra de emociones”**.
7. En la **prevención**, revisar el uso de los modelos basados en la responsabilidad y los hábitos saludables para no estigmatizar a los pacientes.

La tarea por delante es considerable, y supone la inclusión de multitud de actores: investigadoras en las ciencias sociales, de la salud y de la comunicación; pacientes y cuidadores; profesionales de la sanidad; proveedores de redes sociales... Parece adecuado adoptar un enfoque transdisciplinar que ayude en esta tarea.

La transdisciplinariedad se ha definido como una “forma de ser” en investigación, un empuje por integrar las perspectivas de tantos campos como sea relevante, también las perspectivas fuera del mundo académico (Rigolot, 2020).

En los tres campos (ciencias sociales, de la salud y de la comunicación e internet), la transdisciplinariedad ha devuelto resultados positivos. Científicos sociales y de la salud la han utilizado para construir intervenciones más longevas e inclusivas (Rosenfield, 1992). Es, además, un pilar importante en el campo de la bioética, que integra a pacientes para identificar necesidades médicas y psicosociales (Stepke, 2016).

Para investigadores de internet, este enfoque permite una comprensión profunda de lo que significa ser parte de una audiencia y de la línea que separa (o no) los mundos digital y físico (Hunsinger, 2005, 2008). Para continuar en esta dirección, es necesario establecer una conversación con los proveedores como Meta. Una mayor transparencia por su parte también ayudará a crear espacios afectivos más inclusivos. Tal y como demostraron durante la pandemia del COVID-19, las

plataformas como Instagram tiene la capacidad (y, ojalá, la voluntad) de facilitar espacios digitales más inclusivos y constructivos.

Responder a la socialización del cáncer desde un enfoque transdisciplinar supone, pues, buscar una representación consciente del cáncer, que tenga en cuenta las muchas **formas de la enfermedad**.

7. Limitaciones

Ningún trabajo que aborde la representación de una temática social en Instagram puede pretender obtener una imagen global. Desde el principio del proceso de doctorado, esta tesis se ha enfrentado a un campo extenso y habitado por muchas disciplinas diferentes, por lo que ha sido preciso tomar decisiones que limitan su alcance. Enfocar la mirada sobre el discurso de la supervivencia ha supuesto no poder mirar con suficiente atención a otras áreas importantes en la comunicación del cáncer, como la prevención. Futuras investigaciones podrían buscar la convergencia entre ambos temas, extrayendo los elementos de cada uso y contrastando su volumen y las métricas de respuesta a cada una. También sería conveniente buscar una definición de los elementos que reflejan el discurso de la supervivencia, más allá de las sonrisas o los gestos que se recogen en los artículos.

En cuanto a la metodología, tanto el análisis de la imagen como la obtención de datos de Instagram son tareas con riesgos y limitaciones. El análisis de la imagen, un ámbito que pertenece a la semiótica, se nutre de postulados y formas de interpretación con un contraste científico limitado. En el futuro, además de aplicar los principios de los autores destacados, sería relevante implementar procesos automatizados (que pueden revelar elementos no detectables a simple vista) y contrastar la interpretación del autor con la de los espectadores de la imagen, como se sugiere en las conclusiones.

Haber realizado este trabajo durante la fase crítica de la COVID-19 en España también puede haber limitado el alcance y la aplicabilidad de los resultados. A medida que la vida normal vuelve y que los hospitales retoman su actividad pre-COVID, sería relevante plantear el trabajo con las unidades de oncología, o con organizaciones del tercer sector.

