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‘My #CA125 biomarker has halved!’: how women with incurable cancer give meaning to biomedical knowledge on Instagram

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Abstract

To understand how people give meaning to biomedical knowledge in their everyday lives, we studied 60 Instagram accounts of women living with incurable cancer. What sets them apart is that, although they are incurably ill, they sometimes live relatively long lives because of scientific developments. Thus, illness experiences become entangled with biomedical knowledge. We found that women discuss and interpret, for instance, test results or therapy modifications by using biomarkers as hashtags, e.g. #CA125. Biomedical knowledge is constantly mobilised and interpreted to juggle between living everyday lives and being incurably ill for a relatively long time. We also found how the visual element of Instagram allowed the women to make sense of their ever-changing realities, e.g. bodily changes. Studying spontaneous engagement with science on social media enables the perspectives of people who are not able to participate in organised public engagement, e.g. because of illness, to still be heard.

Keywords

Digital science communication; Health communication; Public engagement with science and technology

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1 ▪ Introduction

Science and publics are intrinsically intertwined [Horst et al., 2016]. Publics were traditionally seen primarily as recipients of scientific insights. They were viewed as having a knowledge deficit, causing, for example, misunderstandings or public scepticism towards science. In turn, scientists assumed that these 'deficits' could be resolved by providing more scientific information produced in certified institutions, such as universities [Horst et al., 2016]. Later, with the work of feminist scholars like Haraway [e.g. Haraway, 1988] and Harding [Harding, 2008] and Science and Technology Studies (STS) scholars such as Irwin and Wynne [1996] and Epstein [1995], publics were seen as having valuable knowledge themselves, called situational, indigenous, experiential, and local knowledges. For example, Epstein [1995] showed how AIDS activists used their experiential knowledge about their bodies and disease trajectories to challenge the design of clinical trials to test and develop medication for a life-threatening illness. Wynne [1992] showed how local sheep farmers' knowledge, for example regarding sheep's grazing behaviour, proved useful for scientists to establish adequate procedures for measuring radioactive contamination. Over time, a new 'social contract' between science and society emerged [Gibbons, 1999]. Citizens were no longer positioned as mere recipients of science but invited, for example by policymakers, to participate as scientists' new 'dialogue partners' in the early stages of science and technology developers [Krabbenborg, 2013]. As a result of what is called the 'participatory turn' in science, many public engagement activities, ranging from small-scale interventions — e.g. science cafés — to large-scale societal dialogues [Chilvers & Kearnes, 2015], have been organised — for example by STS scholars, policymakers, consultants — over the past decades with the aim of eliciting public concerns, values, and needs in relation to science.

These organised public engagement events received much scholarly attention [Chilvers & Kearnes, 2015; Rip & Robinson, 2013], but, in recent years, scholars also increasingly examine unsolicited public engagement with science, i.e. how citizens use science in their everyday lives [e.g. Marres, 2012; Maslen & Lupton, 2019; Pols, 2023]. Scholars have shown that science and technology are not merely abstract entities for people. Rather, people evaluate science and technology in the context of their daily lives and actively use science to make sense of their daily life — e.g. their experiences with medical procedures or illness [Pols, 2023; Wendrich & Krabbenborg, 2024]. From this perspective, Davies et al. [2019] and Horst et al. [2016] argue that research into citizens' informal engagement with science — for example at museums, through the internet — enables scholars to unveil whether and in what ways citizens discuss and mobilise science to give meaning to the world around them. For example, Maslen and Lupton [2019], in their research on people seeking out biomedical knowledge on Facebook, showed that knowledge on diagnosis, treatment protocols, and diets was shared based on the personal experiences of what worked effectively for people in their daily lives. Kerr and DeMichelis [2025] showed how women living with the chronic disease fibromyalgia jointly made sense of medical knowledge in online Facebook groups to prepare for consultations with healthcare professionals.

We build upon the scholarship of unsolicited public engagement by focusing on how women living with incurable cancer use biomedical knowledge in their daily lives. What sets these people apart is that, although they are incurably ill, they can experience longer periods of good health — e.g. because of personalised medicine. Thus, some people confronted with incurable cancer find themselves in the healthcare system for a relatively long period of time [Bell, 2013; Prainsack, 2017, p. 97]. Because of their relatively long contact with the

healthcare system, their experience of illness becomes entangled with biomedical knowledge, including 'objects' in which biomedical knowledge is materialised such as medical technologies and artefacts like written results from body scans, biomarker monitoring, or therapy modifications [Bell, 2013; van der Kamp et al., 2022]. Previous research has also shown how biomedical developments — e.g. receiving new test results or healthcare professionals disagreeing with each other on treatment trajectories — cause constant feelings of anxiety and uncertainty [van der Kamp et al., 2022].

1.1 ▪ *How biomedical knowledge comes to matter in daily lives*

Our overall aim is to examine how biomedical knowledge, including the artefacts that contain or produce biomedical knowledge such as body scans, clinical trials, scientific papers, or medical results come to matter in the lives of women living with incurable cancer, that is, make a difference in their lives, as the biomedical knowledge produces particular effects to which women relate and to which they have to give meaning [Kolehmainen & Lupton, 2025]. For example, Peng et al. [2019] showed how, via online forums, people living with cancer shared experiences, challenges, and advice to others living with cancer regarding participation in clinical trials. To better understand how biomedical knowledge comes to matter, we study meaning-making practices in the everyday lives of women living with cancer over a relatively long period of time. By focusing on everyday life with illness — also called illness experience [Bury, 1982] — we refer to the lived experience of patients in which their beliefs, emotions, relations to others, and embodied associations with the disease are navigated in organising everyday life [Pierret, 2003]. As Little et al. [1998] argued, illness experiences are complex and layered, vary per person, evolve over time, and are shaped by social contexts. For example, how illness is experienced in the everyday is shaped through changing biomedical knowledge about the disease, interaction with others such as family or other patients, the influence of cancer's effects on everyday practices such as going to work and spending time with friends, one's self-image, and how one presents 'the self' to others [Broom et al., 2018; Kerr & DeMichelis, 2025; Maslen & Lupton, 2019].

To understand how biomedical knowledge comes to matter in everyday illness experiences, we espouse the analytical notion of assemblages of care, as this foregrounds the multiple and dynamic connections between human actors, for example healthcare professionals, patients, and nonhuman actors — e.g. hospital rooms, clinical trials, and digital health technologies. As Kolehmainen and Lupton [2025] showed, these connections are not static but evolve over time and are all inherently part of everyday illness experiences. For example, encounters with biomedical knowledge in the hospital, where patients experience how medical information is gathered during tests and discussed during consultations with health professionals, are taken home to navigate cancer-as-a-lived-experience in their daily lives — e.g. biomedical knowledge becomes part of spending time with family [Davies et al., 2019; van der Kamp et al., 2022]. Moreover, Broom et al. [2018] showed how waiting for test results from scans and biomarker testing induces constant feelings of anxiety for people living with advanced cancer in between medical appointments.

1.2 ▪ *Assemblages of care in the online world*

As Sánchez Querubín [2020] and Stage et al. [2020] showed, assemblages of care also involve the online world to share illness experiences with others. Building upon insights from

Kerr and DeMichelis [2025] and Maslen and Lupton [2019] on unsolicited and mundane use of science in online spaces, we study how women living with incurable cancer share biomedical knowledge on the social media platform Instagram.[1] As a social media platform, Instagram is characterised by its visual element: people share posts through images and videos. The visual element is accompanied with textual affordances such as captions, comments from other users, and hashtags to link posts to certain topics. Hashtags are written on Instagram by the use of the # symbol. Previous research has shown how the technical affordances of social media create communities with shared norms and acceptable behaviour on the platform [Stage, 2019; Stage et al., 2020]. For people living with illness, social media's affordances, such as hashtags, allow people to build digital peer communities with others who are living with the same illness [Gurrieri & Drenten, 2019; Karlsson et al., 2026; Stage et al., 2020]. For example, Gurrieri and Drenten [2019] showed how women with breast cancer use hashtags to place themselves in subcommunities relating to cancer types or treatments. Through these peer subcommunities, people can share and seek biomedical knowledge and experiences with illness or treatment, regardless of time and space [Maslen & Lupton, 2019]. Seró Torroja et al. [2024] show how Instagram makes the influence of biomedical technologies on everyday life visible through pictures of the body and symbolism — e.g. images of calendars with treatment dates. Through these platform affordances, women tailor assemblages of care by showing only certain elements of their everyday life, for example how they navigate the healthcare system online and receive support from digital peer communities [Frazer et al., 2022]. Limited scholarly attention — exceptions include Gurrieri and Drenten [2019] and Seró Torroja et al. [2024], and Stage [2019] — has been given to how social media's affordances, such as hashtags and visuals, shape how women living with cancer give meaning to biomedical knowledge. We focus on Instagram, as the combination of visual and textual affordances allows us to investigate how women give meaning to biomedical knowledge on Instagram with the help of visuals and texts. Therefore, we pose the following research questions:

RQ1: How do women living with incurable cancer give meaning on Instagram to biomedical knowledge in their everyday illness experiences over a longer period of time?

RQ2: What is the role of Instagram's affordances, such as hashtags and visuals, for the use of biomedical knowledge in the everyday lives of women living with incurable cancer?

2 ▪ Methods

From deliberations, exchanges, and interpretations of science encounters on Instagram, we can deepen our understanding of the roles of biomedical knowledge in the everyday lives of women living with incurable cancer. By biomedical knowledge, we mean the knowledge produced by healthcare professionals — e.g. through blood tests or body scans — and by medical scientists — e.g. through experiments in the laboratory — regarding disease

1. Posts on Instagram consist of photos or videos. They can be viewed individually or in an overview of previous posts on a person's account page, which is called the grid, because the images are presented in a grid format. The photos can be accompanied by digital affordances such as 1) text, which can be found as captions under photos, as comments under posts, and as a user description, 2) emojis, which are small digital images used to express emotion, or 3) hashtags, which are words or phrases preceded by the # symbol and found under posts on Instagram. Hashtags signify that a post is about a specific subject and will be recognised by Instagram users and algorithms. Instagram users can like and comment on posts, find others via hashtags, and follow them, all within a framework consisting of data and algorithms [Sánchez Querubín, 2020].

processes, diagnostic tools, treatment trajectories, and surveillance check-ups. To study Instagram as a space, we used a digital ethnographic approach [Frömming et al., 2017]. Instagram as a social space can be used for digital ethnographic studies by observing social interaction through posting, commenting, and tagging in small datasets to gain in-depth knowledge [Hine, 2000]. This digital ethnographic approach allowed us to observe people's activities on Instagram as a social space [Frömming et al., 2017; Hine, 2000].

2.1 ▪ *Account selection*

We examined 60 first-hand accounts for this paper. To do so, we set up our own Instagram account (@wiekebetten_radbouduniversity) and followed the accounts for a period of 2.5 years. Following the women for such a long time allowed us to see their experiences unfold in real time and to experience Instagram as a platform first hand. We found these women by searching for the hashtags #CA125, #CancerJourney, #CancerSucks, and #FightingStage4Cancer. We also used the following snowballing technique: we followed the accounts of various women to begin with, and then followed other women who commented on their posts. We followed additional accounts by accepting suggestions generated by Instagram's algorithms, based on accounts that we were already following. Some of these accounts were created specifically to share illness stories, but others pre-dated the person's diagnosis.

We followed women with disease trajectories of at least 12 months, as we wanted to uncover the role of biomedical knowledge in everyday life during a relatively long disease trajectory with incurable illness. The women were living with various types of cancer, including different primary cancer sites and metastases, resulting in various treatment trajectories. All of the women self-described their diagnoses as incurable in their bios or posts — e.g. stage IV cancer or chronic metastatic cancer — entailing the treatment and monitoring of the disease for the purpose of prolonging life rather than preserving life. The women had different social set-ups though: some were married but others single or divorced, and some had children but others did not. Some of the women had made a conscious choice not to have children. Others could not have children even though they wanted to because of infertility, sometimes caused by cancer (treatment). The women lived in English-speaking countries and all posts were in English. To secure the women's privacy, we do not show detailed information concerning accounts, but general information is available in Table 1. The women who died during our study were not excluded.

Table 1. Information about the accounts of the women in this study.

Age (in 2021 or at time of passing)	24–51[a]
Primary cancer	Bowel, brain, breast, colon, lung, ovarian, melanoma, myeloma, osteosarcoma, (non-Hodgkin) lymphoma, sarcoma
Year of diagnosis	2009–2020
Countries of residence	Australia, Canada, Ireland, New Zealand, United Kingdom, United States
Number of followers at the end of analysis	108–104,000
Number of posts at the end of analysis	17–3394

[a] Not all women shared their age; this age range is based on the women who did.

2.2 ▪ *Research approach*

After an initial exploration of the accounts, data were gathered and analysed simultaneously. We continued to follow new accounts in order to find a variety of experiences, discussions, and real-life contexts. The data, both textual (captions and hashtags) and visual (pictures and videos), were gathered using Instagram's Collections function to collect posts. The posts were analysed thematically to find patterns in the data [Braun & Clarke, 2023]. We initially used deductive codes (see Appendix) based on previous research on living with incurable cancer — e.g. feelings of hope and uncertainty [Bell, 2013; Broom et al., 2018] — and social media use by people living with illness — e.g. using hashtags to find specific peer communities and medical information online [Maslen & Lupton, 2019; Stage et al., 2020]. Over time, we developed new inductive codes (Appendix) that focused on interpretating biomedical knowledge in everyday illness experiences on Instagram, for example biomarker hashtags and biomedical developments over time. We analysed the posts holistically, by 1) keeping the pictures, captions and hashtags of one post together during the coding, and 2) interpretating the posts alongside our analytical codes in the context of the women's Instagram grids to gain insight into changes over time. Through an iterative process of coding and collaborative interpretation — in which the research team challenged each other's assumptions — we developed themes such as sharing biomedical knowledge and visualising living with cancer (Appendix).

2.3 ▪ *Ethical considerations*

This study was approved by the Research Ethics Committee of the faculty of Science of the Radboud University. In the biography of our Instagram account (@wiekebetten_radbouduniversity), we disclosed that we were researchers studying online stories about illness. We made it clear to the women that we were following them and we indicated in our biography their option to opt out of the study. We acknowledge that, although the posts we analysed were publicly available, they were not created for research purposes. We have therefore chosen not to show the posted images and to pseudonymise the quotes by excluding or changing identifying words and information, such as specific cancer types, biomarkers and treatments. Throughout this paper, we use codes instead of names when referring to the women.

3 ▪ Findings

Our research questions elicited two main findings: first, continuous navigation of biomedical knowledge in personal life-worlds; second, Instagram's affordances as a tool for meaning making in relation to biomedical knowledge and being ill.

3.1 ▪ *Continuous navigation of biomedical knowledge in personal life-worlds*

We found that the women wrote in detail about their medical experiences and discussed complex biomedical research while posting about their daily lives. For example, we saw that the women placed their treatment names or cancer markers in hashtags, such as #CA125, which refers to a biomarker used for ovarian cancer monitoring. We found that these specific biomarker-related hashtags allowed for community building online, because it brought

women together who shared the same diagnoses based on detailed molecular information. As (GH, age 45) wrote 'maybe telling my story connects with others diagnosed with this rare cancer'. The women updated their followers on treatment progress and test results. Responses from people within the online community — often affectionately called 'cancer family' — on these updates were often more welcomed than responses from people outside the online community. In the updates, women enriched the detailed biomedical knowledge with their own experiences and photos by connecting the technical knowledge to their personal life-worlds. We found that women made connections between biomedical knowledge and personal life-worlds in two ways.

First, women give meaning to results from biomarker tests in the context of what it means for their everyday lives and lived experiences. The following post by O illustrates this:

> O (age unknown, diagnosed in 2013) writes under a picture of herself in hospital connected to an IV and smiling at the camera: 'I completed my first cycle of treatment: [immunotherapy] and [experimental drug]. In just a couple of weeks, my #[cancer biomarker] has halved! I can also feel my tumours getting smaller. (…) My body is taking a toll, but it finally seems to be making some progress against cancer #[cancer type] [immunotherapy] #[cancer biomarker]'.

We can see in O's writing that test results on, for example, biomarker levels, shape what it means to live with cancer. We see that the positive test results for the cancer biomarker influence O's lived experience, because she writes that she can physically feel her tumours shrinking. She also interprets the test results as positive scientific progress, while experiencing how her 'body is taking a toll' because of the side effects of treatment.

We also saw how women juggle the interwovenness of living normal life, being incurably ill, and constant screening through biomarker technology. On the one hand, the numerical results from these types of tests can change a person's perspective on health because they can indicate that the person has a deadly disease even though they are asymptomatic [Bell, 2013]. On the other hand, medical results are often presented as fixed numbers but, because they represent a snapshot taken at a single moment in time, they cause great uncertainty about the person's health status as the numbers often fluctuate over time [Gillespie, 2012]. This ambiguity — experiencing periods of relatively good health while being ill — is recognised as part of living with cancer. Yet, the women that we followed are living with cancer for a relatively long time thanks to developments in diagnostic testing and treatment interventions. They are regularly confronted with testing and monitoring of biomarker levels. This constant confrontation with new biomedical insights urges women to reinterpret test results and deal with related feelings of uncertainty many times throughout their disease trajectory. In another post, O shares her perspective on how test results alone do not define her health status. Nonetheless, her recent test results have been different from what they used to be, and this overshadows her perspective and creates feelings of uncertainty and anxiety:

> O (age unknown, diagnosed in 2013) posted an image of a ribbon — as an awareness sign for the type of cancer she is living with — accompanied with the following text: 'Lately my [cancer biomarker] blood test results have been above the normal range. I know that the test is a small piece of the puzzle, but it is enough to have me anxious and rethinking everything (…) #[cancer type] #[cancer biomarker]'.

Second, women give meaning to biomedical developments in the context of what they mean for their prognosis. Medical scientific breakthroughs and the development of new medicine are slow processes and can sometimes take years. Yet, people living with incurable cancer can sometimes live longer nowadays. Therefore, biomedical developments can potentially still result in new treatments during their lifetime. Women constantly have to reinterpret this new information and what it means for their prognosis. A post by OP (aged 25, diagnosed in 2017) shows that this is a continuous process when someone lives for a relatively long time with incurable cancer. She describes how new genetic tests might show that she has a more specific type of cancer than originally diagnosed, resulting in feelings of hope for new treatment options after 5 years of chemotherapy. The new treatment options that might become available through the new genetic tests force her to re-evaluate her feelings of hope regarding her prognosis, disease trajectory, and perspective on the future. OP writes about this under a photo of her in some woods smiling at her dogs. She is wearing a bandana because, as she writes in an earlier post, 'I am still not comfortable with how I look with short hair even though this is the second time I lost my hair':

> 'Last week I received my CT scan results. (…) This all [The results] indicates that my chemotherapy, the treatment I've been on for 5 years, has stopped working. (…) My oncologist is chasing up my genetic testing for mutations such as [tumour marker A] and [tumour marker B], with the hope of finding more possible treatment options. At the moment, I do not qualify for immunotherapy due to being classed as a [cell cycle mediator] wildtype — essentially no mutations. (…) Last time I spoke to [healthcare professional], I was told that there were no clinical trials available, so hopefully that's not the case now (…) #[cancer type] #[cancer stage]'.

The biomedical knowledge on genetic mutations, treatment options, and drug effectiveness influenced OP's feelings of hope and real-life possibilities regarding the extension of her life. This hope on extending life was also represented in the practice of memorialising and immortalising specific moments, as explored in the following section.

3.2 ▪ *Instagram's affordances as a tool for meaning making in relation to biomedical knowledge and being ill*

We found that Instagram as a space offered the women a method for meaning making through the act of posting. Individual posts are visualised in a larger grid resembling a patchwork quilt where multiple small pieces become a whole. Through the visual grid, Instagram becomes a tool to patchwork living with incurable cancer, treatments, and side effects into the fabric of everyday life. The women alternated pictures on everyday life, for

example having dinner with their families, with images in the medical sphere. They shared 'hospital-selfies' while getting chemotherapy, pictures of themselves in hospital beds, or close-ups of PICC lines entering their veins and hands filled with the pills that they had to take that day. The women also shared information from their electronic health records including print screens of test results and photos from MRI scans. By curating the visual grid, women were able to bring certain elements of life to the fore and relegate other elements to the back. This practice allowed the women to give meaning to the ambiguity of living in periods of relatively good health while being ill. For instance, by sharing close-ups of both medicine in the hospital and flowers in the garden, the women shared how they sometimes needed to 'stop and smell the roses' during their disease trajectories.

We found how the women gave meaning to living with incurable cancer and possible shortened life expectancies, for example when biomedical knowledge on their illness is limited or when therapies are no longer effective. We saw how the women can remember moments on Instagram that would otherwise be forgotten, moments that under other circumstances would not become memories [Hoskins, 2018, p. 63]. They do so by posting pictures of certain moments, and writing that those moments will become memories for themselves and family after their passing. By labelling a moment a memory, sometimes explicitly tagging it as memories using hashtags such as #MakingMemories, the women exert control over processes of remembering, that is, how the women would be remembered: not only as someone who navigated living with illness, discussed biomedical knowledge with doctors in the hospital, and was the 'girl with cancer' (H, aged 31, diagnosed in 2017), but also as women who lived full lives, experiencing periods of good health to do everyday activities outside of the biomedical sphere, such as spending time with family or going to work:

> T (aged 40, diagnosed in 2016) writes, alongside a photo of her and her father at a sports event: 'Life for me right now is about taking it day by day. Making memories and ensuring pictures with those I love. Last week, I was on chemo. Today, I am so happy to be at [sports event] (…). I post this rather than the tears, because these are the moments I want to recall (…).

We found that the women give meaning to bodily changes by showing and discussing these changes on Instagram. The women that we followed are living with cancer for a relatively long time thanks to improvements in diagnostics and treatment. This means that they also have to live longer with the effects of cancer and its treatment, which are often bodily and visible for themselves and others. Because Instagram is a space where experiences can be captured in images, we found that the women choose to show their changing bodies on Instagram, including scars from surgeries and blood testing, weight gains or losses, and losing their hair or not losing their hair at all. As the women undergo many treatments — both continual and periodical — in this relatively longer life, their experience of their changing bodies shifts over time. For example, sometimes people have to go through multiple cycles of chemotherapy, which could result in multiple experiences of losing hair, growing hair in between treatments, and losing hair again. Besides navigating new treatment options and medical scientific breakthroughs, women also have to navigate the continuous new effects of different cancer stages and different treatments. ZZ describes this process of navigating her bodily changes:

> ZZ (age unknown, diagnosed in 2013) writes: 'This change in my appearance has been far from easy. I knew when I started chemotherapy that my hair was going to fall out. Before I knew it, my hair was coming out in huge chunks. Traumatic to say the least so I took it upon myself to shave my head. I finally felt like I was in control (…). I've spent the last 3 years living with cancer, and for the first time you can see it just by looking at me. It has been a huge adjustment looking in the mirror and not feeling like myself. (…) Thank you to everyone who shared my photo and sent me words of encouragement (…).

ZZ describes how cancer had control over her and her appearance and how she later reclaimed that control by shaving off her hair. In this post, she also acknowledges the importance of her followers on Instagram who supported her throughout this process. Sharing biomedical knowledge — e.g. the embodied results from side effects or test results from scans — in interaction with others on Instagram also shaped how cancer-as-a-lived experience was communicated on Instagram. As mentioned above, the production of new biomedical knowledge, through for example new test results, caused feelings of uncertainty and anxiety. Yet, we saw how many women write about their illness experiences in a positive manner — for example, by ending posts on disappointing test results from scans with positive sentences such as 'stay positive, stay strong' or 'I have a lot to be grateful for'. The women also describe a complex and ambiguous relationship with being positive, as positivity is experienced as both helpful to get through feelings of uncertainty and simultaneously as something they are forced into as if it is their only option:

> Y (aged 30, diagnosed in 2018) writes next to a picture of her smiling while eating ice cream in her garden: 'Why are you so positive? [restating a question from another Instagram user] Why aren't you? I could choose to be sad, frustrated and every emotion in between or I can choose to focus all my energy into being happy, driven and determined (…)'.

What is interesting here is that women themselves reflect on having a positive mindset for longer periods of time, even when new biomedical knowledge — e.g. from biomarker monitoring — changes their disease trajectories or prognosis. When the women post about their lives in a positive manner, they receive a lot of praise from followers, which further complicates their relationship with positivity. On the one hand, women share how it feels nice to receive likes and positive comments from others. On the other hand, they notice that getting more likes for their positive posts causes them to share positive things only. This shows that the women are aware of the norms in Instagram culture:

> JJ (age unknown, diagnosed in 2017) writes under a picture of her sun-bathing: 'Most of you seem to really like the posts where I talk about how hard living with cancer is and how I spin it around and turn it into something positive. I get it. I like to be inspired too, but living with cancer IS hard. (…) #[cancer type]awareness'.

We saw how being continuously praised for their positivity puts pressure on the women to have a positive mindset, even at times when they do not have this mindset, as 'words of encouragement make us feel like we cannot live up to your expectations' (M, age unknown, diagnosed in 2018). This can become overwhelming and create feelings of pressure and self-doubt, such as the feeling of 'failing at cancer' (PP, age unknown, diagnosed in 2017) or as if there is no room to share the reality of living a relatively long life with incurable cancer.

4 ▪ Discussion

With this study on women living with incurable cancer who share their lives on Instagram, we aimed to give insight into how biomedical knowledge comes to matter in everyday life and is understood, interpreted, and discussed online. We found two main results: 1) new biomedical knowledge is constantly mobilised and interpreted by women living with incurable cancer to navigate both living mundane everyday life and being incurably ill; 2) the visual element of Instagram allows women living with incurable cancer to make sense of their ever-changing realities shaped by the constant production of new biomedical knowledge and characterised by bodily changes and shortened life expectancy.

To answer our first research question 'How do women living with incurable cancer give meaning on Instagram to biomedical knowledge in their everyday illness experiences?', our results show how the women have to continuously relate themselves to new biomedical knowledges and juggle normal life with incurable illness. With regard to the notion of assemblages of care [Kolehmainen & Lupton, 2025], we see how interactions with healthcare professionals and others on social media, spaces including hospital wards and homes, and materials such as medicine and IPCC lines, all contribute to how the women give meaning to biomedical knowledge. The women that we studied mobilise biomedical knowledge that is relevant for their disease trajectories and prognosis. We saw how results from biomarker tests shape what it means to live with cancer in daily life, such as continuing with exhausting treatments and adjusting life patterns. We also saw how test results influence the women's emotions and result in feelings of uncertainty and anxiety. Even when the women know that the newly produced biomedical knowledge — e.g. from biomarker testing — is not the only parameter defining their health status and that their embodied experiences also matter, it still has a severe influence on their feelings regarding their illness, prognosis, and fear of dying. This is in line with previous research showing how medical technologies that require constant attention from patients can be confronting on days where the illness is less experienced through the body [Wendrich & Krabbenborg, 2024]. Due to advancements in diagnostic and treatment technologies, some people with incurable cancer live relatively long lives. However, as a consequence, people need to interpret and give meaning to constant new biomedical knowledge. We found that the women that we followed on Instagram were constantly faced with new biomedical knowledge that they had to interpret in the contexts of their daily lives, disease trajectories, and outlook on their futures. Examples of biomedical information to which the women had to relate themselves include: new test results, treatments that stop working effectively, availability of new drug trials, and possible scientific breakthroughs. Our results show that the long periods in which the women have to wait for test results, scientific breakthroughs, and prognosis updates result in uncertainty. These findings are in line with Brekke and Sirnes' [2011] work on what genetic research means for people, showing that people living with a chronic illness hope for progress in medical interventions. Moreover, in their quest for a cure or to achieve a higher quality of life, people

living with chronic illness often rely on breakthroughs in medical technology [Brekke & Sirnes, 2011]. Brekke and Sirnes [2011] show that waiting for scientific breakthroughs intertwines with feelings of hope and despair, because hope for a better future stems from feelings of despair about the current life with uncertainty, pain, and suffering. Our findings resemble this point, as women have to juggle biomedical information in the contexts of their prognosis. For people who live a relatively long life with incurable cancer, these confrontations with biomedical information happen often, because periodic monitoring of health is continuous during their relatively long lives.

To answer our second research question 'What is the role of Instagram's affordances, such as hashtags and visuals, for the use of biomedical knowledge in the everyday lives of women living with incurable cancer?', our results show how Instagram's visual grid can be a tool that allows women to give meaning to their ever-changing realities shaped by the production of new biomedical knowledge and characterised by bodily changes and the perspective of having a shortened life expectancy. We found that women posted pictures to keep as memories by actively anchoring the pictures as such, for example through labels such as #MakingMemories. Instagram allows for this process of anchoring memories by combining visible captures of moments and hashtags, giving the women control over the memories that are kept about their lives, that is, memorising how their lives are filled with more than just biomedical knowledge from tests and through treatment, as they experience periods of good health outside of the biomedical sphere. Given the increasingly digital world, we point to Hoskins' [2018] research on digital memory work in which he details how the eternal online sphere transforms our memory practices. Through networked archives, people engage in the act of preserving memories, ensuring that they will be remembered in the future, even beyond their own lifespan. We also found that women share how the effects of cancer and its treatment affect the body over time. Instagram allowed for community building through the use of biomedical knowledge in hashtags, such as biomarkers. From these communities, women draw support while dealing with their bodily changes. Instagram also allows women to take control over what they want to share and what they do not want to share online regarding their changing bodies — something experienced as uncontrollable. These findings support the work of Groenevelt [2022], who describes how people who share their stories of living with illness on Instagram and YouTube adopt illness as an element in the presentation of the 'self', but also show other versions of themselves to demonstrate that they are more than somatic data — e.g. genetic modifications or blood concentrations of proteins — and cannot be reduced to the identity of being a patient [see also Mol, 2002; Prainsack, 2017]. We contribute to this work by showing that the visual element of Instagram enables women living with incurable cancer not only to present different versions of themselves — e.g. both a patient navigating assemblages of care including biomedical knowledge such as test results and a person living everyday life — but also to make visible navigating various bodies over time, for example bodies with or without hair or scars as a result of biomedical treatments. Instagram allows space for the women to give meaning to these different bodies over time. We also found how posting about the effects of cancer and treatment is part of the women's reflection on Instagram's cultural norm of being positive and life-affirming, as shown by Stage et al. [2020]. We saw that the women expressed a need for nuance, as they sometimes felt supported through responses on their positive posts, whereas at other times this focus on being positive created feelings of pressure and self-doubt and an overall feeling of not being able to share their complete illness experiences of living with cancer, including non-positive feelings such as anxiety. The women spoke out against the positive cultural

norm on Instagram by discussing varied emotions and visualising different spaces of living with cancer, for example both the hospital and the home, and the effects of cancer, for example bodily changes. By discussing and visualising these different aspects of living with cancer, they contribute to our understanding of what assemblages of care can look like.

4.1 ▪ *Strengths and limitations*

Although we were able to investigate a wide collective of experiences, discussions, and real-life contexts through our longitudinal study approach, this research cannot be viewed as representative of all women living with incurable cancer. As our study is based on data created by Instagram users, the practices of biomedical knowledge interpretation shown and discussed in this paper might be different for women who do not use Instagram. We also point to Instagram's algorithm, which influenced how the women that we followed use Instagram and our own digital ethnographic approach in ways that are not visible. In spite of the algorithm's influence, our longitudinal digital ethnographic approach gave insight into how uninvited public engagement practices already 'out there' exist over time, as it shows how meaning-making processes are not static. Because of the changing nature of the lives of people living with incurable illness, dynamic and continuous meaning-making processes cannot be captured in a singular research intervention — e.g. interviews or surveys. Instead, a longitudinal research design on uninvited public engagement can bring practices to light that can remain unexplored during invited practices [Marres, 2012; Waller & Gugganig, 2021]. We studied how the women respond to posts and comments by others, but we did not explore the interactions between Instagram users in the comment section embedded in the social media platform, for example between healthcare professionals and patients that discuss possible misinformation online [Chen & Tang, 2023]. For future research, Instagram's comment section could reveal how users, including people who are not living with cancer, respond to one another's statements on biomedical knowledge and argumentations for their interpretation. Moreover, our study adds to a body of literature on the experiences of women living with cancer [e.g. Gurrieri & Drenten, 2019; Seró Torroja et al., 2024; Stage, 2019]. In future research, we suggest investigating diverse peer communities, including other genders and diseases.

4.2 ▪ *Conclusion*

In this paper, we have shown how women living with incurable cancer discuss, interpret, and share biomedical knowledge on Instagram. Through assessing and interpreting biomedical knowledge online in the context of their daily lives, the women that we studied were able to give meaning to their continuously changing lives, bodies, and feelings of hope and loss. Researching social media platforms, such as Instagram, can deepen our understanding of how people learn to understand biomedical knowledge and science through embodied experiences with their own bodies [Mol, 2002; Traweek, 1999]. In response to participatory movements in science, studying actions and interactions on social media platforms allows us to go beyond the idea that people are merely recipients of science. In the medical domain, as our paper shows, and in other domains — e.g. agriculture [Waller & Gugganig, 2021] or astronomy [Rüland, 2024] — social media allows people to engage with (new) science and technology developments, without the interference of, for instance, intermediaries such as science communicators or workshop hosts. Social media can be a space where long-desired

two-way communication practices can occur when scientists make the effort to listen to these unsolicited voices. In this way, people who are not always allowed or able to be part of organised public engagement events, for example because of their illness, are enabled to speak and share their visions, needs, and wishes on science and technology and what it means for their everyday lives.

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Appendix: Codebook

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