Grieving in the Everyday: Metastatic Cancer, Life Writing & the Grief of the Dying

Abstract

This chapter draws attention to the grief of those living with terminal cancer. Often the grief of the dying remains unaddressed in the clinical setting and in culture at large. With the concept of the grief of the dying, I consider its likeness to everyday trauma, and suggest non-subsumptive ways of looking for the narratives of such grief. I offer a case study of my experience as a researcher-artist living with metastatic breast cancer, followed by a discussion on how grief figures in the life narratives of the terminally ill. I present four aspects of the grief of the dying: unending uncertainty, the oscillation between immersion and avoidance, fragmented narrative styles and the mourning of one's own death. I suggest that life writing is a useful site for expressing the grief of the dying and for examining it in critical medical humanities.

Background

In her essay "On Being Ill", Virginia Woolf noted how literature and culture lacked descriptive language for the experience of illness. According to Woolf, the position of the ill is starkly separate from the healthy. She saw illness as a critical perspective that the healthy lack: "We become deserters … We float with the sticks on the stream; helter-skelter with the dead leaves on the lawn, … perhaps for the first time for years to look round, to look up – to look, for example, at the sky." (2009). Since Woolf, much has been written about the difficulty of conveying illness in narrative form. Still, during the late 20th and early 21st centuries the experience of illness became a popular theme in memoirs and other forms of life writing (Jurecic, 2012; Nesby and Johansen, 2019). In a sense, illness has been hiding in plain sight in narrative expression. I suggest that the same is true for grief.

This chapter examines the grief of those dying from cancer. Kathryn Schulz has noted that against common misconception, sadness isn't the key emotion linked to grief (Schulz, 2022, p. 64). Instead, as Brené Brown has stipulated, grief is made of loss, longing and feeling lost (2021, pp. 110-11). In this chapter, I define grief not as a procession of uncomfortable feelings with an end goal, but a life-altering temporally ambiguous state. Grief that is hidden or hiding is *disenfranchised* (Doka and Davidson, 2016). It is not recognized or acknowledged and therefore, systems of care and/or entire cultures lack awareness of it. Grief is always related to loss, but not all loss means death. Neil Thompson describes: "… tendency to equate loss with bereavement and thereby artificially restrict grief to situations involving death serves to distract attention from the often major role of grief in our lives in relation to losses that have no connection with death." (2020,

p. 21). Losses pile up when life with incurable illness is prolonged. Compounding losses can lead to the experience of everyday trauma, which while becoming repeated and commonplace, does still cause harm (Bordere, 2017). This is why awareness of grief is paramount in considering trauma and narrative ethics. Robert Eaglestone has characterized "traumatic texts" as disrupted, often referential to history and intra-textual containing portions about writing and remembering, as well as ending without closure (Eaglestone, 2018). Contrary to expectations, trauma-related narratives reveal that "the trauma is constantly there" (Ibid. p. 63), permeating narratives of grief. The everydayness of trauma and grief is present in the life writing section of this chapter.

The development of life-extending medicines for metastatic cancer has led to new trajectories of long-term living. (In the case of breast cancer in Finland see Jääskeläinen, 2022) Living with MC (metastatic cancer) is defined by various and individual embodied challenges, one of those is grief. Quite often research that proposes to study grief as an experience of the ill slides into discussing bereavement. Tackling grief from the perspective of the dying seems to be missing, although Kübler-Ross' seminal study from 1973 examined the grieving of the terminally ill (2014). In writing about death from cancer, Stephen P. Hersh does what often happens: quickly slides from end-of-life symptoms to the grief of those who are left behind (2016, pp. 100-03). Understandibly, the dying process has to be considered from the perspective of the bereaved, but what about the grief of the dying? How does prolonged illness impact the narrative expressions of grief? Do they answer to the stark stereotypes of the gravely ill cancer patients or narrate inexpressible traumatization? What is it like to permanently reside in the impermanence of the horror cabinet of death's vestibule? This chapter is the beginning of an exploration of the grief of the dying. First I present an autoethnographic study of *the grief of the dying* (Jones, Adams and Ellis, 2013; Lykke, 2014; Ettorre, 2017). Then I outline characteristics and concepts, suggesting that life writing provides a resource for studying non-subsumptive narratives of grief, illness and dying (Meretoja, 2018a). I write from a crip studies (Chen *et al.*, 2023) and critical medical humanities stance, underlining the epistemological significance of the ones with the illness experience, who are not just informants or bodies in trouble, but fundamentally humans engaged in living (Whitehead *et al.*, 2016, pp. 35-38). Upon embarking on a situated story (Haraway, 2016), I note that my experience unfolds in Finland where I receive cancer care through the public healthcare system.

Grieving in the Everyday

On the 5th of January 2023, I received news: my treatment was working again! Metastasis in my cerebellum were shrinking. After a six-month breather, I had resumed treatment in fall 2022 once activity appeared on the MRI scans. It was three years from the start of treating brain metastasis of my breast cancer and nearly 9 years since my initial diagnosis at 32. In September 2021 a novel targeted chemo became available in Finland, and I have received it ever since. The medicine saved me from immeadiate death that fall, as all other treatments had failed.

On this January morning, while my oncologist delivered the good news, I thought: *Now I can fly to Catalonia as planned in two weeks*. Only later did I remember that tomorrow I would have to endure another chemo infusion and survive the aftermath. I was excited yet anxious. Counterintuitively, I felt no relief, but a sense of rightness. Things were as they should be.

The next day, I received my treatment at the local cancer ward and then stayed home for a week, taking my medicine on a schedule to fight nausea and exhaustion. I had learned to deal with symptoms a little better in the last months: a palliative doctor was trying therapeutic exercises with me to break the mental association linked to severe nausea. I was learning to take care of myself rather than abandoning and ignoring my body in sadness and rage. I was learning to weather the week a little better. Still, or maybe because of this, a few days after my treatment I became deeply sad over the tufts of hair falling from my head. Despite me wearing an ice hat during treatment, my hair has consistently gotten thinner and bald patches have begun to appear. Over the years I've experienced hair loss four times, but there is no getting used to it. The feeling of my balding scalp under my fingers extenuates my sense of unfamiliarity and loss. It reminds me that almost nothing is in my control. That I am dying.

Laying on the double bed at home, I feel twinges of nausea. I don't want to eat or go for my usual walk. I feel sad. As I write this, I can feel the nausea mildly clenching my diaphragm, turning my throat into a slippery rejection pipeline. It is a memory my body keeps. As I am feeling lousy, I avoid talking to my partner. Instead, I just lie in bed fighting tears. I stay there a long while away from activities that usually occupy the ill days. I feel despair. I remain close to the idea of death. I think about talking to my partner at night. I plan what I will say, but never do. Somewhere in this mush I remember my vacation plans. I will travel with a childhood friend who is an artist. It is our first overseas holiday after Covid-19. I haven't left Finland for three years – an eternity for the terminally ill. This is an adventure I never thought I would participate in. During the past years, I have lost most of my cancer sisters — also living with MBC — and regarding my own mortality,

last years have been a sequence of pessimistic predictions and increasing uncertainty. *I know that I am not supposed to be here.*

By the evening I have spent hours looking at the map of Spain. Instead of grief, I want to talk about restaurants. Then, every day I walk a little, I talk a little longer, finally finding the energy to put the washing machine on, and to wash my hair. A week and a half later I cook for the first time. Then I take my 10-year-old to a café after school. We eat cake and talk about our upcoming birthdays.

Two weeks later I fly to Barcelona.. I feel my lungs restrict as the air pressure changes. For a few hours we wonder around Barcelona admiring the architecture before taking the train to Girona in the afternoon. The train station is a maze we almost do not survive. It takes me a day to stop feeling like I have a lung infection. I often feel like that when I am exhausted. In our room on the hillside of Girona overlooking the old town, I lie in child's pose and worry that I will ruin our holiday. Then my exhaustion disappears. We walk every day, eat beautiful meals and look around. I am joyously alive. When my muscles ache on my legs, I walk more and patch my toes with plasters where they blister. On the train to Figueres to a Dalí Museum we talk about my imminent but postponed death and the death of my friend's father. He died of cancer nearly 15 years ago. We agree that Dalí's playful absurdity reminds us to embrace life, to create instead of dwelling. I take in the beauty, the sunlight, the mountains and the signs of disarray and decay around us.

On the last day of our vacation, we stay in Barcelona and visit the Museum of Contemporary Art (MACBA). We see a Maria Teresa Hincapié exhibition, "If This Were a Beginning of Infinity" (2023). The Colombian artist died in 2008 of breast cancer and left behind an archive of performance art. Hincapié began as a feminist artist commenting on gender and sexuality, particularly women's role in the patriarchy. Her focus was on the everyday. In time, her works grew toward addressing the planetary suffering from capitalism and environmental disconnection. I move slowly through the large spaces where screens and photographs of different sizes have been arranged. Hincapié's works are presented retrospectively and in 2d-form, altering them from their original three-dimensional performance-art format. The body of the artist is missing. Still, I feel soothed in residing in her archive. I am consoled by the acts of preservation that her son and others have taken. This is a space where I can celebrate Hincapié's life, mourn her death, while also grieving my own vulnerability. The exhibition leaflet showcases a quote: "I am not interested in dead art. I believe that life is art, and my body is my living art. It is my body that has to move, that is looking, that is tired, that is exhausted. This is what I propose" (Hincapié) The words send a jolt

of energy down my spine. I am taking in something new and abundant. I feel energized as we return to the city bustling around us in the velvet light of the early evening.

Arriving home, my liver markers are nearly normal. I am ready for another round of chemo that promises extended time. Before then, I host a birthday party for my 11-year-old. I am lucky to be baking and arranging green napkins, balloons and golden candles. Each birthday is a benchmark: *we made it together*. I make big gestures to mark time. Mixed in the elation is anxiety: *is this the last birthday with her mother alive?*

After chemo I lie in the bed for the rest of the day. My child comes and goes bringing nuggets about school and toys. I ask her to stay in the other rooms. I am too unwell to listen. In the evening she cuddles up to me and I hold her. As our bodies relax, she shares with me a quote from the mother of her favorite Star Wars actress: "a cuddle always helps". We agree.

The Grief of the Dying

Next, I discuss four aspects of the grief of the dying: unending uncertainty, oscillation between acknowledgement and avoidance, the fragmentation of narrative, and the mourning of one's own death. The grief of the dying is shaped by continuous uncertainty. This is evidenced in the narratives of terminal illness. This instability has been discussed as a source of "chronic trauma" and can be a therapeutic issue, but grief cannot to be simply equated with trauma (Mitchell, 2020, p.153). Grief needs to be considered alongside it, appearing in partnership with everyday losses caused by MC. According to Linda Nesby and May-Lil Johansen the widely popular memoir *When Breath Becomes Air* (2016) by Paul Kalanithi, emphasizes "the importance of the individual … acknowledging that truth is not necessarily only a biomedical fact but also a vague or subjective phenomenological experience of what it feels like to be ill." (2019, p. 196). For Nesby and Johansen, Kalanithi's prose – a neurosurgeon who died of lung cancer at the age of 37 – is an example of illness writing that more broadly acknowledges the limits of what can be known. This is the scope of the uncertainty. I add that perhaps the entire definition of knowledge is dislodged in the vicinity of death. If knowledge is associated with power, then grief acknowledges what is beyond knowing and therefore also, control. As such, grief should be a central interest in medical humanities.

Metastatic cancer unfurls as a sequence of medical interventions and side-effects – they puncture the everyday and the orientation to past and future narratives. The everyday occurrence of losses has been recognized in the research of non-death losses (Doka and Davidson, 2016; Harris,

2020a; Thompson, 2020). Harris suggests that the dual process model of loss in bereavement can be applied to understanding how non-death losses are dealt with by oscillation between immersion in the experience and avoidance or "getting on with life" (Harris, 2020, p. 10). I propose this model useful in describing the waning and waxing of grief with MC. Importantly, it describes the experience of grief and grieving as intermingling with everyday life (ibid., p. 11). In the life writing segment, I described how in receiving the good news about my health, I turned to an immediate outcome, a vacation while avoiding addressing the contradictory feelings that arose. The segment then exemplifies oscillation as bursts of grief appear everywhere – even on holiday. The illness and its conditioning refuse narrative linearity. In making sense of this, I suggest a non-subsumptive narrative model, which has implications both on how we interpret and create narratives (Meretoja, 2018a, pp. 105-09; 2018b). This narrative hermeneutic approach relinquishes ideals of control, completeness and assimilation to what is already known. Non-subsumptive narrative understanding approaches storytelling as dialogic (Meretoja, 2018b, p. 265), radically relational (2018a, 106); and as explorative counter-narratives to hegemonic narrative practices (ibid., p. 107). From this interpretation a single situated narrative is not by default representative of a whole, but life writing becomes part of the specificity of the narrative and its interpretation. Yet, this particularity does not diminish the narrative because it does not have to fit into pregiven modes. Referring to Hannah Arendt among others, Hanna Meretoja proposes that this is an ethical approach to narratives because it does not presuppose their value, but facilitates the reading of unique identity/story in a state of becoming (2018a, pp. 108-109). Previously, I have presented this potency of life writing with Eve Sedgwick's concept of reparative writing, emphasizing the potential for new insights and new kinds of agency in writing about grief (Sedgwick, 2003; Joutseno, 2021). Meretoja stipulates that "understanding, mediated by language, neither necessarily perpetuates dominant sense-making practices, nor is inevitably oppressive … it can also open new possibilities, experiences and realities" (ibid., p. 104). In my view, grief narratives often do just that and benefit from being interpretated with this model.

In life writing, the grief of the dying is evidenced in narrative fragments; it is in bits and pieces often referring to the everyday. In my archive of art and research, grief flares up at seemingly irrelated instances (see Hubara and Swan, 2019; Swan, 2019, 2021; Joutseno, 2020). For example, in my PhD, I examined two memoirs and blogs by mothers dying from MC (Riggs, 2017; Yip-Williams, 2019; Joutseno, 2021). I propose that to study the grief of the dying, we must close read memoirs, fiction and other forms, but also consider grief's presence in archives such as Hincapié's

artistic archive. If we are to look for the grief of the dying in non-subsumptive narratives, we cannot assume to find neatly ordered linear storytelling. Grief narratives demand acute awareness of the unexpected or new, as well as skilled interpretation of the way in which grief is cocooned not just in narrative but within experience: recall, my description at the Hincapié exhibition, where I experienced a spaciousness for grief as energizing. The non-linear, self-reflexive and multi-dimensional narrative may also discuss the mechanics of narration and its impact on experience. Meretoja stipulates that non-subsumptive narratives "lay bare their own constructedness, processuality and the movement of telling rather than the told" (Meretoja, 2018, p. 108). In his discussion on the impact of trauma on narrative, Robert Eaglestone suggests that ethical storytelling is intertwined, "jagged" and its foundation is "the rubble of history …" (2018, pp. 64-65). Here lies the ethical potential of narratives in relation to the grief of the dying.

Finally, the grief of the dying is tied to a process of disappearing from life. It includes the mourning of one's own death. It is existence on the precipice of the unknown. Even in the ebbs and flows between "ordinary life" and *illness time* (Joutseno, 2020) MC intrudes into dreams and commitments – every facet of relationships, how a past is assessed and future (not) imagined. In celebrating my daughter's birthday, I immediately sensed the edges of melancholia, the anticipation of my absence. As a terminally ill mother I expect to die while my child is young. This is an example of a changed assumptive world (Harris, 2020, p. 10). The assumptive world shattered by illness is an inner schema based on our earliest life experiences. It guides us in making sense of our role in the past, present and future (ibid., pp. 8-9). Compounded losses require the readjustment of the narrative of the self; the "reweaving" of this new temporary position (Meretoja, 2018b; Harris, 2020a, p. 13). I propose that this rewiring does not mean the expulsion of grief nor the acceptance of illness or nearing death – these are too difficult things to completely process. Instead, narratives of the grief of the dying describe the process of reconfiguration; a way of *living with*, permitting the ever-occurring ruptures, changes and losses. Grief cannot be cured or finished. In my view, this is not anticipatory grief (Doka, 2020). Dying is not a process of anticipation but living through tangible and intangible losses (Harris, 2020b, p. 240) while embodying disintegration. The intangible losses that lack physical resemblance entangle with the tangible: for example, the hair loss I describe becomes metaphoric expressing the intangible losses that are difficult to address. *It is never just hair*. Many MC losses remain unexpressed. Yet, the grief of the dying hides and is made sense of in the body (see Brinkmann, 2019). The body is that which is dying. It might be impossible to differentiate between nausea as a side effect of treatment and as an expression of grief because

grief is entangled and experienced as embodiment. In the life writing section of this chapter, I suggested that once I began to address the presence of my grief, I became more able to receive help for my physical symptoms (Joutseno, 2021, pp. 4-5). What I do not wish to suggest is that the symptoms would now be under control. They are not. Time or grieving do not make death any more acceptable. Acceptance should not be required. Grief of the dying is not processual but existential. It is a philosopher's predicament in a world that has little time for philosophy.

Conclusion

Metastatic cancer can be accompanied by long-term grieving, much like everyday trauma. I suggest that in critical narrative medicine (Whitehead *et al.*, 2016) fiction and life writing can be analyzed for better attunement to the grief of those who live with incurable illness; realized via an understanding of what happens to narrative. Combining narrative studies, life writing and insights from hospice and palliative care can aid in the project of critical narrative medicine, which allows for rigorous multi-disciplinarity and is focused on dismantling the dichotomy between medicine, humanities and arts in favor of the non-subsumptive and particular. Hanna Meretoja has suggested that it is in *the narrative imaginary* that our unconscious norm-assimilating and the possibility of subversion –imagining differently - exist (2018b, pp. 18-21). In a wider social context, locating the grief of the dying in our narrative imaginary may allow connections where disconnection often takes hold. This means that narratives of grief, illness and dying may contribute to the transformation of understanding and the alleviation of loneliness. Acknowledging the existence of the grief of the dying helps those living with incurable illness and those closest to them. Further research will yield a well-rounded picture of the linkages between everyday trauma, compounding losses and the grief of the dying.

I have begun to suggest that the grief of the dying is varied, challenging, yet potentially enriching. Its archive needs to be named. I suggest that illness experience is a potential position of knowledge; its expression and exploration is fruitful. Yet, the grief of the dying is not to be mined for knowledge. In their delicate rebellion, non-productive affective existence, such grief narratives may occur as generous gifts in the shared process of coming to understanding. My illness narrative is offered as an example of the multitude of positions and possibilities of reflection and expression. In the absence of a definitive characterization of the grief of the dying, I propose that the variability of grief matters.

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