


Vital Media: The Affective and Temporal Dynamics of Young Cancer Patients' Social Media Practices

Social Media + Society
April-June 2020: 1–13
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DOI: 10.1177/2056305120924760
journals.sagepub.com/home/sms


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Abstract

This article presents results from a research project investigating young cancer patients' general use of social media and their lived experience of the choices and dilemmas involved in using social media in relation to moments of existential crisis. This article's key finding—based on an extensive survey with 205 young cancer patients and 25 qualitative interviews—is that social media becomes increasingly important for young people after a cancer diagnosis and that these young people engage with social media as—what we will call—*vital media*. The analysis in this article focuses on affective and temporal media experiences in the empirical material collected and argues that three dimensions of “media vitality” are salient: (1) that young people engage with social media to *actively produce vitality* in terms of generating a sense of wellbeing or balance by sharing, seeking out, or avoiding particular types of cancer-related content; (2) that young people *experience social media as a vital or “lively” technology* that introduces unpredictable and sometimes unwanted material into their lives; and (3) that young people feel they are expected to *perform or share vital approaches to illness* on social media, such as positive or life-affirming—as opposed to negative or pessimistic—accounts of their illness. In this way, the concept of “vital media” addresses strategic, ecological, and cultural aspects of young cancer patients' social media engagements.

Keywords

illness, affect, time, vital media, existential media, young people, cancer patient, care

Introduction

Each year, approximately 500 young people (age 15–29; Sperling et al., 2015) in Denmark are diagnosed with cancer. For this group, a cancer diagnosis poses particular challenges, as it disturbs important processes of transition (from child to adult) and identity formation (related to education, sexuality, or family building; Boisen et al., 2013; Graugaard, 2013). Culturally speaking, young people with cancer are also positioned in a tension between invisibility and visibility. On one hand, they are culturally (and institutionally) implausible and unlikely victims of the disease (the statistical risk of cancer is low before the age of 50), which often results in late diagnoses and a health care system which is less prepared to handle the specific problems of this patient group (Sperling et al., 2015). On the other hand, they are increasingly culturally visible because they are often more willing to publicly share affectively engaging narratives of cancer on blogs and social networking sites (SNSs; for example, Facebook and Instagram; Abrol et al., 2017; Nesby & Salamonsen, 2016; Stage et al., 2019).

Health communication research has provided detailed insight into cancer patients' general use of the internet, and increasingly also of social media, but more knowledge is needed, when it comes to cancer patients' complex existential, affective, and temporal use and experience of social media. The specific aim of this article is therefore to create thorough knowledge about these illness and media practices by addressing the following research questions:

1. How and why do young cancer patients (not) use social media platforms for cancer-related purposes?
2. How do they experience the existential, affective, and temporal importance of social media in their life during cancer?

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By taking our point of departure in the social media practices and experiences of young cancer patients, we wish to acknowledge the specific perspective of this patient group, but in the article, we focus less on youth-related aspects of social media use (e.g., linked to dating or education) and more on the general existential, affective, and temporal roles that social media play for young cancer patients as these aspects were quite central in the empirical material. In that way, the article contributes both with a social media perspective to research on young cancer patients and with knowledge about the existential, affective, and temporal aspects of cancer patients' social media use to research on cancer patients and digital media. Finally, it adds new knowledge about cancer patients' social media use to research on social media affect and existential media.

To address the research questions, this article will present results from a 1-year research project investigating young cancer patients' general use of social media and their lived experience of the choices and dilemmas involved in using social media in relation to moments of existential crisis (Lagerkvist, 2017; Papacharissi, 2019). By doing so, this article contributes to research on social media by exploring the co-constitutive processes of living a life with cancer and living a life with social media and by shedding light on social media's involvement in sensing, sharing, processing, and modulating the vulnerable body during illness and treatment.

This article's key finding—based on a survey with 205 young cancer patients and 25 qualitative interviews—is that social media becomes increasingly important for young people after a cancer diagnosis and that social media is engaged with as “vital media.” Inspired by Kember and Zylinska's work on how vitality and life emerge and are shaped by processes of entangled, “being-with” technology (Kember & Zylinska, 2012, p. 14; see also Stiegler, 1994)—and by their complication of dichotomies of media representation/presentation and using/being used by media—we focus on three dimensions of vital media in the collected empirical material: (1) how young people engage with social media to actively produce vitality in terms of generating a sense of wellbeing or balance by sharing, seeking out, or avoiding particular types of cancer-related content, (2) how young people experience social media as a vital or “lively” technology that introduces unpredictable and sometimes unwanted material into their lives, and (3) how young people explain a perceived expectation to perform or share vital approaches to illness on social media, such as positive or life-affirming—as opposed to more negative or pessimistic—approaches to illness. In this way, the concept of “vital media” addresses strategic, ecological, and cultural aspects of young cancer patients' social media engagements.

This article focuses less on the posts and content that patients actually share on social media and more on how patients describe their own media practice (Couldry, 2004). In these descriptions, the affective and temporal dimensions of social media practices are often highlighted and our understanding of social media as vital media is therefore

largely based on these patient articulations of how affects and temporalities are produced, modulated, and expected during their life with cancer—and with social media. In taking up these the general concepts of affect, time, and vitality in relation to social media practices during cancer, this article will also contribute to understanding the importance of social media for other types of illness-related existential disruption.

Existing Research

Cancer Patients, the Internet, and Social Media

The life crisis created by serious illness often affords multiple forms of communication, and digital and social media are becoming important parts of living with cancer. Cancer is among the most “commonly searched health topics on the internet” (Nguyen & Ingledew, 2013, p. 662), and patients in a Western context are increasingly using the internet to find information about diagnoses and treatments (Aadland & Lykke, 2015; Castleton et al., 2011; Maloney et al., 2015). However, research has also shown a digital divide (based on age, education, ethnicity and income) in the use of internet resources during cancer (Høybye et al., 2010; Littlechild & Barr, 2013).

Over the last 20 years, health communication and media studies research have investigated cancer patients' engagement with various forms of communication, such as peer support groups; email lists; websites and message boards (Hardey, 2002; Høybye et al., 2005; Orgad, 2005; Sharf, 1997); cancer blogging (Heilferty, 2009; Keim-Malpass, Baernholdt, et al. 2013); and SNSs like Facebook (Bender et al., 2011; Erfani et al., 2012), 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 & Hsieh, 2012; Kim & 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). Previous studies have also indicated that female users are more inclined to share their experiences on cancer blogs compared with male users (Baik et al., 2019; Kim & Gillham, 2015).

The “illness narrative tradition” in research on cancer narratives has often stressed that narrative work can create a healing sense of structure during the course of a “biographically disrupting” illness (Bury, 1982; Charon, 2006; Frank, 1995; Jurecic, 2012). In the available studies of cancer narratives in digital media, this focus on reclaiming a subjective voice during illness has been continued (Coll-Planas & Visa, 2016; Nesby & Salamonsen, 2016; Orgad, 2005), but the changed temporality of sharing stories of illness on social media, which can be seen as ad hoc attempts to grasp changes as they occur (Page, 2012), has also been recognized.

Existing research on 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 interpersonal support. Despite the importance of understanding social media as a tool to cope with illness and to stabilize the self in crisis, such a therapeutic approach generally neglects the complexities and dilemmas related to sharing and engaging with cancer on social media; for instance, how social media can also produce affects of 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 also—inspired by work in medical anthropology that has highlighted the complexity of lived experiences and cultural practices of illness (Good, 1996; Kleinman, 1988)—begin with the premise that social media platforms are not only empowering tool for patients but also multifaceted and contextualized platforms that entangle with cancer narratives, publics, and experiences in new yet under-researched ways. In doing this, this article also situates itself in a field of social media research on other illnesses or disruptions that highlights 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, 2019; Pitts, 2004; Stage, 2017; Tembeck, 2016; Tiidenberg & Cruz, 2015; Tucker & Goodings, 2017; Ytreberg, 2019).

This article adds to existing research on cancer patients' use of the internet and social media in four ways: (1) by focusing on a group of young patients (age 15–29), who are often overlooked in studies of cancer patients' use of the internet and social media (young users tend to be viewed simply as general users); (2) by providing specific knowledge about this young group's media use and experience in a specific cultural context (Denmark) in which the phenomenon has not been researched; (3) by taking a multidimensional empirical approach to social media use during cancer, where media use, media experience, and conversations about shared media texts all form part of the study; and (4) by focusing on the complex uses and experiences of social media during cancer.

This article offers a lacking perspective on social media to a large Danish report on young Danish cancer patients (Sperling et al., 2015). This report (based on 822 respondents) shows that young cancer patients often feel that they are not taken seriously by the health care system, that they are a part of a health care system designed for older patients, and that they lack peers with similar experiences (see also Hølge-Hazelton, 2011). The young patients value continuity in treatment highly and want to be included in decisions concerning their own treatment, and they feel that the system does not always work well in terms of acknowledging the psychosocial dimensions (e.g., loneliness and anxiety) of having cancer as a young person, where questions concerning dating and

sexuality, for example, become important (see also Graugaard, 2013). The report shows that, when a young person has cancer, his or her processes related to education and work are often profoundly disturbed (see also Boisen et al., 2013), his or her relations with relatives become increasingly important, and also that his or her relatives might require more help to manage the situation. However, the report mentions nothing about social media, which is becoming increasingly important for young people's lives and social relations. This article, therefore, fills an important gap in terms of understanding the life of young Danish cancer patients.

Internationally, a few studies of adolescent and/or young adult cancer patients with a particular focus on digital media have been conducted. Abrol et al.'s study emphasizes the importance of social media for young cancer patients and their relational importance during illness. The study found that 41.6% of young cancer patients (102 respondents between 15 and 24) described social media as “essential” to their life and that 51% kept in touch with patients they had met during treatment through social media (Abrol et al., 2017). Kim and Gilman explored main themes in posts shared by 46 young adult (age 20–29) cancer patients on blogs and concluded that the 10 main themes were the following: physical burdens, future prospects, isolation (physical and psychological), guilt, mortality, images of cancer, creating a positive attitude, health care, online social interaction, and cancer survivorship (Kim & Gillham, 2013). In a study of two blogs of young cancer patients, Nesby and Salamonsen showed 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 health care issues than what is often presumed” (Nesby & Salamonsen, 2016, p. 46). This article contributes to this media research by both further supporting the conclusions regarding the importance of experiential knowledge, peer relations, and communication about existential insecurities and significantly adding to these conclusions by emphasizing the many different uses of social media by young cancer patients and highlighting the temporal and affective reasons for engaging with social media as “vital media” during serious illness.

Existential Media, Affect, and Vitality

In emphasizing the existential complexity of narrating crisis and vulnerability on social media, this article situates itself in the burgeoning “existential media studies” field, which focuses on how digital media can simultaneously co-produce existential crisis (e.g., in terms of privacy breaches, digital assaults, or social invisibility) and serve as relational technologies, or “lifelines,” when it comes to managing existential vulnerabilities (Lagerkvist & Andersson, 2017; Langlois, 2018; Peters, 2015). Cancer-related profiles, blogs, or groups

are obvious examples of such digital media practices that revolve around human experiences of disruption, loss, or profound biographical disturbance and that simultaneously express and manage crises by giving them a mediated form. An existential media approach, as described by Lagerkvist, is based on an acknowledgment of the ubiquitous role of digital media in current culture, which entails that individuals are “thrown into” the digital (Lagerkvist, 2017): it is everywhere, it cannot be avoided and it is thus an important element of human existence. This becomes particularly clear during moments of existential rupture—or what Lagerkvist, following Jaspers, calls “limit situations”—when people increasingly turn to media (Lagerkvist, 2017, p. 2).

Lagerkvist draws on the work of John Durham Peters, who has argued that we should view (digital) media as elemental media in the sense that they “lie at the taken-for-granted base of our habits and habitat” (Peters, 2015, p. 1). They sustain and enable being. For this reason, media are often forgotten as media and instead become “ontology” and “how things are”: “Media are our infrastructures of being, the habitats and materials through which we act and are. This gives them ecological, ethical, and existential import” (Peters, 2015, p. 15). Peters furthermore argues that understanding media as carriers of semiotic information is reductive because (social) media is clearly not only used to allow one brain to communicate cognitive input to another. People also feel media and, conversely, media can create and alter affective experiences and enable humans to engage in various forms or bodily, temporal, and sensuous relations of presence (Bucher, 2018; Coleman, 2018; Hillis et al., 2015; Papacharissi, 2015; Wajcman, 2015). Or as Peters remarks, “Social media invite us to think freshly about the communicative affordances of presence and the many mediations of the body” (Peters, 2015, p. 6) and about how digital media serve more as “logistical devices of tracking and orientation” than as providers of “unifying stories to the society at large. Digital media revive ancient navigational functions: they point us in time and space, index our data, and keep us on the grid” (Peters, 2015, p. 7). A crucial question is, however, how this both affective and temporal navigation is played out more specifically during existential zones of crises or “suspended time” (Baraitser, 2017) caused by serious illness among young cancer patients.

Social media has been shown to revolve around, design, and materialize a constant “affective present” (Coleman, 2018) but also to make it possible to modulate time and social rhythms through various processes of compressing, prolonging, and restructuring time (Sandvik & Christensen, 2013; Wajcman, 2015). Judy Wajcman’s *Pressed for Time* (2015), which explores the multiple temporalities enacted by digital and mobile media, inspires this article’s analysis, as it also emphasizes the more sensuous aspects of using media to modulate temporal experience. According to Wajcman, media are not only speeding up processes that help save time or create busier lives (which has become the common sense

understanding of their temporal implications); they can also be tools for making zones of waiting and boredom more meaningful, for example, by turning these zones into spaces for creating intimacy with not-present yet important others. In other words, they can fill in more than speed up time (Wajcman, 2015, p. 154). Furthermore, social media has been shown to take part in various types of “time work”—for example, the re-creation of temporal differentiation—in the wake of crisis as a rhythmic breakdown (Sandvik & Christensen, 2013; Stage, 2014). In this article, we will focus on these temporal aspects as they are expressed in the collected empirical material.

But how should we account for affective and temporal dimensions of social situations? In our analysis, we will appeal to the work of Ben Anderson, who argues that affect can simultaneously be understood as an “object-target” that is strategically produced or aimed for through specific apparatuses (e.g., state propaganda aimed at creating patriotism), a “bodily capacity” that can be moved through encounters (e.g., facing another living creature that suffers), and a “collective condition” or “affective economy” (Ahmed, 2004) that mediates how collectives affectively approach life in general (e.g., a more general sense of precarity linked to late capitalism; Anderson, 2014, p. 4). According to Anderson (2014), “affective life is organized through multiple apparatuses that produce particular kinds of affective objects, particular kinds of subject and collectives, and are embedded in specific modalities of power” (p. 25). Social media platforms are one of these apparatuses that (re)produce affective targets, encounters, and conditions based on the affordances of the particular platform.

In understanding social media as existential habitats characterized by various temporal and affective processes, we have also been inspired by Kember and Zylinska’s concepts of “mediation” and “vitality” (Kember & Zylinska, 2012). Mediation tries to capture how technologies are not simply entities that are either used by individuals or shape individuals and their contexts, but they are also ubiquitous elements of how life emerges and develops. This implies that the social and the biological, as well as the human and the technological, cannot easily be separated:

[W]e human users of technology are not entirely distinct from our tools. *They* are not means to *our* ends; instead they have become part of us, to an extent that the us/them distinction is no longer tenable. As we modify and extend “our” technologies and “our” media, we modify and extend ourselves and our environments. (Kember & Zylinska, 2012, p. 13)

The idea that media technologies are “vital” furthermore refers to the fact that technologies are integral parts of how life and the body is lived, experienced, and continuously transformed, but also that technologies are themselves lively by generating “unprecedented connections and unexpected events” (Kember & Zylinska, 2012, p. xvii). In this article,

we take part in exploring the vitality of media by identifying three overlapping types of vitality in the empirical material that, taken together, underline how young cancer patients co-emerge with social media during their illness: (1) media vitality understood as individual attempts to use social media actively to enhance life, (2) media vitality understood as technologies' inherent unpredictability and uncontrollability, and (3) media vitality understood as the cultural norms and restraints that saturate social media and privilege positive or optimistic accounts of living a life with illness.

Methods and Ethics

Methodologically, this article presents a mixed methods research study which consisted of (1) a detailed and anonymized survey mapping the social media habits and experiences of 205 young Danish cancer patients (Sperling et al., 2016) distributed in December 2018 and January 2019, and (2) qualitative online or offline interviews with the 25 young Danish cancer patients (Kvale & Brinkmann, 2009; Salmons, 2014), carried out in spring 2019. Both the survey and interviews focus on five core issues (1) the patients' general use of social media, (2) the patients' general use of social media after and in relation to their cancer diagnosis, (3) the patients' level of active sharing of cancer-related content, (4) the patients' use of social media in relation to different phases of illness and treatment, and (5) the patients' demographic information. The survey was not built on validated scales from health research, but on a uses and gratifications approach to social media and with the aim of understanding why and how the particular target group chooses to actively (dis)engage with social media to satisfy specific needs. Throughout the survey, it was possible to supplement answers with textual explanations. Before disseminating the survey, its design was adjusted based on comments from two young former patients related to the Danish organization YoungCancer and by a youth panel at Aarhus University Hospital, which consisted of seven patients in their 20s and was organized by researcher and oncology nurse Pia Riis Olsen.

Informants for the interviews were selected from 80 survey respondents who agreed to be contacted for an interview. They were chosen with diversity in terms of gender, age, and region as core criteria. The interview guide addressed the participant's general use of social media, their use of social media in relation to their diagnosis and treatment, their use of social media as means of connecting with other patients and/or their stories, and the normative and emotional dimensions of their social media use: What did and did they not share about illness? To afford a more open conversation about these latter dimensions, the interviews included conversations about elicited screenshots of posts from patients' social media profiles chosen by the informants themselves (focusing on best/worst experience, first post after diagnosis, typical post, and perceived unsharable posts; G. Rose, 2012).

An important ethical guideline for our project was not to cause any negative physical or psychological effects (Franzke et al., 2020; Markham & Buchanan, 2012). In accordance with this guideline, we tried to be as flexible as possible in terms of where, how, and for how long interviews were conducted to respect different boundaries related to trust, energy, privacy, and sense of vulnerability. The 25 interviews were conducted in the informants' homes (15 interviews), over the phone (six interviews), in the researcher's office (two interviews), at the informant's workplace (one interview), and at a local library (one interview). Although the same interview guide was used for all interviews, the interview length ranged from 45 min to several hours. To honor the stories and commitment of the patients who took part in the project, we have prioritized giving them a strong presence in the analytical part of the article through direct quotations.

The collection of interview material was based on informed consent or on parental consent if the informant was 15–17 years old. Informants younger than 15 were not included. The informants could withdraw from the project at any time without sanctions. All participants could choose between remaining anonymous or being named (and thus visible and acknowledged for their contribution). About 12 decided to remain anonymous and 13 decided to have their first name used after quotations. Before we included specific quotations from interviews in our analysis, we emailed these to the relevant informants for final confirmation.

In terms of potential biases, participation in the survey was based on self-selection through primarily digital dissemination of the survey (and word of mouth) but also on visits at selected physical meetings with young cancer patients. The bias of using social media to collect answers—compared with, for example, sending a questionnaire in the post—is likely to be minimal as more than 90% of Danish young people use social media frequently (Slots- og Kulturstyrelsen, 2018). In our analysis of the survey answers, however, we remain aware of certain biases that need to be considered when making conclusions. The survey material was characterized by five types of overrepresentation of patient types: (1) Most of the respondents who completed the survey have now been declared cancer-free (when completing the survey, 19% were in treatment [e.g., receiving chemo or radiation therapy], 6% were in post-treatment control, and 75% were declared cancer-free). (2) Most of the respondents belonged to the oldest age group (8% were between 15 and 19, 30% were between 20 and 24, and 61% were between 25 and 29). (3) Most of the respondents were women (80% women, 20% men). (4) Most of the respondents were from the largest cities in Denmark, Copenhagen, and Aarhus (30% of the respondents lived in the Central Denmark Region, where Aarhus is situated; 29% in the Capital Region [Copenhagen and surrounding municipalities]; 15% in the Southern Denmark Region; 13% in the Zealand Region; 12% in the North Denmark Region; and 2% lived abroad).

(5) Most of the respondents were employed (38%) or enrolled as students of higher education (36%).

Informants for interviews were partly selected to compensate for some of the participation biases, for example, a larger share of young men were invited to be interviewed (nine out of 25). Taking the distribution into consideration, our findings and the general patterns of use emerging from the survey study are however still more likely to describe female, cancer-free patients in their late 20s studying or working in the larger cities than they are to describe young, unemployed men living outside the larger cities. To determine whether or not this is the case, more research on male cancer patients' engagement with social media is needed.

Analysis: Three Dimensions of Media Vitality

In what follows, we will present the results our study taking our point of departure in some of the salient findings from our quantitative survey. In the survey, we probed the respondent's use of social media in general and their use of social media during their time as cancer patients more specifically. We did this to understand their use of social media both as active sharers and more passive consumers of content and to examine social media as an affective tool and environment in relation to diagnosis and treatment. In general, the survey material suggests that the respondents' social media use increased after their cancer diagnosis. In all, 47% of the 205 respondents used social media "more" or "significantly more" after diagnosis, while the remaining 53% used social media on the same level as before their diagnosis. Respondents identified Facebook, Instagram, and blogs as the most suitable platforms for sharing cancer-related material. Snapchat was the platform considered most unsuitable for sharing cancer material (32% considered it unsuitable; 56% considered it suitable). A total of 76% of the respondents have read or followed personal accounts of other patients, 48% of respondents have communicated actively with other patients on social media, and half of the respondents claimed that reading the narratives of other patients can make you feel less alone. This underlines findings from existing research highlighting experiential knowledge and peer relations as crucial motivations for using social media as a young cancer patient (see, for example, Abrol et al., 2017; Nesby & Salamonsen, 2016).

In terms of active sharing of content, 8 of 10 have shared content related to their illness in private or closed groups, while 7 of 10 have shared content in open or public profiles. When asked why they shared content, patients identified the therapeutic effect of sharing/writing (90 respondents), helping other patients and future fellow sufferers (90 respondents), and one-to-many practical information (88 respondents) as the most important reasons. It also appears that respondents are relatively loyal to the health care system, as only 5% of them have shared frustration or anger related to

the system (e.g., waiting time or bad communication). It is also striking that the respondents and informants seem to use social media differently—some share extensively and openly, some share extensively but in more private and controlled environments (such as closed Facebook groups), while others read/follow other patients without sharing (much). The group that posted public content about illness on their social media profile was compared with those that did not post this kind of content. A Mann–Whitney test found that the ones posting public content about illness used social media significantly more after their diagnosis compared with the other group ($M = .70$, $n = 145$, $U = 5,370$, $p = .0050$). This indicates a connection between the will to share public content about illness and an increased level of social media use after diagnosis—a finding that could suggest that use after a cancer diagnosis is affected by general social media user types as some users value privacy higher than others.

In the parts of the study in which we probed the attraction of social media, respondents often mentioned affective and temporal processes in the survey's open text answers and during interviews. Social media platforms seem to be important for patients as both desired and undesired triggers of affect and temporal experiences and as ecologies where certain affective processes seem more accepted than others. In what follows, we will describe some of the dynamics in this production and circulation of affect and time and describe them as different aspects of the patients' experience of social media as "vital media" during existential crisis.

Vitalizing the Self Through Social Media

One aspect of media vitality expressed in the material is linked to patients trying to support their affective wellbeing or liveliness. Following Anderson, patients thus clearly navigate social media in ways that target themselves affectively in desired ways. This can be done, for example, by seeking out content that will put the patient in a certain mood. A patient explains why she reads a particular public Danish cancer blogger (Fiesenberg):

I follow her because I think she has an amazing approach to life. One can do nothing but smile and I almost shed tears of joy due to her positivity even though she is dying. I find that amazing and very inspiring. For me that was a way of seeking inspiration and to be reminded of how lucky I have been. (Female, 25)

However, the type of content patients seek or avoid seems to be connected with subjective coping mechanisms. A different patient thus explains why she avoids the very same blogger:

If I looked at one of those profiles I would think: "No, no, no, no, fuck, fuck . . . Now everything will also go wrong for me and spread and oh no." For a long period I knew about Fie's profile, but I didn't follow it. I looked at it in small doses, but I didn't feel like being constantly confronted with her having no hair and what if that would also happen to me? (Karoline, female, 22)

A male patient also supports this notion of trying to evade particular types of content to avoid attuning himself in negative ways: “I don’t want to actively seek out these things myself, as I am simply afraid of what I will read and the kind of thoughts I will get and this kind of thing” (Theis, male, 25).

Another type of self-attunement occurs when the patients actively share content to create particular affective processes through anticipated and positive feedback loops (Papacharissi, 2015). A female patient explains that the expectation of positive feedback has been an underlying motivation to share:

I really think that I, unconsciously, have thought that I will post something positive, because then I will receive positive feedback, right? [. . .] If you have had a bad day and then post a nice memory or something, right? My mother always sends me these really nice Messenger messages if I post something. Like: “So nice to see how happy you are today, Sweetie.” Suddenly yes, now I feel better (laughs). (Emma, female, 24)

This quotation highlights how social media posting is not only used to express but also to modulate and create affects. Another informant, however, explains that this awareness of the mechanism between sharing and receiving feedback can also motivate shame if communication potentially comes across as norm violations or as strategic for an external gaze (Probyn, 2005):

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. And it is especially the comments, I think, that I get a nice feeling from. (Amanda, female, 27)

According to her, sharing content about cancer:

[. . .] automatically creates a lot of likes, and in the beginning I felt a little ashamed as 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 creates a lot of likes on Instagram. (Amanda, female, 27)

This feeling of shame expresses a sensitivity toward implicit norms of various social media platforms due to which highly personal or emotional posts might be perceived as a norm violation, as inappropriate (Bazarova, 2012; McLaughlin & Vitak, 2012), too intimate or “too much” information by outside observers (Sørensen, 2012).

Another form of self-attunement is described by two male patients. One male patient explained that he preferred using social media to tell people he knew about his diagnosis. Here, self-attunement relies less on what content “does to you” and more on how social media allows you to avoid offline contact and response in a precarious situation. He describes his motivation for using social media to share the diagnosis in the following way:

Thus I don’t have to see, I don’t know if you can call it that, their collapse. Their experience of shock. They will have that experience in front of their screens at home instead of me having to witness it. That moment when people are really shocked in front of me can have a really negative effect on me. So, it helped to keep it at a distance. (Jesper, male, 28)

Jesper’s quotation reflects on experienced advantages of using social media to cope with health concerns. The asynchronicity of online interactions for instance make them more controllable and less socially stressful compared with the immediate feedback inherent in face-to-face interactions (Wright et al., 2011). Another male patient described how he simply avoided sharing information about his cancer and only posted one image after his treatment was successfully finished. He used this strategy of “minimal communication” to avoid being confronted with an overwhelming response from his network. Here, non-communication and “strategic disconnection” (Light & Cassidy, 2014) with social media becomes a way of coping affectively with the disease by trying to control the level of information one receives from the surrounding world:

If I shared it publically on my Facebook profile where I have 1000 friends, over 1000 friends, right, then I would risk receiving 25 Messenger messages every day that I needed to respond to although I barely felt strong enough to stand up. So for me it was the feeling that I wanted to share one correct picture with everyone. (male, 24)

Focusing on how the patients articulate the affective dimensions of their social media practices allows us to explore how social media platforms are not only channels of semiotic communication but are also environments that touch, transform, and shape sensuous and embodied experiences. It also allows us to recognize how important this dimension is for understanding young cancer patients’ use of these platforms as existential media that can process and maybe even counterbalance a sense of crisis.

A different route into understanding the importance of social media during illness is through the patients’ description of temporal experiences of illness and social media. In the empirical material we collected, social media was often described as a practical tool to “save time” through one-to-many communication about the ad hoc activities of living with cancer (Wajcman, 2015):

If I receive bad news now, then I can’t write that privately to 100 people. Then it is much easier to post it on Instagram, where everyone can read it at once, and then I can write to my relatives more in depth. This is also why I have chosen to use Instagram to share, as it would probably feel like too much to write to that many people every time you have had bad news. (Cecilie, female, 18)

This use of social media to make things easier and not “too much” is supplemented by another temporal aspect,

which is touched upon when patients describe how they use media to build routines and re-establish an everyday structure after the diagnosis that often fundamentally disrupts the rhythms of everyday life (Bury, 1982; Lefebvre, 1992; Sandvik & Christensen, 2013; Stage, 2014). This use of media to reclaim the rhythms of the everyday is expressed by two female patients:

I have taken pictures when I have been sitting for example in front of a room waiting to get a MRI. I have taken a picture of the door and checked in on “Riget” [the hospital] in a story. Or just taken a picture of the entrance or in the hallways or wherever you walk around. I think that has become a kind of a habit for me. (Karoline, female, 22)

So I established an everyday life, and I think that is just really important for sick people and people in crisis. To restore an everyday life on the basis of what you have now rather than dwelling on where you were before. And this you can also post online. Try to find an everyday life for yourself, you need to find your everyday life. And you can use social media in this way as well. (Female, 26)

After completing treatment, many patients still attend regular check-ups (a practice which, for many, will continue for several years). Several of our interview informants said they post updates about the check-up, or perhaps just a photo of the hospital, when they meet with the doctors. This contextual and ritualized use of social media in life after cancer treatment seems to signal a new emerging life routine that tames the unpredictability of existential limit situations.

Another prominent temporal observation in the empirical material is the patients’ use of social media to “kill time,” to make waiting time feel shorter and more bearable. As Emma remarks,

So specifically, I think I have liked a lot of Instagram photos while sitting or lying down waiting for some kind of doctor or scan or blood test or similar. I think I used both Instagram and Facebook a little less before my diagnosis. But it is also because I used it mainly to kill time, right? Or if I had to turn my brain off, right? So if you are a little nervous before a scan about the answer you will receive, or if you sit and find it a little annoying that the blood test is taking such a long time or that the doctor is once again delayed or, whatever, some situation in the hospital where I am in a waiting position, then I usually use Instagram or Facebook to just sit and . . . kill time. (Emma, female, 24)

Here, social media is described as a tool that can create immersion and thus eradicate the feeling of being “on hold,” which is so prominent during illness and treatment (Baraitser, 2017). Another patient explains how she significantly increased her use of social media during a period of illness and treatment because of boredom and the need for distraction:

I really turned it up. You could almost say I lived through the phone. It wasn’t that I shared a lot. I was trying to find someone in the same situation as me. And at the same time, I just needed to kill time. (Female, 24)

This patient thus also suggests an entanglement between the human and technology that, according to Kemper and Zylinska, characterizes mediation as “a vital process, a way of being and becoming in the technological world” (Kemper & Zylinska, 2012, p. 153) and which is at the same time both social and biological. In many ways, the patients in our study perform highly entangled cultural, technical, and psychological processes including attunement of the self, their peers, the illness, the treatments, technology, and the social media platforms that also often appear as unpredictable and, in this sense, as “vital.”

Vital Social Media Ecologies

The process of navigating social media content to affect the self in particular ways was not the only vital media logic described in the empirical material. Social media platforms are not only “affective tools” of self-triggering but were also described by informants as vital or lively ecologies that produce unpredictable, affective encounters, via posts and images, that can suddenly touch and hit you and thus strengthen a sense of existential crisis and vulnerability. They were also described as platforms on which it is impossible to predict how others will respond to something you share.

Although half of all the respondents in the survey claimed that reading other patients’ content made them feel less alone, several patients also stressed how news from profiles and groups could unintentionally attune them anywhere and at any time (e.g., through notifications); for example, by communicating shocking messages of illness and death among peers, “It can be really tough, maybe someone from the group has just died, or someone has experienced a really severe relapse” (Female, 28).

Another source of unpredictable encounters is reactions from readers of the shared content. Often responses are sources of happiness (e.g., support from peers or relatives), but these can also have unpredictable and negative effects. Half of the 178 respondents who had shared content on cancer claimed that levels of comments and likes directly affected their happiness, and one out of four felt lonely and overlooked if people did not respond to something they shared. However, occasionally, responses to shared content can themselves trigger unwanted irritation and anger—here described by an 18-year-old female patient with a rare and serious form of cancer:

[. . .] 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 that have cancer, then it is really hard to understand what it means and then what they write becomes

really impersonal. They don't understand you. [. . .] A lot of people write to me that I should not give up, that I should try cannabis and stuff like that. They don't know what I have tried. I have done all sorts of things. Many also write that I should become a member of this Christian society. [. . .] 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. (Cecilie, female, 18)

In this quotation, Cecilie articulates the experience of extreme vulnerability that characterizes the position of a seriously ill patient on social media. Her young age might also trigger her followers' need to contribute unsolicited advice, overall, makes her feel less lonely but, unfortunately, also sometimes makes her feel that people do not understand. Cecilie's experiences are consistent with research suggesting that not all messages intended to provide support live up to that intention (see also Bolger et al., 2000; Priem & Solomon, 2015). This underscores the importance of not only the therapeutic effect of expressing oneself on social media but also of the potentially damaging health outcomes associated with receiving responses (Helgeson & Cohen, 1996; Rook & Underwood, 2000). Furthermore, it stresses that social media platforms as existential media are ambivalent in nature: sometimes relational life-lines, and sometimes generators of vulnerability, frustration, and harm.

This liveliness of social media also has a temporal significance, as the unpredictable influx of communication can make the patients feel de-synchronized or left behind in temporal sphere of slowness, as they are constantly reminded that the rhythms of ordinary and progressive life continues around (and without) them and of "how the world really just moves on" (Female, 24). Jesper, a male patient, unfolds this point further:

And then it happened that I was lying at home and watched 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. It felt that life was completely on hold for me, although it moved on for everyone else. (Jesper, male, 28)

For Jesper, the vitality of social media in terms of its uncontrollability leaves him with a sad reminder of his own lack of bodily vitality and uncertain future by reinforcing a feeling of being stranded in an existential limit situation disconnected from his peers.

Vitality Norms on Social Media

Social media platforms were also described as not only *vitalizing tools* or *vital ecologies of affective encounters* but also as cultural spaces that afford narratives and posts characterized by *vital positivity*. In the empirical material, this "positivity bias" (Waterloo et al., 2018) was sometimes framed as a norm, as something we need more of, and was sometimes disapproved of by patients with a more critical approach to social media.

There was a clear bias toward positivity in the survey. Out of the 178 respondents that had shared images related to their illness, 67% had shared images that communicate positivity and only 28% had shared sad or negative images. In the interviews, the informants also underlined that they often prefer to tell positive stories of illness. This sentiment is expressed here by a male patient:

Yes, so I want to say Instagram, especially, it was just this positivity, and especially in the beginning, now we had a terrifically good summer, and one of the first things I shared is that now I have bought a hat and some sunglasses, but I don't really like all that sunlight when I get chemo. In that way I post a little thing, but with an angle that shows that now I have bought the hat and sunglasses, because it is not a particularly good match with sun and chemotherapy, but that I am now prepared for it. In that way I try to be somewhat positive. And it has been my take on it all the way through on Instagram. And actually [the hashtags] "stay strong" and "fuck cancer" have been part of my image all the way through. (Male, 29)

Although respondents seek and share positive stories, some also describe the importance of acknowledging the existential crisis related to cancer more directly:

I think it is great with most positive stories, but I also think there are shortcomings and that we sometimes lack the negative stories. Not stories about people who die, because I think it is important to show that people do not necessarily die of cancer, but that you get sad when you have had or have cancer. I also think it is important to say that. (Amanda, female, 28)

Another female patient very explicitly criticizes the tendency to add a positive or 'feel good' aura to cancer communication on social media, since this means that many perspectives that are never expressed because of the desire for a positive twist:

It is that way of talking about it where you can say something serious or slightly tabooed, but then you wrap it up with a few lines about the sun shining, or "I'm positive today," it will be OK, wuuh!, a couple of emojis. And I find that this excludes those people who are not . . . That is, I am sure there are many people who do not feel like that and would not write like that about themselves and their illness, but this is never posted. (Rikke, female, 24)

This prioritization of positivity can also be understood as embedded in larger cultural discourses in which restitution or quest narratives are often more publicly acknowledged than disturbing or negative narratives of existential chaos and despair (Ahmed, 2010; Frank, 1995; N. Rose, 2006).

Conclusion

We have argued that social media is used and experienced as vital media on three different levels by the young cancer patients involved in the study. In affective terms, first, social media platforms are used as tools that produce affect as “targets” enacted by patients sharing, seeking out, or avoiding social media content to attune themselves in desired and vitalizing ways or to save, kill, and restore time during existential crisis; second, they are perceived as unpredictable or vital spaces of affective encounters due to the multiple and hypercomplex ways that social media communication affects the patient’s mood, bodily state, and temporal experience through, for example, notifications, news, and responses; and third, they are described as characterized by a collective “affective condition” that affords particular types of vital and positive communication, supporting a temporal journey through and beyond “the kingdom of illness” (Sontag, 1991).

Based on the empirical material, we can also conclude that social media becomes more important for young people in Denmark when they receive a cancer diagnosis. Why is this? One explanation is that social media—in terms of affect and time—is engaged with by young cancer patients to find or establish what could be called “affective temporalities of care” during limit situations characterized by time’s suspension due to serious illness. In suggesting this, we draw on Lisa Baraitser’s work and understand the social media use of young cancer patients as deeply ingrained in navigating life characterized by waiting, delaying, and feeling stuck and in finding peers who share or know the experience of living a life on hold. This type of temporal and affective navigation can, according to Baraitser, be approached as mode of “care.” Care can be defined as human attempts “to deal in an ongoing and durational way with affective states that may include the deep social ambivalence that seeps into the ways we maintain the lives of ourselves and others” (Baraitser, 2017, p. 179). In this way, social media communication is not only a question of restoring threatened identities after the disruption of illness but also of *creating immediate, embodied, and sensorial environments with particular vitalizing, soothing, or caring qualities during ambivalent everyday zones of suspended time, stalled progression, and existential crisis.*

This understanding stresses the ways that patients continuously navigate social media as existential media and with the goal of creating a relationship between affects, temporalities, technologies, and illness that is as livable as possible. Illness clearly enters the life of young patient as a rhythmic shock (or what Lefebvre calls “arrhythmia”), and social media then seems to be used, with more or less success, to

restore some sort of temporal experience and balance the rhythms of life with the conflicting rhythms of cancer (what Lefebvre calls a state of “eurhythmia”; Heilferty, 2018; Lefebvre, 1992). Social media platforms are, however, also described as unpredictable ecologies in which affects and temporalities are triggered and circulated in ways that are difficult to control or as networked cultural spaces saturated with vitality or positivity norms. This highlights the fact that social media platforms are also ambivalent existential spaces in which the affective and temporal care involved in finding peers or experiencing desired content are dynamic processes of mediation that are easily disturbed or even suspended by other dimensions of media vitality.

Fruitful trajectories for future research raised by this article would be to address more in-depth the gender and privacy aspects of how patients with serious illnesses navigate across social media platforms to manage their affective states, but also how comments and other response practices influence the affective life and wellbeing of patients that choose to share illness experiences and existential crisis publicly on social media.

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.

Declaration of Conflicting Interests

The author(s) declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

Funding

The author(s) disclosed receipt of the following financial support for the research, authorship, and/or publication of this article: This article is made possible by a grant from The Danish Cancer Society (KBPF; Grant No. R195-A12017).

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