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What do we talk about when we talk about queer death?

4/ Queering death in the medical and health humanities

ABSTRACT: This is part 4 of 6 of the dossier *What do we talk about when we talk about queer death?*, edited by M. Petricola. The contributions collected in this article sit at the crossroads between thanatology, queer studies, and the medical/health humanities and tackle questions such as: how can queer death studies deconstruct the health-illness binary? How can we rethink the experience of cancer from the perspective of queer death studies? How can this discipline help us focus on “peripheral” deaths like fetal death and pregnancy loss?

The present article includes the following contributions: – Kirey-Sitnikova Y., Bridging queer death studies with public health science; – Böcker J., Queering fetal death and pregnancy loss; – Werner A., Re/orienting to death: queer phenomenology, terminal cancer, and anticipatory regimens; – Tzouva P., Towards a queer death: breaking free of cancerland; – Clay S., A queer account of self-care: autopoiesis through auto-annihilation.

KEYWORDS: Thanatology, Death Studies, Queer Studies, Medical Humanities, Health Humanities.

BRIDGING QUEER DEATH STUDIES WITH PUBLIC HEALTH SCIENCE

As a trans/queer activist with 11 years of experience, I have seen enough criticism directed at health practitioners. For several years I was among the few persons in Russia speaking against trans pathologization, gatekeeping practices and compulsory medical interventions, finding inspiration in trans/gender studies, critical theory, social sciences and humanities in general. Unfortunately, much of this criticism misses its target, as many health practitioners, even those acting with the best intentions, lack training to understand the complex language in which their faults are explained by the activists and academics. Mutually incommensurable theoretical frameworks and worldviews make it virtually impossible to establish constructive dialogue between adherents on both sides. Getting an education in public health thus became an extension of my activism aimed to understand the

field I have been critical of and practice this science in a more meaningful and responsible way. The following is my attempt to bridge the fields of Public Health and Queer Studies via Queer Death Studies (QDS) in a number of ways which came up during my present research in trans health.

1. WHAT IS DEATH IN PUBLIC HEALTH AND HEALTH ECONOMICS?

The science and art of Public Health is grounded in the understanding of health as “a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity” (WORLD HEALTH ORGANIZATION 1947). This definition reintroduced a holistic approach to health which for three centuries since the Cartesian revolution had been subsided by a positivist understanding of a disease as a deviation from the biological norm (AHMED *et al.* 1979). Both health and disease are biosocial constructs that do not exist in a binary opposition towards each other but include many dimensions articulated differently depending on, for example, class and culture (*Ibid.*). This deconstructionist mode of thinking parallels the blurring of the life/death binary found in QDS.

However, when trying to operationalize and quantify “health”, we still find ourselves in a familiar continuum in which more health means less disease, and vice versa. The opposite endpoint of imaginary “perfect health” is “death” which for Public Health is understood as a special type of a disease – the worst “disease” one can get. Two common metrics of health illustrate this point.

Disability-adjusted life years (DALY) is used to measure population-wide disease burden (MURRAY 1994). It is calculated as a sum of *years lived with disability* (YLD) and *years of life lost* (YLL). To calculate YLD, one uses *disability weights* which are tabulated for common diseases (disabilities) in a range between 0 (perfect health) and 1 (death). A related, utility-based metric called Quality-adjusted life years (QALY) also relies on weights in a range between 0 and 1, but 0 is assigned to “death” and 1 to “perfect health” (TORRANCE & FEENY 1989). Interestingly, QALY weights might go down below zero – indicating that certain health states may be perceived as “worse than dead”, raising a number of philosophical and practical issues (ROUDIJK *et al.* 2018).

Morbidity and mortality go hand in hand in many other ways. For example, the International Classification of Diseases began as a list of causes of death, while non-fatal conditions were added in later revisions (ANDERSON

2011). To provide another example, in health economics evaluation, Markov models are widely used. In these models, individuals move between health states with certain transition probabilities. Among other health states, the model usually includes “death” – the probability of staying in this state is 100% once you get there. Aggregation of morbidity and mortality has been questioned on the grounds of their incommensurability (SOLBERG *et al.* 2018), but the mode of thinking delineated above still prevails.

2. IS NECROPOWER A USEFUL CONCEPT IN PUBLIC HEALTH?

If death is considered among the health conditions, how can theoretical concepts of QDS be applied to issues of health and disease? Public Health and especially its subfield of Epidemiology has for decades been criticized for not accounting for power relations in its practices of data collection, categorization and calculation (LUPTON 1995). Its theoretical approaches were called into question for focusing on an individual body as a problem separate from social relations in which it is immersed (WING 1994). This critique is partly out of date, as insights from social sciences are increasingly incorporated into the theory and practice of Public Health, including the development of social epidemiology, integration of intersectional analysis, embodiment theory, to name a few trends (WEMRELL *et al.* 2016). Political epidemiology has emerged as a subdiscipline aimed to account for the role of political factors (political systems, political economy) in shaping health inequalities (BECKFIELD & KRIEGER 2009). While the latter research incorporates the notion of power, the concept of biopower in its Foucauldian sense is lacking. Several factors might explain epidemiologists’ reluctance to employ biopower analysis in their work. First, despite Public Health becoming more interdisciplinary than ever, humanities are still too far away, and biopower in particular is too vague a concept to be operationalized. Second, the concept of biopower has been (and continues to be) applied against the science of Public Health itself, which is rendered as an instrument of control over populations in the name of life and health.

On the other hand, necropower as a power that drives living beings closer to death might better align with epidemiological thinking focused more on risk factors than protective factors. Sovereignty is not only exercised through letting certain people die while making others live (as in the mainstream analysis of biopower), they also expose them to conditions leading to disease and death (MBEMBE 2003). Whereas Mbembe’s analysis

focuses on more visible articulations of violence, a related concept of slow violence (NIXON 2011) considers mundane, everyday exposure to factors detrimental to one's health, such as environmental degradation. Both concepts can be used to explain causation, especially in fields such as environmental and social epidemiology where studies need to rely on observation while experimental designs are often impossible. While several frameworks for incorporation of qualitative research into epidemiology have been proposed (Bannister-TYRRELL & MEIQARI 2020), their practical implementation remains a distant future.

Transgender issues are a good example to illustrate the gap between the current state of epidemiology and QDS. Some epidemiological studies show effectiveness of trans-specific medical procedures, such as hormone replacement therapy and surgeries, in improving psycho-social outcomes and mental health (MURAD *et al.* 2010; COSTA & COLIZZI 2016). Focusing narrowly on medical interventions, this research routinely excludes social context in which trans people live outside the gender clinic, such as pervasive discrimination and violence leading to slow death. On the other hand, necropower has been invoked in relation to trans lives in other academic texts (e.g. SNORTON & HARITAWORN 2013). However, I was not able to find a study where these two modes on looking at trans issues intersect. It would be interesting to examine how medical interventions aimed to alter one's perception in a certain gender act as protective factors against necropower of everyday transphobia. Which social (and not just biomedical) pathways lead to improved mental health? How medical diagnosis of transsexualism/gender dysphoria renders some trans individuals exposed to necropower while disciplining others through biopower?

3. COUNTING ALL DEATHS EQUALLY IN HEALTH ECONOMICS

A different intervention inspired by QDS brings us closer to Health Economics. Cost-effectiveness analysis (CEA) is the most common type of health economics evaluation, aimed to compare different types of treatment, or in many cases treatment and no treatment. Differential costs of two types of treatment and their effectiveness (often expressed as DALYs or QALYs) are used to calculate incremental cost-effectiveness ratio (ICER):

$$ICER = \frac{cost_1 - cost_2}{effect_1 - effect_2}$$

ICERs are commonly calculated in two so-called perspectives: a healthcare

perspective includes costs and benefits for the healthcare system, while a societal perspective is broader and additionally encompasses costs and benefits for other spheres, such as employment, education, criminal justice, etc. But none of these perspectives addresses environmental impact of health interventions. In the “effect” part, quality and longevity of life is calculated for humans only. Likewise, the “costs” part covers costs for humans. That means that deaths of animals during drug development are not accounted for, just as degradation of habitats as a result of environmental damage associated with the production of drugs and medical equipment. To account for these consequences, one might modify the equation above as follows:

- a. Costs. In line with ecological economics thinking, ecological damage should be included not as “externalities” but as environmental costs.
- b. Effects. Non-human deaths and disability should be included in the calculations of effect (for example, in calculating DALYs).
- c. Both of the above approaches may be combined.

To determine cost-effectiveness of a treatment, we further need to compare the resulting ICER with the willingness-to-pay (WTP) which is the maximal amount the society is ready to pay for prolonging life and improve health of an individual. Several countries now have standardized WTP: for Sweden it is 500,000 SEK/QALY, for the UK – between £20,000 and £30,000/QALY. But if environmental costs are included, will WTP stay the same? And who is responsible for determining how many non-human lives we are willing to sacrifice per QALY of a human being?

4. CONCLUSION

Aforementioned are just two ways in which QDS could enrich Public Health Science. Bringing together these diverse conceptual frameworks is a tricky endeavor complicated by disciplinary barriers. Those can be overcome at an individual level by emerging oneself in the theory of a field one has no formal training in. But a structural change in academia is needed to facilitate transdisciplinary research of this kind.

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QUEERING FOETAL DEATH AND PREGNANCY LOSS

On a naïve social constructionist starting point I began to research experiences of miscarriage and stillbirth for my PhD project some years ago. I considered the terms miscarriage and stillbirth to refer to clear medical facts – foetal deaths at different points during pregnancy or birth – and I thought only the ways of dealing with the incident would differ by history, culture and biography. Using a grounded theory approach, I ended up studying how, in fact, a miscarried or stillborn foetus is perceived, (de)constructed, and dealt with as a deceased human being, a *child* lost by its *parents*. I had to let go of my assumptions on the factuality of (death at the) beginning of a human life.

I realized there is a “cultural void” (SAWICKA 2017: 233) surrounding pregnancy loss experiences like miscarriage, stillbirth, late termination and perinatal death. They go along with stigma, isolation and communicative taboos rather than with social routines and rituals. In ritual theory abrupt and ‘unsuccessful’ endings of pregnancies can be seen as incomplete rituals, leaving the formerly pregnant person and the foetus in a “liminal space between different states of being” (KUBERSKA *et al.* 2020: 150). Both have an uncertain status, the stillborn foetus may be seen as “something between a baby and ‘human tissue’” (*ibid.*). According to the modern subject-object dualism, it will be either buried or disposed with clinical waste.

Below, I share some observations of heteronormative (necro)politics, connected with pregnancy loss activism, that aim for official recognition and for parental rights to decide about foetal remains (BÖCKER 2021). Based on this, I point out what queering death and loss around the beginning of a human life could mean instead.

HETERONORMATIVE (NECRO)POLITICS OF PREGNANCY LOSS ACTIVISM

In many countries all over the world activism accounts for filling the social and ritual void surrounding pregnancy loss. In Germany, where my research focus lies, it ranges from local support groups of volunteers who sew small-size clothes for stillborns out of wedding dresses to nation-wide networks and activities to raise awareness around pregnancy loss and to change clinical standards and federal laws.

One of these initiatives, “Petition Sternenkind [Angel babies]”,

achieved a change of the Civil Status Law.¹ The married couple Barbara and Mario Martin – who lost three children during pregnancy – brought in a draft law via the petition committee of the German Parliament in 2009. The draft law was meant to establish a civil status for miscarried fetuses. The goal was for parents to have the choice to officially register and to bury them. Until then, pregnancy tissue and miscarried fetuses were usually discarded as clinical waste and no official record was kept. More than 40,000 people signed the petition. In 2013 the draft law was unanimously adopted by the German parliament. The decision was accompanied by standing ovations for the Martins who had lobbied for the amendment many months.

Miscarried fetuses now can be legally recognised. Bereaved parents may name, register them at a local Civil Registry Office and bury them. Although the law amendment might have enforced overdue parental rights, it implies heteronormative implications and consequences on which I will now expound.

First, there is a new obligation for hospitals to inform about funeral rights and possibilities in case of a miscarriage, whereupon individuals must decide about the foetal remains. Women and couples experiencing a miscarriage might be troubled in a new sense now: they now must legally decide if they want to bury what they have, or will have, miscarried, a foetus or unborn child, with which they may or may not have bonded. At the same time, they are confronted with a growing cultural expectation to do so: to name, bury, and mourn the unborn, their child, and consider themselves as *bereaved parents*.

My research indicates a hegemonic discourse and practice of informing that is foetus-centred and implies foetal parenthood (BÖCKER 2021). The actual decision-making process is accompanied by feeling rules and role expectations, especially those of a *bereaved mother*. To put it more drastically, every failed pregnancy may mean a deceased child and bereaved parenthood now. There is also, to some extent, a rhetorical proximity to anti-abortion activists who use the concept “death of an unborn”. Some Catholic hospitals, especially, use *pro-life* rhetoric to inform about new funeral options and services related to “gravesites for unborn life”.

¹ The Civil Status Law, in German “Personenstandsrecht”, regulates every person’s family status including name, date of birth and date of death. The law distinguishes between live-birth, stillbirth, and miscarriage.

Second, if effected individuals decide against a funeral – that is they don't arrange an individual funeral themselves – hospitals are legally obliged “to collect and to bury miscarried foetuses and unborn children under dignified conditions”. Mostly in practice, the hospitals collect the miscarried foetuses and pregnancy tissue, and local Christian communities organise a cremation and burial as well as a small funeral service. This, by the way, also applies to foetuses who were miscarried by Muslim women.

Third, the requirement to officially register a miscarriage reveals how firmly legal parenthood is still bound (bound again?) to the idea of biological parenthood. The minimum requirement to legally declare the foetus as a family member, and to give it a prospective name, is proof of a former pregnancy and a medical professional's attestation about its end. Since, in Germany, married homosexuals have to adopt their (partner's biological) child after birth, live-birth to be precise here, for homosexual parents there is no legal way for both to be registered as the parents of a miscarried child. On the other hand, since in most German states every *parent* can arrange a funeral after any kind of pregnancy loss, a husband – who is the father of his wife's children by law – is now legally enabled to arrange a foetal funeral, regardless of his wife's wishes. Miscarried children of married heterosexual couples seem to be, to put it in the words of Butler (2004: 30), “more grievable than others”. This is especially startling because the amendment was praised in media as a concession of individuals' rights to self-determination after pregnancy loss.

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Effected women, couples, and the extended families, have to give meaning to the situation, define the miscarried/stillborn/child, define what life/death means to them, find a parental/non-parental identity, and decide on the next steps – all against the background of being responsible for self-care, future feelings of regret and a successful bereavement process.

Queering death around a human life's beginning means to understand to whom that life held meaning – its planning, hoping and preparing for, its coming into being – and to define *what* was that meaning. In this regard, we need queer forms of recognition and acknowledgement after pregnancy loss. The subject-object-dualism applied to the foetus still opposes an officially registered *death of an unborn child* who is buried with dignity to *human tissue* that may be disposed as clinical waste.

In fact, many effected subjects have highly individual, sophisticated and ambiguous conceptions and feelings of what they have lost. For example, they consider their miscarried/stillborn child somehow magical, a kind of divine encounter, acknowledging non-human personhood. Or they might be in a situation to await their beloved child *and* decide for a late termination due to medical reasons. So far this is a moral contradiction, but we need ways to acknowledge these losses as significant without tying them to foetal personhood. After loss some parents want to write a memorial card for their aborted child and send it to friends and family, yet many won't because they feel – and may be held – responsible for their not coming into being.

Non-normative practices of mourning miscarried and stillborn babies, like this, are sanctioned in two ways. On the one hand, they are still “unacknowledged and stigmatized loss[es]” (WERNER-LIN & MORO 2004) because the unborn isn't seen as a human being and grievable loss. On the other hand, some of the recent changes in official recognition seem to reserve bereavement and mourning after miscarriage and stillbirth for those who are considered *real parents*. Apart from the question, what a valuable and grievable life and loss is, we therefore also have to discuss *who has a right to grieve*.

Thus, we also talk about acknowledging “reproductive loss” (EARLE *et al.* 2012) in non-mainstream families and communities. Losses by members of the LGBTQIA* community are likely to be acknowledged less, because they match a mainstream expectation that they won't become biological parents. However, single-mothers, surrogate mothers, lesbians and trans men have miscarriages and stillbirths, too. Their pregnancy losses are often especially painful because the efforts and costs to conceive are particularly high. Members of the queer community may not want to go for an official state record of their miscarriage or a birth certificate, but it is striking they don't have the same legal right to do so.

In Berlin Schöneberg there is “an enchanted cemetery ... where the Grimm Brothers, stillborn babies and gay men are resting in peace” (LAMBDA PROD 2016). The old graveyard is famous for being a last home for many (well-known) gays who died from HIV/AIDS in the 1980s. Today, it is also famous for its beautiful “Garten der Sternenkinder [Garden of Angels]”, a gravesite for stillborn children. It looks a little bit like a playground and is sometimes used like one by siblings of the dead. Offering a place for

the invisible and stigmatized – dead and mourners alike – the graveyard enables community-building and a re-evaluation of what can be considered grievable losses.

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RE/ORIENTING TO DEATH: QUEER PHENOMENOLOGY, TERMINAL CANCER, AND ANTICIPATORY REGIMES

My partner and I drive 3 and a half hours from our remote rural town to the regional cancer centre where I meet my oncologist once a month to discuss my treatment, my blood tests and scan results. We leave the home we hand-built together, drive through farmland, climb a winding forested mountain pass, and emerge from the forest onto the Monaro plain – a barren, brown landscape of huge granite boulders, wind-tortured gum trees, skinny sheep grazing, dead and decaying road-killed wombats and kangaroos lining the sides of the highway.

On the drive we are encapsulated. Physically in our car, hurtling down a highway towards a destination that only exists for us as a site of medicalised examination and information-gathering. We are also encapsulated emotionally and temporally. We are absorbed in our grief and anxiety, knowing that one day we will make this drive together and my oncologist will tell us that the treatment that is currently keeping my metastasised cancer ‘under control’ has stopped working, and that the cancer will now continue spreading until it consumes me and I am gone.

The knowledge that this news is coming, one day, maybe soon, fills us with dread and also with wonder. It orients our time, inscribes the ways that we imagine our futures. In the days leading up to the appointments we are gentle with one another. We don’t often speak about what might be revealed at the appointment, but we feel its maybe-immanence thick in the air, in our embraces, when we fuck. We try to shield our children from our anxiety, try to make their life ‘normal’, arrange play-dates for the days we are at appointments, to distract them/us from what will come.

Our anxiety peaks as we turn off the highway into the outskirts of the city. The road weaves through bland outer suburbia, ringed by desolate

hills, closer and closer to the hospital. We share a Valium. We pass through the covid checkpoint and check in at hospital reception. My appointments are on clinic days at a public hospital: a day full of appointments for all of the patients who don't have private health insurance. It's incredibly busy (so many people, so much cancer), so we wait, sometimes for a long time, smiling at the chemo patients, nodding knowingly at other patients waiting, averting our eyes and choking back tears when we see someone leaving an appointment in tears. We hold hands, knit, read, chat and wait.

The waiting... is... heavy.

I ponder this waiting, I ponder what I'm now waiting for. I *feel* Margaret Waltz's assertion that medical waiting is a site of "temporal domination" which upholds power structures, most significantly those related to class and gender (2017: 818). My class determines my access to medical treatments, access to doctors. As a public patient, my wait times are long, and my appointments are short, as my oncologist rushes to get through all of the patients she must see in a clinic day. But perhaps more than the physical embodiment of waiting in waiting rooms, I am cognizant of, and haunted by, the *waiting for death* that a terminal diagnosis orients me towards. In this, I *feel* Dylan Trigg's observation that temporal experience is bodily and, more acutely, that "the drawn temporality of waiting has less to do with the objective status of the environment, and more to do with a projection *toward the future*" (2012: 31 emphasis added).

As I make these long drives and do my daily, sometimes all-consuming waiting (in waiting rooms, in doctors' offices, in scanning machines, in hospital, on the phone, in bed at 3am, alert with pharmaceutical- and anxiety-induced insomnia) I ponder the ways that I have, upon receipt of this strangely solid and also nebulous diagnosis, been reoriented. The time frame imparted to terminal subjects by our doctors, the expected number of weeks/months/years, imposes limits on the ways we imagine our future, with a concomitant habituation towards medical institutions and the clinical gaze of medical professionals.² The cancer-industrial complex in general and processes of prognostication in particular, yoke terminal subjects to a vanishing future that is simultaneously fuelled by hope and also inherently hopeless. Medical institutions (both as physical structures

² Katherine Kenny points out the very important ways that the 'terminal subject' "derives its ontological being" from the medical establishment and associated institutional gazes (Kenny, 382)

and socio-cultural phenomenon) and terminal diagnoses (as literal numbers which redefine the ways that terminal subjects may imagine our lives *and* as socio-cultural phenomenon which are attended by a series of inscribing narratives) orient terminal subjects within the phenomenological complex of body, place and time (SCHMIDT 2018).

Sara Ahmed, in her work on queer phenomenology, asks us: “What difference does it make what we are oriented toward?” (2006). While Ahmed is talking specifically here about orientation towards objects, I would like to expand this question to consider other orientations, such as those enforced by the anticipatory regimes of late capitalism. As Vincanne Adams describes, under neoliberal late capitalism, anticipation is an “epistemic orientation toward the future” (2009: 254) which enables “the production of possible futures that are lived and felt as inevitable in the present, rendering hope and fear as important political vectors” (2009: 248). We are socialised to orient ourselves towards certain things: straightness, as Ahmed points out, but also ‘the future’, as in Adams’ “politics of temporality” (2009: 246). But the future we orient towards seldom includes death, which is of course the ultimate future certainty. Ahmed points out that “orientations are about the directions we take that put some things and not others in our reach” (2006: 552). A terminal diagnosis orients a patient towards death, and puts an adherence to future-oriented chrononormativity ‘out of reach’. If, as Ahmed suggests, queering may be understood as the making visible and taking notice of that which is invisible or overlooked, then the diagnosis of terminal illness and the associated prognostication of life expectancy is a deeply queering phenomenon.

For a life to count as a good life, it must return the debt of its life by taking on the direction promised as a social good, which means imagining one’s futurity in terms of reaching certain points along a life course. Such points accumulate, creating the impression of a straight line. To follow such a line might be a way to become straight, by not deviating at any point. (AHMED 2006: 554)

Terminality presents an oblique slant to this heteronormative line, thereby queering the life course. Ahmed suggests that queer moments (or in this case, the queering processes of terminal diagnoses), in their obliquity, inhibit the actions of the body, thereby limiting its capacity to “extend into phenomenal space,” forcing the body to straighten, in order to continue

its occupation of that space, since spaces are oriented around the straight body, and exclude other bodies. (2006: 561). Heteronormativity then, is a “straightening device, which rereads the ‘slant’ of queer desire” (AHMED 2006: 562). Similarly, teleological anticipatory modes which exclude death from life narratives, exclude terminal subjects from being able to imagine life. Future orientation, whereby anticipation becomes a “moral economy” (ADAMS 2009: 249) excludes terminal subjects.

Dylan Trigg articulates a sensation of disempowerment and a crisis of vulnerability for self-identity as a result of facing the uncanny, when we “*no longer feel at ease within ourselves*” (TRIGG 2012: 47 emphasis added). This sense of dis-ease is deeply familiar to me. Cancer, and specifically terminal cancer, produces this effect, especially for subjects who are not “ill”. I ‘know’, because of multitudes of medical tests and examinations, that I have a number of cancers in my body that will, in the not-distant future, bring about my death. But I do not experience these cancers. What I experience is an orientation towards death, and an orientation towards the cancer-industrial complex, in the form of daily, weekly and monthly medications, injections, blood tests and scans. Because of this orientation I experience a slanting away from the chrononormative life-lines offered to me by future-oriented late capitalism and a (further) queering of my life course. As Ahmed, following Frantz Fanon, points out, such disorientation calls into crisis my involvement in the world (2006b), and results in what Katherine Kenny calls “precarious selfhood” (2017: 374). My ability to normatively imagine a future for myself, as I have been culturally compelled to do, via the cultural narratives and moral imperatives of “working towards”, “saving for”, “waiting for the right time”, “preparing for”, has been interrupted by terminal diagnosis. A distinct absence of cultural narratives around preparing for or waiting for death means that my own existence within the “timescape of terminality” is characterised by a sense of wading through “thick time³” (NEIMANIS 2014), or a sense of being “out of time” (ADAMS 2009: 255). To some degree I ‘know my future’ (I will soon die from cancer), but I am also living in a state of disturbed stasis, characterised by the heavy waiting, and the temporal and affective incoherence

³ Neimanis articulates thick time as a “transcorporeal stretching between present, future and past”. While her conceptualisation refers to human responses to and interactions with climate change, I think the notion is also useful when considering the spatio-temporal implications of living in prognosis and navigating terminality within the cancer industrial complex.

which Kenny identifies as being fundamental to the experienced reality of cancer. Such radical estrangement from the body that I, as a terminally ill, queer subject experience, is a result of the disorientation offered up by the phenomenal experience of living in prognosis (JAIN 2007).

Time is muddied by prognostication. I am disoriented and reoriented by this muddiness. While Ahmed encourages us to consider sexual orientation as a phenomenological question, I extend this to consider future orientation as a phenomenological question, especially when considered in relation to the bodily experience of terminal illness and associated processes. Queer phenomenology, Ahmed argues, functions as a “disorientation device... allowing the oblique to open up another angle on the world” (2006b: 172). Prognostication does this to death, and as such, it queers our relationship with the end of life. It also, perhaps more significantly, draws attention to the ways that neoliberal regimes of anticipatory thinking, future orientation and chrononormativity exclude terminally ill subjects from participation, further dislodging the terminally ill subject’s sense of self.

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TOWARDS A QUEER DEATH: BREAKING FREE OF CANCERLAND⁴

In their article, “Queer Death Studies: Death, Dying and Mourning from a Queerfeminist Perspective”, Radomska, Mehrabi, and Lykke (2020) explain that “to queer issues of death, dying and mourning means to unhinge certainties, to ‘undo normative entanglements and fashion alternative imaginaries’ beyond the exclusive concern with gender and sexuality that is often associated with the term ‘queer’” (88). They go on to specifically criticize “‘proper’ responses to biopolitical regimes of health- and life-normativity [...] and normative demands to consider life-threatening diseases from the perspective of a heroic battle against an ‘enemy’” (ibid), as it happens with breast cancer. In this context, a “search for different articulations, silenced narratives and marginalised/alternative stories” is important in order to “question(s) and

⁴ This research was supported by the Estonian Research Council (GRANT 1481), by the European Regional Development Fund (Center of Excellence in Estonian Studies), and by the Foundation for Education and European Culture.

deconstruct(s) the normativities that often frame contemporary discourses on death, dying and mourning” (ibid:89). Such articulations and voices, in the mainstream of breast cancer understandings and narratives are few and far between⁵, a fact that points to the need of looking more closely at what happens in the territory of *Cancerland* (EHRENREICH 2001).

In breast cancer culture, women are dispossessed of their own death, dying, and mourning by the same necropolitical, profit-oriented, life-negating structures⁶ that have turned breast cancer into a highly lucrative industry (KING 2006; KLAWITER 2008; SULIK 2011; STRACH 2016). Structures that, moreover, bear the responsibility for circumventing research for the environmental causes of cancer (ibid; see also: BRENNER 2016; RICHTER 2019) and for the marketing of breast cancer in particular as an opportunity to reinvent yourself, re-discover your femininity, and connect to the fighter within (EHRENREICH 2001). This happens not abruptly, but as a natural consequence of a lifetime of necropolitical socialization in the western values of neoliberal individualism and a specific type of white, middle class, heteronormative femininity – a socialization that nearly kills whatever existing possibilities for people to imagine life differently and act upon it. In this context, and in due course, death, dying, and mourning are

⁵ For example, Christina Middlebrook’s *Seeing the Crab. A Memoir of Dying Before I Do* (1996). Middlebrook’s memoir dispenses with linearity, destabilizes chronology, and recreates in the text the author’s experience of fragmentation (RIMMON-KENAN 2002: 19-20). Middlebrook castigates the attitude of health professionals who do not call things by their proper name (1996: 7) and attacks “the well-entrenched American denial system” (1996: 135) that radically refuses the reality of illness and death. She asks for recognition (BAENA 2017: 6-11) and expresses her fury at the outrageous social expectations to suppress negative emotions and be glad she looks good again after a long time, while she knows she is dying (*Ibid*: 99). A couple more of those rare instances are Miriam Engelberg’s *Cancer Made Me a Shallower Person: A Memoir in Comics* (2006), which I have examined elsewhere (Tzouva, forthcoming), and Anne Boyer’s *The Undying: A Meditation on Modern Illness* (2019) – see Nellie Hermann’s very interesting review (2020).

⁶ This is what Breast Cancer Action refers to as *the cancer industry*: “The cancer industry consists of corporations, organizations, and agencies that diminish or mask the extent of the cancer problem, fail to protect our health, or divert attention away from the importance of finding the causes of breast cancer and working to prevent the disease. This includes drug companies that, in addition to profiting from cancer treatment drugs, sometimes produce toxic chemicals that may be contributing to the high rates of cancer in this country and increasing rates throughout the world. It also includes the polluting industries that continue to release substances are known or suspected to be dangerous to our health, and the public relations firms and public agencies that protect these polluters. The cancer industry includes organizations like the American Cancer Society that downplay the risk of cancer from pesticides and other environmental factors, and that historically have refused to take a stand on environmental regulation” (BREAST CANCER ACTION (undated))

owned by pink-washed, infantilizing, unabashedly hypocritical and corporate-supported institutions and, therefore, are understood and performed according to their scripts, which promote breast cancer as nothing other than a *bildungsroman* story. In the ultra-prolific genre of breast cancer memoirs (abounding with epiphanies and, in turns, shallow sentimentalism and neoliberal manifestations of a self who will win the battle and emerge more resilient and powerful) breast cancer is imagined as an opportunity for self-development and affirmation of one's will over an insidious invader⁷. All these are set in a world of pink ribbons (and all things pink), teddy bears, marathons for awareness (still awareness?!), snug support groups and comfy sisterhoods, medals for the survivors and survivors' parades, and the most unbearable to watch – because so pitiful and disturbing – commemoration of the dead. Death, dying, and mourning as actions that, in the context of breast cancer, could be charged with political, activist, and ethical presence, are cancelled and disowned as they are appropriated by and put at the service of the necropolitical machine that spreads and exploits people's demise.

Death doesn't seem to really matter, since steps are not taken to effectively address the environmental causes of cancer, even though there is by now serious evidence that environmental factors are linked to the disease (STEINGRABER 2000; SEAGER 2003; BROWN 2007; GRAY *et al.* 2017). Instead, the emphasis is put on individual responsibility and one's personal lifestyle choices (EHRENREICH & BRENNER 2001). Despite cancer's

⁷ One example of such tendencies – a feel-good narrative from a white, upper middle class, heteronormative, and hyper-feminine position – is Marisa Acocella Marchetto's best-selling comic book *Cancer Vixen: A True Story* (2006). The very first sentence already sets the mood and lets the reader know what this is all about: "What happens when a shoe-crazy, lipstick-obsessed, wine-swilling, pasta-slurping, fashion-fanatic, single-forever, about-to-get-married big-city girl cartoonist (me, Marisa Acocella) with a fabulous life finds: A LUMP IN HER BREAST?!? She kicks its ass, of course – and does so in killer five-inch heels" (2006: 1). Another instance, from a very similar perspective, additionally, accentuating the significance of breast prosthesis and motherhood for a woman to be complete, is GERALYN LUCAS' *Why I Wore Lipstick to My Mastectomy* (2004). Lucas' memoir begins with a section titled "The Lipstick Manifesto: Have Courage, Wear Lipstick", which the author closes as follows: "And maybe applying red lipstick is a simple act of courage – to imagine yourself as someone or something you never thought you could be, and somehow, in a carefully applied swipe of beeswax, to become her. Maybe wearing lipstick is the beginning of a revolution inside your head?" (ibid:xv). It, unsurprisingly, ends with a post-reconstruction comment of the delighted protagonist who, having completed her journey, poses topless for the *Self* magazine: "I have finally learned how to strip" (ibid:193). Lucas' story was made into a TV movie (2006) nominated for an Emmy Award. Marchetto's book is going to the screen, as well. For an excellent analysis of both narratives, see Waples' work (2013 and 2014, respectively).

“inexorable increase [...] in industrialized nations” (EHRENREICH 2001: 48) and its occurrence to “women migrants to industrialized countries” who “quickly develop the same breast-cancer rates as those who are native born” (ibid), some of the major players in Cancerland, such as the Komen Foundation and the American Cancer Society, simply do not share these concerns. The money from the donations at the disposal of these institutions amount to an annual budget of millions of dollars, yet the sum that is allocated to research for the actual prevention of cancer is limited to an absolute minimum⁸, and the same goes for federal breast cancer funding (RICHTER 2019: 4). In the meanwhile, “miscellaneous businesses – from tiny distributors of breast-cancer wind chimes and note cards to major corporations seeking a woman-friendly image – benefit in the process, not to mention the breast-cancer industry itself, the estimated \$12-16 billion-a-year business in surgery, “breast health centers,” chemotherapy “infusion suites,” radiation treatment centers, mammograms, and drugs” (EHRENREICH 2001: 51).

Dying, then, turns into a commercial enterprise feeding the machine that keeps killing women while stuffing the social imaginary with images of fierce battles, heroic survivors, and a revelatory, empowering experience that merits one’s gratitude. And, startlingly enough (much more than enough), even an experience not to be missed (EHRENREICH 2001: 49). In this pink, meek landscape, there is no room for “negative” emotions, such as anger, indignation, or outrage, which would have been not only useful in terms of inspiring collective action, but also perfectly justified. On the contrary, the directive is towards their suppression – preferably elimination – and definitely not their expression, which is seen as pathological and as requiring urgent counseling (ibid:50). And while healthy and warranted emotions are restrained, what *is* emphasized is the ultra-feminine character of breast cancer, the importance of looking good as you go through this body-and-soul consuming trial, and the chances you’re offered to benefit from initiatives such as the “Look Good... Feel Better”

⁸ Karuna Jaggar, executive director of Breast Cancer Action, asks: “If Komen is committed to funding research on causes and prevention of breast cancer, why do they allocate less than 4% of the \$1.9 billion (yes, billion) they have raised to these areas?” (Breast Cancer ACTION 2011). See also: Jill Moffett’s article (2003: 293-295) about what kind of research gets the lion’s share of the funding, due to the corporate affiliations of major breast cancer advocacy groups. Watch the 2011 documentary *Pink Ribbons, Inc.* by Léa Pool, based on Samantha King’s book (2006).

program by the American Cancer Society⁹. In the meantime, proud and cheerful, dressed in pink, and conforming to the mainstream of Cancerland, women are dying. They are, or could be, dying at the same time as they have been declared “survivors” and been given a medal and bask in the glory of their presumed victory, for we know very well that such a thing as a guaranteed victory over cancer does not exist, and metastases can occur at any point. Yet, at this “marketplace” (ibid:45) dying has no more weight than that, and the attitude towards the dead is not much better either.

Mourning is absolutely not of the kind that would have decency, honesty, and an actual and valuable purpose: to commit people to change things. What it is instead, is the deplorable, despicable combination of kitsch and vulgarity Ehrenreich describes in *Welcome to Cancerland*: “They are said to have “lost their battle” and may be memorialized by photographs carried at races for the cure – our lost, brave sisters, our fallen soldiers. But in the overwhelmingly Darwinian culture that has grown up around breast cancer, martyrs count for little; it is the “survivors” who merit constant honor and acclaim” (ibid:48). This attitude towards the dead is confirmed once more later on in her text, and it is, I believe, no accident that she has chosen precisely this as a closure for her report. At a fund-raising event she attends in her town, survivors parade to music and to loud announcements of their years of survivorship and she wonders: “At what point, in a downwardly sloping breast-cancer career, does one put aside one’s survivor regalia and admit to being in fact a die-er?” She thinks then again of the dead and reports back to us from that event a deeply upsetting image: “For the dead are with us even here, though in much diminished form. A series of paper bags, each about the right size for a junior burger and fries, lines the track. On them are the names of the dead, and inside each is a candle that will be lit later, after dark, when the actual relay race begins” (ibid:53). The idea is to commemorate the dead but, in the context of the pink cult, the result can only be superficial, coarse, and deeply disrespectful. This is a case of “how mourning can be reduced to a mere nostalgic, sentimental or utilitarian process – a process that does not challenge or

⁹ This program offers workshops of beauty tips and free beauty kits to women in treatment for cancer. The emphasis on looking good distracts the women from realizing what is at stake and from taking relevant action, and the free cosmetics in the pink bags given to them are full of carcinogens (BREAST CANCER ACTION 2015).

change the intersecting necropowers that cause planetary-scale death and destruction”, as Radomska, Mehrabi, and Lykke assert (2020: 95).

CONCLUSION

Breast cancer as a contemporary phenomenon has very broad ramifications and consequences: ethical, political, economic – ultimately, related to power (DeSHAZER 2013). Writing about it and taking any position through one’s affiliations/organizing/public role of any kind should, thus, reflect this acute ethico-political character and the need for urgent and concerted action. A growing number of theorists from areas such as feminism, disability studies, queer theory, and crip theory (Garland THOMSON 1996; McRUER 2006; KOSOVSKY SEDGWICK 1992; SANDAHL 2003; CLARE 2015) suggest a teaming up of different fields in order to give a joint answer to the coming-together of oppressive discourses that strengthen each other. This is unmistakably necessary in the case of breast cancer, which is predominantly an issue of social justice (<https://bcaction.org/about/social-justice/>). In this light, “the breast cancer movement could forge links with other social justice movements, such as the anti-globalization movement, the peace movement and the environmental justice movement” (Moffett 2003: 287). This activist vision points towards going “beyond breast cancer [...] to highlight the extent to which links between toxic substances and health problems exist [...] and to bring about a more comprehensive implementation of preventative efforts in daily life” (LEY 2009: 201-202).

Such concerns and approaches are not alien to the interdisciplinary field of queer death studies, which “investigates and challenges conventional normativities, assumptions, expectations, and regimes of truths that are brought to life and made evident by current planetary scale necropolitics and its framing of death, dying and mourning in the contemporary world” (Radomska, Mehrabi, & LYKKE 2020: 81). The breast cancer cause is “directly linked to the environmental crisis, capitalist and post/colonial extractivist necropolitics, material and symbolic violence, oppression and inequalities, and socio-economic, political and ecological unsustainability” (ibid), which is precisely the focus of queer death studies. This, then, could be the field that could function as an intellectual and activist springboard to give a collective answer and take collective action in an era “of life made for death [...] Where female death, racially motivated death, disabled,

death, LGBTQ death still do not seem to register as their own nations” (MacCORMACK 2020: 108-109).

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A QUEER ACCOUNT OF SELF-CARE: AUTOPOIESIS THROUGH AUTO-ANNIHILATION

In recent years, discussions of self-care have become overwhelmingly dominated by neoliberal values. Articles from mainstream media tend to frame these ideas as desirable and encourage us to engage in consumerism, become “our best self”, and adopt a positive and disciplined mindset. Brianna Wiest (2021) from *Thought Catalog* urges us to be “the hero of [our] life, not the victim” and suggests *real* self-care ‘is often doing the ugliest thing that you have to do, like sweat through another workout or tell a toxic friend you don’t want to see them anymore or get a second job so you can have a savings account...’ Caroline Shannon-Karasik (2018), among others (NAZISH 2017; O’NEAL 2019), take a similar approach to Wiest and presents self-care as practicing yoga, drinking water first thing in the morning, keeping a journal, sleeping, “hav[ing] a mini dance party”, shopping, and enjoying food.

Scholars have been quick to identify the neoliberal ideals in this materialistic and vacuous conceptualisation of self-care: responsibility and personal health outcomes are highly individualised, self-worth becomes measured through economic productivity, and bodies, identities, and human life are commodified in highly efficient ways (AJANA 2017; DILTS 2011). The conceptualisation of health within neoliberal forms of self-care draws heavily from the biomedical model. This problematic health model urges individuals to follow normative lifestyles, ensure their body functions in the “correct” way, aspire to an athletic and slim physique, and to be a passive and obedient consumer of the health industry (METZL 2010; WADE & HALLIGAN 2004).

It is clear that a new approach to self-care is needed, one that not only resists the trap of neoliberalism but also seeks to unravel this system of violence. I offer a queer form of self-care based on Felix Guattari’s (1995) notion of “autopoiesis”. Guattari describes how we should strive for autopoiesis, a

form of self-becoming that involves incorporating the Other and our surrounding environment to become something greater. We are all connected through this continual state of becoming that affords unexpected connections and creates new assemblages of possibility. Autopoiesis is the “realisation of autonomy” (GUATTARI 1995: 7) because we are no longer bound by rigid ways of being, opening space for creativity and potentiality to flourish. To engage in autopoiesis is to pursue new experiences and examine the world in alternative ways. It is about resisting and dismantling forms of systemic oppression to create an emancipatory future (GUATTARI 1995). A queer self-care praxis based on autopoiesis would incorporate all of these ideas, with an emphasis on the pursuit for agency, embodying personally defined expressions of good health, forging connections with others, and self-becoming.

If we accept this notion of autopoietic self-care as a set of practices grounded in pursuing agency, well-being, connection, and self-becoming, what about self-care practices that involve self-destruction? What might autopoiesis through auto-annihilation look like? Using “viral sex” among gay and queer men as an example, I argue that practices designed to shatter and destroy the self are paradoxically ways that individuals care for themselves and engage in a process of becoming. Self-destruction as a self-care practice is queer in a number of ways: it resists normative definitions of self-care, ruptures preconceived notions of what care might look like, and contributes to the established connection between queerness and the death drive (e.g., DEAN 2008; EDELMAN 2004).

THE VITALITY OF VIRAL SEX

One of the principal health concerns gay and queer men face is HIV infection. There have been international efforts by public health organisations to curb the rate of infection by promoting condom use and regular testing, and encouraging “healthy” lifestyles. However, what about men who desire HIV and position this virus as the erotic focal point of sexual encounters? Gregory Tomso (2008) describes this kind of eroticism as “viral sex” and presents how it is used by queer men as an identity, lifestyle, and tool of resistance against medico-state powers that seek to regulate bodies and identities. Men who desire HIV-infected semen are often identified as “bug-chasers”; those who consensually infect others or provide infectious semen are “gift-givers” (REYNOLDS 2007).

It is by virtue of antiretroviral drugs, pre-exposure prophylaxis (PrEP)¹⁰, and other effective HIV therapies that viral sex has become a growing phenomenon in the Western world. This tension between breaking away from medico-state powers whilst also becoming more dependent on these same problematic systems poses a number of issues. Chad Hammond and his co-authors suggest this fraught relationship may aggravate the sense of subjugation some bug-chasers and gift-givers feel, prompting them to seek out more radical and transgressive forms of sex (Hammond, Holmes, & MERCIER 2016). Adding to this, Tomso argues that viral sex creates a significant ethical and philosophical dilemma because “caring for those at risk of HIV infection can be seen as a violent limitation of gay men’s freedoms” (2004: 89) in addition to creating a public health and biopolitical crisis that ruptures the “state-sponsored violence” of neoliberal governance (2008: 269).

The increasing scholarly work on this unique erotic subculture details the way some queer men use viral sex as an emancipatory practice by actively choosing to become infected with HIV, and then use this new identity as a radical source of queer pride (REYNOLDS 2007). The erotics of HIV transmission is deliberately abject, and leans heavily on imagery of sexual deviancy, “toxic” or “hazardous waste”, “breeding” and becoming “pregnant” with HIV, and re-appropriating HIV-related fear and stigma as tools of empowerment (GARCÍA-IGLESIAS 2020; REYNOLDS 2007). However, viral sex is not just about engaging in transgressive sexual acts to resist and protest the medicalisation of queer bodies and identities by public health; it radically reconfigures the limits of erotic desire and carnal sensation, pushing them to the extreme and creating bodies that “splutter” into a state of suspended meaning and liminality (LONGSTAFF 2019). The erotic exchange of HIV-positive semen can also produce a perverse kind of kinship or “cummunion” (FLORÊNCIO 2018): desire and infectious fluids flow between bodies and orifices, displacing the self, dissolving ego-based boundaries, and welcoming in the foreign and strange.

Viral sex is a praxis of necropolitics that seeks to breach the boundaries between life and death (PALM 2019), affirm bodily autonomy, and open up unimagined pleasures and desires. Leo Bersani describes how these unimagined sensations of queer sex can “shatter” the self in a *jouissance*

¹⁰ This is a preventative treatment available to HIV-negative “high risk” individuals and can reduce the likelihood of HIV transfer by up to 99% (ANDERSON *et al.* 2012).

of exploded limits” (2010: 24). That is, queer sex disturbs our psychic relationship to the world and other people, dissolving our sense of self in profound ways. The act of deliberately infecting the body with a virus also becomes a form of self-shattering because it permanently and significantly alters someone’s body, identity, and relationship to the world: “[viral sex] is, teleologically considered, the renunciation of what Jean Laplanche has spoken of as the sexual ecstasy of the death drive; it is the ascetic discipline necessary in order to be replaced, inhabited by the other” (BERSANI & PHILLIPS 2008: 50-51).

Viruses jump from body to body, mutate and infect, and establish an invisible yet tangible rhizome of connections. To become infected by a virus is a deeply intimate act, and for bug-chasers and gift-givers, it can be a “utopian practice” that “gives a new breath of life” and releases them from the emotional and psychological fear of accidentally contracting HIV (ROBINSON 2013: 120-121). Through the incorporation of alterity and the Other into the body and self, viral sex becomes a form of autopoiesis: the uninfected body is lost, the self is disturbed and unsettled, and the limits of eroticism and the queer body are broken open.

CONCLUSION

It may sound paradoxical, counter-intuitive, and problematic to argue that individuals can practice self-care through actively engaging in self-destructive behaviours. However, this is clearly possible. I suggest self-care is fundamentally grounded in the pursuit for agency, well-being, embodiment, and becoming something greater, and therefore a form of autopoiesis; to practice self-care is to become yourself and move beyond your sense of self. Autopoietic self-care examines how we use our surrounding environment and intimate connections to nurture ourselves and feel more at home in our bodies. This queer approach to self-care seeks to undo systems of oppression and marginalisation, and to resist normative definitions of health, well-being, and “good” lifestyle choices.

Viral sex is a contentious and socially-fraught practice, but it contains a range of emancipatory potentials. Practicing viral sex can be a legitimate form of queer self-care because it provides individuals with a unique way of performing autopoiesis, gaining a sense of agency, and establishing unexpected social connections. It is also grounded in the pursuit of alternative expressions of well-being that might deviate from normative models

of health. This autopoiesis, paradoxically, comes about through auto-annihilation. The self is shattered so that it may become more. We die so that we may feel alive.

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