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# DIGNITY THROUGH TOUCH FOR AN ETHICS OF CARE: PANDEMICAL TALES

ABSTRACT: Six women came together to write this paper. Two from Norway, two from Italy, one from England, and one Italian living and working in England. Their aim was to experiment with writing a collaborative auto-ethnography to share their personal stories about people whose life events at the time of the pandemic resulted in a loss of dignity. They attempt to reveal the importance of dignity, and of touching-non-touching in the lives of elderly and unwell people who lack the resources to demand the rights and respect they deserve and have earned. With varying academic backgrounds, the authors welcome the complexity this creates and learn to speak with a single voice, aware that differences will remain. The authors are feminists who lean towards a new materialist and post-humanist stance, and they explore the importance of this in this text.

KEYWORDS: collaborative auto-ethnography, loss of dignity, touch, new materialism, posthumanism.

# How our collaboration began

Poems and pebbles, I wrote in my mind this morning, thinking of all the personal stories from the night before. Different shapes, with different colours, soft or hard depending on the circumstances in which those stories were formed. They are like pebbles on the beach, creating sounds, rolling together, touching each other constantly, shaping each other, finding ways to sit side by side (From Berit Bareksten's notes, Bømlo, 8th December 2022).

There are six of us writing this article. Two come from Norway, two from Italy, one from England, and one is an Italian living and working in England. We are experimenting with writing a collaborative auto-ethnography, coming together to share our personal

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stories about people we know (or knew) whose life events at the time of the pandemic, resulted in a loss of dignity; learning from each other through this process. We seek to reveal the importance of dignity, and of touching-non-touching; to show how these (or their lack) are significant in the everyday lives of the elderly and unwell who lack the resources to demand the rights and respect they deserve and have earned. We come together from varied academic backgrounds, share differing viewpoints and experiences of the world, and welcome the complexity this creates whilst recognising that although we may learn a lot, may adapt our position(s) and learn to speak with a single voice, historical differences will remain, maybe only partly resolved. We are all feminists, leaning towards a new materialist and posthumanist stance, but how completely and how readily this is embraced remains to be further explored within this article.

Our research together began during the pandemic, in 2021, spurred by a conference workshop on dignity and intimacy led by Berit and Inger Helen<sup>7</sup>. Indeed, the Covid-enforced confinement played a considerable role in focusing our minds on our own situation and that of elderly, and not so elderly, relatives isolated even more than usual by government dictate and fear of infection. We began alone but, as Berit wrote, we became pebbles that rolled together story by story, through working in parallel. Firstly, we wrote solo, then shared these personal narratives, meeting online regularly to dig deeper into this challenging material, finding links between stories of our mothers, grandmothers, daughters, in-laws, our children and our siblings; and, of course, ourselves. We widened our net to embrace them all before narrowing down to draw out the threads that form our *macramé*<sup>8</sup>, for our combined stories are knotted together to form a single text. The individual strands become a shared entity, a collaborative composition (Formenti & West, 2018) that traverses the borders of country, class, age, gender. We pruned unwanted strands and added new ones, tying new knots to achieve a level of universality without losing intimacy.

We wrote freely initially, only later considering supporting theory, as topics emerged within the work. Our writing became a space of inquiry (Richardson & St Pierre, 2005) where knotting, unknotting, and reknotting, as in macramé, refined the combined text that completes this article. But first we share our experiences of the pandemic, whose privations spurred our tentative beginnings into life.

<sup>&</sup>lt;sup>7</sup> The Life History and Biography Network Annual Conference 2021 (LHBN) of ESREA (European Society of Research on Adult Education), Wrocław, Poland.

<sup>&</sup>lt;sup>8</sup> We find *Macramé*, a 'method of crafting a textile that uses several knots to form the basic shape and function of the piece', a useful metaphor for our work (See Thomann, 2024).

## **Our Starting Points – or Individual Contexts**

Gaia recalls: When the COVID-19 pandemic started in March 2020, I was in Milan. We were about to leave for the yearly Life History and Biography Network conference in Canterbury, near London. I remember chatting with Silvia and Laura whilst listening anxiously to the radio in my kitchen.

We decided not to go. We risked getting stuck in a hotel room, which we would have, since the borders with Italy were quickly closed. I have fuzzy memories of the following months. I spent it alone in my flat in Milan. No social memories to support mine. It allowed me to take a pause. It was terrifying to pause. But I started to practice a new pace. Slower and deeper. Fragile and real. I called my family everyday which we do not usually do. In the evening, I would keep the windows open and hear the sound of the tram on the main road two blocks away. I followed groups online, learning about singing, theatre, group dynamics, poetry, and drawing, joined friends' groups – feeling active without moving, feeling alive with others. These synchronised me with others but, overall, it was a time of reflection.

My mother, after Covid, started to reach for the past, researching and writing her family history, and through this her relationship with grandma got lighter. My mother printed copies of her book and gave me one. It presents my lineage, the maternal connections through three generations of Italian women. Whenever I look at it, I am touched by the memories we share.

Sylvia, also in Milan, found solace in meditation: Every afternoon I lie down on the floor with my back flat on the tiles. The weight of my body tells me the seriousness of the situation. I feel an unevenness in the shoulder blades. I inhale and exhale and something gives. I inhale and exhale and the tension in my shoulders loosens. I inhale and exhale and feel the weight of my head, the width of my back. I inhale and exhale and feel myself surrender to the force of gravity. Now it is the floor that supports me, and this feeling generates comfort in me, a subtle sensation, tied to the body.

This is the way I have found to make the anguish of suddenly finding myself in a pandemic, liveable. Lying on the ground, I am alive and healthy in Milan, firstly forced to limit my travel, then to stay at home. In these unexpectedly still days, punctuated by the sound of ambulances and the spring chirping of birds, I listened silently, as inside me grew an awareness of the fragility and uncertainty of our lives, up close. I learned to feel the suffering for the illnesses, deaths and disasters that seem to await us, finding some solace in nature, bonding with the blackbirds we feed on the windowsill.

I found time too, to mourn the loss of family members, my aunt, and my grand-mother whose caring touch, so important to me, is still sadly missed.

Donata writes: Covid for me was a brutal experience that left an indelible sign. To start with, like everybody else, I was incredulous, and I was uncertain, scared, unfamiliar with all the guidelines that kept changing from day to day. I was a bit in denial. I was also glad to stay at home, to share time-space with my husband and my son, not to travel across London every day to go to work. I was happy to slow down. To put some order in my files, to sort out things I left behind. To dedicate time to myself and to my body. I did a lot of sports, I looked after myself. I cared for others, for the community surrounding me and my family.

Then the storm arrived. My beloved brother in Italy contracted Covid during its second wave. He was already frail, having had cancer the previous year. He had undergone a very heavy chemotherapy treatment that left his immune system fragile and unable to fight the virus. He died after two weeks in intensive care. We could not see him. We could not touch him, nor say a final goodbye. My life drastically changed. I am not the same any longer. Covid changed me and opened a wound that does not seem to heal. It was, and still is, a reality for me, not just news on the radio or tv, but a lived experienced that changed my perception of reality and of myself, now without a brother to guide my way in this world.

From Norway, Berit decided: I need to start by telling my mother's story, for it overclouded mine, when we lost touch in all meanings of the word, during the pandemic. My mother was in a care home, beyond my touch, no visitors allowed, only medical staff. I found her someone, a physiotherapist who could touch her for me, restore her connection to the world through touch and in that way seek to give her dignity.

But moving on from her story, I have asked myself; how did this work start? As a kind of wonder or puzzlement? Or from tremendous anger about how we treated the elderly in their own homes and in our care institutions – during (and indeed before and after) the pandemic.

When I write, metaphorically in my story, that my mother became a stone, she wasn't a stone all the time, or towards everyone, but I saw huge changes in her way of behaving towards the world, when I saw her online. I saw a hard attitude towards everything that surrounded her, I saw the softness of sorrows and loss underneath the hard shell. She was, for her, in a totally inappropriate place. She was suffering from isolation, and my mothers' suffering became the lens for me to look upon the sufferings of the world, in the time of pandemic.

Inger-Helen too struggled with not being able to care for a loved one as much as she would have wanted to. She reported: During the pandemic, following my divorce it was my daughters who had the right to care for their elderly grandmother on their father's side, not I, for I was long divorced from this husband and had lost my right to

intimacy with this woman I still loved immensely. The most I could do was to support my daughters to do the caring.

Trust between mother and daughters begins in the womb but can arise later, as with my mother-in-law who gave me the support I needed when my girls were born. I found solace in Marjan De Coster's writing about being both mother and doctoral student; I recognize such conflict. De Coster's supervisor introduced her to relational ethics, showing her how mutual recognition of the limits to our accountability and a collective performativity can lessen the ethical burden we face in times of crisis. To withstand the pressures of neoliberal governance, we need an 'alternative script'; one that promotes openness and challenges the normative business ethics of exchange, allowing an unburdened ethical female subjectivity to emerge. (De Coster, 2020, 751).

Like my mother-in-law we need to open our doors, our hearts, our fridges and refrigerators and share what we have with others whether that be ice-cream (as in her case), caring, or caresses. We need to value each other and stay in touch to feel alive.

In contrast, for Hazel and her mother, the pandemic led to too much contact, too much intimacy. She reflects: Covid in the UK piled new fears on top of concerns about BREXIT. We had a government that many of us distrusted that overnight dictated every aspect of our daily lives, also a cause for concern. For my elderly Mother who lived nearby but on her own, independence was lost immediately, never to be regained. And daily, the TV News spread the gloom.

By nature, I was a toucher, to let others know I care; a scavenger who collected stones, sticks, flowers when I walked outside, a fidget who regularly pushed her floppy fringe back from her face. These actions were risky, habits to unlearn overnight if I wanted to stay safe, and very difficult to discourage in the older generation whose needs were pushed aside, leaving many to die from poor or lack of care. The message from the hospitals was keep your grannies away, care for them yourselves. In our 'bubble' of socially permitted contacts we had an ageing 'toddler', unpredictably demanding, despairing, defiant or desperate who grasped the headlines but not the nuances of life as reported and suddenly wanted (and needed) all the services no longer on offer and steadfastly refused when signing up had been possible. Enforced isolation pared away her stamina, her social awareness, and her *joie de vivre* and was to become a long-term issue.

As Berit saw, and Yeats' claimed in his poem, Easter 1916, "Too long a sacrifice, can make a stone of the heart" (Poetry Foundation), and the pandemic petrified us.

# Picking up the common thread

Those are snatches of the stories we wrote, as we strove to find ways of coping. Stories that rose from their individual *land* scapes to inhabit a shared collective *memory*-scape

between the sea and the mountains, a place where our relatives could gain, through narrative, the dignity they had lost, as we worked together in Norway in December 2022. We retold a brother's, a grandma's, a mother's story as we wrote as daughters, sisters, friends, and colleagues, pulling threads from three different countries, with different cultures and *times*capes, into a universal tale. But this comes later, when we have examined the frameworks that underpin our stories, the meanings we give to and take from terms like dignity, touch, and caring and their ethical practice, and our leaning towards New Materialist and Post-humanist perspectives, the key knots in our *macramé*.

#### How we frame our narrative

## The Dignity Knot

When Berit and Inger Helen ran their workshop at the 2021 conference, they shared a humorous but carefully constructed video performance of two fictitious elderly sisters (acted by Inger Helen and *her* real sister) talking before and after lockdown. This provoked the question: What is dignity? And we were each asked to offer a word or thought in response, and later to contribute ideas to the Google Doc from which this article arose. Contributions were often concrete, examples rather than aspects, revealing dignity to have many dimensions, as the literature confirms.

Starting close to our topic, Lennart Nordenfelt and Andrew Edgar (2005), reporting on their *Dignity and Older Europeans Project*, claim that dignity can be modelled in four ways, relating to merit, moral stature, identity, and *Menschenwürde*, the inalienable dignity of human beings. This seemed relevant to our work, and we also learned that the first three were relative values, the last, an absolute quality.

Looking within philosophy, we saw that dignity is much debated but remembered that we only need to know a little of this. We are academics and practitioners in nursing and education, whose interest is a mix of the personal, as we care for the people around us; and the professional, as we work in sectors where dignity seems an important concept but lacks a shared and unequivocally accepted definition. Exploring the term for our own purposes through secondary sources, we found Michael Rosen's Benedict Lectures on Dignity at Boston University useful (Rosen, 2012). Rosen discusses the term's frequent, if uncomfortable, linkage to human rights and draws attention to critics<sup>9</sup> who feel the term lacks meaning, echoing Arthur Schopenhauer's earlier and controversial complaint that it had become "the shibboleth of all the perplexed and empty-headed moralists" (Schopenhauer, 1965); in other words, a term without any real meaning, used to claim an undeserved superiority. Furthermore, Rosen points out

<sup>&</sup>lt;sup>9</sup> For example, Joel Feinberg and Jan Narveson (1970); Ruth Macklin (2003).

(as we had already realised) that the lack of a single distinctive meaning, stable over time and accepted by all, itself encourages scepticism.

We took a coffee break, and then, refreshed, carried on reading... and learned that Dignity once used to signify high *status* worthy of respect (by the Romans, *and* until the 19<sup>th</sup> century, the Catholic Church). It was used in a much more egalitarian fashion by Immanuel Kant, who inhered to humans an "*unconditional*, *intrinsic value*" and issued the famous statement that "*human beings should always be treated as ends and never as means only*", a view that we fully embrace. We learned, too, that the meaning of Dignity *remains* contestable. Indeed, Rosen traces the development of distinctive strands and presents "three quite different meanings" that are still significant today: that dignity is not merely restricted to human beings; that dignity can be aligned with higher status (perhaps construable as merit); and that dignity concerns *behaviour* that is respectful; indignity a lack of *respect*. This latter meaning is vital in our work.

Feeling tired, we stopped for lunch before continuing to read... and found that furthermore, Kant views dignity as an 'inner' and 'unconditional' characteristic suggesting an alliance with *identity*, and that is not tied to religion. Dignity is, however, concerned with *autonomy*, a characteristic that seems, in part, to equate to *Menschenwürde*. As Kant writes:

Dignity is something that we all have in virtue of the "humanity in our person" and this founds duties of mutual respect and *self-respect* [our italics] (Kant, Ak. 6:436, cited in Rosen, 2012: 27).

In our work, autonomy and self-respect are important, too. Thus, for us, true *dignity* requires recognition that all humans have *unconditional intrinsic value* and a right to *self-autonomy* and should show *respect* and maintain *self-respect* in their *behaviour* towards others. We include non-humans, too. But now we consider Touch.

#### The Touch Knot

Seeking a theoretical basis for touch, Donata led us straight to Karen Barad, to her article "On Touching – The Inhuman That Therefore I Am". Barad (2007: 3) points out that "Touch, for a physicist, is but an electromagnetic interaction... [one] with no actual contact involved", before using the principles of quantum physics to present a physical world that enables an infinite sum of possibilities; one where our 'selves' are defined in relation to others (as Derrida, 1993 had earlier argued), for touch, too, brings the self and others into co-existence.

All touching entails an infinite alterity, so that touching the other is touching all others, including the "self," and touching the "self" entails touching the strangers within (Barad, 2007: 7).

In exploring the physical nature of touch, Barad gives it a scientific grounding. She also seeks to show all touching to be equally valid (her comments in parentheses make

this explicit), and we concur with her desire to promote equality and diversity by sharing an accepted framework that supports this stance. But we also understand that one of the premises on which quantum physics stands is that of virtuality, "a kind of thought experiment the world performs" (Barad, 2017: 4). As a theory, it supersedes others that work less well for contemporary society, but still relies on supposition.

That Barad has the academic credentials and linguistic skills to present and argue her viewpoint is not contested, yet Inger Helen and Hazel were, and still are, ill at ease with a framework that reduces 'life' to its physical origins, wary of a philosophy that, once again, foregrounds the scientific as the major explanatory force. But maybe in arguing that the infinite range of possibilities justifies the inclusion of all, Barad is offering quantum mechanics up to posthuman philosophy, harnessing the physical sciences to serve a human belief system instead?

Sylvia's views of touch are more gently phrased, although also founded in scientific (biological) knowledge. She reminds us that touching is a double action, it is relational, it creates a connection between the inside and the outside of our bodies. She describes touch according to the Feldenkrais Method that she practices in her work (Feldenkrais Method). This sees the touch of another person as enabling us to have an image of the parts that are being touched, thus drawing our attention to body parts that otherwise remain obscured in our neurological image: it is knowledge of self through the other (Rywerant, 2003). Barad argues similarly when speaking about intra actions (Barad, 2007).

In somatic movement (Bainbridge Cohen, Nelson & Stark Smith, 2012) and through touch, separate biological systems coordinate and create one synchronised system (*e.g.*, heartbeat and breath, facial expression and voice are all affected when a change occurs somewhere). A person moves, and through touch, another witnesses the living body of the other moving. In the Feldenkrais Method (Rywerant, 2003), the teacher guides their pupils to experience movements that reactivate sensitivity in the supporting skeletal structure of their body. Having guided experiences in caring allows people to experience behavioural states of calm that enable them to engage in high levels of social interaction; and are the basis of health.

Like all mammals, the human child learns to structure its own identity and to relate to others through touch and physical contact (Porges, 2011). Without this, s/he faces serious developmental difficulties, perhaps to the neural mechanisms that allow symbiotic regulation of behaviour and reciprocity of care. But touch need not only be human to human and during the pandemic the acquisition of pets soared as lonely people sought physical *and emotional* contact (Ho, Hussain and Sparagano, 2021).

#### The New Materialism and Posthumanism Knots

#### New materialism

New Materialism, by asserting the importance of the non-living in shaping lives challenges human dominance, Posthumanism further decentres humankind. The stance that materials can have agency independently of human actions (Bennett, 2010) and that these actions may have bearing upon worldly phenomena' (Forman, 2020) reflected, somehow, our experience. In our work, materialities of the body, objects and artefacts, the landscape, the physical phenomena of illness and ageing, were central to all our stories; touch and feeling and their absence, also important. So too, were the systemic restrictions (structural materialities?) governing human interaction; institutions, visiting and caregiving, indeed, touch and contact of any sort, were particularly constrained during the pandemic.

We acknowledge the strengths and limitations of this position, what Sonia Hazard (2019) identifies as: its *brand* role in providing theoretical rigour, a shared set of concepts and a sense of belonging (although, she argues, exclusionary to spiritual believers and people of different ethnicity); and its *generative* role of encouraging new ways of thinking about the mutuality of the animate and inanimate world; and this does make us think more broadly. However, to acknowledge is not to accept. In challenging the dominance of *human* choice and values, might the New Materialist perspective be seen as disempowering, too? And should the caring human merely accept negative materialities or strive for improvement? Important questions.

#### **Posthumanism**

Posthumanism challenges the dominance of the human species, pushing the boundaries within and beyond the human 'to formulate new spatial philosophies and politics' (Lorimer, 2009). Certainly, we find it important to recognise the rights of others and of other species, and acknowledge that the world is becomingly increasingly technologized, like it or not. Environmental crisis and media coverage have brought the fragility of the Anthropocene and the consequences of historical inequalities into stark focus, raising awareness of the need to think and act more inclusively and to recognise differing cultural practices, to protect habitats and conserve and share resources, and make changes to exorbitant lifestyles. While some deny causality or claim to be indifferent to global threats, few can be unaware that such issues exist.

Within our group, the balance between living and inanimate matter remains a challenge, and perhaps the role of technology in modern life. We are differently dependent on 'devices', partly along age lines, but not exclusively so. This would be too simplistic;

values and choice are relevant. Some technologies support lives, others may constrain them. Hazel rejected the notion of cyborgs (in the sense of humans being constantly contactable) in an undergraduate text about urban planning many years ago. She can no longer recall which publication it was, but clearly remembers the perturbation it caused her. She remains unimpressed with people becoming too dependent on technology. For her, there are issues too, with granting status to AI. Paranoid androids (like Marvin in The Hitchhikers Guide to the Galaxy in Adams, 1979) belong to the realm of satire, not reality. Humans need to *care* more and more *care*fully, not delegate responsibility to 'things' that were created to assist the living.

And this leads us to 'Caring', perhaps the topic most important to our work. We turn to Nel Noddings (1999), to her seminal treatment that makes visible its emotional aspects. We are interested in *caring* with its implicit *for* or *about*, not *care* that includes the possibility of detachment.

# The Caring Knot

Nel Noddings' clear relational explanation of caring from 1981 (Noddings, 1999) remains an excellent exposition. She sets out the circumstances that enable caring, providing structures and language with which to discuss this, but leaves space for readers to apply these ideas to their own contexts, as we do when meeting face-to-face.

She explains that caring cannot be perfunctory or obligatory but freely given if it is to be accepted by the person needing care. To be caring we have to 'feel with', to make ourselves 'disposable' (available) to the other rather than tell them what to do or see them as a problem to be solved. For Noddings caring is built on positive interactions and both parties, carer and care-recipient need to respond in a positive way if it is to be of benefit to the person needing care.

Very relevantly for us, Noddings considers institutional 'care', claiming that this is achievable within education but unlikely within social 'care'. She accepts that society can structure care – by supporting carers, by allocating funds, by legislating in helpful ways, by encouraging employers to allow flexible ways of working – but society itself cannot make itself 'disposable' to others, only individuals can do that. When the group decision that 'something must be done' replaces the individual commitment that 'I must do something' it leads to prescriptive forms of 'care' that leave the care-recipient feeling *un*cared-for. Noddings states that society should enable those who *do* care to do it better and more easily and make the task less onerous. She writes:

I would like to suggest that institutions, agencies and large groups should not undertake what is clearly impossible for them to accomplish, that is, they should not try through any rational transformation to care directly (Noddings, 1999: 53).

These are strong beliefs that have largely gone unheeded by society, and we feel the consequences. Both Berit and Donata saw their loved ones pass into this *unc*aring institutional 'care', a care home for the elderly and a hospital. Inger Helen's situation was difficult but more fortunate as the caring actions of her daughters and other close family members prevented the need for her mother-in-law to enter an institution. Gaia, too, was one stage removed from carrying out care, seeing the relational aspect that Noddings focuses on develop as her mother and grandmother forged a stronger relationship during the pandemic. For Sylvia, the physical caring was professional but on a one-to-one basis, the emotional caring re-ignited by a photograph. Hazel relates particularly to the comments about commitment and 'feeling *with*', finding that over time, when her mother had no-one else to turn to, this became exhausting, made more difficult as physical care needs upturned the parent-child relationship.

Berit and Inger Helen had no choice but to observe those, they cared about at a distance (even watch them turn to stone), Donata was denied even this. All three had to cede the caring to others, leaving painful memories that are hard to address. As Sylvia and Gaia found, photographs and booklets serve as foci for remembrance and celebration of lives lived but do not resolve traces of loss and emptiness that remain. Telling stories can compose differing meanings and emotions into more complex and open pictures. Through sharing, talking, and writing, our collaborative project at least enables us to make better sense of these losses, to think about them and the people we are losing or have lost with the dignity they, and we, deserve.

Having others to turn too, can make the difference between coping and caring as can shedding masculinist traditions of stoicism, independence and self-sacrifice and this relates not only to the elderly, as Marjam de Coster (whom we 'met' earlier), reveals. She felt challenged, caring for her own baby and found support in relational ethics (de Coster, 2020). We six found similar support through relational exchange, through the work we undertook together, the friendships forged during long walks, long talks in Norway over bottles of wine that were refreshing in several senses of the word. Reconsidering performativity (Butler, 2005) we realized that recognizing 'the right performance' is not enough. Like Noddings, de Coster rejects the detached 'care' that society endorses and claims that in the pandemic people failed to problematize accountability and accept that it is not an individual responsibility. By adopting the female role of coping and caring alone when inside we are struggling, we sell ourselves short. Instead, we need:

...a space where an unconditional acceptance and recognition are fostered ... where the limits to our accountability are recognized ... and where the openness and generosity constitutive of the female ethical self are denaturalized (De Coster, 2020: 749)<sup>10</sup>.

## De Coster proposes:

a caring, relational and collectively performing subjectivity that ... stands in sharp contradiction with the rational, calculative and individualized subjectivity that is constituted under contemporary neoliberal academia (De Coster 2020: 751)<sup>11</sup>.

We concur with this approach, see its broader relevance, but wonder if we will ever achieve it, even while we recognise that women working together have accomplished a great deal over the years.

#### The Ethics Knot

We have already discussed Noddings' work which addresses Care/Caring from a philosophical standpoint but now consider psychologist Carol Gilligan's somewhat controversial conceptualisation of the 'Ethics of Care', explored in her 1982 book *In a Different Voice* and updated through a 1993 *Letter to Readers* to capture "the ongoing historical process" (Gilligan, 1993). Neither theorist is cited by de Coster, someone coming newly to this field.

Working alongside Laurence Kohlberg in 1967, Carol Gilligan began to question his assertion that women were capable of less sound moral judgement as they generally achieved lower scores than their male counterparts on his six-stage model of moral development. Gilligan attributed this to Kohlberg's framework being built entirely from data collected from young white male participants and valuing the male lenses of rights, laws and universal principles as a consequence. Later labelling this model based on impartiality and rationalism an 'ethics of justice', she sought an alternative, collecting evidence from a female population instead (NWE, 2022).

Working in parallel purposely, Gilligan retained Kohlberg's three key stages of Pre-conventional, Conventional, and Post-conventional (Sanders, 2023). However, her model followed a different trajectory at its highest level, valuing interdependency and caring for others, favouring emotional commitment over reason, humanity over abstract principles and impartiality. Gilligan recognised the importance of contextualisation and her alternative 'ethics of care' model, valued compassion, responsibility, and relationships, seeing the family as the primary focus, unlike the ethics of justice framework that sets it aside as a 'private' realm.

<sup>&</sup>lt;sup>10</sup> De Coster here is claiming support from Marianna Fotaki and Nancy Harding (2018); Judith Butler (2005); herself and Patrizia Zanoni (2018) and Rosalyn Diprose (2002).

<sup>&</sup>lt;sup>11</sup> De Coster here is citing De Coster & Zanoni (2018).

Gilligan's work was well-received; women felt their views had been acknowledged and legitimised. Its publishers claim the book "started a revolution" but her work was also challenged, for its alignment of care with women – what Joan C. Tronto terms a "strategically dangerous position for feminists" as it enables inferiority (Tronto, 1987: 646); the subordination of women (Kroeger-Mappes, 1994); and, also, with regard to its evidence base<sup>12</sup>. In her 1993 *Letter*, Gilligan obliquely deals with both of these issues by challenging the question of "whether gender differences are biologically determined or socially constructed", a question she finds "deeply disturbing" as it fails to consider "voice". She asserts that, "without voice, there is no possibility for resistance, for creativity, or for a change". Turning to relationships, however, she clearly states that these require "emotional stamina ... a strength of women" which leaves her position more tenuous (Gillligan, 1993).

Gilligan's work was of its time, it drew attention to women's views, a step in enabling social change. Recently, in her 'update', *In a Human Voice*, Gilligan argues against the binary thinking that she formerly supported, perhaps making a claim for currency: "By splitting reason (masculine) from emotion (feminine) ... the self from relationships, the binaries undercut our ability ... to navigate the social world" (Gilligan, 2016: 16). The 'different' voice is now deemed human, a caring alternative that challenges the values enforced by patriarchy that silences women and isolates men emotionally. Thus, care ethics becomes "an ethics of liberation" (Gilligan, 2023: 110). Arguably, the new book is more of a response to criticisms of her earlier work and a re-working of those ideas, for it stops short of embracing new ways of looking. Care, in a more general sense, has become a central facet of Posthuman theories. As María Puig de la Bellacasa showed, to really 'care' presents challenges to contemporary paradigmatic thinking, that, in the Western World is still dominated by Neoliberalism (Zaman, 2024; Rutar, 2023)<sup>13</sup>.

The reclamation of care in approaches to more than human worlds marked by technoscience is a political project that defies the traditional ethical boundaries that have marked critical thinking (Puig de la Bellacasa, 2017: 17).

Furthermore, and, relevantly, talking about the Covid pandemic, Rosi Braidotti (2020) stresses the:

need to develop different ways of caring, a more transversal, relational ethics that encompasses the non-humans. . . . The affective and social climate we are in calls for humility, cooperation, and is antithetical to syntheses and to authoritarian anthropocentric injunctions (Braidotti, 2020: 466).

<sup>&</sup>lt;sup>12</sup> See Christina Hoff Sommers (2000).

<sup>&</sup>lt;sup>13</sup> Anis Zaman (2024) clearly states that 'A neoliberal market-based governance system has engulfed Western democratic societies' (opening sentence); Tibor Rutar (2023) presents a more nuanced argument.

Society slowly inches forwards but there are no certainties. As society embraces posthuman values, the need to question the ethics underpinning care becomes more essential, not less. We need to make sure that 'care' translates as 'caring' and widening the focus does not simply lead to less interest in the 'messy' living things that age and wither, and cannot always be fixed by experts, through mechanical, technological and/ or financial intervention. We urge caution, too, that the meaning of 'human' as linked to humanity is not lost in the newer bigger pictures being painted.

Under systems of New Public Management (Hyndman & Lapsley, 2016) where cost-effectiveness dominates visions for society, and care and education are viewed as commodities rather than essential services, these trends already carry consequences in terms of growing poverty gaps and poorer mental health (OECD, 2020). Feminists (like us) try to address ethical concerns, and foreground caring and consideration in everything we do, whilst remembering the needs of the 'carers' too.

We are mindful of Norwegian philosopher, Arne Johan Vetlesen's (2010) claim that there have been huge changes in the notion of ethics within both our public health systems and in our field, education, as the pressures on these have increased. He shows how nurses and teachers are 'doubly constrained' by (trapped between) the requirement to do more for less reward; their responsibilities increase but not the rates of pay or time allowances. This leads to action paralysis, difficulty in deciding what to do. When all tasks become urgent how does one determine priorities? What can safely be neglected?

During the pandemic, formal care provision deteriorated (ESN, 2021). Those unwell and/or elderly, unable to care for themselves, suffered most and we were witness to that but unable to change things much, if at all. Fears for personal safety and restrictions imposed to curb the spread of disease led to a loss of caring as society struggled to find new ways of living and working.

It was difficult but we were resourceful – when society failed our loved ones, we searched for private solutions... and sometimes, like Berit, found them. At other times we found solace in writing out our thoughts, and in this instance, we achieved this together – and share our story with you now.

#### Life behind closed doors,

#### To care and not to care in covid times

It is midday on Saturday. It is a cold-not-too-cold, sunny and bright winter day. I/we are in Norway. I feel disorientated, a bit lost in this new landscape. In this new mountain-seascape. There is snow, there is water, there are mountains. For me as I grew up these landscapes were very separate. Either you had snow and mountains, cold, freezing weather, or seawater and sand, sun, hot weather. The two could not be together. Now

I am learning to see this water-sea-snow-mountain assemblage in a different way. I am part of it, we, the six of us, are all part of it, yet we are experiencing this differently, we are living this mountain-sea-memory-scape differently. Our own personal stories, our memories merge with the sea-mountain-landscape in different, yet similar ways. We bring to this entanglement, to this *macramé* of thoughts, our individual lived experiences, constructing at the same time our new collaborative experiences, our new memory-scapes of being here together for a few days. In this new togetherness, in our collective work of re-constructing memories through and with dignity.

Memories come to my mind, very fluid, sweet memories. Sharing them with my co-writers make them alive, again. I can feel their presence here in the room with me, with us, merged with our own memories. Mothers, grandmothers, daughters, brothers and sisters. A flow of togetherness, no one any longer distinguishable. We are motherhood-daughterhood-sisterhood all at once and much more. Does it matter whose story it was originally? Does it matter whose memories belong to whom when we write together? Yesterday evening, we actually said, my mother resembles your mother... when you were speaking about your grandmother, I thought she was mine. Shared, lived experiences through generations, time-space-matter. Knitting together on a sofa, sewing stories together, cutting them apart, re-assembling them in an ongoing stream of consciousness of which the mountain-sea-landscape is a very important part, like this wooden house, warm, cosy, protecting, containing our stories, our secrets from the outside. Now, we feel ready to share our stories, our memory-scapes. We feel ready to let our own personal story go, to let it loose, able to merge with the other stories in one new entity. Doesn't matter who is who anymore, we are togetherness in this creative writing, in our attempt to do academic work differently, with care, with dignity and love, from the past through-with-in the present and beyond.

My mother was a creature from the sea. She was born next to the sea, the warm, hot sea, the very defined Mediterranean Sea. She loved the sun, the warm, hot weather. She found herself living in the mountains. In the well-defined, cold mountains, far from the sea, yet not too far. She learned to love the mountain-scape, gradually accepting she belonged to the snow-mountain-coldness of the place she decided to live in for love. But she never stopped longing for the sea, the light blue sea, the sun, the hot weather. Belonging is a verb. It is made of be- and -long. To be, to exist, and to long for. Stillness and movement. She was like that. She was in both places. She learned to be in the mountains, at the same time longing for the sea, yet belonging to both. She is no longer here, yet she is now here with me in this sea-mountain-scape. In this memory-scape. We are here together. We be-long together. She never stopped remembering her sea, not even when her memory was fragile, the sea was there, always. My father, instead, was a creature from the mountains, but that is another story. I am both, and I gradually

learned to accept their coexistence, like here now in this sea-mountain-scape that is disorienting me, yet I feel be-longing to it.

Stories of fragmentation and loss of dignity in our families are not easy to talk about. We feel ashamed because we are just as vulnerable as people at the margins of society. Grandma had never told her story. She says: 'my daughter wants to tell my story, see my village, it is my daughter, she has fun with these meaningless things, so impractical, funny woman!' My grandmother has lived a century, five regions, she is the last child of seven. She never felt beautiful, she had no friends of her own, she never drove, but she was very happy. During the pandemic, my mother recorded a series of phone conversations with her mother while she was isolated in a room in a nursing home for the elderly. She then transcribed the texts and printed a book with photos in a few copies for friends and family.

My mother's story during the pandemic is one of fear and loneliness, as it still is for most of us. Maybe she became a stone to protect herself? The void of not having people around, not even your children and grandchildren, grew bigger every minute, hour, day, and week. If someone turns to stone, too full of feelings to relate to others or themselves, no longer able to find either dignity or respect, what then?

Stay distant No touching It's contagious No touching

My mother-in-law, my children's grandmother, has always helped and cared for us. So, this is a story of intergenerational reciprocity. But then slowly she became old and sick. She has had cancer for eleven years now and needs care herself at the age of eighty. They look after her. She is confused 'is it eleven o'clock in the morning?' she asks. No, 'it's four o'clock in the afternoon', they answer. She asks again and again, they answer her again and again, trying to make her less confused. Grandmother's daily life is filled with home nursing, medicine, a focus on sickness and needs but her two grandchildren give her glimpses of hope and a tremendous amount of love. Her grandchildren now help her – physically by touching her, washing, and massaging her feet, doing her hair, and manicuring her nails, and emotionally by giving her small gifts, baking buns for her, and trying to make her laugh.

The physio met her respectfully and with dignity. Rather than making her walk, he started to touch her legs and gave her a massage three times a week. He came to her 'home' and gave her a place to rest and talk about the most important things in her life, her children and career, continuing until he became seriously ill. Her weeks of full isolation (due to infected others) re-occurred several times during the year and

a half from March 2020 until she died in September 2021. Over the last two years she became untouchable, but he met her respectfully and with dignity.

Mother is reluctant to go outside much but with few remaining friends to visit, she dresses smartly for her own pleasure. When once she rejected most of the clothing that I bought for her when I shopped for myself, she now thinks differently. If I turn up with new items (especially sales goods) she accepts them with delight, no longer bothered that she has 'too many clothes already'. Rather than 'keeping them for best', she wears them. I find her next day, clean, coordinated and content, earrings more important than hearing aids and mask. For her, 'maintaining standards' more independently enables her to accept her changing circumstances and live again with dignity.

In recent months, I have looked at this photo many times. Mourning for the death of my aunt has re-awakened old memories and the empty space, never filled, where I miss my grandmother's caresses has returned to visit me several times. For me, her soap-scented caresses were the haven of my childhood. My grandmother, in the 'sixties at work. My grandmother, who in that photo must have been about fifty years old, is dressed in a white apron and stands next to a table in the retirement home where she worked as an auxiliary. She had told me when I was a child how she had dreamed of becoming a nurse but had not had the opportunity to study. She was very poor.

My brother died in a hospital in an intensive care unit, on his own on the 23rd of October 2020. We could not touch him; we could not give dignity to his death. Maybe the nurses next to him did. Maybe they cared for him with dignity. I was not there, yet I was. I touched him in my dreams, in my memories, in our family memories, in our mountain-scape. He too was a mountain creature, he deeply loved my mother, but not the sea. He never learned to love the sea. It was not part of him. Yet, he loved my mother, and me. He is also with me here now, with us in this mountain-sea-memory-landscape. Are we allowing men to enter our stories? He is not a daughter in our intergenerational collaborative female journey, yet he found a space here. He took care of my mother, to the end, always, with dignity.

NON si può entrare qui No touching DEVE stare fuori No touching Un-dignity.

## Where we pause for now

So that is our story, an intergenerational account of family during the pandemic that blurs the boundaries of individual stories to blend them into a single narrative about dignity and touch and caring during the Covid crisis. We capture a moment in history but believe our work makes a more general contribution to the ways in which society handles the problems of ageing and illness and what that means for family members who look on unable to intervene as they would like. This is not the end of the account but rather a halt. Like D. Jean Clandinin (2013: 201) we recognise that life presses on and when we research real lives, we enter and leave "in the midst". We can only enter a story already in progress and leave it a point further along the journey. For now, we bow out.

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