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Assisted Dying as Intimate Care

By
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Abstract

How does asking loved ones to help you die, to help you commit suicide, bend the limits of our relationships and perhaps of care itself? This paper traces the aesthetic and affective considerations of those deciding to die. Focusing on ethnographic interviews with members of the British right-to die group My Death My Decision, I explore how individuals recruit loved ones and doctors to actively participate in their death through "assistance". This paper will specifically focus on what this assistance looks, or perhaps more accurately, feels like. It will question if the desire for an assisted death in which bodies, actions, and decisions touch and are touched by one another is a demand which exceeds the boundaries of "care". My Death My Decision is campaigning to legalise assisted suicide based on a belief that the individual knows when it's their time to die, regardless of a terminal diagnosis. One member, Pat, has decided that when the time comes, she will travel from London to a euthanasia center in Switzerland where, surrounded by loved ones, she can receive a "kind death" from doctors that care. Unlike colloquial uses of care, here, Pat references a relationship which is not defined by medical interventions to elongate life. This paper argues that presence and touch – both physical and emotional – can produce communal practices and ethics of care which challenge traditional expectations of biomedicine.

Keywords: Death, Assisted Dying, Care, Love, Touch, Intimacy, Laughter

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Introduction

One week after she had accompanied her mother for an assisted death in Switzerland, Jennifer sent me an email with an audio attachment. The audio is the last fifty minutes of her mother, Anabelle's, life. Jennifer had recorded the event for her own records, and with Anabelle's consent, had sent it to me so that it could become a part of my archive. There is something intimate about the phone recording – the device, nestled in Jennifer's bag for the entirety of her mother's death, was on the floor between the two women. It picked up the dialogue, laughter and tears, but also the movement of clothes and arms as the two women repositioned themselves. In the last five minutes of her life, as she waited for the pentobarbital that she had just drunk to kill her, Anabelle breathed deep deliberate breaths coached by her daughter and two Swiss volunteers from *Dignitas*. On the tape, you hear these four breaths inhaling and exhaling together until, finally, Anabelle stops breathing and Jennifer begins to cry.

This article is situated within a larger ethnographic project which examines how new spaces and ethics of care are emerging when confronting death in this setting. During my fieldwork with people planning and preparing for their assisted deaths in Switzerland, I observed how individuals made decisions about their death, including affective and aesthetic considerations. The historian Shai Lavi (2005) presents euthanasia as the ultimate technification of death. In Lavi's narrative there is an almost inevitable progression in the management of death from the realm of the church, to the hospital, and finally to self-determination and human will. He describes this movement as one from "art" to "technique," where the latter refers to mastery over the world. Contrary to Lavi's analysis, I suggest that a defining aspect of assisted death is the imagined construction and performance of a deathbed scene which is reflective of the dying person (see Richards 2017). In other words, an example of what Shai Lavi describes as the *art* of dying where the whole world of a person becomes present when dying.

In this paper I ask: How does asking loved ones to help you die, to help you commit suicide, bend the limits of our relationships and perhaps of care itself? Drawing on ethnographic interviews with members of the British right-to die group *My Death My Decision,* I explore how affective and aesthetic motivations for an assisted death trouble biopolitical insistences on life. In doing so, I follow Mel Chen and Sara Ahmed who consider emotions to operate within "affective economies" and therefore draw individual and collective bodies together passing through and between bodies. Ahmed writes: "I am interested in the way emotions involve subjects and objects, but without residing positively within them" (2004: 119). To which Mel Chen adds: "If affect includes affectivity – how one body affects another – then affect, in this book becomes a study of the governmentality of animate hierarchies, and examination of how acts seem to operate with, or

against, the order of things" (2012: 12). Thinking with these scholars, I consider how seeking help with the decision to die is the reaction to a particular history in the transformation of death and dying in biomedical spaces. I then reexamine the concept of "passivity" to contemplate how assisted dying might re-order the expectation that death operates outside relationality and liveliness. This paper specifically focuses on what assistance looks, or perhaps more accurately, *feels* like. It questions if the desire for an assisted death in which bodies, actions, and decisions touch and are touched by one another is a demand which exceeds the boundaries of "care" as it manifests in the biomedical domain. Focusing on touch and situatedness, like Donna Haraway, "my premise is that touch ramifies and shapes accountability. Accountability, caring for, being affected, and entering into responsibility are not ethical abstractions" (2008: 36), rather, they are modes of address which call into question expertise, relationality, and ways of responding to death in the modern world.

My Death My Decision (*MDMD*) is a UK based campaign group which works to legalize assisted dying in Britain. I first began preliminary interviews with *MDMD* in 2019 and then, spent one year (March 2021- March 2022) in the UK and Switzerland immersed in the lives and choices of over 20 individuals either planning to go to Switzerland or with friends and family who have returned. In particular, I worked with five individuals, at the time of writing, four of whom are dead.[1] Unexpectedly, touch became a central aspect of many conversations. Whether it was the comforting hand squeeze offered to a dying sister, the gentle touch of a foreign doctor, or the tactless way that home-healthcare workers carried out a risk assessment, tactility emerged as a primary concern. Tact, is embroiled in expectations of class and codes of conduct as much as it is in affect and relationality. To be tactful is to be well brought up and to know one's boundaries: what is and isn't the correct mode of comportment. To be overly touchy-feely is generally not expected, or wanted, in British society – even in medical settings, the role of the physical examination has been diminished considerably.

Like other scholars on the topic, I found that the figure most associated with the right-to-die movement is white, for the most part middle class, and secular (Gandsman 2018). I observed a diffuse network in which support is given in terms of financial aid and, perhaps even more crucially, "know how" and expertise, through a relatively small group of centralized individuals. My inclusion to this network resulted in my interpellation to care. If I were to engage in ethnographic research here, I would also have to form intimate bonds and lend my expertise, support, and knowledge to those who needed it. I widen this network to include academic interlocutors alongside those I interviewed. In recognition of my role as an anthropologist within this network,[2] I consider this a genuine commitment to the concept of intimacy as a form of knowledge production grounded in relational

and affective bonds rather than extractive ones. I am working with a definition of intimacy which focusses on collaboration, embodiment, and affective sociality through which social life is lived and where situated and relational knowledge is gained (Raffles 2002)[3].

Guided by my interlocutors' anxieties, this paper makes a somewhat too crude dichotomy between two types of care; one which people I spoke to sought to avoid, and one which they saw as being possible through an assisted death. Marc-Antoine Berthod and a larger research team working on assisted dying in Switzerland have used Vincent Crapanzano's concept of "imaginative horizons" to render visible the production of desire in assisted deaths (2019). They argue that images and memories of other people's experience of death become part of a "negative imaginary". Through this terminology they draw their reader's attention to the way it becomes possible to appreciate assisted death as a possibility. I too commonly heard a comparison between what was imagined in hospitals and care homes and what was imagined through assisted dying. Where one form of care is linked to progress through idioms of cure, the other was articulated among my interlocutors through motifs of permission, finality, and love. A key difference between these kinds of care is the role that the body plays in the production of knowledge. On the one hand, there is a type of care where the body is objectified and transformed into an archive of information made legible through biomedical techniques (Mol 2003, Jain 2013). On the other, is an intimate and embodied knowledge which is co-produced by a multiplicity of actors.

Care has been linked to the production of knowledge by scholars who argue that we must attend to where and what we care about (de la Bellacasa 2017). In an article which develops the link between care and affect, sociologist Astrid Schrader, while examining the role of care in knowledge politics asks: "how to *begin* to care?" (Schrader 2015: 68, emphasis in original). Schrader argues that compassion becomes conceivable through the relinquishment of self-preservation and a recognition that vulnerability is something shared among all mortals. This, she argues should be the starting point to care and an understanding of this realization can teach us to *begin* to care. Despite working with many of the same thinkers and concepts as Schrader, my starting point is modestly but significantly different. Rather than asking how we can care *about* or *for* someone or something, I ask what it feels like to be cared for. Unlike work in STS[4] which speaks to the importance of understanding the entanglements of the world from the perspective of the care giver, or the caring scientist, this paper deals with how touch (and laughter as a sonic form of touch) become ways to assert oneself while inhabiting a position as an object/ subject of care. I argue that intimate care, that is to say an affect laden and aesthetic care, based in relational and collaborative demands, is a kind of care which maintains personhood and focusses on experience rather

than future benefit. This is not to say that care cannot or should not be directed to non-human beings, but merely to understand that as caring beings, we are also, ultimately cared for beings. My intervention in this article is therefore to elaborate on this dialectic form of care and subject formation and to propose a logic of care which attends to aesthetics and affect so that the dying person (the cared for person) can experience their dying. Through such an attention, we can begin to think through modes of care and address which resist the dehumanising or objectifying aspects of care (see Ticktin 2011).

Anaesthetic Care

I begin by exploring the opposition being created among the narratives I was told between a care which was *desired* and one which had been seen for dying parents or friends and relatives – a care which was referred to as inappropriate, or even, at times, torturous. Individual nurses or care workers were singled out as kind or helpful, however the general experience of dying in Britain was perceived as exhausting, cruel, and impersonal. It is worth noting here that the comparison being made here is exaggerated through the lens of fear and anxiety. I will introduce two women, Elizabeth and Emily, through whose experiences the term "anaesthetic care" will be explained. Elizabeth was one of the first people I interviewed as part of my PhD research. On the occasion that I first met her, she told me how she had become a member of *My Death My Decision*. Unlike *Dignity in Dying*, the most prominent British right-to-die group, *My Death My Decision* or *MDMD*, do not believe that there should be a terminality clause embedded in any law for assisted dying in the UK. This is of import to Elizabeth and signals some of her motivations. Elizabeth indicated that the decision-making process behind "going to Switzerland" was not only medical. She told me that she and three other *MDMD* members were planning a trip to Switzerland to get "a feel" for each organisation: *Dignitas, LifeCircle*, and *Pegasos*. The metaphor of "feeling" was introduced to conversations which might otherwise have been entirely bureaucratic or logistical. The need for such a trip – a recce as she called it – highlights the affective and aesthetic considerations made by my interlocutors. Reflecting on mood, feeling, and setting, those I worked with introduced considerations around the death bed which cannot be reduced to the desire to "master the world" through biotechnical means (Lavi 2005).

Running alongside this imagination of what she wanted her death to be and feel like, Elizabeth also recounted a memory of looking after her mum as a key reason why she was interested in assisted dying. The distinction made by Elizabeth between two types of care is one that I began to recognise as a pattern in my interviews. Elizabeth recollected the isolation and confusion she had felt when her

mother was dying. She had been left to advocate for her mum and to coordinate the local care services which were offered. Rather than experiencing this "support" as caring, the goal-setting style of targets which set "progress oriented" objectives was felt to be a managerial, bureaucratic ticking of boxes. "I mean," she said to me with evident frustration, "the woman was *dying*." As if she, Elizabeth, were the only one to notice. While caring for her mother, who needed at-home health visitors, Elizabeth witnessed the fulfilment of a risk assessment in her mother's home. At first, Elizabeth was delighted with this level of attention, until it came to light that the risk assessment was for the healthcare workers, and not for her mother. It was therefore perceived by Elizabeth as having little to do with her mother's care – "absolutely tactless!", she told me. Here Elizabeth's mother's death becomes part of the "negative imaginary" of dying in Britain.

Elizabeth's choice of language when describing her mother's death demonstrates how the care she experienced was disembodying: "tactless." That Elizabeth felt that the care provided had nothing to do with her mother as she knew her displays the lonely aspect of a kind of care which is both overbearing and, because it is directed towards an abstract patient figure rather than a person, displacing. The kinds of targets that Elizabeth told me about were all around improving her mother's ability to walk, even though it was clear that such targets would never be met and could become quite stressful. When the health care visitors entered her mother's house, rather than that feeling like an intimate form of care within the home, it was experienced as an invasion of public figures into the private domain. Despite being in her own home, her mother transformed into the figure of the hospitalised patient. Writing on the hospital as a total institution, Goffman has stated that:

> the patient is greeted with what passes as civility and is said farewell to in the same fashion with everything going on as if the patient weren't there as a social person at all, but only as a possession someone has left behind" (1961: 341-342).

This description resonates with Elizabeth's experience. Goffman is not referring to an identity which gets placed on top of the patient's previous identity, but to an actual stripping of personhood. The patient becomes a mask, superimposed onto the body of the person, who then performs her role accordingly.

My use of the word mask is intentional – not only does it adequately invoke the performative nature of subjectivities, it also suggests a depersonalisation of the body by which the face no longer acts as a plane of identity and communication. Under the medical gaze, the body, rather than the face or voice, is used to discern the truth. More precisely, the inside of the body is mined for evidence of

disease, prognosis, or improvement (Mol 2003). The body is then related to and interacted with as an assemblage of parts no longer best known to the person who inhabits its skin but instead, one which is dependent on medical expertise and technology to be rendered legible (Draper 2002). The dissonance of becoming a mask – of literally losing face – is a dispossessing feeling resulting in profound disembodiment and loss, of self, and of bodily, material presence. The othering of one's own body and the dependence on doctors to "read" meaning into the body in institutionalised settings of hospitals, hospices, and care homes therefore leads to an experience in which one is no longer in control of their body in a double sense. The first is the standard explanation for an assisted death which could be found in talk radio shows, newspaper articles or Facebook accounts during the time of my fieldwork. Often described as a loss of dignity; the loss of control of one's body and particularly the loss of control of one's bowels was perceived by almost all my interlocutors as unbeatable (see also Norwood 2009 and Ramierez et al. 2014). The second is a loss of control over how one can communicate. It became apparent that this fear of losing face is also entwined with a subtler loss of control of the body. That is, a form of control as it relates to self-determination and control over what the body means and represents. This second fear is a response to the way in which the body in the hospital – or in a pseudo hospital like setting – becomes an indicator of ailments rather than a marker of identity. Losing face, experienced as losing one's name and one's person is best explained by Emily.

Emily was a sixty-something year old woman who suffered from Parkinson's; at the height of the COVID pandemic, she was hospitalised after a fall. While in hospital, Emily says she felt "trapped in [her] bed" and was given little to no personal attention. She recounted one unpleasant experience in which she was unable to move and had "the choice" of defecating in her bed or in her lunch box. Towards the end of the interview, she told me that she didn't think that anyone in the hospital had called her by her name. This gesture was the thing that was left hanging as unforgivable, almost more than anything else[5]. She emphasised this moment to impress upon me the feeling that it didn't matter who she was in the hospital just that she was a patient, the care that she received was organised around her body rather than her as Emily, as a person. Like with Elizabeth's mother, Emily is speaking about the material experience of being a body in hospital as a space where the senses, as a mode of perception, are overridden by medical discourse and technology. Under such a regime, there is a separation of person and body, where the body becomes a medical instrument rather than an assemblage of sensorial perception.

These stories were related to me by Emily so that I could begin to understand why she was choosing to end her life through an assisted death. In both Emily and Elizabeth's explanations we can see the emergence of the negative imaginary of

death, that which I am describing as "anaesthetic care". Anaesthetic care[6], as I am imagining the term, is the combination of a particular relationship between doctor and patient, alongside an experience of profound disembodiment. It is epitomised by the image of the anaesthetised patient. It is not a form of abandonment, rather a desensitisation of care. Anaesthesia has the effect of arresting pain and numbing the patient's body. The first successful demonstration of surgical anaesthesia was in 1956 and marked a shift in the values and ethics of the time: pain was no longer thought of as religious punishment but was now perceived as a biological phenomenon which could be controlled by medicine; it had become secularized (Caton 1985). Pain and consciousness were managed to such an extent that the surgeon no longer had to concern themselves with showing empathy to the patient and could focus entirely on the task at hand—saving life (Buck-Morss 1992). With this shift, the body itself changed in its very materiality. Or at least, the body in the hospital (Mol 2006) Indeed, training doctors to see bodies as parts to be mended, as opposed to persons, is a process that medical students must actively learn and struggle with (Good 1993). Anaesthetic care is a feeling many of my interlocutors described when justifying or explaining their own logic of decision making shaped the "negative imaginary" (Berthod et al. 2019) of many of my interlocutors' expectations of dying in Britain.

The anaesthetisation of care is bound up with a larger history of medicine which has been studied by medical anthropologists who have noted the transformation of death into a technical problem – or biomedical failure. Writing on dying in modern American hospitals, Sharon Kaufman argues that "the bureaucracy of the health care system does not allow the *person* to age and then die" (Kaufman 2005: 83, emphasis in the original). Through work in a modern ICU Kaufman considers how the focus on saving life has transformed death into something which can and should be mastered. However, because of the fact of death, this mastery is never complete. The result is that death is considered an external threat to the body which ought to be fought off (Jain 2013). Death is pushed as far away as possible to conserve life at any cost, the quality of this life is not of concern to biomedicine which simply sees death as a "failure" (Illich 1980, see also Livingston 2012, Farman2013). Kaufman's work demonstrates how a final choice regarding treatment is given to the patient or the patient's family. At the crucial moment when the patient slips from the realm of the living to the futile position of the terminal patient, doctors step back and the obligation to "choose" how to act is thrust on to kin, leaving them alone without the expertise of the hospital. As Kaufman and others have shown, this means that death is approached shamefully and without any institutional support (Corwin 2010). "Care" in both Emily and Elizabeth's narratives was not perceived to be caring. In large part this was due

to the lack of affectivity felt by either of these women who had become "patients" rather than people.

Another woman, Pat, also revealed a desire to die which emerged from a prior experience witnessing deaths in her family. In the same interview, she articulated what could be different with assisted dying. Pat told me, in an exasperated tone, that her mother was "tortured to death with care" and that her cousin became unrecognisable through continual interventions to elongate her life. "I've got a cousin of ninety-something who… actually suffered sepsis earlier this year," Pat explained to me.

> Well, she managed to be brought back from that. And she's even worse now. She can hardly…. she doesn't get out of bed in the nursing home and she's in a nappy and I can't tell you how smart this woman was, you know? In her dress, her appearance, everything about her. And how vibrant she was. And this is what society has brought her to. 'Cause they keep fixing her!"

Like most of the respondents that I interviewed, Pat was contrasting these two differing types of care. One was a numbing, repetitious, deadening form of care – one where there was no space for "vibrancy". While the other was one that she imagined for her own death. In addition to pain management, my interlocutors paid attention to presence and the construction of a personal dying scene. For Pat, for example, of key import is the ability to die with others present, particularly her children. She tells me that she has seen a video of an assisted suicide and that if people could see "that family can be a part of it" then people would "understand." I asked her to explain the video to me. She paused and said: "It's the kindest most loving thing you will ever, I think, witness." I asked her why:

> Well, the doctor in charge: Errm, the person who is going to die is in bed…there are a few tears perhaps, I think she – the doctor - would say something like: "Well how do you feel? Do you want... Do you want to go ahead with this now?" Something like that. And she'll say: "well, take your time, if you want to stop, you stop and just not do it." Things like that go on and she holds, it was a man, she holds the man's hand, and she… when he starts to press it she says; "it will be alright," she's stroking… it's a really…
>
> [At this point, Pat starts to choke up.]

> Sorry - I'm getting a bit emotional here, it's a really kind way she allows them to go, and I wish that people could see somebody, it's very hard. I wish people could see that...And the other alternative to that is, I wish I could have taken a video of [how] my mother died, and the way things were for her.

Pat begins to cry at the point she describes the doctor's use of touch in her comforting of the dying man. It is an embodied disposition and form of care which is not present in the lonely decision-making so familiar to Pat. It is quite clear from the phrase "the way that she allows them to go," referring to the doctor, that the emotive part of this video is not that the dying person has gained ownership or control over his death. The doctor is *allowing* him to go through kind words, by stroking his body and through relating to death with sensation; through skin-to-skin touch, which enables the personhood of the dying patient to linger on past what is allowed in the anaesthetic setting of biomedical care as we currently understand it, where physical contact is minimised and life as an entity of its own is overvalued. In the video, it is precisely touch, this holding of the hand, which allows the dying person to remain present up until the moment of death, this makes the experience both kind and loving.

Animating care through touch

The remainder of this article will demonstrate how my interlocutors appealed to touch to experience their death, or the death of a loved one, as an intimate and personalised scene. I will explore how the process of assisted suicide manifests a form of care in line with Joanna Latimer's call for care as "being-with", thus emphasising a collaborative aspect to care (2013). Latimer, also concerned with the care offered to the elderly in the UK, suggests a need for forms of embodiment and relational practices in UK care homes. She describes how currently, "care" in care homes for the elderly is conflated with provision, leaving the elderly lonely and isolated. Latimer urges a movement away from care as matter of conduct, towards care as matter of being-with and being-in-the-world. She notes that the current assumption of frailty in the elderly population is in fact *produced* through the current infrastructures of what she calls care-as-provision. Care-as-provision is defined for Latimer as a limited response to the elderly. Latimer writes that even when care is "directed at maintaining face, self, and choice" (2013: 45), it forecloses creativity, vitality, and relationality". For those I worked with, assisted dying was constructed as an event through which to resist this type of dehumanising and depersonalising care.

At the heart of the desire to die an assisted death conceptualised in this way is a rejection of the biopolitical insistence that life is worth living at any cost. The attention to love, kindness, and permission outlined by Pat indicates that Lavi's (2005) conception of euthanasia as the ultimate technification of death does not tell the whole story. In contrasting the art of dying with dying as a technique, Lavi contends that euthanasia became thinkable when dying moved from being a private matter in the home and church to a societal concern where life and death became modes of governance through biopolitics. Like Goffman, Lavi introduces the identity of the patient as a depersonalising figure. To die as a patient, Lavi demonstrates, make it impossible for death to be an art. He argues that medical euthanasia is the ultimate technical mastery of death in part because it is articulated through a language of autonomy and human mastery over the natural world (death). However, as we have seen, the assisted deaths that those I worked with were looking for, cannot be captured by a language of mastery, control, or technique. Where we will agree with Lavi on the beginning of his argument, that the right to die is a reaction against "the growing invasion of medical technique" (2005: 164), I suggest that a closer look away from the "negative imaginary" that makes death thinkable and towards what is desired, will lead to a different conclusion from Lavi's.

To do so, we must consider the meaning of art and aesthetics. Rather than a discourse of beauty, the definition of aesthetics that this article works with is more clearly defined as a bodily reaction. "Aisthisis" writes Susan Buck-Morss, "is the sensory experience of perception. This original field of aesthetics is not art but reality — corporeal, material nature. As Terry Eagleton writes: "Aesthetics is born as a discourse of the body." It is a form of cognition, achieved through taste, touch, smell, hearing, seeing — the whole corporeal sensorium." (1992: 10). Buck-Morss, drawing on Terry Eagleton, is not thinking of aesthetics through taste, but rather through experience. Aesthetics then not as a "sensibility" but as that which is sensuous. What might an art of dying look, or feel like, through this lens? I suggest that when considering aesthetics as a business of the sensorial, the opportunity for death to resist the biopolitical insistence on life and reject the technification of the management of dying becomes possible.

In Mel Chen's (2012) book on biopolitics and racial and queer mattering, they argue that thinking in terms of animacy redefines the boundary between the living and the dead. Reconfiguring what they term "animate hierarchies," Chen draws their reader's attention to the networks of connection, impulse, and attraction which are rendered visible through an appreciation for animacies. "In its most sensitive figurations," they write, "animacy has the capacity to rewrite conditions of intimacy, engendering different communalisms and revising biopolitical spheres" (Ibid: 3). So, how could we engender the dying body with a form of animacy,

therein sparking a sense of experience, liveliness, and almost magnetism? To do so, is not only to "transgress proper intimacies" (Ibid: 7), it is also to highlight configurations of care and attachment which do not presuppose the inherent value of life. A focus on animacy, vitality, or vibrancy, rather than life, thus offers the opportunity to appreciate a response to dying in which an ethics of care does not exclude death, but instead might provide opportunities to turn towards death as a fact which demands attention even if it cannot be changed (See Rose 2012). To turn towards death rather than away from it, generates an encounter based in being *there* despite not being able to change the course of events.

Unprompted by me when I asked, one man, Vincenzo why he had chosen to die at Life Circle rather than one of the other two centers, he described the tactile nature of Dr. Preisig, who runs *LifeCircle*. Vincenzo, who has early onset Alzheimer's, clarified that when he says that Dr. Preisig is tactile, he doesn't necessarily mean physical touch. Even though for Vincenzo tactility is literal, he appreciates that this might not always be the case. However, he does link tactility with empathy.

> Okay, so what does Erica do that's different? … When Erica's there, she's very tactile. Not necessarily tactile, just by touch. Because some people wouldn't like that. I accept that. I'm fine with touches, just like, again, that's Italian Irish. … So it, it's just kind of empathy doesn't have to be said. … In fact, I think it is best demonstrated. And I think that's the same as being tactile. It's something that you can see in a person without them actually giving you a big hug.

Dr. Preisig's body language and manner is cited as the way in which this empathy is shown. For Vincenzo to consider empathy as tactile, is to appreciate the relational aspect of touch. In an exploration of Reiki and "therapeutic touch," Mark Paterson argues that there is an ambiguity to touch. "Such sensory experience," he writes, "is emotive, active and passive, shared in and between bodies; affective" (2005: 162). By bringing affect and touch together in this way, Paterson is emphasising a form of touch which is expressive, through which empathy is invoked. Thinking of touch as both active and passive he brings relationality to the forefront in understanding that touch is an interpersonal experience which, while asserting the boundaries of two distinct things, is also a "gesture [which is] both given and received" (Ibid.: 166). Here, reception of care as touch is equally important as giving. This allows being touched to remain an active and chosen state and provokes re-considering the taken for granted hierarchy of action between touching and being touched. What is therefore accentuated by Paterson is a desire to "feel with" wherein therapeutic touch is differentiated from professional or

task-oriented touch. Consequently, tactility acts as a form of resistance against the objectifying medical gaze.

To offer one's touch is also to be touched and to enter a relationship of exchange. This suggests that the assistance in assisted suicide is grounded in sociality rather than expertise – the goal, so to speak, of this form of care is not cure but instead provides the opportunity to have others be implicated in your death. Vincenzo's clarification that he is talking about an act of love also exhibits an intense quality to tact. Writing on the benefits of thinking through touch, Maria Puig de la Bellacasa argues that touch not only evokes a specific and forceful reaction, it also brings with it an affective charge: "Starting with being touched – to be attained, moved – touch exacerbates a sense of concern, it points to an engagement that relinquishes the distance of detachment" (2017: 300).

A tactile relationship therefore brings people into being and offers precisely what anaesthetic care denies: 1) a relationship between doctor and patient as people with complex personhood and 2) an embodied sense of self. For Vincenzo, "care" is not quite a forceful enough word, and he turns to love in search of a death which enables him to be sure that he is known by those around him. What Vincenzo means by tactility is a kind of communication which is not reduced to words, symbols, and meanings. As Vincenzo explains, "It's not a medical procedure, it's an *ACT of love*. It's an act of compassion. And it's an empowering act that she's assisting you but gently and at your pace and at your level." The emphasis here is on the way that Dr. Preisig's manner and stature allows her to respond to her patients in an intimate way. The effect of these affective and bodily ties is that the dying person appears to experience his or her own death. Love is empowering because, in Vincenzo's mind, it emerges from an "affective economy" (Ahmed 2004) of sharing and respect which is absent from the medical gaze. His good feelings about his future death emerge with and through Dr. Preisig binding them together. Rather than the relationship of observation and prognosis identified in the section on anaesthetic care, here the relationship between Vincenzo and his future doctor is characterised through the binding qualities of love. Much as Latimer proposed, we might think of this as an act of "being-with". Through Dr. Preisig's groundedness and connection to the patient, the dying person is given the opportunity to, or to use Pat's phrase, is "allowed" to die an easeful death. Although material presence is vastly important, tactility refers to an embodied relationality which fosters sensorial strategies for knowing and acting.

Intimacy as care without futurity

I only met Rick once, but we spent three hours discussing his sister's death at *Dignitas*. For Rick, the ability to be implicated in his sister's death was thought

of as exceedingly positive and provided forms of intimacy that had previously been foreclosed by their relationship. Though Rick definitively defines his sister's death as a good and caring experience, the journey to *Dignitas* was, in his words, anything but peaceful as their plane was unexpectedly held at the airport and their taxi driver got them lost. In fact, there was a comic tragedy tone to his account:

> Rick*:* It was all the very opposite of the calm send-off that you're expecting. It's so bizarre that we actually started to see it as quite funny. It was beyond chance and we just burst out laughing. I mean we'd gone through embarrassment, pain, indignity, and this is just a complete… Americans have a word for it: Clusterfuck! [wiping comic tears] Clusterfuck is exactly right. That's exactly what we were living. And it was one of those happening before our very eyes. Anyhow. I don't know how many suicides they do in a day…But. It was quite clear that we ought to get on with this [still laughing].

After listening to music, discussing their childhood, and going for a walk in the garden:

> Jane said "I'm ready" and we went in and she took the medication and erm… er… I think she then got on to, not a couch, a low bed, I held her hand. Really tightly. And she squeezed back really tightly. And after 20 to 30 seconds her grip slackened. After a minute there was no grip at all. I realised that she was completely unconscious at that point. Erm... I carried on holding her hand for about another 5/ 6 minutes.

At which point, the two Swiss helpers—one male with better English, and one female, with a more "empathetic aura"—came back into the room and they confirmed that his sister was dead, "completely dead." In Rick's description of his sister's death, he described the importance of music and their morning spent listening to some of Jane's favourite tracks. Through sensorial engagements with sound as well as the experiences of eating and laughing together, the night before Jane died, not only does Rick extend Jane's deathbed scene to beyond the moments just before her death, Rick was also able to conjure up a memory of this time which is for him entirely related to his knowledge of Jane as who she was in life, rather than as a shell of herself or an anonymous dying person. The whole sensorial is called upon in the retelling of this scene. Rather than reconstructing Jane's life through songs and memories alone Rick demonstrates a kind of knowledge which is not language-based but image and sensate based. This is what Michael Taussig (1992) would describe as tactile knowledge. Taussig makes a distinction between

sense and sensuousness, where tactility refers to an appropriation of knowledge in a distracted, peripheral manner. For Taussig, tactility is a mode of everyday apprehension of knowledge; we see in Rick's description a primacy placed on this intimate and everyday kind of knowledge over the knowledge generated in biomedical settings which rely on depersonalising statistics (Farman 2013, Jain 2013) and the objectification of the body (Sharp 2000, Mol 2003). Disability rights activists imagine an ethics of care that displaces the expert and transforms the doctor-patient relationship. Such thinkers offer the opportunity to reimagine hierarchies of (Mingus 2011, Hedva 2018). Interestingly, "helpers" was the term Rick used to describe himself, his wife, and the volunteers in Switzerland. We see in Rick's narrative a reframing of who and what counts as an expert or expertise around the death bed.

By demanding an aesthetics of death which does not subscribe to a sterile touch, my interlocutors are placing an emphasis on presence and intimacy. In such a way, the present moment is more important than any futurity. As Vincenzo once told me: "It's about process, not the product."

> Rick: Jane's grip was fading so quickly it was obvious that she was on the way out and that was a comfort to know it was quick and, er, you would certainly need that. You would need to be in touch with a person. Literally in touch. Yeah. I mean I think touch is so much more, vital than say.… Reading their favourite poem or whatever it might be. Yeah…
>
> Miranda: Had you had a tactile relationship before her death?
>
> R: NO! No no no. British Middle class: You don't touch family [laughing]. Only if you trip over somebody accidentally. No no no.
>
> M: You said when you described her death before that you both squeezed each other's hands tightly?
>
> R: Yes
>
> M: Were things passed through that squeeze?
>
> R: Yeah, she squeezed back. I mean, I've got quite a strong grip and women don't usually have a very strong grip. But she was gripping back yeah. So, it was supportive and I knew that, and I kept it going and then

> it was obvious that she was under. Yeah -so that's probably one of the few times in my life when I touched her.

Almost without taking a breath, Rick then told me about a serious motorcycle accident he had in his twenties which left him unconscious for three days:

> R: I remember waking up to find there was a nurse just gripping my hand…… [under his breath] critical. Absolutely critical. Really was. [choking up] Can't say how important that was. Clinically, utterly irrelevant I mean, I had been unconscious but to wake up to that comfort: absolutely vital, yeah [whispering]. So, what had worked for me, as a recipient, I hoped might be equally helpful.

In the passages quoted above, there is a desire by Rick for a certain type of touch. Rick continues to hold his sister's hand after she dies. He notes the apparent contradiction that touch in this context, or in the context of his own accident, is "clinically irrelevant" but also "vital." What might this vitality be when we are talking about a relationship in which one is conscious and the other is not? Rick himself is unable to make sense of his decision to hold his sister's hand because, as a practice, holding hands is perceived by Rick as strange and counters the idea of his British, masculine identity. He has let me in on a moment of vulnerability and intimacy which even he wasn't quite expecting to do. In order to understand how this touch might be "vital," we must approach the word in a new light. Vitality, which is used to connote strength, energy, and activity, is not a word that often describes death and the moments immediately after. To return to Chen, to do so is to re-order hierarchies of animacy. Queer theory, particularly work on femme sexuality, has approached the topic of power, passivity, and receptivity in a useful way. Examining butch-femme discourse, Ann Cvetkovich (2003) argues that submission is an action. "The sign of intimacy," argues Cvetkovich, "is not having to say everything, being granted the dignity of refraining from the trauma of rehearsing the pain and humiliation again" (Ibid: 66). Here, Cvetkovich is detailing the subtleties of not doing or saying things which are equally as important as things that are done and said. What is important is the relationship between two people in which space is created for vulnerability and withdrawal. Cvetkovich illustrates how intimacy is not a space where there is no trauma or pain, but how it is a space where that trauma can be creatively responded to. In the context of assisted death, the re-appropriation of submission and passivity allows us to understand how intimate touch is an adequate response to death and dying.

Based on his own experiences of being held while unconscious, Rick consciously chose to hold his sister's hand while and after she had died. He did

this despite the fact he had no conception of the afterlife or the fact this was one of the only times he had touched her in their adult life. In an act that was entirely unprecedented and which even he cannot fully understand, Rick and Jane chose to override the invasive and traumatically penetrative gestures of medical care: her oxygen tank, future intubations, perhaps even a feeding tube, for a far more passive response to cancer. Although her death was organized by, and saturated with, Jane's desires and sense of self, her final moments can be characterised by a relationship with her brother which was not typical of their dynamic. Reconsidering passivity allows us to further complicate what it means to choose something, in this case death. Because of touch's immediate and processual elements, immanence is valued over transcendence, thereby avoiding both biomedical and religious interpretations of death as nothing but suffering. It's worth noting that touch is not limited to physical touch. When I discuss "touch" and "tact," I'm referring to a sensation that is both affective and communicative. What's important is the sensuousness of touch, which follows a logic that can intimately relate to that which is unknowable without attempting to explain it. Care in this mode is not concerned with diagnosing and treating, it is opened to something *else*. Lisa Stevenson's ethnography on imagining care outside the biopolitical limitations of "saving life" grapples with this topic in a section entitled "song" (2014). Stevenson looked for "forms of recognition that did not depend on knowing the 'truth' about—or fixing the identity of any person" (Ibid: 157), Stevenson is searching for an ethical way of *listening*. Tactility offers a similar form of recognition. Pain is still present, along with fear and suffering, however through an insistence on a social death which is brought about through laughter and touch, death and dying becomes less individualised; it becomes, in a sense, shared.

Another woman who was preparing to go to Switzerland used laughter in a similar way. In part because of COVID restrictions and in part due to some embarrassment over her physical deterioration, Fran and I conducted our weekly conversations over the phone. They always began with the same scene: I would ask her how she was, and she would say: "pretty terrible," followed by laughter. As well as being a coping mechanism, the laughter opened a space for me to be part of her life and her pain. She could not share her pain with me, but humour and laughter were a contact zone where we both could gather. Laughter enables a meeting point and a communication which does not have to be restricted by sense-making or patterns of thought. Laughter is, or can be, in its very nature surprising and eruptive (Macphearson 2007). For Bataille, laughter can disarm predictable and rational thought (Bataille 1985). It is excessive, extreme, and opens up a space for non-thought (Botting and Wilson 1997). Laughter, much like crying, is corporeal, its at times inappropriate and unexplainable bursts force the body to materialise affect even before it is processed by the mind. Its infectious

and animating properties give laughter a tactile quality. Laughter can be thought of as a kind of auditory caress, one which Yvon Bonenfant argues requires a redefinition of listening and exchange:

> If sound can be understood to act very much like touch, and to exist on the haptic register, then vocal sound can be understood as a kind of intimate, human-generated touch. The vibratory fields that we create when sending our vocalic bodies out into the world touch others. They reach; further than our fingertips (2010: 13).

Laughter, as an intense form of vocalic touch, operates in precisely this fashion. It demands a form of listening and understanding beyond syntax. It is a social sound which elicits a response. A familiar laugh can also be all that is needed to identify a person or a voice; it resonates with us through vibrations which touch us and simultaneously bring forth a smile as well as, perhaps, memories which are then brought into the current frame. The ability for this sonic touch to move us in our memories eschews any idea of linearity in terms of the passing of our lives.

Like touch, laughter and humour operate in a temporality of the present, of the here and now. Care in the mode of humour places greater emphasis on notions of presence rather than productivity or improvement. As Mordechai Gordon notes, "humour involves the temporary suspension of practical concerns in order to feel pleasure and be amused" (2012: 113). There is an attention to play and a non-instrumental focus to humour which has an intrinsic value regardless of external goals or further justifications. In his examination of humour and aesthetic education, John Morreall writes that "in the aesthetic or humorous frame of mind, we are not locked into looking at things in just one way, but are free to shift our perspective, several times if we choose, to see things and even to build fictional worlds" (1981 59). When Rick told me of the "clusterfuck," noting "that it was as if someone didn't want this to happen," he was using humour to reposition his own perspective and allow for multiple emotions to be present in that same moment (his desire to support his sister, his willingness to assist in her death, and his sadness and stress at helping her to die). Laughter was a way of sharing Rick's emotions with me as an outsider and relative stranger, as well as a way to make sense of Jane's death in an organisational structure which did not demand coherence and allowed for a multiplicity of affects and which shifted hierarchies of value normally associated with the desire to keep death at bay (Illich 1980).

Conclusions

Let us return to the scene I opened with, Jennifer and Annabelle breathing with the volunteers as Anabelle ends her life. As they breathe in together Jennifer and the volunteers instruct Annabelle, coaxing her into the rhythm of her last breath. In this act, Annabelle looks to the experts for help and the guidance that she receives comes equally from her daughter and the volunteers. A similar rearrangement of expertise occurs with Rick who refers to both himself and the volunteers as "helpers". The sounds on the tape that Jennifer sent me tell me that Jennifer is physically close to her mother, but the breath itself can be considered a form of touch in the sentimental definition of the term. I asked at the outset of this article how asking loved ones to help you die effects those relationships and care itself. Using ethnographic context drawn from over 12 months in England and Switzerland, I have explored the relational experience of care. Through an aesthetic reading of assisted dying, I have argued that care for dying can be an embodied and relational practice. Touch emerged as passive actions which though not changing the course of events, allowed my interlocutors to feel supported.

How do we reconcile this approach with the focus on autonomy and individuality that is so prevalent in modern discourse of assisted dying such as that of Shai Lavi who considers the technification of modern death as movement away from the art of dying? Judith Butler, considering the sequence between vulnerability and acts of resistance, argues that bodies (and thus people) are both "supported and acting" (2016: 15), Butler offers a perspective from which autonomy need not be separated from relational personhood. Similarly, Carolyn Dean, in her discussion of dignity and atrocity photographs, suggests that "injurability might not preclude autonomy" (2015: 255). Both Dean and Butler draw attention to a feminist political subject who is both embodied and interconnected. This politics of care embraces the idea that, as finite and vulnerable beings, we are always already intertwined with others. Intimate knowledge of our own needs can lead to an obligation of care. To reject the reading of assisted death as a technique becomes an invitation to consider how helping someone die is, in Vincenzo's words, an act of love. From such a vantage point death might become a moment where acknowledging our limits opens for a more inclusive form of care.

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Endnotes

1 Due to the nature of my project, I had to ensure that my research plan was in accordance with the ethics review committee at The New School for Social Research. In addition, while in the field, I took care to let those I was working with lead the shape of their involvement in my work and the direction interviews took. I was aware that my role as a researcher should not intrude on the situations I was a part of, in particular at moments where I was witness to people dying.

2 I see this article as an ethical mode of address; an anthropological form of storytelling which aims to produce diverse ways of considering secular death without attempting to "fix", "know", or "solve" death. By widening this network, my work in this setting provided a space through which my interlocutors were able to continue to experiment with their own perceptions of their deaths and choices.

3 Useful texts on the concept of intimacy include Berlant (1998) on attachments and the making of worlds, Latimer and Lopez Gomez (2017), and Raffles' (2002) definition of intimacy and intimate knowledge.

4 See Martin et al. (2015) for an overview of this literature.

5 For an extensive discussion on "anonymous care" see Stevenson 2014.

6 My attention to the intersection between medical care and the sensorium has been influenced by Dr. Abou Farman's work on aesthetics and synesthesia (2019), which highlights the regulation of the senses and the resulting production of apparently self-possessed and bounded subjects.

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