A World of Touch in a No-Touch Pandemic

Living with Dementia in a Care Facility during COVID-19

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ABSTRACT: Touch is essential when living with dementia for communication and remaining connected with the world, and it is also unavoidable when performing body care. Thus, it is impossible to think of living and caring for people with dementia in the absence of touch. Drawing from my ethnographic fieldwork conducted with therapy animals and people living with dementia in Scottish care facilities, in this article I argue that the public health measures taken against the spread of COVID-19 infections need to be reimagined by taking into consideration the role of touch. Furthermore, I try to draw attention to the lessons that we should learn about touch and the role of intimate bodily entanglements in dementia care from the high COVID-19 death tolls amongst British care home residents.

KEYWORDS: atmosphere, attunement, body work, dementia, sensory anthropology, touch

Her tiny hand, with skinny fingers like tree branches, gently pats my hand. Now and then, she straightens my hair and nods. I nod back and lay my other hand on top of hers. She is all a smile, a playful giggle at times, and holds on to my hand for as long as we stay next to each other. When I am on the other side of the lounge, she follows me with her deep brown eyes, and her smile fills up the room like the hot air in a balloon. When I come back, and she looks distracted or confused, I lightly touch her shoulder. She turns her head to me, welcoming me with her smile. Sometimes Rusty, the therapeut, joins our conversation. He greets us with his wet, curious nose, nibbling on some forgotten crumbs lying in Jean's lap. Jean bursts into laughter and reaches to Rusty's long fur. He responds to Jean's touch by turning his head for another stroke of his ears. At the other end of the leash, Jim, the human therapeut handler, sprints into our wordless conversation, holding back Rusty's ram-bunctious enthusiasm. He lightly pets Rusty to guide him in how to behave with Jean. We all converse in this bubble, emerging through our touch.¹

Most probably, Jean does not remember who I am, even though I have been spending quite some

time with her during my visits to Garden Views Care Home. But during my fieldwork, I developed a warm friendship with Jean despite her significant loss of memory and apparent loss of language. She has been living for a few years now with very advanced dementia at Garden Views, where I conduct my fieldwork for my PhD. Through my research, I try to learn how people living with dementia in Scottish care facilities and animals bond during Animal-Assisted Therapy (AAT) activities. In defined terms, AAT is an alternative form of therapy in which a domesticated or tamed animal – dog, horse, pony, owl, Guinea pig, hedgehog, etc. – helps with someone's treatment (Coren 2015), social isolation or living in confinement (Chandler 2012). Mary DeCoursey and colleagues assert that AAT 'may be the only available complementary therapy to offer therapeutic touch to socially and emotionally isolated people' (2010: 213). At the same time, touch transforms over time the intimate bodily encounters facilitated by AAT into human-animal bonding. As such, touch is built into, if not constitutive of, my object and subjects of an-

thropological enquiry into human–animal relationships even though it involves a terminal illness that triggers cognitive decline.

In my research, one of the aspects I am most interested in is how the atmosphere of the care home makes the symptoms of dementia better or worse, and how therapists may change this. As Mikkel Bille (2015) claims, the atmosphere is something that always must be felt and requires co-presence. Therefore, sensorial domains and embodiment play a fundamental role in my methodology. Through my embodied senses, I try to attune to how people living in care facilities experience their everyday life. In this, touch becomes the medium of conversations that attune bodies as if in a dance (Blake 2011; Manning 2007). This allows a refocus from a semiological/cognitive perspective of what matters to an embodied communication of ‘partial perspectives that attune themselves to each other’ (Despret 2013: 61). In attuning through touch, people become bodily *response-able*: capable of engaging in conversation. Furthermore, such attuning can contribute to creating a safe, secure place for bodies to interact in a comforting way. That is because attunement is ‘an intimate, embodied practice of engaging with the environment in ways that are highly sensitive to minute atmospheric changes’ (Kanyeredzi et al. 2019: 452). For someone with dementia, this kind of place and interaction might make a huge difference to how the condition is experienced.

In the following, I will try to show how touch is pervasive in dementia care: as a way of connecting when family ties are diminished or lost, allowing mutual engagement, and by being intimately entangled in body care as a condition of living. In designing the public health measures against the spread of the COVID-19 infections in terms of no-touch, I argue that people with dementia living in care facilities – one of the highest at-risk populations to infection and death from the new coronavirus – have been excluded. Finally, I advocate for reimagining safe touch during a no-touch pandemic through emergency actions, but also beyond the pandemic by radically transforming institutional care on a long-term, sustainable basis.

Becoming Kin through Touch

Touch is more than what lays at our fingertips. The anthropology of senses emphasises that how we perceive the world through our senses, let alone what the senses are themselves, varies significantly across cultures (Classen 1997). Nevertheless, even though

there’s no such thing as a universal language of touch, there is still something quite universal about it: it requires close physical proximity, a *co-presence* of bodies. Even more so, our whole body is covered in skin, our organ of touch, the ‘site of tactile sensation and social practice’ (Blake 2011: 3). As such, we live in and experience the world through the wholeness of our bodies, primarily as tactile beings.

Studies (e.g. Tempesta 1972) have shown how incredibly important affectionate touch is for newborns and infants in experiencing the world and learning about it. During the life course, we tend to take for granted, more or less, our opportunities to touch and be touched. However, when growing older, these opportunities can decrease dramatically (Hogstel 1985): children move to their own homes, partners and friends may pass away. In an even more dramatic way, as one study shows, residents living in long-term care facilities and their visiting relatives did not touch very often (Routasalo and Isola 1996). The atmosphere of the care home rarely affords the intimacy of touch in the same way as the familiarity of a home. Paradoxically, there is not much research about what comforting touch – or, for that matter, the lack of it – does at the other end of the life spectrum, especially when accompanied by cognitive losses due to dementia.

However, in practice, touch pervades all aspects of dementia care, albeit most of the time in a discreet way as a primitive sense strongly linked to memory and emotions (Nolen 1987); integrated in policies, training and guidelines of care, as well as in therapies (e.g., AAT, Touch Therapy); merged in the design of soft objects for sensory stimulation; and essential in providing body care. Touch becomes powerful, however, not only by being comforting, but also by being used as a tool for harm or abuse (Edwards 1998). In nursing and medical studies more generally, touch has been a topic of discussion for decades: they have highlighted its importance in communication; for offering comfort; for creating a safe space; and for being an expression of compassion, empathy, care and presence (Kelly et al. 2018).

There is a warm atmosphere in a home where those who engage in touch are connected as in a net of kinship. Aisha, a young care worker with an eternal lovely smile, told me that when she hugs the residents, she feels closer to her grandparents, who live in her native country of Uganda. In affectionately touching those she cares for, Aisha recreates her kinship network broken by physical distance. ‘This is what we need more’, said Shirley when Aisha hugged one of the residents. Shirley also lives with

advanced dementia, like most residents at Golden Age Care Home. Her two daughters live far away and can visit her only once a year. Before moving to Golden Age, she had two dogs, Stevie and Dingo, which she remembers fondly. The way she pets Bonnie the therapeut, I can tell how much she misses her past life, but also how touch reconnects her, as someone with very short-term memory, to the present. This temporal anchorage is, in fact, one of the therapeutic potentials of touch: it creates 'presence through the immediacy of sensory experience' (Pater-son 2007: 24). Although petting an animal should be acknowledged in its own right as part of our sociality and intimacy with other species, quite often this form of touch seems to substitute for the lack of affection-ate human touch.

Jean also has all her sons living abroad, but her dementia advanced too far to be able to articulate that she needs an affectionate hug. At times, indeed Rusty seems to fill up this hole in the kinship net. Doreen, a light-spirited lady, is one of the residents who recently moved to Garden Views when I started my fieldwork. She likes chatting, although most of the time it is difficult to understand what she is saying. Quite often, as sometimes happens when someone with dementia relocates to a care home or is hospitalised, she is very anxious, and her lovely face with doll-like eyes becomes contorted by painful crying. Janet, another resident, takes her hand and holds it between hers. 'This makes her feel better, you see', Janet told me. Janet herself has been diagnosed with dementia, and her cognitive losses seem more moderate. Yet, her gesture makes it possible to continue to care, to be a source of comfort beyond words, just like Jean holding my hand makes it possible to converse despite her advanced forgetfulness and lost language. Medical anthropologist Janelle Taylor speaks about how her mother living with dementia continued to show care, through an 'embodied knowledge of how to take care' (2010: 47), at times by simply patting her hand. In these gestures, there is a relaxing atmosphere around bodies that are worked on as part of institutional care around who cares and are cared for. Touch allows us to humanise these bodies, to acknowledge their continued embodied personhood and their ability to mutually engage in care and conversation. Janet is the one who taught me that Doreen finds comfort in holding hands, and to pay attention to it: to attune my touch to Doreen's anxiety. It is a lesson about the importance of touch, but also about advanced dementia and how to be a caring researcher in the field, which I learnt from someone living with dementia. When holding hands

though, quite often I feel that Doreen is the one who cares for me, making me feel at ease about my potentially intrusive presence.

'Can you hold my hand too?' Ian asked once when he saw me holding Doreen's hand. Ian is an imposing gentleman with an intimidating appearance. A glorious white beard covers his face, making his deep blue eyes even more shining. From the height of his specially tailored wheelchair, he extended his hand to me, suddenly making me think of the famous scene of creation in the Sistine Chapel. ('What if God lives with dementia in a care home, wandering around in a wheelchair?' I involuntarily thought in my head.) In reaching towards me, Ian not only drew me into relation, but also enabled 'the creation of worlds' (Manning 2007: xv): the creation of relations that re-invent those who *get in touch*. I took his hand and asked him how he was doing. 'Is Mary coming today?' he asked me. I did not know how to answer that, let alone who Mary is. But, in holding hands, he initiated conversation and recreated me into the image of a familiar person. In holding hands, we had become kin.

Entangled Bodies, Professionalised Touch

In institutional dementia care, touch is also present and unavoidable in advanced stages in another way: as professionalised touch performed daily through body care. In assisting with eating, washing, cleaning, dressing, walking – all of which involve a great deal of touch (Gleeson and Timmins 2004) – bodies of carers and residents become intimately entangled as a condition of living. This form of professionalised is called 'necessary' as opposed to 'non-necessary' (Routasalo and Isola 1996), and is also referred to as 'caring/comforting touch'. Echoing Michael Gleeson and Fiona Timmins (2004), I find this categorisation an 'anomaly': what criteria are used, and by whom, to deem touch as necessary and non-necessary? Moreover, what is the harm in asserting such a dichotomy? In practice, however, there is a transgression between 'necessary' and 'non-necessary' touch. In a beautiful article about the introduction of robotic lifting devices in Japanese nursing homes, James Wright (2018) speaks about how caregivers repurpose the touch implicit in daily care into a comforting act. Yet still, in safety protocols, touch remains divided between task-oriented, professionalised touch, and caring, comforting touch, with a concern for the overwhelming importance of the former (Gleeson and Timmins 2004).

Nevertheless, body care and its unavoidable touch do not bring only *care*. Body labour and touching bodies can also be a source of illness, infection and even death. When having fallen ill or carrying a virus, bacteria or microbe, bodies of workers can become a source of infection brought from the outside world and spread between residents. Conversely, the bodies of residents can become a source of infection for other residents or staff, potentially resulting in a shortage of body labour. This shortage puts a strain on the bodies of the remaining carers, and the extra workload can lead to reduced attention to detail, further injuries, or infection. The infection can spill, through the bodies of workers who become infected, into their families and their community. This tight entanglement between bodies in long-term care, where body work is the primary source of labour (Cohen 2011), is implicitly acknowledged in the organisational structure of these institutions. Each care home or care provider has their infection control committee, with strict protocols on how to address an outbreak. These protocols, however, are focussed on the professionalised nature of touch, most of the time omitting how to safely provide comforting touch. Despite these strict measures, infections in care homes spread like wildfire through the nature of care as a series of bodily entanglements. Without a proper way of protecting all of the bodies involved, care workers and residents can become, albeit in a different context to that described by Miriam Ticktin (2011), ‘casualties of care’.

A No-Touch Pandemic

On 12 March, the day after the World Health Organization declared the COVID-19 pandemic, most care homes across Scotland closed their doors to all external visitors, family members and therapists included. This measure was taken independently from the UK government (Asthana 2020), which at the time was still considering herd immunity, despite heavy criticism from public health specialists and organisations. The UK general population went into lockdown 11 days later (i.e. 23 March). A few days before, we watched, in disbelief, as Prime Minister Boris Johnson tried unconvincingly to reassure us that the threat of the virus was insignificant, shaking hands with hospital patients, some of them with confirmed coronavirus. After a few weeks, the Prime Minister fell ill with the virus, raising questions about his *careless* touch, catching and potentially spreading the virus. We have seen, in the poor example of the UK

leader, how infection through touch does not follow a political agenda.

There is overwhelming scientific evidence that the virus is much more likely to develop into deadly infections in bodies with underlying conditions, creating disproportionate risks for different groups. In this picture of starkly uneven ‘togetherness’, people living in care homes, most of them with dementia, have been hit particularly hard. In Scotland alone, almost half of all people who died from the novel coronavirus were care home residents (National Records of Scotland 2020).

The measures against the spread of the virus have politically and medically instrumentalised our bodies and their capacity to touch and be touched. The strategies for reducing the viral infections have transformed the world and our intimacy at an unprecedented level through no-touch guidelines. In public health advisories, the potentially lethal nature of touch in the transmission of SARS-CoV-2, the virus responsible for the COVID-19 disease, has been central. As such, guidelines were focussed on isolating bodies from touching and being touched by bodily fluids, particularly saliva, that carry the virus even in small droplets. However, bodies are not uniform, and what the lack of touch or the reduction to professionalised touch can do to people and their bodies is far from having equal consequences. A no-touch pandemic brings back into discussion the anomaly of categorising touch into ‘necessary’ and ‘non-necessary’. As caregivers become overwhelmed with workload, and relatives and therapists are not allowed to visit, most people with dementia are left without comforting touch, one of their primary means of communication and engaging with the world.

In an extremely moving story of dealing with physical separation during the pandemic, an American lady took up a dishwashing job in a care home to be physically present with her husband, living there with early onset Alzheimer’s (Bremner 2020). Following up on this story, I discovered a United-States-based Facebook group called ‘Caregivers for Compromise – Because Isolation Kills Too!’ The group members, who advocate family visits to care homes during the pandemic, offer thousands of incredibly heart-breaking accounts of the devastating decline of their relatives, most of whom live with a form of dementia. With almost no exception, touch features in their stories as the only way of maintaining meaningful contact and providing comfort. As we count the excess of deaths in care homes, most caused directly by infection with the virus, and others by the more insidious way of extreme social isolation.

tion, we are left with a plethora of issues that need to be addressed differently. Yet, there are fundamental lessons to sadly be learnt about what touch (or the lack of it) can do to people living in care homes, particularly to those living with dementia.

Towards a World of Safe Touch in a No-Touch Pandemic

As we moved online, in the safety of our homes, we aimed to keep our bodies safely out of touch but remain 'in touch' with each other. However, living with dementia in a care facility is a strong reminder that we need to rethink and design our connection with the world beyond merely our eyes and ears. More than a methodological tool, being attuned through all our senses rekindles empathy, something that allows us 'to think . . . with our bodies' (Despret 2013: 71). It has been impossible to move online my fieldwork conducted with people living with advanced dementia. Beyond methodological restrictions (i.e. I cannot capture the atmosphere of a care home through digital means) and practical limitations (i.e. the care homes do not have the technology to facilitate online communication), not moving online has been an ethical decision: this form of communication would put a huge strain on people whose attention span lasts, at the very best, a few minutes or seconds. In this respect, my fieldwork is body labour: it requires co-presence of bodies, with all their embodied senses. If, at times, I have been privileged to hold a participant's hand, this has intimately transformed my knowledge about dementia and my experience of connecting with those living with this condition.

On the other hand, the advice we received from officials, backed up by public health experts, has altered the intimacy with our bodies: do not touch your face, eyes, nose or mouth. Touch appears not only to be lethal through its capacity of materially connecting bodies and surfaces, but also by transporting the virus into our bodies through self-touch. For someone living with dementia, the advice of not touching your own body can easily be superfluous. It would be extremely hard to remember this advice on a permanent basis, let alone that such a practice involves a significant amount of self-awareness and monitoring even when not struggling with cognitive loss. In designing the no-touch measures against the virus, people with dementia became excluded from the global health guidelines of how to safely deal with the virus. A safe world from the virus designed based on no-touch, paradoxically, eliminates those at

highest risk of infection and dying from COVID-19, by exposing them to the risk of dying of extreme isolation. Thus, we need to reimagine a world and public health measures wherein touch is not eliminated, but bodies can get safely, and comfortingly, in touch.

From the beginning of the pandemic, the UK government's strategy was focussed on protecting the National Health Service (NHS) from being overwhelmed (the initial slogan was #Stay Home #Protect the NHS #Save Lives). This has supported the exclusionary rhetoric of NHS heroism in the 'fight' against the deadly virus. As such, the government issued on 2 April a guideline (Department of Health and Social Care et al. 2020) 'recommending' that hospitalized older patients should be discharged to care homes without needing to test positive or negative for COVID-19. This was, following philosopher Erin Manning (2007) on the politics of touch, *tactless* and careless politics. If tact, as she asserts, is to know when *not to touch*, then imposing that vulnerable, but virus-free bodies, live alongside infected ones in a place where touch is unavoidable, is a *politics of lethal touch*.

To provide safe touch that is professionalised and comforting, we need first to look at the complexity of touch. If our whole bodies can become sources of infection for COVID-19, we need to think of safe touch beyond maintaining the safety of hands in the model of clinical (Lammer 2007) and health-care facilities (Pink et al. 2014) – albeit these remain mandatory. In thinking of safe touch in relation to our whole body, it can be illuminating to expand on Manning's (2007) politics of touch as bodies in movement: a *politics of safe touch* during the pandemic should look at bodies in more continuous movement and at their protection in this process: before, during and after getting in touch.

Concretely, a strategy of safe touch should be a conjoint political support action (including financial support) and locally accommodated practice, depending on each living arrangement. These should facilitate both emergency action and a long-term, more radical transformation of institutional care. As such, I suggest two potential emergency actions based upon my own fieldwork observations and upon recommendations offered by care specialists. First, there is the protection of carers' bodies in their movement to, from and between different work locations, which would allow safe professionalised touch. Second, there is the inclusion of family members in the care assemblage, following the model of 'key/essential workers', which would allow safe comforting touch. For the long-term transformation of institutional care

supporting emergency measures in the eventuality of a future pandemic, I suggest three potential directions: smaller living arrangements; long-term care based on living arrangements that allow couples / family members to move in permanently or for short-term visits (e.g. for a few days or for the duration of the pandemic); and the development of multi-species institutional care facilities. These suggestions are, by no means, either the best or exhaustive. Rather, they are intended to incite people to rethink, practically, the global public health measures against a virus that proves to have anything but equal effects across generations, and across ethnic and racial and socioeconomic groups.

During a no-(inter-human) touch pandemic, there has been an enormous turn to our non-human companions for comfort. Despite its zoonotic origin, animals – and in particular companion animals – cannot carry the virus, and therefore remained safe for (comforting) touch. People with dementia already live in social isolation and ‘lockdown’ on a more permanent basis, deprived of comforting touch, even in the absence of a deadly virus. Nevertheless, I strongly believe that this no-touch pandemic can teach us something invaluable about the potential of developing dementia care as a more-than-human living arrangement. Thus, I believe that the intimacy afforded by touching an animal in the absence of human, comforting touch, should be looked into as a great potential source for a long-term, sustainable way of remaining in (safe) touch with the world.

Conclusion

Providing care for someone living with dementia is intimately entangled with touching and being touched. In dementia care, touch becomes the glue in the assemblage of bodily care. If our bodies are vectors for the virus, then public health measures have to consider that the high mobility between bodies entangled in care work (i.e. carers working in multiple care homes; moving to and from work; moving between residents) be managed beyond simply offering the necessary Personal Protective Equipment (PPE). Just as we need to rethink the necessary/non-necessary divide of touch in dementia care, we need to reconsider the protection of care workers’ bodies, their physical mobility and what it is touched in the process. Similarly, we need to consider as essential the comforting touch provided by families and other-than-human companions. This needs to be acknowledged, supported and put into practice through political

and financial commitments that ensure safe touch in emergency actions and the long-term reform of living arrangements.

We like to say that knowing a person with dementia means you know *one* person with dementia: each person and their carers will have a unique way of experiencing this condition. It is a recognition and acknowledgement achieved with difficulty after decades of stigma and misperceptions of lost humanity and personhood. Yet, deaths of those with dementia continue to be generic statistics under this homogenising label. When statistics step into the picture of dementia, we lose touch with people with dementia as humans, as persons that emerge through connection, like any of us. The COVID-19 pandemic high death toll amongst care home residents, most of them living with dementia, only confirms this, once again. But there are some more general lessons to be sadly learnt from these numbers. First, public health policies cannot work homogenously, as was assumed through no-touch measures during the COVID-19 pandemic. And second, government public health policies against a deadly virus need to look deeper into the nature of intimacy afforded by bodily touch in dementia care: as a condition of living and of dying a dignified, good death, and also as a structural issue of long-practised tactless, careless politics that lost touch with its most vulnerable citizens.

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Note

1. All names have been anonymised, and some features (e.g. gender) were changed to maintain confidentiality.

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