



Ugly media feelings: Negative affect in young cancer patients' experiences of social media

by Carsten Stage, Lisbeth Klastруп,
and Karen Hvidtfeldt

Abstract

In contemporary media culture, social media have become important publics of care for young people with a serious illness. While much previous research has focused on the positive aspects of online support networks, this article investigates the affective experience of what we call 'ugly media feelings', such as envy, shame, annoyance, irritation and scepticism, based on an in-depth interview study of 25 young Danish cancer patients' (aged 15–29) experiences of social media. We argue that ugly media feelings can be analysed, firstly, as indirect revelations of the communicative ideals and media investments that young cancer patients make when they turn to social media during their illnesses and, secondly, as entangled with media cultural changes that have created new affectively unpredictable spaces for interacting about serious illness outside home and health institutions.

Contents

- [1. Introduction](#)
- [2. Existing research](#)
- [3. Methods and ethics](#)
- [4. Analysis](#)
- [5. Conclusion](#)

1. Introduction

Research on cancer patients' use of digital media and communities has predominantly explored and focused on the therapeutic, supportive and relational potentials of these technologies (Kingod, *et al.*, 2017). This article takes a different approach by investigating the negative or even 'ugly' — in the sense of traditionally 'unwanted', 'unprestigious' or 'undesired' — feelings produced when young (current or former) cancer patients engage in cancer communication on social media. It presents the results of a thematic analysis of 25 qualitative interviews with young Danish cancer patients (aged 15–29). In general, the interviews support the idea that social media are central sources of 'peer-to-peer' relations, experiential knowledge and affective support for young cancer patients, but it also nuances the simplistic equation of social media with

therapeutic and relational support. In 21 of the 25 interviews the involved young people shared experiences with social media that were described as *e.g.*, irritating, depressing, sad, characterised by scepticism, shameful or disappointing. The article seeks to understand how, when and why these 'ugly media feelings' — defined as *negative and undesired affects linked to (social) media practices* — are created according to the young (previous or current) cancer patients involved in the study.

The three key research questions addressed in this article are:

- Which negative/ugly feelings are articulated in relation to which social media practices by the young people involved in the interviews?
- How is the production of these ugly media feelings described and explained by the participants?
- How do these ugly media feelings relate to broader media, cultural and health institutional changes?

After presenting the theoretical framework of the analysis and the methods and ethical consideration underlying the study, this paper will focus on the informants' articulation of ugly media feelings in relation to four aspects of social media use: 1) reading the cancer experiences of others; 2) sharing one's own cancer experiences; 3) receiving comments to one's own shared cancer experiences; and 4) communication of cancer on social media in general.

In general, we found that the patients in the study used social media to maintain a sense of agency/control during illness and build supportive relations. As a consequence, the article shows that 'ugly media feelings' seem to occur when social media instead become intertwined with actual or imagined experiences of suspended agency and social disconnection. Last but not least, this article discusses whether ugly media feelings might be inherently intertwined with the formation of new semi-public forms of illness communication and 'sick roles' that transgress the boundaries and more stable social contracts of home and health institutions.

Despite its focus on negative affect, the aim of the article is not to paint a pessimistic picture of the influence of social media on young cancer patients. On the contrary, it contributes to existing knowledge about the existential importance of social media when young people are suffering from a serious or even terminal illness such as cancer, and provides new insights into the affective complexity of reading, following and sharing cancer experiences as a young person. In other words, we show that although social media for a majority of our informants are experienced as a mainly positive aspect of their life, 1) almost all of them have experienced negative feelings in relation to illness-related social media use; and 2) some of them experience social media as predominantly problematic or affectively disturbing.

Inspired by American cultural theorist and feminist scholar Sianne Ngai, we understand ugly feelings as both informative and productive forces. In *Ugly feelings*, Ngai (2004) in particular takes interest in minor and unprestigious feelings as envy, irritation or disgust — in contrast to major and powerful feelings like anger and rage or classic Aristotelian emotions as horror and pity. According to Ngai the examination of the dynamics and aesthetics of these marginal and often ambiguous emotions opens for critical understandings of late modernity. In this article we ask what ugly feelings can tell us about current media and illness practices instead of using them as evaluations of whether or not social media are good or bad for the psychosocial well-being of young cancer patients. With reference to Sara Ahmed's (2004) work on the *Cultural politics of emotion*, we underline how feelings are negotiated in the public sphere and shaped by and through social relations, in this case specifically on social media. In that way, this paper adds complexity and balance to the therapeutically orientated research approach to young cancer patients' use of social media, but without giving a pessimistic and 'panicky' account of social media (Drotner, 1999). Our goal is rather to explore what these negative affects can potentially teach us about present entanglements of social media and lived cancer experiences, and about broader rearrangements of the social position and public visibility of illness narratives. Hopefully, this research will hereby contribute to creating a fuller and more detailed

understanding of the everyday use and affective-existential complexity (Lagerkvist, 2017) or ambivalence (Phillips and Milner, 2017) of simultaneously living a life with cancer and living a life with social media.

2. Existing research

2.1. Young cancer patients and social media

Every year, more than 40,000 Danes are diagnosed with cancer, and approximately 300,000 individuals currently live with the disease in Denmark (NORDCAN, 2018). Approximately 500 young Danes aged 15–29 are annually diagnosed with cancer (Sperling, *et al.*, 2015). Research has shown that this patient group experiences multiple serious psychosocial consequences of the disease — not least because it disrupts fundamental processes linked to the transition from childhood to adulthood (Boisen, *et al.*, 2013; Graugaard, 2013).

Over the last 20 years, health communication and media studies research has investigated adult cancer patients' engagement with various forms of communication such as peer support groups, e-mail lists, Web sites and message boards (Hardey, 2002; Høybye, *et al.*, 2005; Orgad, 2005; Sharf, 1997), cancer blogging (Heilferty, 2009; Keim-Malpass, Baernholdt, *et al.*, 2013) and social networking sites like Facebook (Bender, *et al.*, 2011; Erfani, *et al.*, 2013), Twitter (Sugawara, *et al.*, 2012; Tsuya, *et al.*, 2014), Instagram (Vraga, *et al.*, 2018) and YouTube (Foley, *et al.*, 2015). The content shared by cancer patients on social media has been shown to be predominantly experiential and opinion-based rather than focused on medical knowledge (Chiu and Hsieh, 2012; Kim and Gillham, 2015). This underlines the fact that patients often focus on the psychosocial dimensions of illness when using social media (Keim-Malpass, Albrecht, *et al.*, 2013; Ressler, *et al.*, 2012). Erfani, *et al.*'s literature review, as well as their own study of a Facebook cancer community, demonstrate (Erfani, *et al.*, 2017) that there is a positive relationship between use of Facebook and patients' psychological well-being as they are able to find both emotional and informational support online. Jiang (2017) also found a positive relationship in his study of cancer patients social media use, but notes that well-being is also strongly associated with how actively engaged the user herself is (*e.g.*, in terms of looking for information, posting), and how well users are able to manage their own feelings. In their study of young cancer patients use of different communication channels for relational interaction, Darabos, *et al.* (2019) aptly points out that whereas most studies of the use of media by cancer patients have focused on social support, little is still known about the relational impact of cancer-related media use on feelings.

While general cancer patients' use of the Internet and social media is well-researched, there is still limited research-based knowledge on how young cancer patients use social media for various cancer-related purposes and experience living with a cancer disease in a cultural situation where social media are increasingly important. A few international studies on adolescent and/or young adult cancer patients have been conducted with particular focus on digital media. A study by Abrol, *et al.* (2017) emphasises the importance of social media for young cancer patients and their relational importance during illness. In that study, 41.6 percent of young cancer patients (102 respondents between the age of 15 and 24) described social media as “essential” to their life, and 51 percent stated that they kept in touch with patients they had met through social media during treatment (Abrol, *et al.*, 2017). Kim and Gilman explore main themes in posts shared by 46 young adult (aged 20–29) cancer patients on blogs and conclude that the 10 main themes are: physical burdens, future prospects, isolation (physical and psychological), guilt, mortality, images of cancer, creating a positive attitude, healthcare, online social interaction and cancer survivorship (Kim and Gillham, 2013). In a study of two blogs by young cancer patients, Nesby and Salamonsen show that blogs “may contribute rather unique experience-based knowledge and reflections about existential issues to other young blog readers, who may otherwise not get access to this aspect of life” and that through the genre of the illness blog, “youth stand out as more competent when it comes to illness and healthcare issues than what is often presumed” [1].

As shown, existing research on (young) cancer patients and the Internet has, to a large extent, stayed within a discourse of patient empowerment by primarily exploring social media platforms as channels for exchanging information or for interpersonal support. Despite the importance of understanding social media as a tool to cope with illness and stabilise the self in crisis, such a therapeutic approach often seems to underexplore the complexities and dilemmas related to sharing experiences and engaging with cancer on social media — for instance, how social media can also produce discomfort or stress. Although it draws on previous findings concerning levels of media use, content, user motivations and therapeutic potentials in existing health communication studies, this article will therefore begin with the (media studies) premise that social media platforms are not only empowering tools for patients, but also multifaceted and contextualised platforms that are entangled with cancer narratives, publics and experiences in new, underexplored ways.

This study adds to existing research on cancer patients' use of the Internet and social media by focusing on a group of young patients (aged 15–29) who are often overlooked in studies (young users tend to be viewed simply as general users) and by focusing on their complex affective experiences of social media during cancer. In doing this, this article also contributes with new empirical knowledge about young cancer patients to a field of social media research on other illnesses or disruptions highlighting the multiple and sometimes conflicting cultural, affective and temporal practices of living a life with both social media and bodily or health challenges (Lagerkvist, 2017; Lupton, 2016; McCosker, 2013; Papacharissi, 2018; Pitts, 2004; Tembeck, 2016; Tiidenberg and Gómez Cruz, 2015; Tucker and Goodings, 2017; Ytreberg, 2019).

2.2. Social media, affect and illness

The potential negative effect of social media use on (affective) well-being has been researched and contested intensively over the last decades. While individual studies, such as Sherry Turkle's work on rising forms of digitally connected loneliness and discontent [2], has explored the general negative emotional effects of digital and social media use, recent meta-reviews studies of the psychological effect of social media use have found only a small negative effect on psychological well-being, also in regard to adolescents (Orben and Przybylski, 2019; Appel, *et al.*, 2020; Saiphoo, *et al.*, 2020; Toma, *et al.*, 2020). Appel, *et al.*'s (2020) meta-review concludes that there is no basis in existent research for claiming that social media has dramatic effects on people's psychological well-being. Their analysis of other meta-reviews demonstrates a small negative effect of SNS use on measures such as loneliness, self-esteem, life satisfaction, or self-reported depression. Saiphoo, *et al.*'s (2020) meta-review shows that there is a small negative relationship between SNS use and self-esteem, and in addition found that the relationship was more prevalent when measuring problematic SNS use (*i.e.*, addictive SNS use). This leads them to conclude that more studies of the positive effects of social media use are needed (see also Casale and Bianchi [2020]). Hawi and Samaha (2017) also argue that there is a correlation between social media addiction and low self-esteem, but not necessarily between social media addiction and dissatisfaction with life in general. A smaller meta-review study of the use of social media and psychological wellbeing (in information studies) shows that SNS use predominantly has positive effects (Erfani and Abedin, 2018). These meta-reviews also demonstrate that many of the studies on the relation between social media use and psychological well-being have been carried out in the U.S., drawing on cohorts of healthy college students, and that many apply a one-dimensional approach to what well-being is (*e.g.*, conflating it with self-esteem).

Based on these meta-reviews it is perhaps not surprising that cancer patients — like any other social media user — can experience some level of negative emotions when using social media. In the field of research dealing with cancer patients' use of social media, this research theme is however underexplored as most studies have focused on positive user effects like de-isolation, peer support and reduced loneliness (see the previous section 2.1). Furthermore, if we look across the field of (social) media studies in general, this research on negative feelings related to social media as something else/more than bad and undesired consequences of media use (*e.g.*, low self-esteem) is an important contribution in itself. This article is innovative in this context by transgressing the understanding of negative feelings as bad consequences of media use gone

wrong. Instead it investigates negativity as important empirical material for an analysis of the affective complexity of living a life with social media as a young cancer patient.

The notions of ‘ugly media feelings’ and ‘negative affect’ play central roles in our article as we explore young cancer patients’ articulations of a particular dark range of immediate and visceral bodily responses that occur as part of their cancer-related use and experience of social media. In some of the foundational theories on ‘the affective turn’, the distinction between affect and emotion was crucial. ‘Affect’ designated a spontaneous, transindividual, non-conscious force or intensity transmitted (and complicating the borders) between bodies, while ‘emotion’ was used to describe the cognitive categorisation, simplification and individualisation of these more primary or immediate affects (*e.g.*, as sadness, anger, love) (Brennan, 2004; Clough, 2008; Massumi, 2002). Later work has tried to extract cognition and meaning-making from the distinction between affect and emotion, instead stressing that emotions are more personal/individual and demarcated, while affect is more pre-personal, relational and dispersed (Anderson, 2014; Ngai, 2004; Tucker and Goodings, 2017). For the purpose of this article, we will not distinguish between affect and emotions, and we use the terms interchangeably. In doing this, we follow the work of Margaret Wetherell, Sara Ahmed and Lisa Blackman, who have argued that creating too clear-cut distinctions between affect and emotions produces a problematic split between body and mind (as well as individual and collective) that does not acknowledge the complex ways in which cognitive, personal, cultural and social processes influence how affect and emotions are produced, circulated and sensed (Ahmed, 2004; Blackman, 2012; Wetherell, 2012).

Research on affect and social media is a rapidly growing field (Paasonen, *et al.*, 2015; Parikka, 2010; Sampson, *et al.*, 2018). and has focused on various affective dimensions, including how social media facilitate rapid processes of affective contagion, virality, political mobilisation and crowding (Knudsen and Stage, 2012; Munster, 2013; Papacharissi, 2014; Sampson, 2012); how social media platforms offer new (safe) spaces where affect can be expressed in cultural communities based on shared norms, ideologies, discrimination or existential crises (Benski and Fisher, 2013; Döveling, *et al.*, 2018; Raun, 2012); and how social media platforms themselves become able to track and respond to the moods and affects of users due to new forms of artificial intelligence and sentiment analysis (McStay, 2018). The scholarship on illness, social media and affect is of course more limited (Stage, 2017; Stage, *et al.*, 2020; Tucker and Goodings, 2017). An important exception is McCosker’s work on *e.g.*, the affective labour of illness bloggers (McCosker, 2013) and health influencers taking part in affective and “peer-led support practices” on social media in relation to mental health issues (McCosker, 2018). Another important contribution is Tucker and Goodings’ work on the digital atmosphere in online peer support groups for people suffering from mental illness (Tucker and Goodings, 2017). They emphasise the caring atmosphere as crucial, but also that the community itself produces distress in relation to, for instance, entering the group and sharing something for the first time, or if a member suddenly deletes their account, which causes uncertainty and anxiety among the remaining members. Tucker and Goodings therefore conclude that the idea that the explored online community is simply a tool for expressing distress is “too simplistic; as it does not draw attention to the multiple ways that experiences of distress are shaped by being enveloped within digital atmospheres” [3].

Our article contributes to this existing line of research by focusing more specifically on the empirical field of young cancer patients and trying to outline a broader register of ugly media feelings related to this group’s use and experience of social media. The focus on a variety of ugly feelings is also a contribution to the relatively small number of (not affect-orientated) studies that stress the potentially disturbing implications of sharing illness on digital media by investing *e.g.*, fake illness stories online (Enli, 2015), cultural codes in online breast cancer communities (Orgad, 2006) and the privatisation of illness, responsibility and treatment supported by personal illness blogs (Pitts, 2004). In focusing on the analytical and critical potentials of exploring negative or ugly feelings on social media, we have been inspired by Susanna Paasonen’s work on the affective ambivalence and constant affective modulations taking place on and through social media via their entanglement with a “complex nexus of personal histories, life-events, surroundings, and encounters (...)” (Paasonen, 2016). Paasonen stresses that social media

platforms should be approached as affectively ambivalent and polyrhythmic attention technologies (Paasonen, 2018, 2016) and that “the distractions of social media are bound to escape one-sided positive affective management — and their allure may just as well draw on their disturbing qualities” (Paasonen, 2016). Following this, we are also indebted to Sara Ahmed’s critique of the cultural obsession with happiness, which is intrinsically linked to the reproduction of norms and assumptions regarding the objects and life forms that would ensure a happy life (Ahmed, 2010). Due to these norms and assumptions, cultural negativities are positioned as practices to be avoided or ignored due to their unhappy and uncomfortable inclinations, rather than phenomena that should be explored as important aspects of current (media) cultures.

Another crucial inspiration is Sianne Ngai’s research on how late capitalism — and its emphasis of individual willpower, productivity and growth — produces experiences of suspended agency that motivate ugly feelings like envy, irritation or anxiety. Ngai, in other words, tries to understand ugly feelings as more than simply individual reactions or idiosyncrasies, but rather as crucial material for analysing current cultural transformations and predicaments as they call “attention to real social experience and a certain kind of historical truth” [4]. Our concept of ‘ugly media feelings’, referring to *negative and undesired affects linked to (social) media practices*, explores the same affective range as the one described by Ngai, but with a specific focus on articulations of negative affect in relation to the use or experience of social media. Following Ngai (2004), we use the concept of ‘ugly media feelings’ to describe and understand the negative, and often undesired, affect that can be produced when young cancer patients read, share or interact about cancer experiences on social media — and thus to reflect on the link between these ugly media feelings and broader media and cultural transformations.

This line of ‘grey’ affect research — represented here by Paasonen, Ahmed and Ngai — is interesting in terms of understanding cancer communication on social media, as it offers an approach focused on understanding and identifying affective complexity and negativity as a crucial component of social media life with illness. Furthermore, it accentuates that negative affect should not be analytically approached as simply bad. On the contrary, it is often an interesting vehicle for cultural analysis and critical reflection. In other words, we take from Paasonen, Ahmed and Ngai an affirmative interest in how focusing on negative affect might produce new knowledge about cancer communication on social media by not beginning with the usual research question: “Is social media good for the well-being of cancer patients?”

Instead, this article asks how and why ugly feelings are produced, and what they might tell us about the complex social media lives of young cancer patients. Ugly media feelings have been underexplored in health communication research on cancer patients’ use of the Internet (and social media), and the article’s main contribution to this field is therefore to produce knowledge about this topic.

3. Methods and ethics

The 25 interviews analysed in this article were made as part of a research project that also completed a comprehensive survey mapping 205 current or former Danish cancer patients’ social media use (respondents were between 15 and 29 years old when the survey was conducted). The survey consisted of five main sections, which focused on 1) the respondents’ *general use of social media*; 2) *general use of social media in relation to their cancer*; 3) *own sharing of cancer content and formation of relationships on social media*; 4) *use of social media in relation to different phases of the treatment process*; and 5) *general information concerning the respondents*. The results of the survey have been published elsewhere (Stage, *et al.*, 2020, 2019) and will only be mentioned briefly in this article, which will instead focus on the recurring theme of affective negativity in the interviews.

The survey included the opportunity to indicate whether the respondent wanted to be contacted for an interview. In order to create the largest possible demographic and geographical diversity, 25 young patients were selected (see [Table 1](#)). The 25 interviews aimed to create more in-depth knowledge about young cancer patients' use and experience of social media.

Age	Gender	Cancer type	Treatment status	Region	Primary social media
15	Female	Other	Remission	Zealand	Instagram Snapchat
18	Female	Thyroid	Terminal	Central	Instagram Snapchat
18	Female	Bone	Remission	Zealand	Snapchat Facebook Instagram
20	Female	Ovarian	Remission	Zealand	Facebook Snapchat
20	Female	Brain	Remission	Southern	Instagram
21	Male	Leukemia	Remission	Capital	Facebook Snapchat Instagram
22	Female	Soft tissue	Remission	Capital	Instagram Snapchat
22	Male	Lymphoma	Remission	Zealand	Facebook Snapchat Instagram
24	Male	Birthmark	Remission	North	Snapchat Facebook Instagram
24	Female	Bone	Remission	Southern	Facebook Instagram
24	Female	Lymphoma	Remission	Central	Facebook
24	Female	Ovarian	Remission	Central	Instagram Facebook
25	Female	Bone	Remission	Central	Facebook Snapchat
25	Male	Birthmark	Chemo	Capital	LinkedIn Facebook Instagram Snapchat
26	Male	Bone	Remission	Central	Facebook
26	Female	Eye	Remission	Capital	Instagram
27	Female	Birthmark	Remission	Capital	Instagram Facebook
27	Male	Other	Remission	Capital	Facebook

28	Female	Leukemia, birthmark	Remission	Capital	Instagram Snapchat
28	Male	Lymphoma	Remission	Central	LinkedIn Facebook Instagram
28	Female	Breast	Remission	Central	Facebook Snapchat
29	Male	Leukemia	Remission	Central	Facebook
29	Male	Lymphoma	Chemo	North	Facebook Instagram
29	Female	Lymphoma	Remission	Capital	Facebook Instagram
29	Female	Breast	Remission	Southern	Snapchat Facebook Instagram

The interviews were conducted as recorded semi-structured interviews based on an interview guide focused on the same five main themes as the survey (Kvale, 2007). As part of the preparatory work, we also asked patients to find specific posts from their social media profiles and take screenshots of 1) the first post they shared after the cancer diagnosis; 2) a typical post; 3) a (potentially imagined) screenshot of something the informant would never share or regretted sharing; 4) a screenshot that referred to the informants best experience with social media in connection with cancer; and 5) the worst experience with social media in connection with cancer. Using screen shots as an integral part of the interviews (Rose, 2012) allowed the informant to reflect on experiences and media behaviour that do not always unfold easily in a spontaneous interview, as well as enabling more dialogic conversations.

The interviews required a number of ethical considerations, especially because the informants might be in a vulnerable state, but also because they might be very different from each other with varying wants and needs (Franzke, *et al.*, 2020). The interviews were based on informed consent with the possibility to withdraw from the study at any time and without sanctions. A part of the project's ethical basis was therefore to adapt the interviews to the informants' conditions. The informants decided where the interviews should take place (at home, in a public space, at the researcher's office, on the phone), and the duration varied because we wanted the interaction to be defined by how much the informants were willing to share. Anonymity was optional, and 12 out of 25 informants chose this possibility, while 13 chose to be mentioned by name. This choice is reflected in the representation of their statements below.

The 642 pages of interview transcripts were processed and analyzed by the authors through the following steps. First, the large set of transcripts was data reduced (Lindlof and Taylor, 2011) through a reading and selection process where quotes providing information about the key research foci of the project were retained, grouped and condensed into recurring themes (Braun and Clarke, 2006). This process provided detailed information about 1) respondents' general use of social media; 2) their general use of social media in relation to their cancer disease; 3) their own sharing of cancer content and formation of relationships on social media; and 4) their use of social media in relation to different phases of the treatment process (Stage, *et al.*, 2020, 2019). Various types of unexpected or undesired affective encounters with media were documented in this first reading, but not in a sufficiently systematic way. The authors therefore decided to reread the entire dataset with a particular focus on 1) if articulations of negative affects were present in the interview (this was the case in 21 of 25 interviews); and 2) which types of negative affect were mentioned in the transcripts (*e.g.*, shame, irritation). After this open coding of specific negative affects, the authors identified how these affects were articulated by the respondents as linked to different media practices (Couldry, 2004): 1) reading the cancer experiences of others;

2) sharing one's own cancer experiences; 3) receiving comments to one's own shared cancer experiences; and 4) communication of cancer on social media in general. Subsequently, mentions of specific ugly feelings (*e.g.*, irritation) in relation to each of these media practices were grouped. This was done in order to identify central 'affective themes' articulated by the respondents in relation to each of the media practices (*e.g.* nervousness in relation to personal sharing or 'annoyance' in relation to receiving comments). The analysis will be structured by the four media practices and explore in-depth the key affective themes mentioned by the respondents in relation to the particular media practice.

4. Analysis

General findings in the survey and interviews are that young Danish cancer patients use social media to communicate with their network and follow the lives of others (Stage, *et al.*, 2020, 2019). The patients use social media in many different ways, but a majority uses them for sharing material about their own disease, reading other patients' experiences or actively interacting with these patients. Overall, the reason for using social media is to gain insight into experiences they would otherwise not have access to in their social circle, and half of the respondents find that reading other people's cancer stories can make them feel less alone. In that way, social media are used as a central resource for the creation of networks between young people and for finding knowledge about other young cancer patients.

However, this is not the whole story. Throughout the interviews, ugly media feelings are articulated in multiple ways that need to be analysed to acknowledge the affective complexities of social media use for younger cancer patients. To do this, we explore how ugly media feelings arise in different communicative connections or contexts in order to clarify when and how these feelings are experienced in relation to social media use. The first of these contexts is when young cancer patients read or follow the cancer experiences of others on social media.

4.1. Reading and following cancer experiences: Sadness, stuckness and irritation

Although reading other young people's cancer narratives on social media is most often described as a positive source of de-isolation, it is also clear that some participants in the study try to avoid this type of material because of its ability to trigger feelings of fear, sadness and depression. A female (28) uses the word "depressing" about the communication taking place in cancer communities on social media, which has brought her to leave most of these groups and turn off notifications in order to avoid constant and unwanted information. She had a great initial desire to connect with other patients in groups, but they ended up making her too "sad".

Some participants describe sadness, depression and fear as an effect of encountering a media text with a particular emotional quality, which then affectively rubs off on their own mood, while others view these feelings as linked to a process of identification. In the latter case, negative affect occurs because the young person is afraid that they 'will be next' and thus take over the suffering subject position represented in the social media communication in question. Karoline (22) *e.g.*, describes why she stopped reading a particular blogger, as "I did not feel like being confronted with the fact that she did not have any hair, and what if that also happens to me?" A male (26) also explains that he left a particular patient group because several members entered a terminal phase "and I couldn't cope with that, because I was afraid that I would also be declared terminal". As shown, this type of ugly media feeling is often caused by actual encounters with the communication of others but can also be the result of imagined potential outcomes for the informants themselves, for instance when searching for illness narratives and experiences. In both cases, ugly media feelings are treated by the young informants as phenomena to be strategically avoided, either by abandoning platforms, groups or profiles or by not using them in the first place (Light and Cassidy, 2014). Some of these choices are permanent, while others are taken during day-to-day negotiations of personal affective states and moods.

A different emotional range is described by several participants who explain how the sharing practices of others in their network, who are not patients, can also create sadness and a sense of pressure or being 'left behind'. For instance, Jesper (28) describes a slightly envious feeling of being on hold — or of suspended agency — motivated by encounters with social media communication in his personal network:

“And then it happened that I was lying at home watching how other people were out traveling and enjoying themselves. (...) Well, it was insanely tough for me to see how well everyone else was doing. I can even remember that I found out through Facebook, while I was sick, that my former girlfriend for six years had become pregnant and everything. I felt that life was completely on hold for me, although it moved on for everyone else” (Jesper, male, 28).

A female (24) adds to this by articulating a feeling of “pressure” and “bad consciousness” linked to a tension between being tied to one’s bed and seeing that “the world moves on” on social media. These examples stress that ugly media feelings are not only linked to communication about actual cancer experiences, but can also be triggered by the ‘normal’ communication of achievements and experiences of peers who are not ill.

A different emotional response among the participants in the study is the irritation linked to content shared by other patients. Irritation seems to relate to either experiences of receiving illness information that is ‘too much’ — *e.g.*, too personal or too extensive — or to reading narratives of illness that are perceived as told in a wrong way or as not nuanced enough when compared to the experiences of the reader. A male (22) for instance feels that his personal limits were transgressed in a group where someone posted intimate images of body parts that had been removed through surgery. Karoline (22) also feels that people often overshare when they post cancer narratives on social media: “Facebook is a bit like: ‘Now you all have to hear my story, and now you all have to like my post because I have cancer’.”

A related source of irritation is when cancer patients feel that other patients tell overly positive or heroic narratives that somehow monopolise or idealise the actual and stressful experience of having cancer. Rikke (24) explains:

“(…) If you’ve not run that marathon or written that book and been the heroic type, right, who just copes with the fact that you have cancer in a really cool way, then what? What if you’re actually feeling pretty bad and have a stress disorder and things like that? Because that’s a bit how I felt, right? I didn’t think I had, honestly, accomplished a lot with this disease (...) And are you then not an awesome cancer patient or what?” (Interview, Rikke, 24).

A female (29) adds to this feeling of misrepresentation by articulating her dissatisfaction with ‘quest narratives’ (Frank, 1995), where illness is turned into something positive and life-transforming: “And then there is the thing where people write like ‘I don’t wish it any other way’ or ‘It has taught me a lot about life’ and so on ... I would clearly have preferred it any other way”.

4.2. Sharing personal cancer posts: Nervousness and shame

As shown, ugly media feelings related to the social media communication of other patients take on different shapes in the material, *e.g.*, as sadness and fear linked to depressing content or bad news, feelings of being stuck or left behind when reading the updates of non-patients on social

media or irritation at encountering communication that is perceived as too personal, too strategic or too much in line with heroic cancer discourses.

Ugly media feelings are, however, not only linked to the communication of other patients, but can also be an aspect of the participants' own sharing of cancer experiences. Here, the emotional range seems to move from sadness, stuckness and irritation to nervousness and shame — that is, negative feelings that are generally more focused on the potential and distressing lack of validation of the communicating self on social media. Questions like “Will I harm anyone with my communication?”, “What will others think of me in light of my sharing?”, “Should I have communicated differently?” or “Am I connecting or disconnecting with my network through sharing?” seem to be crucial. Ugly media feelings are in this regard less linked to actual communicative actions of others, or to a feeling of not being able to act, and more to an affective process of communicative self-reflection and relational attentiveness.

An example is Victoria (15) who explains that she initially limited her illness communication on social media in order not to make her family more sad about her condition: “What restrained me from sharing during that period when it (*cf.*, the diagnosis) happened was that it affected my family quite a lot” (...) “I asked my family if it was okay to share something. And, I don't know, for some reason I just felt that it would make them sad or something like that”. A female (29) also explains that she avoided sharing sad images to avoid upsetting her mother: “She would have found it very distressing, and then I didn't want to make her sad”.

A different aspect is articulated by various participants who are afraid of being perceived as ‘oversharers’ (Raun, 2017) or patients strategically sharing to become objects of pity and attention. Tea (20) holds back communication because she does not “want to be the type that people find extremely annoying (...) I think that is the reason why I restrain myself, because I think a lot about what people think of me and what they think about my actions”. A male (29) also points to accusations of oversharing to explain why he did not share very much about his illness on Facebook. He describes the sharing style that he does not want to be identified with: “I think we all have that one Facebook friend who shares everything and where you can't help thinking: Please, no more. Stop yourself”. The same male, however, also describes how his lack of communication about illness created a feeling of bad consciousness and pressure building up over time because his friends and relatives demanded some sort of update on his situation.

Amanda (27) links reflections on self and sharing to the feeling of shame and describes the feeling as an indirect result of her joy of sharing and getting response, rather than as a reason not to share in the first place. Amanda feels ashamed both because she finds the positive response nice and comforting and because she is afraid that her network will look at her as a strategic sharer:

“I guess I feel ashamed. About the likes, and what I said earlier, but it gives me a really positive and nice feeling when someone appreciates what I share”. Sharing cancer content “(...) automatically generates a lot of likes, and in the beginning I felt a little ashamed because this was not the reason why I shared it, actually. It was not to get likes, sincerely, because it was more of a therapeutic thing for me and a very vulnerable thing to share. But still I have to struggle with the feeling I get when I share something because the ‘cancer card’ automatically generates a lot of likes on Instagram” (Amanda, female, 27).

As shown, ugly media feelings related to the young person's own sharing practices include nervousness about making relatives sad and fear of or shame related to being perceived as a strategic sharer and/or oversharer. Moving on to ugly media feelings in relation to (lacking) comments on or responses to shared content, the emotional range takes a more annoyed and disappointed tone.

4.3 Receiving responses and comments: Annoyance, disappointment and discomfort

The participants generally find social media useful as public spheres for accessing and sharing personal and supportive approaches to illness, and positive accounts and interaction are the norm (Stage, *et al.*, 2020). In other words, sharers seem to expect to be supported, not confronted or treated thoughtlessly, when it comes to their shared perspectives on living with an illness. This also implies that non-empathetic responses (*e.g.*, comments or private messages) can become a source of annoyance.

Cecilie (18) — a terminal patient during the time of the interview — describes how she feels provoked by people who comment on her posts or contact her on social media without being able to understand how their communication might affect her negatively:

“(...) some of the people who write to me really piss me off (...) Like when they don't have cancer themselves or don't know anyone from their families who has cancer, then it is really hard to understand what it means and then what they write becomes really impersonal. They don't understand you. (...) Many also write to tell me that their husband or wife has just died from (a rare cancer disease), and that is like ... why do I need to hear about that? (...) It happens a lot. Especially if I write a long post. Then I receive 17 private messages about random stuff. (...) Yes, or they tell me: 'I know for sure that you will be cured', and I am actually sitting here reading it and I know that I will not get well. It is like they don't understand my situation. And then I have to try to accept it although other people think that they can save you. I find that very annoying”.

Not being understood or respected in one's own subjective experience of illness is also a source of annoyance for a female informant (26). She describes an occurrence where someone “questioned whether the feeling I had was correct. And that is nonsense (...)”. A female participant (24) shares a similar experience of non-validation, caused by a comment that disregarded her unpleasant encounter with an impolite child in a public space by telling a new story about racism as a different kind of public discrimination. The participant felt that this ‘second story’ (Page, 2012) hijacked her illness experience and turned it into something different: “How was that even related to my post?”

A female participant (25) more explicitly describes the difference between expected supportive comments and the negative impact of insensitive comments. She shared a post on the bad weather keeping her from going outside, and describes how the pleasant comments told her to just stay inside and enjoy the day. But one comment indicated that she should just put on some more clothes, and the participant felt that it hinted that she was lazy or “not doing anything”. All these examples indicate that comments that question or hijack the experience of the poster seem to be a common source of ugly media feelings among sharers of cancer content.

However, it is not only insensitive or non-validating comments that can spur ugly feelings. A lack of comments — experienced as receivers being silent or uninterested in what is shared about illness — can also create *e.g.*, feelings of disappointment. A female (28) set up a Facebook group where her friends and family could follow her treatment, but she explains that she “didn't quite get the interaction that I wanted. I would have liked more. It was mostly in the beginning when people were more affected that I received longer and more comments. At some point it became a routine, and then interaction was more limited, or people gave a like or a heart or ...”.

A male participant (29) had a similar experience of disappointment regarding the level of interaction in relation to his posts, and he uses this experience to articulate a piece of advice:

“(...) then they just liked it or something, right? or gave a heart. No, it actually surprised me. If I was asked about my most important advice to a person’s network, if the person gets cancer, then it would be: Write to the person, ask how the person is doing, at least show the person that you have been thinking about them and that you care”.

A last range of ugly media feelings related to responses from followers is less focused on specific insensitive comments, but rather on the sheer volume of responses or attention that can become discomforting in itself. Some participants have experienced such a sudden upsurge in public interest, while others explain that unwanted attention from strangers is one of the reasons why they avoid communicating about their illness on social media in the first place. Emma (24), for instance, had a public profile where she shared posts about her illness, and when a Danish celebrity commented on one of her updates, she faced a rapid increase in comments and followers. That made her consider making her “profile private again, because I found it a bit unpleasant that people visited and followed my profile only because they thought that I had some sort of relation to a popstar”. A male patient (29) explains how he avoided public communication of particular and more negative issues because he didn’t want to be part of a “shitstorm”: “I didn’t have the strength to receive a lot of calls or to face strangers who would talk shit to me or something”.

4.4. Expressing general social media feelings: Scepticism

As shown, ugly media feelings related to responses from followers/readers include irritation and annoyance after insensitive comments/messages, disappointment about too little interaction and discomfort about too much (actual or imagined) attention. A final aspect of ugly media feelings in the empirical material is less specifically linked to particular media practices but rather seems to express some participants’ broader negative understanding of social media and their role in society. A female (28) explains that she is generally very “sceptical” towards social media and the trend that people share “the moment”, because it often creates inferiority complexes among receivers and supports stereotypical understandings of what cancer is (*e.g.*, a war or something to be overcome through heroic activities) (Sontag, 1991). Another female (29) also feels general “scepticism” towards cancer communication on social media and wants to avoid being associated with an understanding of cancer patients as ‘warriors’: “I don’t want people to associate me with such a dreadful notion or their own stereotypes regarding what cancer is”. Following these examples, social media are understood as inauthentic because they afford superficial relations and promote problematic illness discourses (Syvertsen and Enli, 2020).

Kasper (29) likewise describes himself as “sceptical”. However, he focuses more on how social media disseminates disinformation about cancer and treatment, but also how users tend to find information that they already agree on. According to Kasper, social media support the spread of unscientific information, and therefore he has strong reservations when it comes to searching for information about illness. “Something like: It is actually the sunscreen that gives you skin cancer. It doesn’t protect you. And if you just sunbathe without sunscreen, then everything will be fine. (...) Stuff like that actually triggers me. Not much does, but this does”.

A female participant (29) shares the same concern regarding misinformation but instead frames medical information found on social media as a source of unnecessary worries. Social media and the Internet are thus constituted as a counterpoint to trustworthy medical information by this participant: “I trust the hospital and the doctors and what they tell me. And I have decided to trust the info that they give me. If something is not working, then I should contact them and call them, I should not begin googling a lot of stuff, because that’s dangerous”.

As shown, the feeling of “scepticism” is used by the participants to describe a range of general concerns about inauthenticity, misinformation and illness stereotypes on social media. Scepticism thus seems to explain a generally restrained or cautious approach to sharing or reading about illness narratives and medical information. It thus signals the participants’ critical preoccupation with ‘healthy’ or even ‘authentic’ social relations and information sharing.

4.5. Why study ugly media feelings?

We do not regard the articulation of ugly media feelings we observed in 21 out of the 25 interviews as a reason to conclude that social media are bad for young cancer patients. On the contrary, the general patterns of the analysis suggest that social media are crucial 'mediated lifelines' (Lagerkvist and Andersson, 2017) used for peer support and exchange of experiential knowledge. The specific articulations of 'ugly media feelings' can, however, still teach us something important about the imagined or experienced failures of these 'lifelines' and about the worries and disconnections that are also part of social media life as a young cancer patient.

We would suggest that ugly media feelings should generally be approached both as 1) indirect revelations of the communicative ideals and media investments (Probyn, 2005) of young cancer patients when they use social media during their illness; and 2) linked to media and health institutional changes that have created new affectively unpredictable spaces for interacting about serious illness. A counterargument to such an approach is that the ugly feelings identified in the material actually have very little to do with social media. It is unsurprising that cancer patients experience ugly feelings of sadness and anxiety during the existential crisis of getting and living with cancer, and therefore these feelings are not particularly linked to processes of mediation. Media in this line of thinking simply becomes a channel for expressing existential anxieties. Another already mentioned objection could be that ugly feelings are an inherent part of using social media, which constantly entangle the self in affectively ambivalent experiences of *e.g.*, social comparison, context collapse, self-evaluation, compulsive checking and algorithmic datafication (Bucher, 2018; Karppi, 2018; Lovink, 2019; Syvertsen and Enli, 2020). In other words, ugly feelings could be argued to be quite ordinary feelings for social media users and not specifically salient among ill users (see section 2.1).

Facing these counterarguments, we would argue that ugly media feelings are produced in complex relational configurations of social media, patients, others users and illnesses. Young cancer patients are of course also 'ordinary social media users', potentially influenced by wider affective economies, as well as 'ordinary patients' with a disease and its inherent affective distress. However, concluding the analysis here would miss out on the opportunity to understand what can be learned about social media life as a young cancer patient by scrutinising moments of affective negativity. As argued, we suggest approaching ugly media feelings as an entry point to understanding the positive media ideals of this user group through the situations where these investments fail (thereby creating moments of affective negativity), and how wider cultural transformations of current patient practices — in terms of where, how and with whom cancer experiences are shared — might partly explain the ugly media feelings outlined above.

In our study, young cancer patients in general use and engage with social media as 'participatory patients' (Stacey, 1997) who take on the responsibility of searching for knowledge, lived experiences and connections that create a sense of control or de-isolation in the midst of the existential crisis of illness. But social media also constitute an ambivalent arena (Phillips and Milner, 2017), where supportive communication and existential support co-exist with an array of more unpredictable communicative flows. On the one hand, social media are crucial for the everyday life of many young cancer patients — as also stressed in existing research (Abrol, *et al.*, 2017) — but on the other hand, they are difficult to control in terms of the informative and connective processes that they enable. In that sense, social media are 'tensional' or 'dis/connective' for younger cancer patients; they are important resources or tools for finding information and establishing relations that help them cope with and shape the affective life of illness, but these processes take shape on platforms where disconnections, unwanted information/contact and sharing norms entangle — and sometimes clash — with the desire to connect, know and share during an existential crisis. Social media thus simultaneously produce multiple positive relational outcomes and experiences of disconnection, 'wrong' narratives and 'being stuck' in unwanted interaction. Our point is that the salience of 'ugly media feelings' in the interviews is exactly linked to this ambivalence, and that they can be understood as moments of affective disruption where patients' desired use of social media for support, peer connections, trustworthy information, agency and existential control is both blocked and indirectly revealed.

According to Ngai (2004) the attention to ugly feelings — understood as mainly passive and non-cathartic states of feeling such as anxiety or irritation — allows us to examine moments of stagnation and ambiguity, which is a significant part of coming to terms with serious illness as a young cancer patient. This also shows to be the case across the findings of negative and ugly feelings in our material. In the analysis above, sadness and fear linked to, *e.g.*, depressing content or bad news reveals an obstructed wish for communicative positivity and vitality; the feeling of being stuck or left behind when reading the updates of non-patients on social media reveals a blocked desire for narrative progression beyond illness, while irritation over posts that are perceived as overly personal and strategic reveals a hindered longing for ‘authentic’ dialogue and relationships. Irritation over insensitive comments reveals a blocked desire for unconditional support; disappointment indicates an unfulfilled wish for more substantial interaction with relatives, while shame at feeling the warmth of likes and comments reveals the goal of being perceived as a genuine communicator. Last but not least, general social media ‘scepticism’ reveals a disappointed desire for media that can be trusted and used for establishing meaningful relations during life with a serious illness. Thus, the ugly feelings prove to be productive in the sense that they reveal disturbed communicative and social ideals and point towards feelings of suspended agency entangled with online illness communication.

Besides this, these ugly media feelings can also be understood as a consequence of media and health institutional changes that move personal accounts of illness outside both the private sphere and health institutions. Here, receivers of personal illness experiences are not related to the patients through the social contracts of family members or friends or by the formalised roles of physicians or nurses. Illness is instead suddenly shared in algorithmically and relationally complex media ecologies where norms related to different types of respondents (*e.g.*, friends, family or strangers), private vs. public communication and the culturally appropriate way of narrating illness are often more opaque and debatable. This produces a more unpredictable space for interacting about illness. It is to some extent socially unclear what is ‘too much’ or ‘not enough’ in terms of sharing and responding practices, whether narratives should focus on positivity or be as ‘realistic’ as possible, and whether they should be shared in private or public settings. Therefore, we would argue, ugly media feelings potentially become a more engrained part of this type of illness interaction.


In light of this, the salience of ugly media feelings in our material can be understood as intertwined with the formation of new semi-public and algorithmically complex forms of illness communication and new ‘sick roles’ (Parsons, 1951) that transgress the boundaries and more stable social contracts of home and health institutions. It is in other words less clear what is suitable in terms of sharing and responding to personal illness experiences, and therefore the risk of subjective experiences of norm violations or social disconnection is substantial. In that way, studying ugly media feelings also allow us to understand current cultural and technological transformations of how illness circulates and stimulates interaction in new ways.

5. Conclusion

This article has investigated young Danish cancer patients’ use and experience of social media. It has shown that negative feelings are articulated in relation to four different aspects of social media use: 1) reading the cancer experiences of others; 2) sharing one’s own cancer experience; 3) receiving comments on shared cancer experiences; and 4) communication of cancer on social media as a general activity. Central ugly media feelings related to the social media communication of other patients are sadness and fear linked to depressing content or bad news, feelings of being stuck or left behind when reading the updates of non-patients on social media and the irritation of encountering communication that is perceived as too personal, too strategic or too much in line with heroic cancer discourses. Typical ugly media feelings related to the young person’s own sharing practices include nervousness about making relatives sad and fear of or shame related to being perceived as a strategic sharer and/or oversharer. Ugly media feelings triggered by responses from followers/readers include annoyance at insensitive

comments/messages, disappointment about too little interaction and discomfort about too much (actual or imagined) attention. Last but not least, some participants articulate a more general feeling of “scepticism” to describe a range of general concerns about inauthenticity, misinformation and illness stereotypes on social media and to explain a generally restrained or cautious approach to sharing or reading about cancer and medical information.

Ugly media feelings can be analysed, firstly, as indirect revelations of the communicative ideals and media investments (Probyn, 2005) that young cancer patients make when they turn to social media during their illness. Ugly media feelings in other words constitute moments of disruption where patients' desired use of social media for support, peer connections, trustworthy information, agency and existential control is both blocked and indirectly revealed through affective negativity. Secondly, ugly media feelings could be explored as entangled with media cultural changes that have created new affectively unpredictable spaces for interacting about serious illness outside home and health institutions. In this media cultural situation, social media have become important publics of care during illness (by facilitating social bonds between peers with relatively rare diseases), but also arenas for either imagined or actual communicative mismatches, context collapses and ugly media feelings triggered by encountering too much or too little information from all the wrong people.

This research contributes to existing health communication research on cancer patients' use of social media by acknowledging and giving a detailed account of the affective complexity of this practice. It furthermore adds to research on the relationship between social media use and emotional well-being in media studies by approaching negative affective moments of disconnection and suspended agency as analytical material that indirectly allows us to understand the more affirmative media investments and ideals of cancer patients. In making these contributions, this article complicates what Kling (2000) has termed the ‘standard model’ approach to digital technologies — where technology is framed as a tool that is implemented to reach certain positive goals (*e.g.*, well-being or happiness) — in favour of a more culturally contextualised analysis that prioritizes a detailed account of the social situations where affective negativity is produced. Going back to Sara Ahmed, the findings thereby transgress an implicit prioritization of happiness in health communication and media research. Instead of overlooking negativity or framing it as a consequence of bad or undesired media use, the results emphasises that negativity should be studied in detail to give a nuanced account of the lived social media experiences of young cancer patients. 

About the authors

Carsten Stage is Associate Professor in the School of Communication and Culture at Aarhus University.

E-mail: norcs [at] cc [dot] au [dot] dk (corresponding author).

Lisbeth Klastруп is Associate Professor in the Department of Digital Design at IT University of Copenhagen.

Karen Hvidtfeldt is Professor in the Department for the Study of Culture at the University of Southern Denmark.

Acknowledgements

We would like to thank the 205 respondents and 25 interview respondents who shared often painful and intimate details of their life with us and without whom this article would not have been possible.

Funding

This article is made possible by a grant from the Danish Cancer Society (KBPF), grant no. R195–A12017.

Notes

1. Nesby and Salamonsen, 2016, p. 46.
2. Turkle, 2011, p. 12.
3. Tucker and Goodings, 2017, p. 639.
4. Ngai, 2004, p. 5.

References

- E. Abrol, M. Groszmann, A. Pitman, R. Hough, R.M. Taylor and G. Aref-Adib, 2017. “Exploring the digital technology preferences of teenagers and young adults (TYA) with cancer and survivors: A cross-sectional service evaluation questionnaire,” *Journal of Cancer Survivorship*, volume 11, number 6, pp. 670–682.
doi: <https://doi.org/10.1007/s11764-017-0618-z>, accessed 14 May 2021.
- S. Ahmed, 2010. *The promise of happiness*. Durham, N.C.: Duke University Press.
doi: <https://doi.org/10.1215/9780822392781>, accessed 14 May 2021.
- S. Ahmed, 2004. *The cultural politics of emotion*. Edinburgh: Edinburgh University Press.
- B. Anderson, 2014. *Encountering affect: Capacities, apparatuses, conditions*. Abingdon: Ashgate.
doi: <https://doi.org/10.4324/9781315579443>, accessed 14 May 2021.
- M. Appel, C. Marker and T. Gnambs, 2020. “Are social media ruining our lives? A review of meta-analytic evidence,” *Review of General Psychology*, volume 24, number 1, pp. 60–74.
doi: <https://doi.org/10.1177/1089268019880891>, accessed 14 May 2021.
- J.L. Bender, M.-C. Jimenez-Marroquin and A.R. Jadad, 2011. “Seeking support on Facebook: A content analysis of breast cancer groups,” *Journal of Medical Internet Research*, volume 13, number 1, e16.
doi: <https://doi.org/10.2196/jmir.1560>, accessed 14 May 2021.
- T. Benski and E. Fisher (editors), 2013. *Internet and emotions*. London: Routledge.
- L. Blackman, 2012. *Immaterial bodies: Affect, embodiment, mediation*. London: Sage.
doi: <http://dx.doi.org/10.4135/9781446288153>, accessed 14 May 2021.
- K.A. Boisen, B. Askholm, P.R. Olsen and G. Teilmann, 2013. “Unge og kræft,” In: C. Johansen (editor). *Kræft – senfølger og rehabilitering*. København: Hans Reitzels Forlag, pp. 430–452.
- V. Braun and V. Clarke, 2006. “Using thematic analysis in psychology,” *Qualitative Research in Psychology*, volume 3, number 2, pp. 77–101.
- T. Brennan, 2004. *The transmission of affect*. Ithaca, N.Y.: Cornell University Press.
- T. Bucher, 2018. *If ... then: Algorithmic power and politics*. Oxford: Oxford University Press.
doi: <http://dx.doi.org/10.1093/oso/9780190493028.001.0001>, accessed 14 May 2021.

S. Casale and V. Banchi, 2020. "Narcissism and problematic social media use: A systematic literature review," *Addictive Behaviors Reports*, volume 11.

doi: <https://doi.org/10.1016/j.abrep.2020.100252>, accessed 14 May 2021.

Y.-C. Chiu and Y.-L. Hsieh, 2012. "Communication online with fellow cancer patients: Writing to be remembered, gain strength, and find survivors," *Journal of Health Psychology*, volume 18, number 12, pp. 1,572–1,581.

doi: <https://doi.org/10.1177/1359105312465915>, accessed 14 May 2021.

P.T. Clough, 2008. "The affective turn: Political economy, biomedicine and bodies," *Theory, Culture and Society*, volume 25, number 1, pp. 1–22.

doi: <https://doi.org/10.1177/0263276407085156>, accessed 14 May 2021.

N. Couldry, 2004. "Theorising media as practice," *Social Semiotics*, volume 14, number 2, pp. 115–132.

doi: <https://doi.org/10.1080/1035033042000238295>, accessed 14 May 2021.

K. Darabos, M.A. Hoyt and J.S. Ford, 2019. "Relational processes and psychological adjustment among young adults with cancer: The role of technology-related communication," *Psycho-Oncology*, volume 28, number 12, pp. 2,406–2,414.

doi: <https://doi.org/10.1002/pon.5269>, accessed 14 May 2021.

K. Döveling, A.A. Harju and D. Sommer, 2018. "From mediated emotion to digital affect cultures," *Social Media + Society* (25 January).

doi: <https://doi.org/10.1177/2056305117743141>, accessed 14 May 2021.

K. Drotner, 1999. "Dangerous media? Panic discourses and dilemmas of modernity," *Paedagogica Historica*, volume 35, number 3, pp. 593–619.

doi: <https://doi.org/10.1080/0030923990350303>, accessed 14 May 2021.

G. Enli, 2015. *Mediated authenticity: How the media constructs reality*. Berlin: Peter Lang.

doi: <https://doi.org/10.3726/978-1-4539-1458-8>, accessed 14 May 2021.

S.S. Erfani and B. Abedin, 2018. "Impacts of the use of social network sites on users' psychological wellbeing: A systematic review," *Journal of the Association for Information Science & Technology*, volume 69, number 7, pp. 900–912.

doi: <https://doi.org/10.1002/asi.24015>, accessed 14 May 2021.

S.S. Erfani, B. Abedin and Y. Blount, 2017. "The effect of social network site use on the psychological well-being of cancer patients," *Journal of the Association for Information Science & Technology*, volume 68, number 5, pp. 1,308–1,322.

doi: <https://doi.org/10.1002/asi.23702>, accessed 14 May 2021.

S.S. Erfani, B. Abedin, and F. Daneshgar, 2013. "A qualitative evaluation of communication in Ovarian Cancer Facebook communities," paper presented at the International Conference on Information Society (i-Society 2013), at <https://ieeexplore.ieee.org/document/6636388>, accessed 14 May 2021.

N.M. Foley, M. O'Mahony, E.A. Lehane, T. Cil and M.A. Corrigan, 2015. "A qualitative content analysis of breast cancer narratives hosted through the medium of social media," *British Journal of Medicine & Medical Research*, volume 6, number 5, pp. 474–483, and at

<https://journaljammr.com/index.php/JAMMR/article/view/12693/23219>, accessed 14 May 2021.

A.W. Frank, 1995. *The wounded storyteller: Body, illness, and ethics*. Chicago: University of Chicago Press.

a.s. franzke, A. Bechmann, M. Zimmer, C. Ess the Association of Internet Researchers, 2020. "Internet research: Ethical guidelines 3.0," at <https://aoir.org/reports/ethics3.pdf>, accessed 14 May 2021.

- C. Graugaard, 2013. "Intimitet," In: C. Johansen (editor). *Kraft – senfølger og rehabilitering*. København: Hans Reitzels Forlag, pp. 389–401.
- M. Hardey, 2002. "'The story of my illness': Personal accounts of illness on the Internet," *Health*, volume 6, number 1, pp. 31–46.
doi: <https://doi.org/10.1177/136345930200600103>, accessed 14 May 2021.
- N.S. Hawi and M. Samaha, 2017. "The relations among social media addiction, self-esteem, and life satisfaction in university students," *Social Science Computer Review*, volume 35, number 5, pp. 576–586.
doi: <https://doi.org/10.1177/0894439316660340>, accessed 14 May 2021.
- C.M. Heilferty, 2009. "Toward a theory of online communication in illness: Concept analysis of illness blogs," *Journal of Advanced Nursing*, volume 65, number 7, pp. 1,539–1,547.
doi: <https://doi.org/10.1111/j.1365-2648.2009.04996.x>, accessed 14 May 2021.
- M.T. Høybye, C. Johansen and T. Tjørnhj-Thomsen, 2005. "Online interaction: Effects of storytelling in an Internet breast cancer support group," *Psycho-Oncology*, volume 14, number 3, pp. 211–220.
doi: <https://doi.org/10.1002/pon.837>, accessed 14 May 2021.
- S. Jiang, 2017. "The role of social media use in improving cancer survivors' emotional well-being: A moderated mediation study," *Journal of Cancer Survivorship*, volume 11, number 3, pp. 386–392.
doi: <https://doi.org/10.1007/s11764-017-0595-2>, accessed 14 May 2021.
- T. Karppi, 2018. *Disconnect: Facebook's affective bonds*. Minneapolis: University of Minnesota Press.
- J. Keim-Malpass, T.A. Albrecht, R.H. Steeves and S.C. Danhauer, 2013. "Young women's experiences with complementary therapies during cancer described through illness blogs," *Western Journal of Nursing Research*, volume 35, number 10, pp. 1,309–1,324.
doi: <https://doi.org/10.1177/0193945913492897>, accessed 14 May 2021.
- J. Keim-Malpass, M. Baernholdt, J.M. Erickson, M.E. Ropka, A.T. Schroen and R.H. Steeves, 2013. "Blogging through cancer: Young women's persistent problems shared online," *Cancer Nursing*, volume 36, number 2, pp. 163–172.
doi: <https://doi.org/10.1097/NCC.0b013e31824eb879>, accessed 14 May 2021.
- B. Kim and D. Gillham, 2015. "Gender differences among young adult cancer patients: A study of blogs," *CIN: Computers, Informatics, Nursing*, volume 33, number 1, pp. 3–9.
doi: <https://doi.org/10.1097/CIN.000000000000118>, accessed 14 May 2021.
- B. Kim and D. Gillham, 2013. "The experience of young adult cancer patients described through online narratives," *Cancer Nursing*, volume 36, number 5, pp. 377–384.
doi: <https://doi.org/10.1097/NCC.0b013e318291b4e9>, accessed 14 May 2021.
- N. Kingod, B. Cleal, A. Wahlberg and G.R. Husted, 2017. "Online peer-to-peer communities in the daily lives of people with chronic illness: A qualitative systematic review," *Qualitative Health Research*, volume 27, number 1, pp. 89–99.
doi: <https://doi.org/10.1177/1049732316680203>, accessed 14 May 2021.
- R. Kling, 2000. "Learning about information technologies and social change: The contribution of social informatics," *Information Society*, volume 16, number 3, pp. 217–232.
doi: <https://doi.org/10.1080/01972240050133661>, accessed 14 May 2021.
- B.T. Knudsen and C. Stage, 2012. "Contagious bodies: An investigation of affective and discursive strategies in contemporary online activism," *Emotion, Space and Society*, volume 5,

number 3, pp. 148–155.

doi: <https://doi.org/10.1016/j.emospa.2011.08.004>, accessed 14 May 2021.

A. Lagerkvist, 2017. “Existential media: Toward a theorization of digital thrownness,” *New Media & Society*, volume 19, number 1, pp. 96–110.

doi: <https://doi.org/10.1177/1461444816649921>, accessed 14 May 2021.

A. Lagerkvist and Y. Andersson, 2017. “The grand interruption: Death online and mediated lifelines of shared vulnerability,” *Feminist Media Studies*, volume 17, number 4, pp. 550–564.

doi: <https://doi.org/10.1080/14680777.2017.1326554>, accessed 14 May 2021.

B. Light and E. Cassidy, 2014. “Strategies for the suspension and prevention of connection: Rendering disconnection as socioeconomic lubricant with Facebook,” *New Media & Society*, volume 16, number 7, pp. 1,169–1,184.

doi: <https://doi.org/10.1177/1461444814544002>, accessed 14 May 2021.

T.R. Lindlof and B.C. Taylor, 2011. *Qualitative communication research methods*. Third edition. London: Sage.

G. Lovink, 2019. *Sad by design: On platform nihilism*. London: Pluto Press.

D. Lupton, 2016. *The quantified self*. Cambridge: Polity.

B. Massumi, 2002. *Parables for the virtual: Movement, affect, sensation*. Durham, N.C.: Duke University Press.

doi: <https://doi.org/10.1215/9780822383574>, accessed 14 May 2021.

A. McCosker, 2018. “Engaging mental health online: Insights from *beyondblue*’s forum influencers,” *New Media & Society*, volume 20, number 12, pp. 4,748–4,764.

doi: <https://doi.org/10.1177/1461444818784303>, accessed 14 May 2021.

A. McCosker, 2013. *Intensive media: Aversive affects and visual culture*. Basingstoke: Palgrave Macmillan.

doi: <https://doi.org/10.1057/9781137273512>, accessed 14 May 2021.

A. McStay, 2018. *Emotional AI: The rise of empathic media*. London: Sage.

A. Munster, 2013. *An aesthesia of networks: Conjunctive experience in art and technology*. Cambridge, Mass.: MIT Press.

doi: <https://doi.org/10.7551/mitpress/8982.001.0001>, accessed 14 May 2021.

L. Nesby and A. Salamonsen, 2016. “Youth blogging and serious illness,” *Medical Humanities*, volume 42, number 1, pp. 46–51.

doi: <https://doi.org/10.1136/medhum-2015-010723>, accessed 14 May 2021.

S. Ngai, 2004. *Ugly feelings*. Cambridge, Mass.: Harvard University Press.

NORDCAN, 2018. “NORDCAN projektet,” at <http://www-dep.iarc.fr/NORDCAN/DK/frame.asp>, accessed 14 May 2021.

A. Orben and A.K. Przybylski, 2019. “The association between adolescent well-being and digital technology use,” *Nature Human Behaviour*, volume 3, pp. 173–182.

doi: <https://doi.org/10.1038/s41562-018-0506-1>, accessed 14 May 2021.

S. Orgad, 2006. “The cultural dimensions of online communication: a study of breast cancer patients’ Internet spaces,” *New Media & Society*, volume 8, number 6, pp. 877–899.

doi: <http://dx.doi.org/10.1177/1461444806069643>, accessed 14 May 2021.

S. Orgad, 2005. *Storytelling online: Talking breast cancer on the Internet*. New York: Peter Lang.

- S. Paasonen, 2018. "Affect, data, manipulation and price in social media," *Distinktion*, volume 19, number 2, pp. 214–229.
doi: <https://doi.org/10.1080/1600910X.2018.1475289>, accessed 14 May 2021.
- S. Paasonen, 2016. "Fickle focus: Distraction, affect and the production of value in social media," *First Monday*, volume 21, number 10, at <https://firstmonday.org/article/view/6949/5629>, accessed 14 May 2021.
doi: <https://doi.org/10.5210/fm.v21i10.6949>, accessed 14 May 2021.
- S. Paasonen, K. Hillis and M. Petit, 2015. "Introduction: Networks of transmission: Intensity, sensation, value," In: K. Hillis, S. Paasonen and M. Petit (editors). *Networked affect*. Cambridge, Mass.: MIT Press, pp. 1–24.
doi: <https://doi.org/10.7551/mitpress/9715.003.0002>, accessed 14 May 2021.
- R.E. Page, 2011. *Stories and social media: Identities and interaction*. New York: Routledge.
doi: <https://doi.org/10.4324/9780203148617>, accessed 14 May 2021.
- Z. Papacharissi (editor), 2018. *A networked self and birth, life, death*. New York: Routledge.
doi: <https://doi.org/10.4324/9781315202129>, accessed 14 May 2021.
- Z. Papacharissi, 2014. *Affective publics: Sentiment, technology, and politics*. New York: Oxford University Press.
doi: <https://doi.org/10.1093/acprof:oso/9780199999736.001.0001>, accessed 14 May 2021.
- J. Parikka, 2010. *Insect media: An archaeology of animals and technology*. Minneapolis: University of Minnesota Press.
- T. Parsons, 1951. *The social system*. Glencoe, Ill: Free Press.
- W. Phillips and R.M. Milner, 2017. *The ambivalent Internet: Mischief, oddity, and antagonism online*. Cambridge: Polity Press.
- V. Pitts, 2004). "Illness and Internet empowerment: Writing and reading breast cancer in cyberspace," *Health*, volume 8, number 1, pp. 33–59.
doi: <https://doi.org/10.1177/1363459304038794>, accessed 14 May 2021.
- E. Probyn, 2005. *Blush: Faces of shame*. Minneapolis: University of Minnesota Press.
- T. Raun, 2017. "'Talking about his dead child, again!' Emotional self-management in relation to online mourning," *First Monday*, volume 22, number 11, at <https://firstmonday.org/article/view/7810/6559>, accessed 14 May 2021.
doi: <https://doi.org/10.5210/fm.v22i11.7810>, accessed 14 May 2021.
- T. Raun, 2012. "DIY therapy: Exploring affective self-representations in trans vvideo blogs on YouTube," In: A. Karatzogianni and A. Kuntsman (editors). *Digital cultures and the politics of emotion*. London: Palgrave Macmillan, pp. 165–180.
doi: https://doi.org/10.1057/9780230391345_10, accessed 14 May 2021.
- P.K. Ressler, Y.S. Bradshaw, L. Gualtieri and K.K.H. Chui, 2012. "Communicating the experience of chronic pain and illness through blogging," *Journal of Medical Internet Research*, volume 14, number 5, e143.
doi: <https://doi.org/10.2196/jmir.2002>, accessed 14 May 2021.
- A.N. Saiphoo, L. Dahoah Halevi and Z. Vahedi, 2020. "Social networking site use and self-esteem: A meta-analytic review," *Personality and Individual Differences*, volume 153, 109639.
doi: <https://doi.org/10.1016/j.paid.2019.109639>, accessed 14 May 2021.
- T.D. Sampson, 2012. *Virality: Contagion theory in the age of networks*. Minneapolis: University of Minnesota Press.

T.D. Sampson, D. Ellis and S. Maddison (editors), 2018. *Affect and social media: Emotion, mediation, anxiety and contagion*. London: Rowman & Littlefield International.

B.F. Sharf, 1997. "Communicating breast cancer on-line: Support and empowerment on the Internet," *Women & Health*, volume 26, number 1, pp. 65–84.
doi: https://doi.org/10.1300/J013v26n01_05, accessed 14 May 2021.

S. Sontag, 1991. *Illness as metaphor, and AIDS and its metaphors*. London: Penguin.

C.D. Sperling, G.S. Petersen, A.K.M. Andersen, A.C.I.S. Heerdegen and J.L. Knudsen, 2015. "At være ung og få kræft" — En spørgeskemaundersøgelse af de unges behov og oplevelser under og efter sygdom og behandling. København: Kræftens Bekæmpelse.

J. Stacey, 1997. *Teratologies: A cultural study of cancer*. London: Routledge.
doi: <https://doi.org/10.4324/9781315004983>, accessed 14 May 2021.

C. Stage, 2017. *Networked cancer: Affect, narrative and measurement*. London: Palgrave Macmillan.

C. Stage, K. Hvidtfeldt and L. Klastруп, 2020. "Vital media: The affective and temporal dynamics of young cancer patients' social media practices," *Social Media + Society* (18 June).
doi: <https://doi.org/10.1177/2056305120924760>, accessed 14 May 2021.

C. Stage, K. Hvidtfeldt and L. Klastруп, 2019. *Unge danske kræftpatienters brug og oplevelse af sociale medier*. Aarhus: Kræftens Bekæmpelse.

Y. Sugawara, H. Narimatsu, A. Hozawa, L. Shao, K. Otani and A. Fukao, 2012. "Cancer patients on Twitter: A novel patient community on social media," *BMC Research Notes*, volume 5, article number 699.
doi: <https://doi.org/10.1186/1756-0500-5-699>, accessed 14 May 2021.

T. Syvertsen and G. Enli, 2020. "Digital detox: Media resistance and the promise of authenticity," *Convergence*, volume 26, numbers 5–6, pp. 1,269–1,283.
doi: <https://doi.org/10.1177/1354856519847325>, accessed 14 May 2021.

C.L. Toma, Y.A. Chen, C. Olson, T. Fan and B.B. Brown, 2020. "Youth, social media use and well being," In: J. Bulck, D. Ewoldsen, M. Mares and E. Scharrer (editors). *International Encyclopedia of Media Psychology*. Hoboken, N.J.: Wiley Blackwell.
doi: <https://doi.org/10.1002/9781119011071.iemp0210>, accessed 14 May 2021.

T. Tembeck, 2016. "Selfies of ill health: Online autopathographic photography and the dramaturgy of the everyday," *Social Media + Society* (30 March).
doi: <https://doi.org/10.1177/2056305116641343>, accessed 14 May 2021.

K. Tiidenberg and E. Gómez Cruz, 2015. "Selfies, image and the re-making of the body," *Body & Society*, volume 21, number 4, pp. 77–102.
doi: <https://doi.org/10.1177/1357034X15592465>, accessed 14 May 2021.

A. Tsuya, Y. Sugawara, A. Tanaka and H. Narimatsu, 2014. "Do cancer patients tweet? Examining the Twitter use of cancer patients in Japan," *Journal of Medical Internet Research*, volume 16, number 5, e137.
doi: <https://doi.org/10.2196/jmir.3298>, accessed 14 May 2021.

I.M. Tucker and L. Goodings, 2017. "Digital atmospheres: Affective practices of care in Elefriends," *Sociology of Health & Illness*, volume 39, number 4, pp. 629–642.
doi: <https://doi.org/10.1111/1467-9566.12545>, accessed 14 May 2021.

E.K. Vraga, A. Stefanidis, G. Lamprianidis, A. Croitoru, A.T. Crooks, P.L. Delamater, D. Pfoser, J.R. Radzikowski and K.H. Jacobsen, 2011. "Cancer and social media: A comparison of traffic

about breast cancer, prostate cancer, and other reproductive cancers on Twitter and Instagram,” *Journal of Health Communication*, volume 23, number 2, pp. 181–189.
doi: <https://doi.org/10.1080/10810730.2017.1421730>, accessed 14 May 2021.

M. Wetherell, 2012. *Affect and emotion: A new social science understanding*. London: Sage.
doi: <http://dx.doi.org/10.4135/9781446250945>, accessed 14 May 2021.

E. Ytreberg, 2019. “Control over stories of illness and life: The case of a career media participant turned media professional,” *Nordicom Review*, volume 40, number 2, pp. 37–48.
doi: <https://doi.org/10.2478/nor-2019-0023>, accessed 14 May 2021.

Editorial history

Received 7 September 2020; revised 30 November 2020; revised 11 December 2020; revised 19 January 2021; revised 27 January 2021; accepted 27 January 2021.

Copyright © 2021, Carsten Stage, Lisbeth Klastrup, and Karen Hvidtfeldt. All Rights Reserved.

Ugly media feelings: Negative affect in young cancer patients' experiences of social media
by Carsten Stage, Lisbeth Klastrup, and Karen Hvidtfeldt.

First Monday, Volume 26, Number 6 - 7 June 2021

<https://firstmonday.org/ojs/index.php/fm/article/download/11093/10144>

doi: <http://dx.doi.org/10.5210/fm.v26i6.11093>