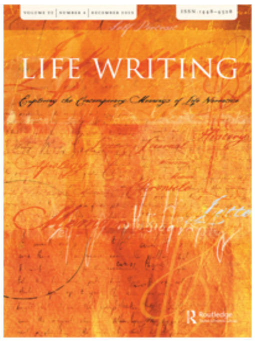

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Glamorous Healing and ‘Rebellious Hope’: Tracing Grief in Transmedial Cancer Life Writing

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ABSTRACT
This article investigates transmedial autobiographical writing practices by women ill with metastatic cancer. Their multi-platformed and mediated life writing normalises the writing about and commercialising of grief and dying. I draw examples from two popular cancer life writers: Canadian Nalie Agustin and British Dame Deborah James, who inscribed their lives and selves on digital platforms until death. I look for their performances and omissions of what I have named *the grief of the dying*; a particular form of grieving that impacts those living with incurable illness and a heightened sense of death’s nearness. Examining the limits and possibilities that transmedial life writing affords, I trace the transmutations of hope and healing in the autobiographical construction of metastatic cancer. Inscriptions of selves/lives take place in a transmedial network and are informed by the cultural landscapes of intersecting differences. I propose that a highly public life writing practice addressing illness and dying re-inscribes norms of acceptable ill selves and lives, while at the same time exposing illness cultures to critical examination. For the dying life writers, what I describe may ultimately be a hindrance – an ambivalent space when it comes to grieving.

KEYWORDS
Grief; dying; metastatic cancer; life writing; digital culture; transmediality

Introduction

In the past decades, the emergence of digital life writing from blogs to platformed social media and the so-called memoir boom (Rak 2013) has replaced a silence surrounding living with illness and the process of dying. Now there exists a wealth of autobiographical portrayals of everyday life with cancer and other chronic illnesses as well as depictions of caring for those dying and of bereavement (Joutseno 2021a; Joutseno 2024; Jurecic 2012; Stage 2017; Sulik 2010).[1] As life writing these accounts elucidate social and cultural ways of dealing with adversity or the insides of medical care, but they also portray meaning-making from experience, the transformation of identities and the re-inscription of the narrative of the self. In the case of terminal illness, life writing exists in the vicinity of death. It attaches itself to difficult affects such as grief. Examination of these attachments is imperative if we want to better understand how it is to exist on the threshold of life and death.

The goal of this article is to explore how grief is (or isn’t) expressed and made legible within the multi-platformed, transmedial (Freeman and Gambarato 2018) life writing practices of those dying of metastatic cancer. I analyse the life writing of Canadian Nalie Agustin and British Dame Deborah James who published on digital platforms and media outlets and wrote memoirs while living with metastatic cancer in their early adulthood (James, ‘@bowelbabe’ 2024; Agustin, ‘Nalie’ 2025; Agustin, *The Diary of Nalie* 2021; Agustin, ‘@nalieagustin’ 2024). In these life writing environments identities, selves and lives are produced in relation to cultural norms and narratives (Meretoja 2018, 11–14) as well as intersecting differences (Collins and Bilge 2016). Success is measured in growing audience participation and lucrative deals with companies and cancer advocacy groups. What terminal cancer brings are ruptures in portrayal. Agustin and James must become experts in negotiating transmutation and in attaching different meanings to *healing* and *hope* as their illnesses progress.

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I consider this multi-platformed writing as *a life writing practice* in the terms that Tamarin Norwood presented for this special issue, separating the practice, process and product. Norwood described writing practice as the 'murky knowledge' that is difficult to name. I understand the praxis to be a process of portrayals and depictions of the transmutations of self and life in relation to terminal cancer. I have identified the underlying embodied and instigating knowledges required in this case as (a) experiential knowledge of cancer, (b) interest and practice in autobiographical modes and (c) relationship with forms of mediated digital culture (intentions, desires, knowledge). These define 'the murky knowledges' that motor the life writing practice of those ill and dying.

I am interested in the material entanglements iterated in the autobiographical expression of those who are dying and their platforms, audiences, publishing means and praxis. Focusing on grief, I examine what becomes (im)possible in layered modes of 'self-life- inscription', as Anna Poletti calls such forms of telling lives and selves in *Storie of the Self: Life Writing after the Book* (2020). I ask are the underlying knowledges and material entanglements supportive of addressing grief. Or does the experience of cancer contain something so difficult, abject or endangering that it is rendered illegible in the process and product of ultra visible transmedial life writing?

When it comes to the thematic of dying and being born in this special issue, it is necessary to emphasize the materiality of not only lives, but selves and technologies of life writing. This means that writing, literature, media and digitality are all material phenomena. Not only because of their descriptive and prescriptive relationality to human and animal living, but because of the materialities that are produced and produce them. This point comes to life writing theory from New Materialist and Posthumanist directions of multidisciplinary feminist and queer theory (Barad 2008; 2014; Haraway 2019; 2016; Hayles 2017). In addition to materiality, I want to consider liminal spaces in which binaries meld into each other. The threshold of material/virtual is ghostly or haunting in a similar way that definitions of life and death can escape a clear binary (Joutseno 2021a, 2021b; 2022; MacCormack 2025). Instead of considering them as distinct existences with definite borders, I approach life/death and material/virtual as continuums where the marking of the exact nature of existing can sometimes be troubling. I propose that grief experiences benefit from being approached as a spectrum as well. It is with this viewpoint and interest that I will present the grief of the dying as a concept and examine its relation to the performance of lives and selves by the cancer influencers. My analysis is divided into five sections according to themes:

Transmedial Self-life-inscription; Dancing Through Funny Cancer; Grief of the Dying; Well/Illness in Capitalism; Glamorous Healing, and 'Rebellious Hope'.

In addition to being a researcher and a songwriter, I live with cancer in the central nervous system. I was first diagnosed with breast cancer in 2014 at the age of 32. In 2017, I received a metastatic cancer diagnosis. I continue my life with ongoing treatments having encountered multiple moments when it has seemed likely that all options have been exhausted. Because of my experience and working through it as an artist, I have had time to follow the changes in how life with cancer is portrayed culturally, socially and in the arts. While this article is not based on autoethnographic analysis, I will apply my experiential knowledge where it may clarify my argument.[2]

Healing, hope and the transmutations of grief

Transmedial self-life-inscription

The contemporary cultural requirement to participate in constructing a self and a life via digital platforms applies to the healthy and ill alike. Since 2010, platformed life writing has transformed to multi-channel creation where lives are constructed in fragments (Graham 2019; Hearn and Banet-Weiser 2020; McNeill and Zuern 2019; Poletti 2011). Both Dame Deborah James and Nalie Agustin created their illness narratives on multiple platforms consecutively and at the same time, travelling from one to another. Blogging led to broadcasting and interviews in the case of James, who then continued her story on social media while writing and publishing her memoirs at the same time. Agustin moved from blogging to vlogging and then to platforms and finally published a memoir.[3] While some of these were being written/spoken/filmed and published simultaneously, others signified a location shift. Measured via reader-audience numbers and engagement, the women were successful, reaching audiences of millions.

In this article, I call the life writing or the multimodal autobiographical acts (Smith and Watson 2024) of the authors *self-life-inscription*, following Anna Poletti (Poletti 2020). The term highlights the relationality between digital platform technologies and the praxis of life writing – or of media and the autobiographical. With inscription Poletti takes up the -graph of auto/bio/graphy expanding its reference from textuality to processes of writing, portraying and recording (13). This is an invitation to approach autobiography as 'the inscription of self and life', drawing attention to the textual exploration of *subjectivity* and *life* as embedded in materiality and mediation and producing the social setting for 'acts of autobiography' (14).[4]

I take it as a premise that the medium of autobiographical expression and the phenomenon of transmediality contribute to the performances of selves and lives or connections that become possible (Paasonen 2013, 2020; Poletti 2020). Experiences and selves are not just transferred via narrative to their mediated forms but are born via mediation. This is related to affects: digital platforms are an affect economy where *sticky affects* induce viewing and the circulation of content, which means that it is lucrative to depict selves and lives that attach to strong emotions (Lehto and Paasonen 2021; Paasonen 2020; Stage 2017). So, it is not enough to tell the tales of a well-constructed self, but to portray the self with its life in a manner that engages the viewer-lurker – an intimacy between strangers – which makes users return, comment and create bonds.

Philippine-Canadian Nalie Agustin was 24 when she was diagnosed with breast cancer and began her blog Nalie (nalie.ca) in 2013. Agustin was diagnosed with metastatic breast cancer in 2017. By 2019 her blog activity had been replaced by Youtube-vlogs, the 'Nalie show' where Agustin interviewed others living with cancer or specialists who gave advice. In addition, Agustin regularly updated her social media accounts. She reached an audience of millions and can be described as a social media influencer.[5] Another layer of life writing about Agustin was produced by media in Canada and in the USA. They described her advocacy and her life contributing to her fame. After Agustin's death in May 2022, relatives and friends started The Nalie Foundation, which supports young women with breast cancer.[6]

British Dame Deborah James was diagnosed with metastatic bowel cancer at 35 in 2016. James became known as Bowelbabe. She shared her life with cancer on her blog, then Instagram (as @bowelbabe) and other social media accounts. Together with Rachel Bland and Lauren Mahon, James co-hosted the award-winning BBC-podcast series 'You, Me and the Big C' (Bland et al. 2023) which covered nearly the complete time of five years that James lived with bowel cancer. While becoming a loved broadcaster, James embraced (social) media for sharing information about bowel cancer, raising awareness, collecting funds, and celebrating life. James died in June 2022. In 2023 the BBC published a documentary film 'Bowelbabe in Her Own Words' based on her social media content as well as family videos.

James published two memoirs (James 2022; 2018), newspaper columns and appeared on TV in the UK. Shortly before her death she set up the Bowel Babe Fund for Cancer Research UK (https://www.bowelbabe.org).

Both Agustin and James were by all measures successful and inventive in their life writing practice. They were, as Dyer and Abidin have described platform users '[…] already socially embedded agents in carefully curated and designed socio-technical space' (Dyer and Abidin 2023, 15). The authors were agential, capable and skilled at navigating the platformed systems, and at constructing (narrative) identities so that they function legibly, draw attention and construct (affects, reactions, comments, action both on the platforms and in the material social cultural reality of the ill and further out) selves that do not fall outside the norm.

In an economy based on affect circulation (Sather-Wagstaff et al. 2017), the intensities attached to illness and dying become the draw – the human-interest perspective – that is tethered to selling products, collecting money for research and raising awareness. This is an intensification of the Pink Ribbon -logic, which was introduced into breast cancer awareness campaigns in the early 1990s, and has justly been criticised for disregarding the lived experience of women with cancer (Sulik 2010, 2014). Due to the entanglement of self-life-inscription and the marketplace, I think it possible that the complexity of human experience as a dying being is not sufficiently addressable here. By sufficient I mean that the mediums may interfere with ability to address grief.

Thus we can situate the self-life-inscription practices of James and Agustin within a wider landscape of transmedial life writing, theory, and their own previous work. As we will see, within this landscape several strategies can be employed to negotiate the underlying knowledge of cancer and grief, of which the first I examine is humour.

Dancing through funny cancer

Considered as narrative illness self-life-inscription is a negotiation with the cultural frameworks associated with illness (Jurecic 2012; Meretoja 2018). Therefore, depictions of hospitals, treatments, and hair loss fit the recognisable framework of cancer. But shared frameworks and master narratives have their limits. Some experiences, affects and iterations fall outside interpretation. Humour is one style of suturing such a falling: of marking a gap.

Humour is useful in negotiating the difficult, often unreal -seeming situation of being in the middle of life while factually dying (Melton 2016). Existence on this precipice calls for contradictory manners of survival and an agility to move between states of acknowledging suffering and avoiding rumination in favour of being present in the moment at hand.

It is possible that to address the humorous side of cancer is a choice made when the other option would be addressing grief.

In their Instagram and YouTube publications, Agustin and James constructed a sense of drama tinged with humour. Even hospital updates could be coated with jokes or a quickly discovered silver lining. Usually, hospital updates offered an immediate emotional reaction to medical information, new treatment plans, or urgent changes.

Deborah James called her multimodal advocacy ‘talking about poo’. It was an endless source of jokes how ‘poo-talk’ got James into visible places and granted high honours (James 2022, 210), such as an honorary doctorate and Dame-hood just prior to dying. In her sprite and perky appearance – often with a drink in hand – James appeared an old-fashioned comedienne: sometimes wearing a children’s poo costume, more often glamorously dressed in draping evening gowns. Her self-presentation underlined a knowingness around her body. As long as it was possible, she aimed at cis-feminine sexiness and an attitude of purposeful avoidance and optimism in the face of embodied devastation.[7]

Nalie Agustin published videos filmed on her way to and from the hospital, when experiencing initial reactions to the unfolding events and the newest medical information.[8] Compared to James’ manner, Agustin was more serious and visibly upset in her hospital posts, although if the results were positive, she appeared overjoyed with relief. In those instances, Agustin was funny too.

In James’ late-in-life hospital updates her humorous self-presentation juxtaposed with visual and textual descriptions of emergency surgery, long stays at hospital, cancer advancing, and the fear of death.

The presence of humour serves at least two purposes: it makes content easier to access, less scary and thus affectively sticky (the reader will return and want to know more of the platform life writer’s unfolding ‘story’) (Demjen 2016), and it makes the weight of mortality more palatable. It keeps the deepest troubling feelings and thoughts out of the frame.

Deborah James regularly updated Instagram from the treatment chair (or near it) while receiving chemo. In her videos she danced alone or with a nurse, realising what she termed ‘dancing through it’ – making the best out of a difficult situation. In her memoir James describes how this ‘singing in the rain’ attitude was modelled to her by a friend who died of cystic fibrosis and who wanted to enjoy the sensation of rain on his skin with Deborah on their last meeting.

Singing in the rain and dancing through trouble became a coping strategy James constructed in her posts and memoir (James 2022, 189–190). In grief studies it is almost a cliché that illness experience and dying produce an urgency of experiencing each moment of life, prioritising what really matters. Terms such as meaning making, associated with the benefit of illness narratives (Nielsen 2019) or ‘learning how to live’ and ‘relearning the world’ offered by Thomas Attig, point to the process associated with forging a life while aware of dying that can hold both the losses and the joys of that experience (Attig 2015: 9).

While I understand meaning construction in ‘making the most of it’ to be an empathetic phenomenon, it appears in the transmedial self-life-inscriptions to be gaining, yet again, a limiting status. It turns into an imperative to squeeze every exceptional second and fecund experience out of life – to optimise the limited time and thus to fit the life constructed in this depiction into the preferred form of restitution or quest narrative.[9] This cultural imperative then has an impact on the construction of the self-life-inscriptions. What gets pushed to the margins in ‘dancing through it’ is everything that stops the flow, anything that would tell a different story.

Grief may appear to be such a stoppage, something undanceable from the perspective of cultural norms. And as such, grief is difficult to express and to interpret. There is an ambivalence at the heart of it. Central to ambivalence is the concept of the grief of the dying.

Grief of the dying

To make the case for the experience of grief of the dying, I now situate my concept in the landscape of grief studies. How does grief of the dying relate to disenfranchised grief or bereavement?

In my published and yet to be published grief research I have discovered that grief studies continue to focus on bereavement at the expense of other forms of grief (Joutseno 2024; Joutseno TPB 2026). Many griefs are therefore unnamed and underrepresented in research and culture at large. The term disenfranchised grief describes the lack of social and cultural recognition (Doka 2020; McCoyd Judith and Walter 2016). Experiences of violence, isolation, racism, and social disenfranchisement can be cause for such hidden grief. McCoyd and Walter summarise Doka's original concept to refer to personal experience of grief in a way that is unmatched in the surrounding culture's definition for grief (21–22). Such experience remains on the fringes. Disenfranchised grief perpetuates a sense of not belonging or not being accepted. Support won't usually be offered, and sufferers rarely seek it (Bordere 2017).

The grief of the dying is a disenfranchised grief and deserves to be studied on its own, to better recognise it and its impact on societies, relationships, art and the knowledges we produce around grief.

I propose that James' and Agustin's self-life-inscriptions function as examples of how the grief of the dying comes to be (not) expressed, enmeshes with the everyday, and does not always take the form of sadness and tears.

The grief of the dying is experienced by people medically diagnosed with incurable, terminal illness, who live in an aware state of their approaching death. In palliative and hospice settings, the grief of the dying has remained obfuscated by the focus on the immediate needs of a person in active dying and the support offered to the relatives as bereavement counselling.[10] This is understandable, because until recently there was not much time between metastatic cancer diagnosis and death. With access to the latest targeted cancer treatments in the Northern hemisphere, there now are months, sometimes years between incurable diagnosis and death. Thanks to the development in diagnostics and medicine, more lifetime is spent living with illness and more people exist in states in-between so-called healthy life and death from a chronic or terminal illness.

In my research, I have found that where the grief of the dying is mostly depicted is in art, creative expression (Joutseno TBP 2026) and life writing (Joutseno 2021a, 2021b; 2024). In such forms grief is often not directly referred to, as is the case in the examples of James and Agustin I provide. Instead, grief must be gleaned from context – even from what is not expressed. This ambiguity has been recognised with non-finite or chronic grief, which is defined by living losses and the ongoing-ness of grief (McCoyd Judith and Walter 2016, 22–23). Darcy L Harris uses the term *non-death loss* to describe the multiplicity of losses during a lifetime (Harris 2020). These losses pile up when life with incurable illness is prolonged. They include multiple readjustments to the sense of time (past, present, future) the loss of physical function, body parts, familiar routines and social changes (Mitchell 2020; Nesby 2019). In terms of trauma theory, compounding losses such as these can lead to everyday trauma, which in turn is cause for further risks to wellbeing (Bordere 2017). What makes this litany of complications insufficient in describing the grief of the dying, is that its carriers often are the most insistent on remaining partial to everyday routines, parties, work life and everything in between. So, defining this grief is not possible by looking only for the lack of joy and the piled-up losses.

It is widely accepted that bereavement has a temporal structure, and grief disorients/reorients the experiencer's sense of time (Fuchs 2018; Higgins 2024; Ratcliffe 2023). It is also true that anticipation of loss can be sufficient cause for grief. Still, it is false to suggest that the dying merely anticipate a loss in future time. I propose that the grief of the dying carries several time-relations: it is related to the living losses and everyday trauma which accompany dying from an illness such as cancer; it is the grieving of the past selves, abilities, relations and identities which are no longer valid; and the mourning of the future that is lost on the part of the life writing self. Therefore, it is crucial for the full agency of the dying that their grief is not labelled as anticipatory grief (Doka and Davidson 2016), but is examined as a transformation process taking place as illness and as dying; impacting the way pasts, futures, and the present are interpreted, the way meaning is given to life and all its aspects.

The grief of the dying is a companion to life with illness and not something to be expunged. It is an ongoing re-negotiation of the self, its relations to and constitution with others. This is why life writing in all its forms serves well as its exploration medium.

With this definition, I return to the appearance of James' and Agustin's grief in relation to their inscriptions of selves and lives.

Well/Illness in capitalism

I turn to the metanarratives of platformed self-life-inscription that proliferate as audiences grow, and cancer progresses. Within these metanarratives are the blurred borders between commercial interests and the suffering of individuals with cancer, and the muddling of the role of the ill life writer who acts both as an agent of commerce, a narrator of suffering and as a peer supporter. Crucially, negotiating cancer experience implies participation in the digital wellness culture, which promotes positive thinking, healthy living, exercise and has also provided opportunities for scamming by selling false hopes and quackery even to cancer patients.[11] Agustin and James were not involved in such scams nor were they selling alternative treatments.

Culturally we give different meanings to dying depending on age. The heightened attention to James' and Agustin's self-life-inscriptions may partly be explained by the timing of their illnesses and deaths: both died in their young adulthood, which denotes the years between 25 and early 40s (McCoyd Judith and Walter 2016, 173). This is *off time* in lifespan terms, which adds to the difficulty of facing death, and to the interest coming from others.

The timing itself is a source of grief for the young adults, according to McCoyd and Walter, as is the impact terminal illness has on immediate relationships (interruption to independent living i.e. return to parent's care, possible impact on parenthood and relationships), work life and work ambitions. McCoyd and Walter note that chronic illness and resulting grief at this point of life makes the ill more self-focused and at the same time, may 'catapult young adults towards what is most meaningful in life' as they realise that time is limited (2016, 180). Considering my examples, platforms appear to offer ways of making this necessary self-absorption useful: the misfortune of terminal illness becomes a product, which can be sold as suitable performances of lives and selves.

Over their relatively short time in existence, digital platforms have become sites of intensification and merging of capitalist consumer culture with individualistic identity construction (Poletti and Rak 2014). Some manners of self-creation are more lucrative than others. One description of what is going on is the circulation of affects which attach to some cues better than others and produce attention gathering and monetary gain. Here what Lauren Berlant termed 'compulsory optimism' (Berlant 2008) merges with the digital wellness culture and becomes evident in self-life-inscription around cancer (Boyer 2019; Sulik 2010). In the 'intimate publics,' the production of the experience of individual pain threatens to become just another narrative calling for 'civic-minded' compassion of the followers, rather than cause for political and structural changes (Berlant 2008, 40–41). In the case of Agustin and James, this means that their end-of-life depiction is consumed as entertainment or used for commercial gain. At the same token, this affective digital performance is contradictory: femininity as 'an aesthetic structure of affective expectation' (Berlant 2008, 4–5) is threatened by cancer which promises to disfigure before killing. Still, these women's digital life writing aspired to conform to the platformed logics and reinforced the gendered ways of conveying survival/living with cancer (Sulik 2010, 87–88). And they became a smash hit!

The feminine intimate public is useful in describing what is born: Berlant's 'intimate spheres *feel* like an ethical space' while they regurgitate and make use of the logics of 'white universalist paternalism, sometimes dressed as maternalism.' (Berlant 2008, 6) As such the platforms appear to unite people over a shared 'women's culture' – a feminine cancer culture – and to provide continued attachment to resemblance of 'normalcy' (8). But for James and Agustin, whatever is being constructed is simultaneously being dismantled. Whatever becomes lucrative – wellness/illness in the forms of hopefulness and healing – cannot be sustained. Therefore, something else has to be for sale instead.

Both James and Agustin repeatedly ask how and where to construct their selves and lives best. In her memoir, addressing the enmeshment of capitalism and life writing James mentions her Instagram posts describing how she receives gifts from cosmetics companies and donates these items forward. Mentioning the pleasure of giving, she offers the example of discovering scarfs by a company that donates to cancer research and how she then received said scarves to be gifted (2022: 196). A defense of this as her love of 'random acts of kindness' ensues: 'These people don't expect anything from me in return – they just want to do something nice that will make someone else feel good. And when I gave out the scarves, I wasn't expecting anything back. […] my first thought was cheering up some of my fellow patients because it's rubbish being in hospital. […]' (James 2022, 197) This illustrates how the author normalises and defends the enmeshment of platformed capitalism and cancer as a harmless form of selfless giving. The defense itself belies a discomfort.

This next example from Nalie Agustin shows how the materiality of cancer treatments collides with the changing conditions of narrating online: in a YouTube-video 'Where have you been?!?! | full 2020 update' [*sic*] [12] Agustin returns from a (social) media break. She has gone through whole brain radiation for brain metastasis. Agustin addresses her followers and their worry about her silence, saying that she has been updating on Instagram, which is easier, less time-consuming and immediate.

In the first minutes of the video Agustin appears with a bald head, wearing a white vest. She is both apologetic and justifies her silence by telling of illness progression and the continued need to tell her story: 'There's a lot that needs to be said and even if it is not necessarily what I wanted to say at this point in my journey … it's still my story and I wanna be the one to tell it.' This is an assertion of agency as much as an expression of nuanced familiarity with the transmedial self-life-inscription she engages in telling about her adverse experiences.

Another sign of narrative and formative control are the video edits. Suddenly the visual cuts to another time: Agustin has a head full of short hair and is wearing a blue t-shirt. As if a celebrity who owes her followers an explanation she begins: 'Hello my beautiful YouTube family', then saying that the first part of the video is what she posted on her platforms after her break.

Agustin notes how much more work it was to write a blog in the early days, or to make vlogs compared to the ease of updating Instagram. Mostly the video addresses James' illness progression conveying its seriousness and difficulty both medically and as a lived experience. Agustin takes care to mention how she paused her podcast 'Thriver Talks' and halted 'Thriver's Guide' book writing (5:42) – she suggests that there is a deeper meaning to be gleaned hinting at numerology (reference to the date May 20 in 2020 that she was given her recent diagnosis) as part of her illness 'journey'. Agustin then frames her online break as a conflict between other people's worry and her personal trust in healing, saying: 'deep down inside the moment I found out I knew I was going to be ok' (3:52). This conveys a belief that her 'healing' is negatively affected by worried others. Projecting grief and the fear that this is part of the dying process (as opposed to healing the cancer) onto other people and away from her can be a way of generating agency and self-reliance.[13] It can be a form of protective denial. In her Instagram posts and memoir, Agustin mutes fear and anxiety with trust in a 'bigger plan'.

Suffering can become part of the self-life-inscription if emphasis is on coping and the timing of narrating is hers to make. This is evident when Agustin refers to her lack of energy and her unwillingness to share her brain radiation experience as it unfolded. It shows that in inscribing herself and life, she constructs the narrative instead of churning out experience without the art of story (often a claim made about platformed life writing). Agustin controls how her story appears, is it survival or suffering. I wonder, is it editing at her own expense? This also draws attention to the materiality of the acts of self-life-inscription.

When it comes to identity construction online, the platform dictates what is possible. Dyer and Abidin refer to Judith Butler's *Gender Trouble* (1993) in their description of how 'technology is not only something that we are thrown into, but also something that is designed in ways that often articulate expected behaviours and bodies, punishing, demeaning, mocking and threatening bodies that are coded as incorrect and deviant.' (Dyer and Abidin 2023, 8). This emphasises the preconditions of platformed life writing and exposes how vulnerable and potentially endangering it is to publish about one's life with metastatic cancer and the process of deterioration leading to death. This to me suffices as an explanation as for why difficult illness experience is narrated after the experience.

On the platforms Agustin and James had to straddle the implicit requirement to both perform youthfulness, femininity and health (Kanai 2017) while offering up their vulnerability. Their self-life-inscription often reveals the breaking points between the intensities that produce commercial gain and the intensities that produce suffering and grief (even if via witnessing this process). Counterintuitively, the disconnect which occurs, produces attachment to these performances – both for followers and authors. I come to this conclusion because as their life writing becomes visibly representative of the dying process, online following and media attention grow.

Meanwhile as death was nearing, healing and hope remained integral to the way James and Agustin constructed themselves, as I elucidate below.

Glamorous healing

It may be impossible to comprehend dying and death as an ongoing experience for more than short sentences at a time, yet as the material deterioration of the body becomes visible, online celebrity status increases for Augustin and James. Still, avoidance of directly addressing grief persists and much effort goes into fostering the promise of healing and hope.

Shortly before her death, Nalie Agustin self-published *The Diary of Nalie* (Agustin). The memoir extended the style of her life writing towards a more poetic expression. Consisting of diary-like pages, affirmations, poems, and lists that emphasise healing and positivity, Agustin addressed treatment failure and dying. The layout of the small, printed book arranges sentences in various layers and lines with lots of white space left on the pages. The book has a fragmentary feel, freed from the coaxing of social media platforms, although it continues with the same message: until the very last pages, Agustin presented a hope for continued life: 'Today I write to you from a place of continued healing […]' (Agustin 2021, 172). This bond with healing appears more nuanced than just denial of her embodied state or avoidance of grief. Agustin's *healing* is easy to connect with the use of hope as an element in the construction of the contemporary mainstream cancer culture with its victorious cancer 'survivor' figures to be admired (Boyer 2019; Nielsen 2019, 58–59). Gayle Sulik locates the beginning of this feminine and hope-centered portrayal of breast cancer to the early 1990s, when the pink ribbon campaigns to collect funds for breast cancer research began (Sulik 2014, 660; Sulik 2010). Once Agustin's survival is not a possible narrative, she continues to address hope. This hopefulness ties to something different.

Towards the end of her life, Agustin's life writing is peppered with diagnostic terms and complications. Her cancer treatments slow down, until they halt. Just before this point, on an Instagram post from October 22, 2021, there is a photograph of bald Agustin sitting in a hospital bed looking at her hands in her lap with a wide window behind her and a hospital blanket on her lower torso. Agustin describes ongoing difficulties to treat metastasis (brain, lungs, liver) effectively as 'spinning plates'. She then depicts her inner calm:

> […] this particular plate within me. Like an orbit circulating around the sun, it spins within my heart and lights up my solar plexus with power. It is my why. My reason for living. The love and prayers I receive. The conversations we had at my book signing. The way you say my words get you out of the bed in the morning. My boyfriend's kisses on my bald head. The laughter I share with my brothers. This plate can never shatter. It is my spirit. And when I get through this, it's the only plate I choose to serve with. #thediaryofnalie To be continued … (Agustin October 22, 2021 [part 51])

The spinning plates gesture to the instability and uncertainty that define her life with terminal illness. Her 'spirit plate' cannot break, she says, confirming that when she 'gets through this', it is the only one she'll use. This can be understood either as a belief that her cancer will still be healed, or it may be understood as a reference to becoming 'a spirit', transforming to another kind of existence – through dying. Agustin's late-in-life writing comes with a side of mystical, magical expression. Meanings slide, leaving more for the followers to interpret. Meanwhile visual images depict steep decline in health.

Posts from March 6th, 2022, addressing a 'new path' and February 28th, 2022, depict Agustin in a wheelchair in different locations (New York, hospital, treatment centre, café, theater, receiving doctor's check-ups and alternative medicine). Augustin's appearance is dramatically changed: her posture is slumped, legs are thin while her face is puffy, and she wears wigs or hats on her head. Agustin appears in rapid decline.

In her final autobiographical post, February 28th, 2022, Agustin details her family's trip to NYC for care and for sharing time together, enjoying dream-come true moments such as a night at a Broadway show, seeing Hamilton the musical.

These late-in-life self-life-inscriptions portray a reframing process: by March 1st, 2022, the main image of the post is of a group of five looking at the New York skyline together with Nalie in the centre in a wheelchair wearing a silver puffer jacket, taking a picture. The written update talks about her new ‘prism glasses’ that help her see while her eyesight has been impaired by tumours. Agustin presents this non-death loss of sight by focusing on the surprising timing of the glasses arriving just in time for New York:

> God gave me the gift of clearer vision (literally and figuratively) […] I was able to see Hamilton with ease […] But most importantly, I was able to see the faces of those I thought I’d never see again. My heart is full of gratitude for these #simplethings [heart emoji]. (posted on March 1st, 2022)

Here Agustin’s spirituality becomes evident as she describes gratitude and joy over seeing a musical performance with her loved ones. My inclination is to read the increasing visual impairment caused by brain metastasis as a story of loss – an expression of grief over the physical abilities. Yet, Agustin foregrounds the momentary fix of her vision.

This is not unusual. In the early 2000s, Mary DeShazer found that a method of avoidance and denial was often employed by illness life writers regarding death (DeShazer 2005). Augustin’s celebration of the prism glasses is also in line with the cancer narrative forms where adversity must be overcome (Nielsen 2019; Sulik 2010). Still, the expression of gratitude and joy at this point in life and with so many physically debilitating losses, could also be a sign of coming to terms with death’s nearness – having ‘learned to live while dying’ (Attig 2015, 8). As such, Agustin’s post does not signal denial, but a conscious framing. Significantly, to draw us back to the practices of life writing, the healing still occurring in her final posts can be the consequence of telling one’s story. Healing through life writing. This is an aspect of healing associated with illness life writing or pathography, which both critical medical humanities and earlier studies of illness narratives agree on (Nielsen 2019, 36–40). I do not believe that Agustin herself gave such meaning to her writing practice, but it is nevertheless compelling to mention this possibility.

Whatever the interpretation, the viewer of this post sees the visual evidence of fast approaching death, therefore facing the task of feeling something. This evokes grief. But here the sense of the wrongness of grief is produced as an issue of timing. While Agustin’s post portrays physical deterioration, it is simultaneously telling the viewer not to consider the outcome. Borrowing Patricia MacCormack, it is possible that the followers of the life writer see her as already dead, because illness has marked them as unable to sustain life (MacCormack 2025). MacCormack’s portrayal of human exceptionalism as an issue of ‘killability’ (Butler 2006) and deadness highlight the possibility of becoming treated as dead while alive (MacCormack 2025, 14–17). From this view, the dying self-life-inscribers offer themselves up for the rest of us to hold on to a false sense of safety – as if by investing emotionally in the death narratives of Agustin and James, the readers are less likely to die. Thus, the reader-consumers are negotiating their own aliveness as they teeter on the deadness of others to define and separate themselves from this danger zone. As witnesses to such life writing from the edge, they ‘accept’ the dying others thus keeping their own aliveness intact. This is especially difficult and pertinent with fellow cancer patients, who both identify with the self-life-inscriber and labour to not become the same.

The images of the final post on Instagram are not taken by Agustin and do not have the same style as the rest of Agustin’s self-life-inscription. This is the point where autobiography turns into biography and shifts to the voice of Agustin’s brother: he depicts his sister while also drawing attention to the alternative treatments that Agustin is trying (and some of which her brother was selling). The transition of voice is significant in considering the threshold of death. There comes a moment when self-life-inscription becomes impossible, where the dying is stripped from narrative agency. Yet, this is not the end of the life writing nor the termination of commercial wellness interest.

Following her death, Agustin’s autobiographical expression transitioned through her brother to an unspecified group voice – the family – who continue the Instagram account as the Nalie Foundation to this day. The digital platform and account, which became the last updated self-life-inscription site for Agustin, now safeguards her memory and collects funds towards supporting others.

I interpret another readerly entry point into grief in the distance that grows between the camera lens and the autobiographical subject. A transition occurs and becomes evidence for the approaching loss of life which in turn opens space for grief – of the reader/follower. In this sense it is possible to grieve the dying of the self-life-inscriber and to make divergent interpretations, to read beyond the lines and images, past hope and healing.

'Rebellious hope'

Hope is a generative concept, which in the feminine digital wellness culture and mainstream cancer discourse is linked to potential for self-redefinitions – the limitless potential for more. When hope is attached in these contexts to illness that cannot be cured, it blurs the edges and hard corners of ending medical treatment, death and other finite losses. Here, hope is employed passively, it does not denote action. Thus, it functions like optimism (Berlant 2008) and remains dissimilar from hope defined by Rebecca Solnit as an *activating force* for change (Solnit 2016).

As the health of Deborah James was rapidly collapsing, an ever-larger audience engaged with her self-life-inscriptions. Companies increased their partnerships with her, so that instead of a quieting down, dying became suffused with acts of memorialising and products for sale. At the same time, grief became something read from the images and words and soothed by selling and buying products. Nearing her life's end, 'dancing through it' was no longer possible. James spoke from her bed at the cancer hospital, and then from her parents' garden where she was living out the rest of her days. Her self-life-inscription addressed grief and loss more explicitly than Nalie Agustin's. Still, she carried along an attachment to finding 'rebellious hope'. In James' life writing a hopeful rebellion manifests as a preparation to die and as glamorous outfits. It also became the work that was aimed at a future after the death of the author.

I understand one aspect of the 'rebellious hope' James created to be the allowance of some expression of grief while remaining open to life. It is her way of holding on to the mainstream concept while it must be transformed. Mostly, James allowed grief to others but not herself. References to her own crying and sadness increased in James' self-life-inscription during the last months of her life. She addressed these emotions particularly openly on her final episodes of 'You, Me and the Big C'-podcast (Bland et al.). Her phone memos recorded at the hospital were published as three episodes of the BBC podcast 'You, Me and the Big C' as were her last discussions with her co-hosts and producer.[14] In these recordings, James' voice often cracks and is interrupted with her crying as she addresses her disappointment and the trauma of all the surgeries and treatments given in effort to save her from immediate death. James continues to refer to her body as the entity that can no longer go on even though she would like to live longer. In these episodes, grief is easy to locate. Through her tearful, sad, fearful even hopeless memos, a compassion appears both towards her body and those caring for her. Amidst the sadness, similarly to Agustin's thankfulness about the prism glasses, James offers gratitude for her sense of being held by the medical professionals and by her loved ones.

Grief featured increasingly in James' Instagram posts too. Like Agustin, James appears in a wheelchair in her final posts. On May 9th, 2022, James wrote that she had been moved to hospice care after months of grueling emergency hospitalisations and announced the news about her namesake foundation, the Bowelbabe Fund for Cancer Research UK.[15] The post's only image is an official photograph of James from a healthier time and the logo of the fund. The text below the image starts with the words 'The message I never wanted to write'. A separation is re-iterated between mental ability versus the body. James refers to her state as 'my body simply isn't playing ball'. She then describes how during the five years of living with bowel cancer, every Christmas was a potential last. She had been unlikely to see her children enter secondary school, then she has always gotten more time, until now: '[…] I never envisaged writing the one where I would actually say goodbye. I think it's been the rebellious hope in me.' Here, James pinpoints the cutting experience of living past medical predictions and then arriving at finality. She writes from the sharpest point of loss, addressing grief and the discrepancy that remains. It appears almost unfathomable to be writing while holding the acute awareness that death is about to silence her.

This is where James positions her 'rebellious hope' – which by this point she had made the slogan of products she was launching with various companies and a device in her memoir (James 2022). In the context of a life writing practice 'rebellious hope' has become an inscription-device for suturing the paradox of an animate 'life' and a dying 'self' – for filling the hollow gaps that grief creates. Rebellion transforms hope. It is no longer tethered to healing or more lifetime, but to something spaciously undefined.

Between early May and June 28th, when her death was announced on Instagram, James' visual depiction remains stylised, beautiful, smiling, glamorous and composed. Yet, photographs, just like Agustin's, portray a withering body. James' yellowing skin, extremely narrow arms exposed by flowery dresses and 'Rebellious hope' t-shirts become sings of decline. Her end-of-life medical care is visible in the images through patches of gauze and plasters on her arms. Dying and grief are not cleaned away; they are the topics of this life writing, but so is joy and beauty.

The consequent posts are extraordinary self-life-inscriptions of an unusual dying process where the commercial ties to transmedial life writing only intensifies as Prince William brings her an honorary medal (she comments in her post on May 13th, 2022: 'I'm humbled and blown away that 5 years of talking about poo can lead to Dame hood'). As James describes getting sleepier, she nevertheless continues the summing up of her activities during the cancer years and re-iterates her thankfulness and wish that 'poo talk' might help others.

James then launched her memoir *How to Live When You Could Be Dead* (May 17th), her clothing line, which collects funds for Cancer Research UK (May 19th), and a rose variety carrying her name (May 20th). These posts do not clean away grief for her deteriorating state as she keeps participating in the creation of special occasions and continuing her acts of self-life-inscription and her ties to commercial entities, for example, by throwing a slumber party for her loved ones. In the post, she describes the discrepancy between the happy beautiful memories they are creating and her day-long crying before the event. Still, she also depicts the services that the teepee company provided.

Glamour, joy and suffering from the dying process leak into each other when just two weeks before her death, in a June 12th post, James sits in her wheelchair surrounded by a garden. She is wearing an evening dress and new shoes with her husband next to her. Juxtaposing the glamour of the photograph James describes the difficulty of getting ready for even a short outing: 'But be under no illusion! I'm knackered! I've worked out it takes me longer to get ready and organised to go than the time I actually last anywhere!!' It is in such depictions that James' life writing does appear to be in rebellion – a kind of counternarrative gracefully unwilling to relent to just one interpretation. James manages to conjure up a lust for life together with and an unwillingness to die while she is dying, without completely muffling her grief.

On unbecoming

In 2021, after living with metastatic cancer for four years – seven years since I was first diagnosed with breast cancer, I wanted to understand the grief that ebbed and flowed through my everyday life. I had entered a stage where life's continuation was uncertain, so I expected to discover research literature, advice and best practices but was met by a shapeless apprehensive silence. In the ensuing years of my attempt to examine and describe the grief of the dying, I have studied the literature of grief studies and located the shadows and empty spots where this grief should be. In this search, I discovered life writing to be a mainline to the source. In memoirs, films, documentaries, novels, songs and poems to name just a few forms, lives the evidence of grief.

The platformed self-life-inscription practice then is a distinct form of such life writing. It is not art, although sometimes it becomes art.

There is a chasm between the ultra-visible, liberal-capitalist normalising of this life writing and the role afforded to grief. In the near-death self-life-inscriptions of Agustin and James visual and textual fragments construct tension between glamour and suffering. Some gestures diverge in their meaning making. It is difficult to parse out death from life. There is the disquieting unease when looking at photographs of the actively dying women: positivity slogans, hope and healing paired with the images of withering bodies, bloated faces, and hospital equipment; one woman posing with a prince in their back garden, another enjoying a night at the opera in New York City. Cancer's advancing enmeshes with exceptional experiences, lucky connections and commercial interest. There are tears in the netting of narrative, elements appear uncommitted to cohering to one story.

As death nears, hope and healing are transformed as spirituality or as rebellion and can include imminent life loss and grief. Grief induces the appreciation of beauty and the creation of a legacy; all is left for others to continue, but even so dying appears out-of-the-ordinary and difficult to address.

James and Agustin fit their self-life-inscriptions to the coaxing of platforms. This takes effort, time and knowledge. Format and stylistics become integral to producing resonance. This entails presentation that negotiates master and counter-narratives of cancer by allowing the whole to be interpreted as being about cancer (instead of just being life writing about beauty products and wellness for example), but it also requires attachment and positioning in relation to other normative digital inscriptions styles (regarding femininity, gender, race, mothering, beauty and more). These platforms facilitate commercial, liberal capitalist interests extending their reach and the possibility to turn identity and self-life-writing into lucrative business until the very edge of death. Product launches and advertising campaigns interject a profitable moment, readerly affects lead to actions of purchasing. The buying of a t-shirt becomes an extension of intimacy – an act of grieving, honouring and remembering a dying woman – while at the same time enmeshing with digital consumerism that makes use of affects and the lived experience of the influencers.

Life writing as a praxis and grief as a continued process can be described as transformations of selves and lives. Inscriptions of grief could generate renewed perspectives, new stories or connections or they might hold space for their possibility, even if no investigation of grief ever really ensues. Transmedial forms of self-life-inscription facilitate the exploration of uncertain terrains with a continued connection to others (as audiences, commentators, peers, followers, fans). This might be a supportive practice *because* it is tied to communities and commercial circulation and not despite them. This is because in its current form *life* is tied to this commercial existence and therefore transaction is part of living.

Yet there is something about grief and where its watercolour trail cannot follow. Death hovers ghostly and unimaginable and unproductive – an unbecoming – on the very edge.

Life writing produces the netting for grief, but it is a substance that moves through the holes. There, yet not there. Maybe it doesn't have to be caught either.

At the heart of this inquiry is the experiential knowledge of cancer and dying. So far, I know that the shape of this grief shifts depending on the expression and that as with many griefs, this complex affect often remains unmentioned, but there, like a shadow of a tall building. Still, what at first seems absent is often a failure of understanding, inability to notice or difficulty to recognise. This sense of incomprehension haunts my own analysis and its incompleteness.

In writing this article I have come to see the coaxing done by platforms as too limiting. I think in the end the prize of success for Agustin and James was high – they served the demanding multi-platformed format, and not the other way around. Much of the hesitation and brittle difficulty of grief was stifled by the dictates of belonging. I come away critical of the potential benefit of this kind of life writing for the terminally ill. It turns experience of dying into products. It does not compare to the open forms of life writing possible in music or literature – at least it very rarely does. To be allowed to explore this threshold experience of existing, I would wish to be in community and not just in extreme visibility. To be seen and heard is a restitutive experience, but if its price is the moulding of a self and life so exceptional and inspiring as to becoming a celebrity, I fear that it does nothing to help us with mortality and suffering – the only commonly shared signs of life.

Notes

1. Examples include neurosurgeon Paul Kalanithi's *When Breath Becomes Air* (Kalanithi 2016); *Grief Works* (2017) by Julia Samuel, where she noted the growing role of digital platforms as facilitators for expressions grief by those who are themselves in the process of dying (Samuel 2017). In her memoir *Between Two Kingdoms* (2021) artist and journalist Suleika Jaouad describes the discovery of life writing when she was bedridden with leukemia at 22. The self-supporting function of a life writing practice is evident also in ongoing research on bibliotherapeutic practices (Kinnunen et al. 2024; Meretoja 2018)
2. I present my findings as conclusions from a large set, giving exemplary summaries and quotations for the illustration of my argument. Researching material produced by now dead people and working with content regarding their illness, I do not show images from the material. I trust that the authors were intent on participating in public discourse as they consistently published online, appeared in other media and published in memoir form. Considering possible harm, I lean on the public availability of the material, because of which my research does not inflict new strain on the diseased or their living family members.
3. In examining the digital life writing practices of mothers (Joutseno 2021b), I presented lawyer-blogger-memoirist Julie Yip-Williams' and poet/blogger Nina Riggs' cancer-related autothanatography as counter narratives to both mothering and illness (Joutseno 2021a). Their illness life writing occurred as blogging and as posthumous memoirs (Riggs 2017; Yip-Williams 2019). Both countered the "tragic victim" portrayal of mothers dying of cancer by refusing to reproduce normative hope and by addressing grief in their everyday practice of life writing.
4. I take up this invitation to theorize life writing in the vicinity of critical/feminist/queer media studies and new materialist and posthuman thought. My earlier contribution to this transdisciplinary approach was my doctoral research. I worked with the materialities of the digital and the boundaries that get built in life writing between the digital and the material (Joutseno 2020, 2021, 2022).
5. Oxford English Dictionary definition of the social media influencer: attentionhttps://www.oed.com/dictionary/influencer_n?tl=true
6. On the site it says: "The foundation was created in memory of Natalie 'Nalie' Agustin, an inspiring author, speaker, and wellness advocate who thrived with metastatic breast cancer. Nalie's authenticity and creativity

made her a beloved icon to countless people who sought to heal and turn their adversity into purpose." (https://www.naliefoundation.com)

7. This is confirmed in the episode "Deborah Jame's Last Dance" of the "You, Me and the Big C" -podcast (https://www.bbc.com/audio/play/p0c5yjv9), where James discusses how dressing up and make-up continue to be her ways of uplifting herself.
8. For example: YouTube, May 24th, 2017, "My CT scan results after six rounds of chemo" https://www.youtube.com/watch?v=oUAUg4QwilM and "SCAN DAY during a global pandemic" https://www.youtube.com/watch?v=LUXoNR9EBEY
9. Autobiographical life writing about cancer is produced in relation to the cultural master and counter narratives of cancer to the extent that stories can only be understood in these frameworks (Sulik; Meretoja 2018; DeShazer 2005, 2013; Nielsen 2014). According to Gayle Sulik "the personal story of the survivor gained significant public status by the mid1990s, and breast cancer narratives became a new genre within mass media." (324) The narrative types Sulik identified were restitution and quest narrative with the added structuring power of the medicalized language around cancer. Narrating against the contemporary master narratives of cancer produces challenges on the level of communication and interpretation.

   Within the large cultural and social frames, the restitution narrative and quest story (both underlining survival) continue to dominate cancer narratives.
10. Elisabeth Kübler-Ross' seminal *On Death and Dying* (1969) examined the experience of the dying in hospital setting, but the results of her research – particularly the five stages of grief model – have mostly been applied to the bereaved, the central population whose grief is studied and for whom grief counseling and support is targeted. In the fields of philosophy, death studies, psychology, therapeutic and palliative strands of medical research few direct mentions of the grief of the dying can be found here and there: Thomas Attig (2015) has defined the processes of living with incurable illness as "relearning the world" and "learning to live with" (2015). Attig looks at the grief of those aware of their immediate or imminent dying process. In his book *Loneliness of the Dying*, Norbert Elias (1985) focused on the social and cultural history of dying, suggesting that the loneliness of humans was increasing as people mostly died in hospitals.
11. Without making it part of this article, I want to mention the phenomenon of online "wellness influencers" who have tried to sell cancer patients almost anything and who have pretended to be ill themselves. See for example *New Yorker* article "The Cancer Scams That Foreshadowed MAHA" by Jessica Winter (February 6th, 2025)
12. "Where have you been?!?! | full 2020 update", https://www.youtube.com/watch?v=T3NCgk8Z0Zg
13. For Agustin healing is a concept influenced by a family culture that is distinct from the Western wellness culture of the digital platforms. In this sense healing may refer to a return to self, an adjustment and acceptance process rather than curing cancer and avoiding death. In fact, I think that both ways of thinking about healing are present here. I return to this in the last analysis section of this article.
14. In episode "About Where Debs is at right now & Saying Goodbye" James discusses the recording with her cohosts Steve Bland and Lauren Mahon (https://www.bbc.co.uk/programmes/p0btc50r)

    In episode "Deborah James' Last Dance", James is speaking from her parents' garden where she is living out her final days (https://www.bbc.com/audio/play/p0c5yjv9)
15. It raised four million pounds within its first days. To date, it has raised 17 million pounds (https://www.bowelbabe.org).

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